

Inclusive data taskforce

Executive Summary



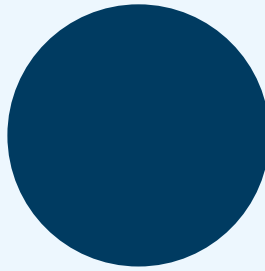
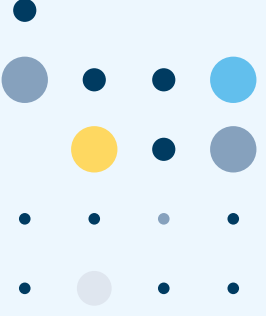
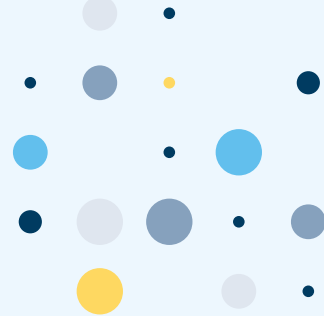
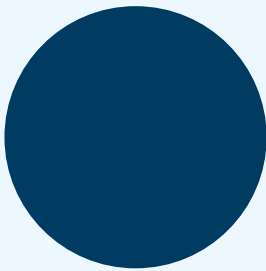
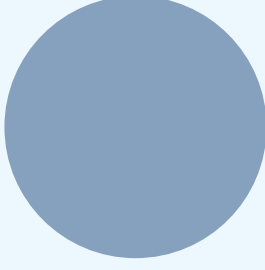
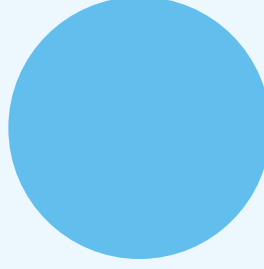
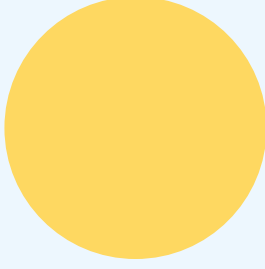
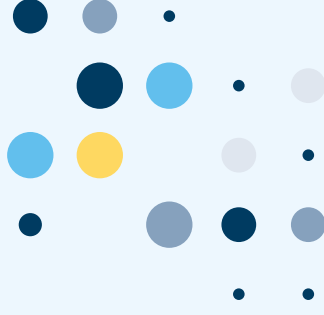
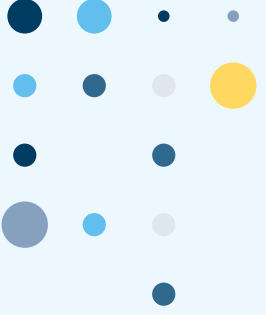
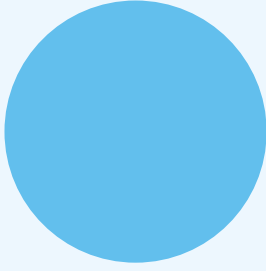


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Who we are

In October 2020, the National Statistician invited us, a diverse group of senior academics and civil society leaders with wide ranging expertise across equalities topics, methodologies, geographies, and data ethics, to form an independent **Taskforce**, chaired by Dame Moira Gibb. Our purpose was to develop recommendations on how best to make a step-change in the inclusivity of UK data and evidence.

We were asked to look at four important questions:

- 1** How can we improve inclusiveness in the collection, analysis and reporting of data and evidence in the UK?
- 2** How can we make most effective use of existing data, such as administrative, census and survey data to understand equalities and inclusion?
- 3** What are the critical data gaps that hinder our understanding of equalities and inclusion and how can we address them?
- 4** How can we build on our own and others' experiences in improving our approach to equalities and inclusion going forward?

We are very grateful to all those who shared their views and experiences with us and have tried to do justice in our recommendations to the wealth of information that they gave us. For those interested in having a more detailed look at the main findings, recommendations and findings from each of the consultation activities, they have been published separately and are available to view online.

This summary report is also available Welsh, Polish, Romanian, Punjabi, Mandarin, Cantonese, Arabic and Farsi. Easy Read versions of this report are also available in these languages. **If you require another format, please email us at equalities@ons.gov.uk or call 0800 298 5313.**

What we did

We began by commissioning a range of activities to listen to and learn from people across the UK, including those who may be asked to participate in research and share their data with researchers, and those who collect or use data and evidence. This involved:

- a 12-week online open consultation on CitizenSpace
- seven roundtable discussions and six in-depth interviews with senior central and local government representatives, and those in the devolved nations
- four roundtable discussions and two in-depth interviews with academics and representatives of learned societies
- discussions with over 80 civil society leaders working in 15 different equalities areas
- discussions with over 90 members of the public with lived experience of equalities issues

Participants in the discussions and in-depth interviews were drawn from a range of backgrounds and were selected based on the equalities work that currently takes place.

