

Humanising Healthcare



Agenda

Co-production workshop

30th May 2025

10am-1pm

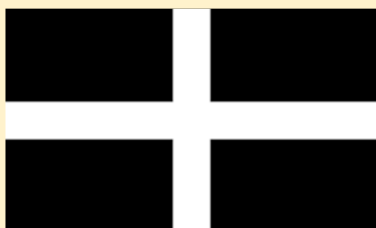
Things we will do



Welcome and reminder
about what the project is
about



Introductions



We will give an update
on the project

Things we will do



The main thing we want to ask you about today is something called **open data**



Open data is where information is put online and other people can use it for their own research.

Humanising
Healthcare

Co-production
Dictionary

We will add this word to our dictionary. We will explain this more when we get to this part of today's workshop

Update



We have now finished interviewing people.



We have been analysing interviews. We will do lots more next week. We will talk more about this at the next co-production meeting.



We will soon visit the research participants in Cornwall and Wales.

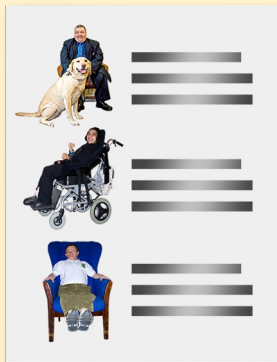
Part 1

A word from our dictionary

Data (1)



Data is information that we collect during this project.



Our project **data** includes information like:

- Facts about people who take part in the research
- What they tell us in the **interviews**
- Things we notice when we watch their health appointments



Data (2)



We **analyse** this data/information so that we can understand better.



We share summaries of what we find out.



We hope what we find out, helps people make better decisions about how to care for people with learning disabilities.

Data (3)



It is very important that we keep the **data** or information we collect very safe.



There are **laws** that help us keep it safe. **Laws** are rules that we all have to follow.



For example, we keep who people are safe by using fake names when we share what we find out.

Open Data Part 1



Open data is where information is put online and other people can use it for their own research.



The online place people put their data is called an **archive**. When we put data in the archive, we call this **archiving**.



More and more people are being told to archive their data and to follow open data guidelines.

In your other
research work, have
you been involved in
talks about **open
data** and/or
archiving?

Part 2

Open Data Part 2.1



We are funded by the Economic and Social Research Council. They get their money from the public.



As we are funded by the public, we have to engage with open data and archiving.



There are good things about this, but also some things we have to be careful with. We will talk about both today.

Open Data 2.2



There are lots of ideas that guide open data.



One idea is that data collected with public money, should be made open so it can help the public as much as possible.



Another idea is that we need to give enough information so that the data we archive is useful to others.

Open Data 2.3



We need to also make sure that we protect the people who take part in the study and take care of sensitive data.



Another idea is that we shouldn't waste this money or the time of people who take part in research.



You could reuse someone else's data to answer new research questions. This could save a lot of time and money.

Open Data 2.4

Example



On the Humanising Healthcare study, we are looking for the 'good stories' so we can find out what humanising healthcare looks like for folks with learning disabilities.



But other researchers could learn new things from our data if they asked different questions to us.



Questions like...

Open Data 2.4

Example



People's experiences of complaining about their healthcare.



What motivates nurses to choose to specialise in learning disability nursing?



How can we make waiting rooms more inclusive?

Open Data 2.5

Discussion



What are your first thoughts on **open data** and/or **archiving**?



Some other questions...



As expert researchers, what kinds of data would **you** be interested in?

Open Data 2.5 Discussion



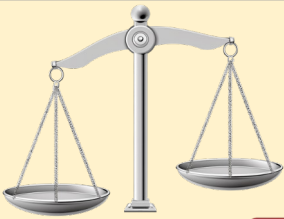
What kinds of data do you think healthcare workers would like to use?



What advice have you produced that we should share with others?

Part 3

Open Data 3.1



Data archiving has value, but we have to be very careful.



We need to protect the people who took part in the research.



We have so much data on everyone who took part. If we just put the data in the archive and change names, we think people could still work out who took part.

Open Data 3.2



We also have a lot of **sensitive data**. Sensitive data includes data like who a person is, their health, and disability.



There is an extra risk of harm if personal data is not looked after carefully.



Some people suggest that all sensitive data should be removed when archiving. If we did that, we would have nothing to archive.

Open Data 3.3



We also do not know what other researchers will do with the data.



Some researchers do think negatively about disabled people, and it does affect the research they do. We cannot stop them using the data.



We do not know if other researchers will co-produce the work with people with learning disabilities and/or autistic people.

Open Data 3.4



Some of the data also does not make much sense to people who did not collect the data. It is hard to give enough information so that other researchers can use it.



A lot of the data also involves Nikita and Bojana's data. Who they are is harder to hide than it is for people who took part in the research.



Some researchers who do observations argue that their notes from watching people in research should not be made public until they have died.

Open Data 3.4



Other researchers, like people who study race and the experiences of Black, Asian and indigenous people, think open data is a big problem when thinking about power.



For example, indigenous people know lots. But society does not value the things they know. Governments and the public have treated indigenous people badly. If their data is archived, what they know is now owned by the government and the public. That does not seem fair.

Open Data 3.5



We think this point may also be important for thinking about people with learning disabilities and autistic people.



Disabled people also experience discrimination. People with learning disabilities and autistic people know lots of things, but this is not always valued by society.



How can we properly value and showcase this knowledge, without doing harm?

Open Data 3.6

Discussion



What kinds of data are we comfortable with sharing?



We have different types of data.



We have interview data from people in Cornwall and Wales.

Open Data 3.7

Discussion



We have notes from when we have watched people's healthcare appointments in Wales and Cornwall.



We have the co-production and executive work we have done together.



We also have done interviews with you all, and the group interviews you did with one another.

Open Data 3.8

Discussion



How do we make sure that no one can find out who took part in the research from what we archive?



How do we archive in a way that is safe and fair to everyone involved?



How do we do all of this whilst sharing humanising healthcare stories?