

### **Thank you!**

Many thanks for taking part in our recent research survey! The University of Cambridge NHS/HSC Health Data Consent Survey (study registration number [ISRCTN 37444142](#)) was open from February to September 2020. It was anonymous, meaning that people taking part could not be identified.

### **Who took part?**

More than 29,000 people from across the UK responded to our survey about sharing health data. Most people told us they heard about the survey from their general practitioner (GP), hospital, or another healthcare provider. A minority heard about it from other sources including social media, charities, or from a friend.

### **Sharing identifiable health data for direct clinical care**

#### ***What happens at the moment?***

We asked about people's understanding of how their health data is currently shared within UK health services, for their own care. Thirty percent of participants (30 out of every 100) thought that clinical health data is shared across the whole of the UK without them being asked each time, and 14% that it was shared across their home nation (England, Northern Ireland, Scotland, or Wales). A further 42% thought that it is automatically shared across a region or a local area, and 15% thought that it was not automatically shared at all between different parts of the health service. In fact, some local areas and regions have automatic sharing systems, some nations have systems for sharing limited information (e.g. the Summary Care Record in England and the Emergency Care Summary in Scotland), and more are being developed, but there is no automatic sharing of health data across the UK.

#### ***What should happen?***

We then asked what *should* happen: should people's identifiable clinical data (data that identifies who you are) be shared for their own clinical care, without being asked each time? Fifty-five percent of responders supported sharing across the whole UK and a further 21% wanted it shared across a smaller area.

However, a significant minority of 20% did not want it shared without being asked each time. (3% were not sure.)

People were happier to share their identifiable clinical data with parts of the health service closer to home than further across the country. The longer the distance, the less people were willing to share. People were slightly less willing to share mental health data than physical health data. Forty percent of those taking part said they had had a mental health condition at some point in their lifetime (3% preferred not to answer), of whom 85% had used some form of mental health service, including their GP.

For this part of the survey, we also introduced a “framing” statement. This meant that you saw one of three different descriptions about the sharing of health data, before you answered questions about sharing your mental or physical health data. Which statement you saw was randomly allocated, meaning that everyone was allocated to see one of the three statements by chance. The statements seen were all true, but each expressed a slightly different perspective about health data sharing. One was a neutral statement, simply asking participants for their views about mental health and physical health data. The second possible statement mentioned previous surveys that had found greater concern about sharing mental health data than physical health data. The third statement talked about the ways in which mental and physical health illnesses affect each other, and the importance of “holistic” or whole-person care. We wanted to know how much these statements would “frame”, or affect, people’s preferences at the time. The “concerned” framing statement made people less willing to share their mental health data. This was a very small difference, but nonetheless shows the need for clear wording in future documentation.

### **Sharing de-identified health data for research**

Let’s move on to questions about the sharing of de-identified data (data with all details that can identify you removed) for research purposes. People generally preferred to share de-identified “structured” health data than de-identified “free text” data. As a reminder: “structured” de-identified data means diagnosis codes, blood tests, appointment dates, and so on, whereas “free text” de-identified data means descriptive information typed by health care professionals, after identifying information (such as names) has been removed. In principle, there is a slightly higher risk of being identified from free text data, although that risk remains extremely small and NHS research

systems are designed to prevent this happening. These differences in preference were small.

However, there were very big differences in people's preferences according to *where* the data goes. There was overall support for research sharing to the NHS, to academic institutions (such as universities doing research), and to national research charities. Support and opposition were equally balanced about sharing to profit-making companies researching treatments. There was overall opposition to sharing to other kinds of companies, and to sharing this kind of data publicly.

### **Changes in preference related to the COVID-19 pandemic**

We launched the survey in February 2020, and in March 2020 the national COVID-19 "lockdown" began. This might have affected people's views in several ways. NHS and NHS-related organisations were instructed by the government to share data in a different way (sharing more for purposes related to COVID-19), and this was covered in the media. Some of the press coverage related to how the UK could best stop the spread of COVID-19, and some coverage raised concerns about data privacy. About 8,000 people responded to our survey before the start of the first national "lockdown", and about 21,000 afterwards, so we compared preferences before and after this point. Overall, people's preference increased for national sharing of their data for their own clinical care. The same happened for some research uses of data.

### **How people should be asked about their own data**

A clear majority supported the idea of a single NHS/HSC consent system to choose how and where their data is used for clinical and research purposes. A higher proportion preferred to record their decisions through a web site or in person (at a healthcare setting) rather than by downloading an app or via a paper form.

The proposed consent form was generally well liked. People generally agreed that statements should be added about data security and where the consent information would be stored. They also suggested extra options for being contacted about research. Many commented that extra information should be provided about who exactly would have access to the data. Over 50% of responders were either unclear or unaware of the current NHS National Data Opt-Out.

## **Linking NHS data to other types of data for research**

There was broad support for linking de-identified health data (data that does not identify you) to other non-health data (e.g. educational data, housing data, etc.) for research. There was reluctance for linkage to data held by private companies: on average, people opposed this.

## **Volunteering for research**

Finally, we noted that there are currently many individual websites where people can sign up to take part in research. Examples we gave included charity websites, the national “Join Dementia Research” register, and the National Institute for Health Research (NIHR) “be part of research” campaign.

We suggested an alternative might be a national sign-up portal, on a web site, where people could register their preferences about taking part in all NHS research. Sixty-four percent of participants felt there should be a national NHS research website where people could sign up or register preferences. Fourteen percent felt this should be two separate websites, one for physical health and one for mental health research, and 13% felt everything is fine as it is (8% were not sure).

## **Thank you again!**

We hope this gives you an insight into the results from our survey. Further analysis of the survey results is currently underway and will be made available on our website [www.climbproject.org.uk](http://www.climbproject.org.uk) soon.

We would like to thank you once again for taking part in our survey!

With all best wishes,

The CLIMB study team