Consultation events were held online, as they took place during the pandemic, when face-to-face meetings were restricted. To ensure we heard from people who may be less able to access the internet, we also did a paper-based consultation by post with those at risk of digital exclusion.

Additionally, we considered papers and presentations on a wide range of topics relating to inclusive data and evidence. Other groups and organisations also invited us to events that they organised and provided us with written submissions to contribute their perspectives to the consultation.

Our findings

We carefully considered all the evidence gathered within our consultation and engagement activities, the findings of which are summarised in this section.

Critical data gaps

We recognise that complete and appropriate data are crucial for understanding the needs and circumstances of different groups of people, to ensure that everyone counts and is counted, and no one is left behind. The findings from our consultation activities revealed that, while there are data available across the UK data infrastructure to explore the experiences and outcomes of a range of people with different characteristics, significant gaps exist. Some groups or characteristics are missing entirely from the data, for some groups there are insufficient data, and for some the data are not of good enough quality.

Examples that were highlighted to us of **missing groups or characteristics include**: transgender, non-binary and gender-diverse people, non-residential household populations (for example, people living in residential establishments such as care homes or prisons, and homeless people) **and groups often deemed 'harder to reach'** (for example, Gypsy, Roma and Traveller groups, ex-prisoners, asylum seekers, victims of domestic violence and undocumented migrants or victims of human trafficking). Some of these groups include the most vulnerable and disadvantaged people in the UK, making it especially critical to address the lack of data reflecting their lives and experiences.

Many participants in our consultation activities also identified **children as a group for whom data are missing**, particularly looked-after children, children who have experienced abuse or neglect in early childhood, young carers, migrant children, **disabled children**, and Gypsy, Roma and Traveller children.

Various participants described gaps in the understanding of why and in what circumstances people may be at risk of **digital exclusion** and how well the **digitally excluded population** are represented in routine data collection. Some participants felt that the measures put in place in response to coronavirus (COVID-19) may have led to their further exclusion from research; many surveys have moved to online platforms, potentially generating charges for participants, and restricting their access.

Participants also identified gaps in topic coverage which can limit policy and explanatory insights. These include a lack of **income data from the censuses** which limits the understanding of disadvantage, and a lack of data on **socio-economic background**, an important variable for understanding topics such as educational inequalities.

There were several examples provided of where insufficient information is available. A number of participants said that **religion** is often not collected in surveys, and when collected, is not routinely reported or is often conflated with beliefs and practices, which can obscure inequalities. Although data on sexual orientation are collected within several UK data sources, information on the differing experiences and outcomes of people linked to their **sexual orientation** is lacking. Additionally, despite **pregnancy and maternity** being protected characteristics under the equalities' legislation in Great Britain, information on inequalities in pregnancy and pregnancy outcomes is partial. Participants also described a lack of data on personal characteristics relevant for equalities monitoring in **administrative data sources**.

Even where relevant groups and topics are included in survey or administrative data, participants identified risks that data **quality may be poor. Information provided by proxies may be inaccurate**. For example, where data are available for children, this is often collected from people other than children themselves and therefore children's own voices may not be heard. There may also be problems of **missingness in data** relevant to inclusion. This is particularly the case in relation to census questions that are voluntary, such as religion, and therefore have lower levels of response than compulsory questions. **Information carried forward from previously collected data sources can also become inaccurate over time**, for example, where people express preferences for particular groupings in different contexts or at different times.

Issues with data quality can produce a misleading picture, making it difficult to identify where discrimination and misrepresentation are occurring and people's life chances are being reduced, so we see addressing these gaps as a priority.

Inclusivity and data collection

Collecting the right data from the right people is fundamental to develop the level of understanding of inequalities we need to take appropriate action. However, our research with Civil Society Organisations (CSOs) and individuals from relevant groups and populations indicated that there are a wide range

of practical, cultural and emotional factors that have a combined impact on people's willingness, ability and opportunity to provide their personal information and participate in formal research exercises.

Trust emerged across all of our consultation activities **as a barrier to participation in data collection**. This included a perception among several participants that there is a general sense of distrust in the government, as well as in government statistics, particularly, though not exclusively, among under-represented groups (specifically described as affecting those from Gypsy, Roma and Traveller communities, other minority ethnic groups and documented and undocumented migrants).

They described how this could result in some groups being under-represented or effectively invisible, ultimately leading to policy decisions which may not adequately reflect these populations and increasing their distrust. Some participants noted a degree of uncertainty and apprehension among relevant groups and populations about how their data may be used by the government, including fears that disclosing their status could lead to unequal treatment, discrimination or worsen their situations.

