



## Interview & Focus Groups Questions on Theme 3: Data Sharing and Re-use

These examples raise or address concerns **about data sharing**. By this, we mean instances where data collected by one organisation is then shared with another organisation.

Previous participants have said they have found these complicated (and a bit overwhelming to start with) so don't worry if you feel the same. Read through them stage by stage and we will discuss all together as a group.

**NHS antibiotic prescribing project:** The first example is an NHS research project about antibiotic prescribing. Prescribing too many antibiotics is a problem, because it means that people are becoming resistant to them. Because of this, antibiotic resistance is a public health crisis. The research project aims to understand antibiotic prescribing in order to reduce it and so address the antibiotic resistance crisis.

What do you see happening in this visual? What does the visual tell you about what the NHS does with data in relation to antibiotic research?

*Fill in the gaps – add to the description collectively produced by participants, as needed, for example:*

The NHS Antibiotic Prescribing Research Project gathers data from a range of sources (eg visits to GPs and hospitals, data about deaths, or about the deprivation of local areas).

1. University researchers request access to the datasets they need to do their project.
2. This data is linked together by NHS Digital and CPRD (Clinical Practice Research Datalink, a service supporting public health and clinical studies). In this process, the only organisation that receives identifiable patient data is NHS Digital, the statutory body in England with legal authorisation to receive this type of data.
3. The linked data is shared with University of Manchester researchers who analyse the data to understand the factors that affect antibiotic prescribing and to try to improve how this is done. Individuals can't be identified by the people with whom the data is shared.
4. The researchers produce dashboards for GPs and health policy makers to improve / reduce antibiotic prescription.

What do you think about this data process? (*Prompts: What stands out to you here? Does anything surprise you, and if so, what? How do you feel about what you see?*)

**NHS Covid-19 Data Store:** here is an illustration of the NHS Covid-19 Data Store. NHS was commissioned by the government to develop a national, secure data store to hold data in one

place to help the organisations responsible for coordinating the Covid-19 response (e.g. the government and NHS) to stay up to date and make decisions. This Data Store is not the same as the NHS Covid-19 contact tracing app.

What do you see happening in this visual? What does the visual tell you about what the NHS does with patient's data?

*Fill in the gaps*

1. Microsoft, Amazon Web Services, Palantir and Faculty helped to build the NHS COVID-19 data store.
2. NHS England collect patient data related to Covid-19, from GPs and hospitals, call data from 999 and the 111 coronavirus helpline, and test and trace data from Public Health England. This is then checked by NHS England and uploaded to the secure NHS data store. This data is 'de-identified': personal information has been removed, but someone with the right knowledge and resources might be able to identify the individual.

What do you think about this data process? (*Prompts: What stands out to you here? Does anything surprise you, and if so, what? How do you feel about what you see?*)

**BBC Own It app:** here is an illustration of a BBC experiment with 'personal data stores', where a person's data is stored in a secure place that belongs to and is controlled by them. It is called Own It, and is currently available for use. Own It is a free app designed by the BBC to support, help and advise children when they use their phones to chat and explore the online world. Own It communicates directly with the child, without the involvement of their carer/s. Own It consists of a custom keyboard and companion application. The keyboard becomes the default keyboard for all apps used on the phone onto which the Own It app has been downloaded.

What do you see here? What does the visual tell you about what happens to personal data on Own It?

*Fill in the gaps – add to the description collectively produced by participants, as needed, for example:*

1. After a child has downloaded Own It, the Own It keyboard becomes the keyboard for all their mobile use.
  2. Through this keyboard, the app can gather data on what children using Own It type into their phone, how they 'self report' their feelings and their responses to quizzes and questionnaires set by the app
  3. Own It assesses children's phone use to provide 'in-the-moment support' (in the form of alerts or recommendations) for issues that children may experience
- EG 1: a child has the Own It app installed on her phone. She is about to send her phone number to a contact on a social media platform popular with children. Own It intervenes and says 'are you sure you want to send your phone number?'
- EG 2: a child is typing a message to a friend and receives an alert from Own It asking him whether he is sure he wants to send the message. This is because the Own It app has scanned the text of the message and identified words which suggest the child might be bullying his friend.

