



Interview & Focus Groups Questions on Theme 2: Data Ownership and Control

In this focus group, we will be looking at data uses and processes which address or raise issues relating to **data ownership and control** – that is, who owns and controls data about you.

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.

BBC personal data stores: The first two examples are taken from some BBC experiments with 'personal data stores.' In a personal data store, a person's data is stored in a secure place that belongs to and is controlled by them, rather than being stored and controlled by organisations, like the BBC itself, Netflix, or Facebook/Instagram, which is what usually happens. The first example is a prototype device called BBC Box. This is an experiment and is not yet in circulation.

What do you see here? What does the illustration tell you about what happens to data in BBC Box?

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

You use BBC Box by uploading data about what you watch or listen to (for example on the BBC or Spotify).

BBC Box then creates a personal profile identifying your likes and interests, based on this data and quizzes that you have completed.

This data and your profile are stored securely in the BBC Box, your personal data store.

You can then choose to share your personal profile with the BBC or other services.

If you share your profile, you will receive recommendations about content that you may like to watch or listen to, or things you might like to do.

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?*)

The second example is the BBC Own It app, which *is* currently available for use (unlike BBC Box). 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 children's 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?*)

B. 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 illustration? What does the visual tell you about what happens to patients' data in the data store?

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

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?*)

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

C. Comparison: These examples address or raise issues relating to **who owns and controls data about you**. We are now going to zoom in on some specific aspects of these examples and ask your opinion about them (p4, but also some aspects of previous pages).

What issues relating to data ownership and control can you see arising in these examples? Where is data stored? Who has control and ownership of the data in these examples?

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

BBC Box: People using BBC Box are the controllers of their data. They are in control of what data to upload to the box, who can access their profiles and whether to share their profiles to organisations in order to receive recommendations.

On **BBC Own It**, BBC collects anonymous data about how the app is used. This data includes things like how much time has been spent on the phone, what emotions were identified or whether children using Own It have found recommendations helpful (stage 4).

Children using Own It can control what happens to their data (stage 5). The BBC states that it will not see the data connected to the individual children who use it, and that all identifiable data stays on the child's phone or device.

This data is collected by the BBC for the purposes of app development, but it is not about and cannot be traced back to individual Own It users.

Children using Own It can control whether their anonymous data is shared by turning this feature off– information about the option to turn this feature off is communicated to in the Information for Parents section of the app.

NHS Covid Data Store: the NHS are the legal data controllers. The NHS have contracts with commercial organisations so they can act as data processors (stage 3). The access granted is under contracts which specify how this data can and cannot be used, but the details of the contracts are not transparent. 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.

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

Or do you feel differently about:

Adult BBC Box users controlling data about their viewing habits in order to control the recommendations that they receive?

Child BBC Own It users controlling their data without the involvement of a parent or carer?

Child BBC Own It users controlling whether they share anonymous data about their use of Own It with the BBC?

NHS controlling Covid-related data that multiple commercial organisations also have access to?

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 BBC Box = people control their own data & who has access to it; people receive personalised recommendations

Concerns about BBC Box = whether data is secure if all in one place; whether individuals have the time & expertise to manage their own data

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

Concerns about Own It = interventions in children's wellbeing take place without parent/carer involvement or knowledge

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 has access to data & 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.

If you feel like you can, I'm going to ask you to click on and drag your post it to a position between the benefit and concern. If the concern matters to you most you would place it closest to the red text. If the benefit matters most you would place it closer to the blue text. It's okay if you feel too unsure to move the post it at all, or if you are stuck in the middle you could place it on the dividing line. To move the post it, simply click and drag 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.