We also heard about other barriers which may affect **willingness to participate**, including the burden of repeated requests for participation in research from some population groups, particularly for those with competing pressures in their day-to-day lives, and their perceptions that there was little if any personal or community benefit from doing so.

Additionally, it was suggested that people may be prevented from participating due to **inaccessibility of data collection exercises**, such as online data collection instruments excluding those who have no or limited digital access or skills, failure to consider the language, literacy or comprehension needs of different population groups, and the personal identity and characteristics of those responsible for designing and carrying out the data collection and analysis not reflecting diverse population groups so discouraging participation.

The labels used to capture individual characteristics within data collection were also described as a potential barrier to participation. The ability for people to select categories in surveys and on forms that reflect their personal characteristics and circumstances was seen as critically important. Some participants highlighted the outdated nature of certain survey questions, including those on ethnicity and those on physical disability. There were suggestions from some that disability data collection shift from a focus on the medical model, which looks at an individual's impairments or differences, towards the social model of disability, exploring the individual's needs and perspectives, as a means of better addressing the organisational and structural barriers which limit people's participation in society.

Inclusivity of data analysis and outputs

Several issues were highlighted to us that affect both data collection and analysis, and which can undermine the representativeness and relevance of the findings produced.

Participants described how a **lack of harmonisation** of data on personal characteristics hinders the ability to examine groups in detail and compare data across different countries of the UK. The use of outdated harmonised standards was also seen as failing to adequately reflect the diversity of the population currently, for example the continued use of ethnicity standards from the 2001 UK censuses.

We were also told about the **conceptual challenges** in the existing data and the impact this has on the quality of the evidence based on it. For example, relating to the lack of clarity in concepts that are collected across different sources using the terms disability and ethnic origin. Inconsistencies in the definitions for the term 'disadvantaged' were also mentioned as a significant issue for analysts.

Participants also highlighted the issues that arise from **small sample sizes** in household surveys, including the impact this has on the **granularity** of the analysis that can be produced, whether that be by sector, geography or characteristic, and which can render entire groups invisible in data. The resulting aggregation of smaller groups into larger categories was said to have the



potential to marginalise and alienate some groups and populations. Small sample sizes also hinder the ability to produce robust **intersectional analyses**. This can undermine the potential to understand specific sub-groups of the population, the relationship between different characteristics and their combined influence on various outcomes.

Frequency of data collection was also raised as an important issue. It was acknowledged that the UK Censuses are a valuable source of inclusive data, providing insights not achievable with other data sources, but the 10-year gap between censuses means that the resulting data are often several years out of date.

Some participants felt that statistical data alone cannot provide a comprehensive understanding of lived experience. Given the complexity, richness and intersectionality of issues affecting people's lives, participants viewed it as crucial that both qualitative and quantitative data be used where appropriate.

Dedicated research capacity and the skills needed to source and analyse data were also common issues raised across the different consultation activities, viewed as limiting the potential analyses that could be conducted even when the required data are available.

We also heard about issues in relation to the **accessibility of data and evidence**. Organisations who took part in the online consultation described a **lack of readily available and easily accessible data for analysis** and some participants also reported uncertainty in knowing exactly what data were available and where to access them. Some also emphasised the need for the use of clear, accessible language to convey statistical interpretations and the availability of data and evidence in range of different formats to enable access for diverse audiences.

Learning from others

In addition to the main findings from our consultation activities summarised here, we also considered how we can learn from experiences in the UK and elsewhere to improve our approach to equalities and inclusion in the future. Participants in the consultation activities shared examples of promising practices with us to complement those that we are aware of through our own experience. Further details of some of these are in the main findings report. Additionally, the supporting evidence reports outline the more extensive findings from each of the consultation and engagement activities that were undertaken.

Inclusive Data Principles

Based on these findings, we have developed a set of 8 principles, with specific recommendations underneath each, to improve the UK inclusive data infrastructure. The principles are:

1. to create an environment of trust and trustworthiness
2. to take a collaborative whole system approach to improve the UK data infrastructure
3. to ensure that groups are robustly captured
4. to ensure that sufficient data are available for robust and reliable disaggregation and intersectional analysis
5. to ensure that concepts are appropriate and clear
6. to broaden the range of methods used and create new approaches to understand everyone's experiences
7. to review harmonised standards regularly adapting to evolving social norms and needs
8. to ensure that UK data and evidence are equally accessible to all

The full set of recommendations beneath each of these 8 principles can be found in the main findings report. If fully implemented, these will **help to bring about the needed step-change in the inclusivity of UK data and evidence.**

Contact us

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