

Using demographic data

June 2022

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About this guide

This guidance outlines an approach to demographic data collection and common data standards, and tips on how to analyse data and present your findings.

Alongside this, we have produced a [Question Bank](#) that includes tips on designing questions and answers for surveys and providing a wide range of examples. This includes the standard Healthwatch taxonomy to collect demographic data in line with best practice and align with data collection systems across the network.

There is also an e-learning resource explaining [what demographic data is and why it matters](#) and a guide on [how to collect demographic data](#).

Why demographic information matters

Demographic data is used to generate insights and understand health inequalities, including challenges some groups face in accessing health and social care services. There are several reasons why Healthwatch should collect and analyse demographic data:

- To accurately represent the diversity of local people and comply with the law. Healthwatch is required by the legislation that sets us up to obtain the views of local people concerning health and social care, and the term 'local people' is defined as being representative of the area.
- To demonstrate that you are inclusive and treating everyone equally. Often, local authorities and providers want to see that the evidence used to support recommendations is representative and inclusive. Collecting and analysing demographics is an excellent way to prove to stakeholders that you speak for every member of your community.
- To understand who you are reaching and who you are not reaching. Demographic data shows who you are reaching and ensures you accurately represent your community. It also allows you to identify who you are not reaching, to actively engage them.

Data standards

GDPR and demographics

As Healthwatch, we need to collect information on demographic characteristics, including special category data. The Data Protection Act 2018 and the UK General Data Protection Regulation (GDPR) require us to balance the need to collect and analyse findings to understand health inequalities with the need to collect only the data you'll use ("data minimisation").

What about special category data?

Our national strategy includes an explicit commitment to amplifying the voices of communities whose views go unheard, overlooked, or ignored and reducing the barriers they face. We, therefore, need to collect demographic data that falls into the special category data requirements of GDPR.

This includes:

- Ethnicity
- Physical or mental health condition
- Religious beliefs or other beliefs of a similar nature
- Sexual life or orientation

To process special category data, you must have an **additional lawful basis**.

You must tell research participants that you are collecting special category data and how you'll use it.

Our guidance on [designing a survey](#), [data protection](#) and [how to write an information sheet](#) provide further information on how to comply with data protection law when collecting demographic data.

Healthwatch England's standard demographic taxonomy

The following demographic categories form part of Healthwatch England's standard taxonomy.

- Age
- Gender
- Ethnicity
- Disability
- Long-term condition



- Religion or belief
- Sexual Orientation
- Gender reassignment
- Marriage or civil partnership
- Pregnancy and maternity
- Carer

Healthwatch England standard demographic taxonomy:

The classification of demographic data into groups with standardised terminology ensures that analyses and insights directly map across data collection systems and across the network.

- We have provided standard demographic questions and responses in the [Question Bank](#) guidance. By using them, you will help to ensure we can aggregate data we receive from across the network and with other external datasets.

It may not always be possible or desirable to collect data on all the characteristics outlined above. As a minimum, we recommend attempting to collect information on Age, Gender and Ethnicity across all activities.

Healthwatch should aim to collect information on as many characteristics as possible when carrying out signposting activities and other routine work to fulfil our commitment to understanding and representing health inequalities.

Regarding the principle of data minimisation, you should feel confident collecting demographic data even when there is no immediate use. Demographic data serves a broader purpose of understanding who you are reaching and who you are not reaching in your local community. When data is aggregated across the network, Healthwatch England uses it to understand health inequalities at a national level.

What about research and engagement activities?

As a local Healthwatch, you may find it helpful to establish a core set of demographic characteristics which you will agree to collect across all data collection methods. For research and engagement activities, we recommend building on these core categories, depending on the focus and aims of your research.

You must balance what is helpful and a reasonable amount of data to collect.

Adopting common data standards

By adopting common data standards across the network, we can ensure an influential voice at a local, regional and national level. Policymakers increasingly call on Healthwatch England to provide health and care evidence about how different groups experience a particular issue and where and why this is

happening. The key strength of local Healthwatch is our reach into every area of the country.

