

Collecting demographic data

August 2021

About this guide

This guidance discusses how to collect demographic data from people while carrying out research, engagement activities or signposting. It includes:

- Why demographic data matters
- when to ask demographic questions
- How to ask demographic questions
- What to do when it may not be realistic to ask demographic questions
- how to tackle tricky communication situations
- Supporting your staff and volunteers

Why collecting demographic data matters

It's part and parcel of being an effective Healthwatch:

- Healthwatch are required by the legislation that set us up to obtain the views of local people in relation to health and social care, and the term "local people" is defined as being representative of the area.
- It shows who you are reaching and ensures you are accurately representing your community.
- It allows you to identify whom you are not reaching, so you can proactively engage them.
- It helps you generate insights and understand health inequalities that exist, for example due to age, gender, disability or ethnicity, including people who struggle to access services.
- It helps you meet your public sector equality duty; and to prove it to local authorities and funders by including them in your analysis and reporting.



What can influence someone's health, wellbeing and access to services?

Many factors can affect an individual's experience of or access to health and social care services. Here are just a few examples:

Gender

Young women have had concerns about having the Covid-19 vaccine because they think it could affect their fertility.

Age

Young people feel that healthcare professionals don't always treat them with respect, especially those with caring responsibilities.

Older people may struggle to use digital systems to access care.

Ethnicity

Black African and Black Caribbean people have been more reluctant to take up the Covid-19 vaccine than White people.

People whose first language isn't English may find it difficult to communicate with health care providers.

Identity and belief

Trans people feel their GP did not believe they were trans as they lacked understanding about gender identity.

Muslims might not want care workers to come at prayer time.

Disability or long-term condition

British Sign Language users might prefer information to be given to them in a signed video rather than a letter or email.

Family situation

People who live alone are more likely to have experienced impacts on their mental health compared to those living with other people during the Covid-19 pandemic.

Financial situation

People on the lowest incomes can't access dental treatment if dentists aren't willing to provide NHS treatment. They may not be able to afford a broadband contract, so can't access video consultations.

Housing

During the pandemic some people have had to spend more time in homes that are overcrowded, damp or unsafe, with an impact on their health and wellbeing.

Occupation

People who work full time can find it very difficult to get GP appointments if all appointments are allocated at 8am each day when they are travelling to work.

Data protection and collecting demographic

data

Data protection legislation states that you must tell people what personal data you are collecting, explain what lawful basis you have for processing it and how you are going to use it.

Some demographic questions will form special category data, which is particularly sensitive. The demographic categories that form special category data include:

- Health, including wellbeing and medical treatment
- Ethnicity
- Sexual orientation
- Religion or belief

By using the approaches described in this guidance, you can comply with the law as well as collect data about different communities' experience of health and social care. You may find the following pieces of guidance helpful:

[Our guidance on data protection and processing](#), which covers the lawful bases for collecting special category data and how data minimisation (collecting only the data that you need) applies to the collection of demographics.

[Telling people how we use their data on the phone and in-person](#)

When to ask demographic questions

You can collect demographic data:

- During outreach and engagement activities
- Through surveys, questionnaires and qualitative research
- From people whom you help with signposting and information

Always include demographic questions when undertaking research projects.

How to ask demographic questions

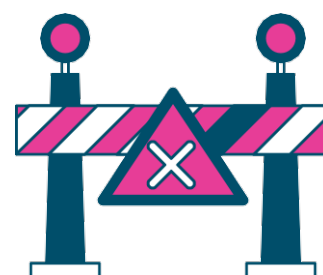
You may experience different barriers in collecting demographic data consistently and accurately, particularly on sensitive topics such as gender identity, sexual orientation, mental health, religion or financial situation.

You can ask demographic questions at the beginning or end of conversations with people. If you find that a daunting prospect, it's possible to weave demographic data collection into conversation while doing outreach or providing signposting. Use the approaches outlined in [Telling people how we use their data on the phone and in-person](#) to tell people how you'll use their data.

Here are three ways in which you can gather demographic data when talking to people about their experience of health and social care:

1. **Make notes of relevant information** that the person volunteers in the course of recounting their experience.