What do you think about this data process? (*Prompts: What stands out to you here? Does anything surprise you, and if so, what? How do you feel about what you see?*)

[where there are stages that don't get discussed here, let participants know that you'll come back to them later]

**Comparison:** These examples raise or address concerns **about data sharing**. We are now going to zoom in on some specific aspects of these examples and ask your opinion about them.

In these examples, where can you see instances of data sharing and re-use?

*Fill in the gaps – add to the description collectively produced by participants, as needed, for example:*

**NHS Antibiotic Research:** De-identified data is shared with and re-used by researchers at the University of Manchester to help understand and improve antibiotic prescribing.

**NHS Covid Data Store:** NHS collect data for the data store from a variety of sources, for example NHS England, Public Health England and 999 call data. It is collated in one single database and used to inform decisions. This data is 'de-identified': personal information has been removed, but someone with the right knowledge and resources might be able to identify the individual. The NHS are the legal data controllers and commercial organisations are given access to the de-identified data to enable them to process it. The access granted is under contracts which specify how this data can and cannot be used. Patient data and other advocacy groups were concerned that not enough detail had been provided about contracts with commercial partners to fully understand who had access to data, for what purposes and for how long. They were also concerned about the controversial history of some of these companies, such as Palantir. In December 2020, the contract with Palantir was extended to December 2022 (21 months after the first UK lockdown began). Lobby groups argued that the contract shouldn't be extended and that the public should be consulted about such things. In March 2021, the government conceded to these requests and paused the Palantir contract extension.

**BBC Own It:** The BBC will not see the data connected to the individual children who use it. The BBC states that all identifiable data stays on the child's phone/device. Using Own It produces anonymous, aggregated data (eg how much time has been spent on the phone, what emotions were identified, whether children using Own It have found recommendations helpful) which is not linked to individual users. This anonymous data is collected and used by the BBC to improve the app. The BBC often collaborates with university researchers and may share this anonymous data with them in the future to help evaluate and develop products like Own It. How do you feel about the ways data is shared in the examples?

Do you feel the same about all three examples? Are you equally comfortable / uncomfortable with all three examples?

Or do you feel differently about:

de-identified health data being shared with researchers for the purposes of health research?

anonymised & aggregated data about Own It app usage being shared with the BBC?

anonymised & aggregated data about Own It app usage being shared by the BBC with university researchers in the future?

Who is involved (eg NHS, BBC, commercial organisations)?

Why/why not?

I'm now going to share a link with you in the chat, which I would like you to click on. It links to a whiteboard which shows some of the benefits of and concerns about these data uses:

**Benefits of antibiotic research** = address public health crisis of antibiotic resistance

**Concerns about antibiotic research** = whose data is shared (could it be children's?); who the data is shared with (could it be pharmaceutical companies, who could eventually profit from it?)

**Benefits of Covid data store** = data gathered together in one secure place to inform the national response to the pandemic

**Concerns about Covid data store** = lack of clarity about who data is shared with & the contractual arrangements with commercial organisations; commercial companies may be able to use data from the data store to develop their technologies and potentially increase their profits

**Benefits of Own It** = children receive personalised wellbeing advice and support without identifying data about them leaving their device

**Concerns about Own It** = potential for anonymous data from Own It to be shared with University researchers & whether this possibility was made clear in the complex data agreement.

I would like you to move the post its with your name on to the position on the board that best reflects how you feel. Simply click and drag your post it- if you have a problem, I can do this for you, just let me know. Once all of the post its are in position, I will take a screenshot.

Can you tell me why you placed your post its where you did?

[discussion of benefits and concerns]

Having heard the views of others, do you want to keep your post it in the same position or move? If you would like to move it, please do this now. Once all of the post its are in position, I will take a screenshot.