Adopting common data standards allows us to ensure you are represented and making a difference at a national level by facilitating the comparison of insights across the network and with other national datasets.

Understanding health inequalities

When designing your research, you will want to consider collecting information on other categories which are useful in understanding additional axes of inequality.

This may include:

- English Language skills
- Digital skills
- Education level
- Occupation status
- Financial situation
- Housing situation
- Poverty indicators
- Our [Question Bank](#) guidance includes template questions around these additional demographic categories.

Below are examples from Healthwatch England and local Healthwatch reports, demonstrating how demographic information can highlight inequalities and differences between groups.

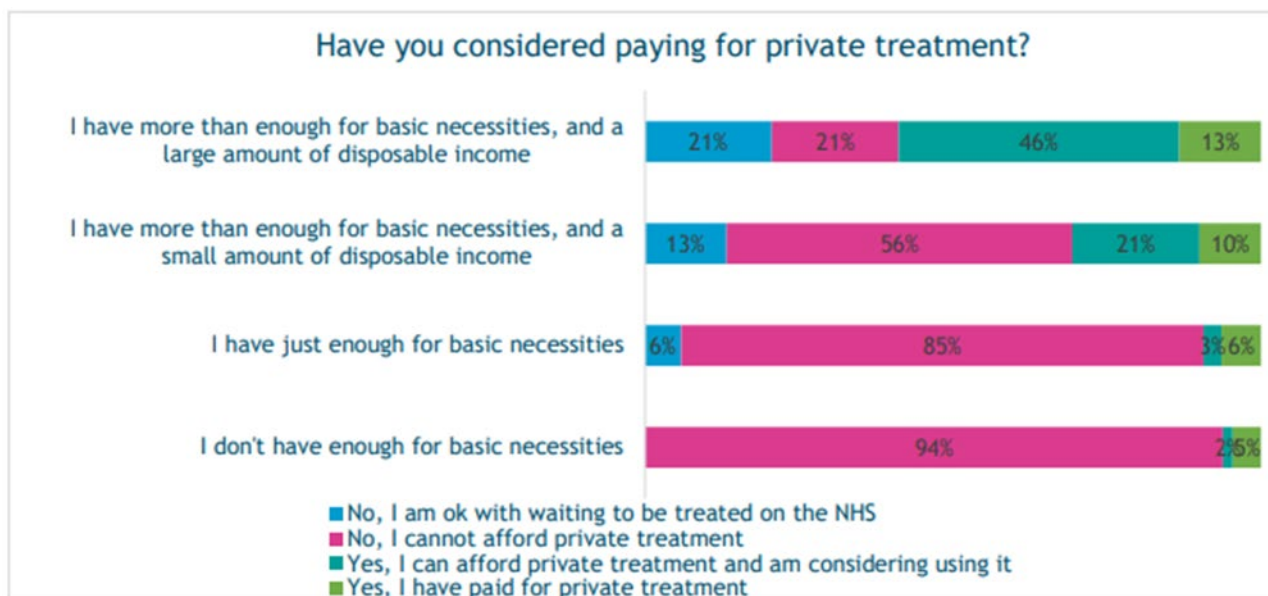
Financial situation

Example one: What are people telling us about delays to hospital care and treatment? – Healthwatch England, November 2021

A briefing produced by Healthwatch England reported on 1075 people waiting for treatment or receiving treatment in a national survey. The findings highlight inequalities in terms of people's access to private treatment. The Healthwatch survey asked respondents if they had considered paying for private treatment and found that nearly two thirds (65%) said they would not go private as they could not afford to.

This question about financial situation tells us about differences between people experiencing different financial situations. The more financially secure the respondent, the more likely they were to say they can afford private treatment and are considering it; however,

those who are most well off appear to potentially be ok with waiting to be treated on the NHS. Financial stability also affected responses, with the least financially secure twice as likely to require travel support for themselves or their family (35%) compared to those with larger disposable incomes (17%).



