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## Data partnerships and the pandemic: reflections from our parliamentary webinar

By Tom Harrison, Senior Policy Officer.

Back in March we published [a report](#) which investigated what the public thinks about third parties accessing NHS-held data. By third parties we mean private companies but also charities, universities and other research organisations. We learnt a lot from the process which pulled together insights from three citizens juries and a national survey. The findings indicate that the public want to have a say in how health data is used and expect all data partnerships to focus on equitable public benefit.

Since we published the research, the response to Covid-19 has elevated the discussion about how to use health data to a new level of public and political consciousness. In light of this, we were delighted to outline our key findings to the [All Party-Parliamentary Group for Data Analytics](#) and the [All-Party Parliamentary Health Group](#) at an online webinar convened with [Policy Connect](#).

Here are 4 key takeaways from the discussion.



Left to right: Jack Tindale, Policy Connect; Pauline L'Hénaff, Open Data Institute; Chis Carrigan, useMYdata; Dr Murat Soncul, Government Digital Service; Lord Hunt of Kings Heath, Labour Spokesperson, House of Lords (Chair); Dr Natalie Banner, Understanding Patient Data; Simon Madden, NHSX. Source: APPG for Data Analytics Twitter.

## 1. Be open about private sector involvement

Our research clearly identified that concerns about private sector involvement are one of the biggest barriers to people feeling able to trust NHS data partnerships. Responding to findings outlined by Natalie, a clear theme amongst attendees and speakers was that concerns about third-party access to NHS data have heightened in recent months. This is due to high-profile data partnerships involving commercial companies, such as the [Covid-19 Data Store](#).

In his remarks, Dr Soncul, Head of Privacy at Government Digital Service, highlighted that the response to Covid-19 has identified good examples of data sharing and emergency research. But he also acknowledged that there's work to do in Government to improve transparency:

"It falls on all of us to be open about third-party involvement [in health data partnerships] and to address concerns, acting coherently, fighting against myths but also laying out potential risks. Central leadership on this is key."

## 2. Ensure there is a 'whole NHS' approach to forming data partnerships

Both our research and the discussion at the event have highlighted the need for more consistency around NHS health data partnerships. To make that happen, NHS organisations require support and tailored advice on the terms of agreements, and on decisions about governance, transparency and public involvement.

Reflecting on this, Pauline L'Hénaff, Senior Consultant at the Open Data Institute, called for a more integrated approach across the NHS in forming partnerships. More support would respond to what citizens told us in our research: they worry that NHS organisations could be outmanoeuvred in negotiations with large technology companies.

"We need a whole NHS approach: [we] can't just park it with the IT or legal side"

## 3. Involve people in decisions

Ensuring that the public have a say in decisions about access to NHS data was one of the key recommendations in our report. While Covid-19 presents challenges to involving the public because decisions need to be made at speed, panellists agreed there is an opportunity to involve people as [public understanding of health data use has recently increased](#).

It was encouraging to hear speakers agree that it's crucial to find ways to involve the public in decisions about NHS data. Simon Madden, Director of Policy & Strategy at NHSX, reflected on some of the work NHSX is doing, including appointing [two patient and public voice partners](#), and recognised that earning public trust in data use will be an ongoing process.

#### 4. Get communication right

There was broad agreement that the opportunities to generate new insight and medical advancements through data partnerships are too important to be missed due to poor communication. All the speakers recognised that the response to Covid-19 offers a unique opportunity to communicate with the public about the potential benefits of third-party use of NHS data. It is also what the public expect. 82% of respondents to our survey said they expect the NHS to publish information about health data partnerships.

Chris Carrigan, Expert Data Adviser at use MY data, argued that whilst awareness about health data has increased hugely since Covid-19, there's a need for more transparency about exactly how data is used:

"[Public] awareness has increased but [...] when you try to find out what's been done with data in response to Covid-19 it is actually quite hard to find and to shout about good examples."

#### What's next

It was brilliant to hear the findings of our research discussed in detail and with such enthusiasm. In the upcoming Data Strategy for Health and Care there is a clear opportunity to feed the views and concerns of the public into day-to-day NHS practice. The newly announced [Centre for Improving Data Collaboration](#) is also a good step towards this goal and we hope its work will be further supported by developments from the UK-wide National Data Strategy.

If you'd like to know more about our research findings or are interested in our work, we'd love to hear from you. You can write to us at [hello@understandingpatientdata.org.uk](mailto:hello@understandingpatientdata.org.uk).

[Download the full report.](#)