For example, a service user may mention their ethnicity when talking about their experience: "I think this nurse treated me differently because I am Pakistani".



2. **Ask demographic questions throughout the conversation**, if relevant, to further your understanding. Any questions not already covered can be asked at the end.

Example: Member of the public: "Because of my condition, it is hard for me to communicate with my doctor".

Healthwatch: "I see- would you consider yourself to be disabled? And if yes, what is your disability?"

3. **Combine asking about personal circumstances with providing relevant signposting.** Use questions about personal circumstances to identify areas where signposting or information may be needed and to provide more relevant information.

Example: If you asked a patient about their level of English fluency, and they say that they do not speak English at all, you may want to mention to them that free English as a Second Language (ESOL) classes are available locally, or that they can book an interpreter when attending medical appointment- along with practical instructions on how to request one.

What if it's not realistic?

It's not always possible to ask for demographics in all circumstances. This may sound obvious, but you can't ask someone who has written a letter or provided feedback on a Facebook post. It is tricky to get to get demographics from someone who emails you, although some Healthwatch have found that some people will respond to a follow up email asking for some demographic data.

In some cases, **limited time or the personal circumstances of the person** you are talking to may make it difficult to ask the full range of demographic questions, and you may need to prioritise.

- Make sure you attempt to **collect at least some basic demographics** across all possible interactions (for example: gender, ethnicity, age and disability).
- After the basics, **prioritise demographic/personal circumstances questions that are relevant to your current insights and community engagement priorities.** For example, if one of your priorities is about the impact of digital NHS services on patient experience, prioritise asking about access to devices and ability to use the Internet.
- **When in doubt**, ask as many demographic questions as you reasonably can within any possible interaction. Some respondents may choose to skip some of the questions or end the discussion before you had the chance to ask everything, but **having incomplete data is better than having no data.**

How to explain why you are collecting demographics

These approaches could encourage more people to answer demographics and personal circumstances questions.

Explain WHY you ask certain questions

- It helps us understand how your life circumstances impact your experience with services.
- We need to make sure we engage with people from different backgrounds
- Our funder/ the local authority needs us to collect this data.
- We want to make sure local services work for everyone/people like you. We can highlight how services need to change to meet the needs of different groups in our county/city/town.

You can provide further reassurance by explaining to respondents that these are standard questions for all respondents, and that you are not just asking them, specifically, based on your own assumptions about them.

Explain HOW you use data

Here are some things you could say:

- We'll remove any detail that would identify you before we publish our report.
- We've got the following ways of keeping your data safe and separate e.g. keeping interview transcripts in a locked cabinet or in a restricted part of our IT system, removing any information from quotes we use in reports that could identify you)
- Your answers are anonymous
- It would be impossible to recognise you from the data you share with us

Being able to show a data protection policy or confidentiality policy can provide reassurance.

In-person or over the phone

Take a moment to introduce the demographic questions before asking them:

"These are some questions which some people may consider a bit unexpected; we ask them because they help us make sure that we engage with people from different backgrounds and discriminate against no-one."



Reassure people that it's OK not to answer but encourage them to answer.

"You don't need to answer any questions you find too personal, but if you answered in confidence it would really help us understand our local community"

When face-to-face, for particularly sensitive questions, offer respondents the option to input the answer themselves before handing you back the survey.

When respondents fill in forms on their own (e.g. online surveys or by post)

Ask demographic questions at the end. Respondents will have built a rapport by then and will better understand why you ask them.

At the beginning of the survey, add a short explanation of why you are collecting the data and how you will use it. Include links to your **data protection and privacy policies**.

"Your answers are strictly confidential. A report based on everyone's aggregated answers will be shared with the local authority/the hospital; it will be impossible to identify you from it."

At the beginning of the demographics section, add a short explanation about the demographic categories that you are going to collect, particularly any that might be "special category data" and why you ask those questions. Demographic questions should always be optional and include a "Prefer not to say" answer.



For example:

"In the next section, we will be asking you some questions about yourself and your life, including [insert those demographics that form special category data]. Your answer helps us make sure that we engage with people from different backgrounds and that we understand the needs of different groups in our community."

For further information, see our guidance on [survey design](#).