Gender and Sexual Orientation

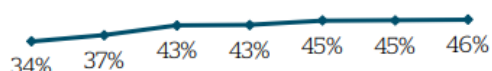
Example two: *My Health, Our Future: Children and young people’s mental health and emotional wellbeing in Suffolk* – Healthwatch Suffolk, 2021

Healthwatch Suffolk reported on children and young people’s mental health and emotional wellbeing in Suffolk, receiving 4,522 survey responses. The survey included several demographic questions, including gender and sexual orientation. Of those who responded, three per cent preferred to describe their gender in another way, other than male or female. 18% of responses were from young people who identified as LGBT*Q+.

Healthwatch Suffolk identified several key differences relating to these groups. Those who identified as LGBT*Q+ tended to experience poorer wellbeing than their peers. They were also more likely to report self-harm, lower self-esteem and poor outcomes than other groups.

Healthwatch Suffolk also identified that female students were more likely to report low self-esteem than male students. Those who preferred to describe their gender in their own way were the most at risk of low self-esteem.

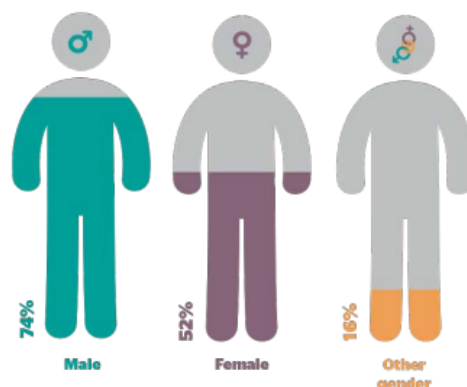
The number of students reporting low self-esteem increased with school year.



Year 7 Year 8 Year 9 Year 10 Year 11 Year 12 Year 13

Female students were more likely than male students to report low self-esteem. Those who preferred to describe their gender in their own way were the most at risk of low self-esteem.

Levels of 'Normal' or 'High' self-esteem across all gender categories:



When to think about demographics in projects

It is important to consider demographics at each stage when carrying out a project.

Demographic data can inform new research projects and priorities, for example:

- If your current data and insight tell you that some demographic groups are underrepresented, you might think about actively engaging them in targeted research.
- Suppose your current data and insight tell you that some demographic groups are affected by issues you are interested in learning more about. In that case, you might consider designing a project that focuses on a demographic category or multiple characteristics.
- At the [research planning stage](#), you will need to think about which demographic characteristics to capture and how to make sure you ask the right demographic questions.
- When analysing your data, you will need to conduct a demographic investigation of your findings. See our guidance on [quantitative](#) and [qualitative](#) analysis.
- When [writing up your results](#), you want to tell a story with your data and weave demographic analysis throughout your report, highlighting your key demographic findings.

Integrating demographic data into your analysis and reporting

Demographic data helps to describe and understand a population's structure and composition. You should briefly describe your demographic findings in your report to describe the people you have reached.

This helps contextualise your results and understand if your evidence represents your local community. An introductory paragraph about your sample may be as simple as highlighting some key characteristics.

Example three: Accessing Mental Health Support, Healthwatch Cornwall, 2021

397 people aged 16 years and above took part in the survey. Just under a quarter of respondents did not provide age, gender or other demographic information. Of those who did, most were between 35 and 74 years (83%), female (78%), and White British or White Cornish (92%).

Rather than presenting all your data from the demographic categories, focusing on a few key characteristics in your introduction can be more effective.

It would be best to decide which categories to include based on your research objectives and what you have found. You can always include the complete detail of your results in the appendix or upon request.

Analysing your key findings by demographics

Once you have summarised the key characteristics of your sample population, you should integrate demographic findings throughout the rest of your analysis, highlighting the challenges different demographic groups face. This will help to understand the health and healthcare needs of your population.

One approach would be first to identify your key findings and then further explore these by demographics, looking for differences or similarities in the experiences of different groups.

This helps you weave demographic analysis throughout your report and focus on interesting findings as they emerge. When putting together your report, you should focus on those findings which emerge as most important to present in

the most impactful way. It is unnecessary to provide a breakdown of all your findings by each demographic characteristic.

