

Four lessons the pandemic has taught us about health data

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Data has played a critical role during the pandemic. It's helped to assess the impact of new treatments, track trends in the quality of care, and identify the needs of the most vulnerable. The government publishing data about the number of cases, hospitalisations and deaths has also been an important way for the media and public to track the impact of COVID-19.

As the UK slowly emerges from the pandemic, data can play a similarly significant role. This includes understanding longstanding issues (like rising levels of mental health conditions, and long waiting times for care), more immediate priorities (like [the rollout of Integrated Care Systems](#)), or even [how the NHS in England compares with other health care systems internationally](#).

At the Health Foundation, we have been on a journey since 2014 [to use data to improve health and care](#). However, the COVID-19 pandemic has been a steep learning curve for everyone. We want to be sure that we learn from the successes and failures in how data has been used during the pandemic and take advantage of the unique opportunities ahead to improve health and care for all.

Here are my four lessons from the pandemic with regards to health data:

1. Don't let missing data render some experiences invisible

Despite all the efforts to ensure datasets are representative of the whole population, the experiences of many groups remain missing from the data we collect about people's health. This affects the ability of the NHS and wider public health system to respond to everyone's needs.

To give one example, we know that people with learning disabilities are generally at increased risk from infectious disease. But four months into the pandemic, there was still very little data on how they had been affected by COVID-19, [as Chris Hatton explains](#). The situation steadily improved, but these information gaps made it much harder to marshal action for this group. Similar problems around missing data have affected many other groups in our society during the pandemic.

This raises a profound challenge for anyone interested in the use of health data. Missing data is not just a technical issue. We are increasingly reliant on data collected through digital systems, and the ability of people to use these systems is shaped by deep practical, economic, political and social considerations. We need to understand these impacts so we can design systems to work for everyone.

2. Include public and patient involvement as standard in health data projects

There are many reasons to involve the public and patients in health data projects. It gives the public confidence that their information is being used according to their wishes, and it can also make for a better end product.

Examples abound. The COVID-19 contact tracing app went on to make a valuable contribution to managing the pandemic. However, by any reckoning, it had a rocky start. This was in part because of public concern about how the data would be used, and whether the app was the right solution. These problems might have been avoided with more public involvement.

It's an approach that doesn't always come naturally to health data people. But we've been pushing ourselves to develop our own practice in this area at the Health Foundation, and are [already reaping the rewards](#)

3. Make open analytics the norm

A recurrent theme throughout the pandemic is that decision makers and the public haven't had access to the data they need. Often data is collected in different parts of the system, but isn't shared. For example, local public health teams haven't always had access to data held nationally. But where data has been shared in ways that are trustworthy, [massive leaps have been taken](#).

The [Open Data Institute](#) has done some fantastic work in supporting organisations to make their data open. It can be challenging, with technical and cultural issues to work through, but the benefits are a more efficient and transparent ecosystem.

Creating linked data systems is something close to our heart at the [Networked Data Lab](#), where we're also pioneering sharing the code as well as the data. We recently published our first analysis from the Networked Data Lab on [the pandemic's impact on the clinically extremely vulnerable population](#). My colleague [Kathryn Marszalek talks more here](#) about how open analytics could help us to address key issues for population health and care services.

4. Address the unequal benefits of data and technology

There is still a lack of good mixed methods data about the impact of technology on health inequalities. [A handful of studies in the United States](#) have indicated that people from specific minority ethnic backgrounds may be less likely to receive care as a result of new technologies, but these studies have not been replicated in the UK.

There are further reasons to be concerned. For example, [our polling during the pandemic](#) revealed that people in lower paid jobs were less likely to download the contact tracing app, despite arguably being at more risk of the disease. This apparent mismatch between need and benefit suggests the potential for technologies to be worsening health inequalities.

Over the last year, we've announced two new partnerships in this area. We're [working with the Ada Lovelace Institute](#)

to examine the impact on health inequalities of some of the technologies introduced during the pandemic. And we're [partnering with the NHSX AI Lab](#) to support research aimed at improving the impact of the next generation of artificial intelligence technologies on black and minority ethnic communities in particular.

What can be done?

Everybody can play a role in improving the impact that health data, and new data-driven technologies, can have. It's important to be relentlessly curious about how data shapes the world around us. During the pandemic, [food deliveries were prioritised using data in part drawn from non-confidential health records](#). That is a remarkable fact. Fast forward twenty years, what impact might health data be having on society?

Data teams need to ensure that data collections are representative, and that subsequent analysis is inclusive. They also need to be involving public and patients in their work, and sharing code using GitHub wherever possible. Managers need to be making resource available for this and should set aside time for their own development to learn about modern approaches to reproducible, ethical analytics.

With the right action, we can ensure that advances in the use of health data benefit everybody.

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