What if people feel uncomfortable or offended by you asking them demographic questions?

At times, some respondents may feel uncomfortable or offended being asked certain questions. While we cannot predict when that would happen, it is essential to be prepared in order to prevent and address this.

Fear of prejudice and the social desirability bias

As a rule, people want to portray the best versions of themselves - even when it is not completely truthful. This is why people may be reluctant to answer truthfully about things like their financial situation or their level of IT literacy.

In more extreme cases, people may fear answering truthfully questions about things like their ethnicity, disability or sexual orientation because they fear judgement or discrimination. In other situations, simply asking the question may prompt the respondent to express unsolicited prejudiced views.

What you can do about it

- Ensure that the discussion takes place with as much privacy as possible
- Reiterate that answers are anonymous/confidential
- Maintain a neutral, polite attitude whatever the person says. Don't express your opinion.
- Reiterate the purpose of data collection if needed

Time for reflection!

Look at the following examples of conversations around tricky questions. How could you handle them?

Situation 1

INTERVIEWER: What is your ethnicity?

RESPONDENT: What does it matter?? We're all citizens of the world!

What would you say in this situation?

Here's what you might say:

INTERVIEWER: This helps us understand how people from different backgrounds may have a different experience of services; and helps us make sure we talk to lots of different people with varying needs.

This response explains why we are collecting the data - to understand different people's experiences.



Situation 2



INTERVIEWER: Do you have any long-term conditions or disabilities?

RESPONDENT: Are the answers anonymous and confidential?

What would you say in this situation?

Here's what you might say:

INTERVIEWER: They certainly are; we do not ask for your name. We only share a summary of anonymous data from which it's impossible to identify individuals.

RESPONDENT: OK then... I'm a recovering alcoholic and have been recently diagnosed with schizophrenia. My family and the people at work don't know about this, I need to keep it secret.

This response reassures the person that we won't identify them and encourages them to open up more.

Situation 3

INTERVIEWER: What is your sexual orientation?

RESPONDENT: Why, I'm NORMAL!! I think homosexuality is a sin.



What would you say in this situation?

Here's what you might say:

INTERVIEWER: At Healthwatch we have the duty to treat everyone equally; this is why we ask everyone and we are non-judgemental. We need to understand everyone's experience. Now, back to the questions...

In this response, we explain calmly and politely why we are asking for this information. The person may still refuse to give the information but the situation shouldn't escalate.

Supporting your staff members and volunteers

Some staff members and volunteers may feel reluctant to collect demographic data during outreach or signposting. Reasons why they may feel that way include:

- Feeling that they don't have enough time to go through all the questions.
- Feeling awkward asking "personal questions".

- Expecting service users would be reluctant to answer, for example, “sensing” that people won’t want to give you their demographics after a long, involved and emotional conversation and don’t even ask if people are willing to provide this information.

You could practice tricky situations by role play. This could include:

- Asking questions in a non-pressured way, encouraging respondents to answer while giving them the option to decline
- Ensuring respondents do not feel judged by the interviewer and that they know their information is safe.
- Explaining why certain questions are being asked.

Once your staff members and volunteers have started collecting demographic data from local people, it is important to regularly engage with them on how this is going and the obstacles that they may be facing, in order to identify supportive strategies or the need for further training.



TIME FOR REFLECTION!

What obstacles do you think your local Healthwatch may be experiencing in collecting demographic data?

How can you overcome them?

And finally...

Analyse your data by demographics

Once you’ve collected demographic data, don’t forget to analyse your feedback or research findings by the data you’ve collected to understand the difference between people’s experiences.

For further information about using demographic data, see [this guidance](#).

Report findings by demographics

Incorporate your findings into your report. For further information, see this guidance on how to [write an impactful report](#).

Undertake research with seldom heard groups

In order to truly represent the voice of your local community, you need to make sure that you engage with different groups and different types of people. This guidance provides top tips collected from Healthwatch across the country on how to undertake [research with seldom heard groups](#).

This report by Healthwatch Tower Hamlets on [digital exclusion](#) analyses the main findings by ethnicity.

This report by Healthwatch Leeds on [Covid-19 vaccination take up](#) analyses the findings by age group, gender and disability/long term condition.