Example three: Accessing Mental Health Support, Healthwatch Cornwall, 2021

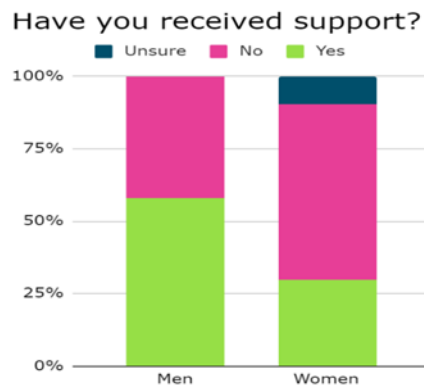
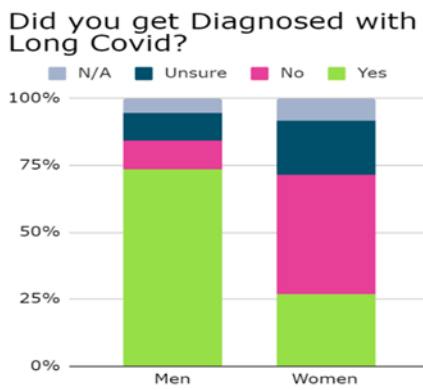
One in two people accessed support for their mental health in the last six months from a range of sources, including online information and advice, family and friends, and NHS mental health services. When we looked at only those aged 65 years and older, only one in three had accessed support compared to over three-quarters of 16 to 24-year-olds. Further work is needed to encourage recognition and to reach out for mental health support among older people, and ensure equitable access across all ages.

Example four: Voices of disabled residents and COVID-19, North East London Healthwatch, 2021

We carried out a survey with 580 residents who were disabled or living with a serious long-term condition. 61% stayed informed about Covid through traditional media such as TV news, radio, and newspapers. Four per cent depended exclusively on friends and family for information. They were more likely to belong to these groups: neurodivergent/learning disabilities, sight impaired, women, Black, Asian and minority ethnic especially Black ethnicities, digitally excluded.

Example five: Living with long Covid, Healthwatch Richmond, 2022

Our data shows a stark gender divide in access to diagnosis. 74% of the men who answered the survey received a diagnosis of long Covid against 27% of women. Similarly, 58% of men accessed support for their symptoms, against 30% of women. This is despite men and women reporting the same severity of symptoms and men showing marginally more improvement in their symptoms than women.



Using demographic data to create influence and impact

When you integrate demographic data throughout your analysis and reporting, you can identify potential health inequalities and areas where you can create influence and impact.

This type of interpretation is powerful in identifying specific problems that need to be resolved, as it allows us to dig into the nuances of experiences within health and healthcare. This empowers us to provide stakeholders with the information they need to ensure no one is left behind, as we can more meaningfully address the question: who do services work well for and who is left behind or inadequately supported?

This means that, in turn, we can provide recommendations that are taken seriously and work collaboratively with local health and social care providers to make services better for everyone ultimately.

For more tips on developing effective recommendations, please see our [guidance](#).

Example six: [Accessing Mental Health Support, Healthwatch Cornwall, 2021](#)

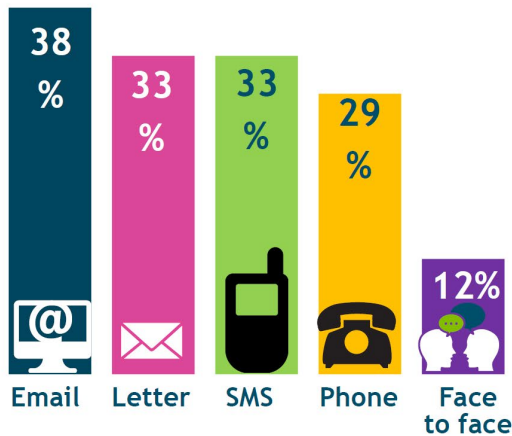
Recommendations: we need to ensure services identify, target and deliver support to specific age groups, such as the over 65s who are less likely to seek support and younger adults who are at increased risk of anxiety and depression.

