

## Comment

## Covid-19



# Data decisions

The pandemic has seen research needs put before privacy—should that continue?

**Cian O'Donovan** is a researcher at the UK Pandemic Ethics Accelerator, working from the Department of Science and Technology Studies at University College London

**M**asures brought in during crises have a way of becoming permanent, and of being applied in situations beyond those used to justify them. As the crisis stage of Covid-19 ends in the UK, a review of the temporary pandemic measures is now in order.

On research data, one key tool has been control of patient information (Copi) notices. It is usually illegal to share patients' identifiable information without their consent for purposes beyond their individual care. Copi notices, issued by the health secretary, not only make this legal, but require it.

One Copi notice, for instance, requires GPs to supply data to UK Biobank, a huge biomedical database that records the genomic and health records of 500,000 consenting patients. This can then be released to researchers. Other Copi notices have gone to NHS Digital, NHS England and local authorities.

Copi notices are a means of prioritising one set of values over another. During the pandemic, research practices that placed a premium on patient privacy have been traded for fast-flowing data.

These notices must be renewed every six months; unless NHS Digital requests another extension, the current

batch will expire in March 2022. At some point, the Department for Health and Social Care will have to decide what measures to keep, what to adapt, and what to de-commission.

The game to muster influence is already afoot. Experts in data science and artificial intelligence, convened by the Turing Institute, have noted that "consideration might be given to how the best aspects of Copi might be retained, whilst ensuring that the permissiveness does not undermine individual rights and protections".

## Uncertain times

There are important points on all sides. Researchers using the data are reluctant to give up their productivity gains. Privacy and open-science advocates want to shine a light on the infrastructure for public health data.

Perhaps the clearest argument is this: there is still lots of science to do. The data, disease specialisms and disciplines needed to understand long Covid, for example, remain uncertain.

Some researchers are likely to see Copi notices as a means of doing things that they should already have been able to do. This stance, though, risks overlooking a dramatic shift in public attitudes. Moves to use

emergency measures to drive post-pandemic data strategies must contend with increasing strains on citizens' confidence in public data.

This was evident in the summer, as the health department and NHS Digital were caught on the hop during the long-planned rollout of the General Practice Data for Planning and Research (GPDP) programme. In June alone, over 1.2 million people opted out of sharing their GP data.

The controversy shows that the debate around data and trust has changed. This is no surprise. Parliamentary committees have challenged the public value of huge spending on NHS Test and Trace, while campaigners against NHS privatisation objected to a £23 million contract that the government awarded US tech company Palantir to run the Covid-19 Data Store. If data controllers are struggling to gain trust, it is because goodwill has been squandered during the pandemic.

## Improving trust

Policymakers must recognise these changes. We don't know what the public thinks of Copi notices, because they haven't been asked. Neither do we know much about their long-term impact on research, although

work by the PHG Foundation is due on this soon.

NHS Digital cannot afford another GDPR-style controversy. Recent research by the UK Pandemic Ethics Accelerator shows that the public wants trust in institutions to be improved and meaningful involvement in pandemic policymaking. Without this, expanding emergency data measures risks perpetuating a cycle of distrust.

Data institutions must show they can be trusted and make a better case for public benefit. For instance, any process to make Copi notices permanent should be accompanied by public dialogue and open debate. The health department, NHS Digital and the UK genomics community must make the case for how public data benefits us all.

Data projects must also work out how to address individual and collective concerns together. Debates should not be reduced to individual privacy versus population health.

It looks likely that Copi notices will be renewed in March next year, possibly with the proviso that this is the last time. That gives data controllers 10 months to make a better case for why we all should buy into these benefits. That is less time than it might seem. ☹



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