Example seven: [Voices of disabled residents and COVID-19, North East London Healthwatch, 2021](#)

There is no 'one size fits all' solution for communication with disabled people on topics such as their health services during the pandemic and Covid vaccination. Information presented simply, with clear explanations, is accessible to more people. Written materials can be made more accessible with large print and plain formatting; however, some may do better with information in other languages.

How respondents prefer to be contacted about the vaccine

Not a "One size fits all" approach



12% would prefer to only be contacted verbally, via phone or face to face, without written text.

54%

of respondents with sight impairments preferred to be contacted by phone



Why 'no difference' is a result

You may find that there are no differences between groups when exploring your key findings by demographics. This is still a perfectly valid and interesting result.

*Example eight: **Reviewing patient experience of dental services in Redbridge, Healthwatch Redbridge, 2021***

We are pleased that our survey received responses from people living in most postcode areas in the borough (11 out of 14 postcode areas), showing a strong geographical reach ... Healthwatch Redbridge wanted to understand if there were certain parts of the borough where people were finding it more difficult to book an appointment. Of those who shared their postcode data with us (55), feedback did not show a significant difference in any area when seeking an appointment.

Some groups may be more likely to face difficulty when accessing services depending on where they live, particularly those from areas linked to greater deprivation. Therefore, this is a valuable finding because it tells us that access to NHS dentistry is a widespread issue that affects everyone, regardless of where they live.

What if I have small numbers in some demographic groups?

When analysing your data, you may find that you have very small numbers in some demographic groups, making it challenging to explore differences. In this instance, you may be able to group some of your findings to make inferences about your study population.

It is worth noting that often sample sizes are too small to draw robust conclusions. Nonetheless, it is still worthwhile to carry out demographic analysis

and caveat your work as indicative findings for further investigation. For example, 'we can't say for certain that X group experience services more negatively, but our results indicate they might and that this is worth exploring further.'

Even if numbers are too small to analyse, you can still state this in your work so that the reader is aware and demonstrates that you have considered demographics.

When considering the different demographic categories, you may have several ways to aggregate your data. You will need to think carefully about what makes sense in the context of your findings and what you want to know. You should consider factors such as the granularity of your categories and the number of responses in each category.

Age

You may often collect a spread of data across age categories but with relatively few individuals in some groups. You can regroup the age categories into broader groups, for example combining the younger age groups (>25), ages 25 to 64, and the older age groups (64<), to look at the differences.

There are other ways of thinking about the implications of age on health differences and outcomes, for example, looking at differences between young people (>25) and all older age groups.

Ultimately, groupings should be guided by the issue you are investigating. For example, if investigating experiences of youth services, a 24-year-old and an 18-year-old are likely to have quite different experiences, so you may not want to group them. On the other hand, looking at social care experiences, they aren't likely to differ much, and it may make sense in this context.

Ethnicity

An aggregated ethnic group is one that combines the more detailed categories.

The Healthwatch England standard taxonomy collects data on 18 different classifications of ethnicity. Often, sample sizes are too small to present robust data for these groups separately. There are several different ways you could consider aggregating ethnicity data.

One recommended approach outlined by the [Office for National Statistics](#) is to aggregate your data into the five broader groups: Asian, Black, Mixed, White, and Other. Alternatively, you may consider that other ways make sense, for example, grouping those of 'Mixed / Multiple ethnic groups: Asian and White' into the broader 'Asian' group.

There is no correct answer; ultimately, you will need to apply your own approach depending on the amount of available data. For example, suppose you have many responses from one ethnic category. In that case, you may decide to retain this level of detail and analyse this group separately rather than combining it with a broader ethnic group.

Sometimes, your sample sizes may be so small that you can only reasonably apply a binary split to your data (White/Other than White, or White British/Other than White British). The analytical value of splitting your data into the broader groups outlined above will be limited as the experiences and outcomes of people may be markedly different. Nonetheless, we encourage considering different ways of splitting your data to determine if there are important inferential differences.

If you need further help

When outlining your analysis plan, we recommend having these discussions to consider how similar or different aggregated groups are, both in their outcomes and the characteristics of the people in them.

You can always reach out to the research team at research@healthwatch.co.uk, and we will be happy to have these discussions with you to help you decide on the most reasonable approach.



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