Health data and Covid-19: taking action while maintaining trust

A recent Intelligent Health webinar brought together discussants from across the world to talk about the long-term implications of how data is being used in the response to Covid-19. There were three key reflections for organisations using health data. Written by Tom Harrison, Senior Policy Officer at Understanding Patient Data.

It's becoming increasingly clear that data is critical to overcoming the coronavirus outbreak. In fact, patient data has never been more central to public discourse. Infection rates, test results and cumulative death rates provide a daily benchmark against which measures to contain the spread of disease have been scrutinised. Health data has also been critical for identifying vulnerable people as part of 'shielding' strategies to protect those most at risk of Covid-19.

New models of sharing, analysing and using patient data for research and planning purposes are being trialled by governments across at the world at an incredible pace. We've already seen initiatives such as the Johns Hopkins Coronavirus Resource Centre established as a result of governments and industry sharing real-time data.

The dependence on data means that questions about how it is used have rarely been more important. Decisions made during this crisis could fundamentally change how health data is accessed and managed. Understanding Patient Data took part in a webinar on 3rd April to discuss these issues, alongside a brilliant panel which included speakers from the African Alliance of Digital Health Networks, the World Health Organisation and World Economic Forum. There were three main takeaways from the discussion.

1. Include sunset clauses on emergency commercial data partnerships

A pandemic requires many types of organisations (academic, charitable, commercial) to access and use health data to develop the intelligence that informs public health responses. There have a been a plethora of data partnerships created between many actors in response to Covid-19. In the UK, this has included some health data being shared with commercial retailers to identify citizens to prioritise for food delivery slots.

Recent research we conducted with the Ada Lovelace Institute shows that the public are only comfortable with commercial access to health data when there is clear public benefit. Data sharing agreements that support the pandemic response and benefit the public now, will need to be reviewed after the crisis when the balance between risks and benefits will shift.

Webinar panellists proposed 'sunset' clauses for data partnerships formed with commercial companies in response to the pandemic. This would ensure that partnerships are time-bound and created solely for the purposes of Covid-19 mitigation. Any data use beyond this would be subject to a further decision process and oversight.

2. Set new digital standards for contact tracing and symptom tracking

Discussants raised concerns about the long-term implications of using contact-tracing apps that have been part of the response in countries such as China, Singapore and South Korea. These apps notify users when they have been in close contact with another user

that has displayed Covid-19 symptoms,
and are proposed as a potential route to relaxing lockdown measures.

Whilst contact-tracing apps could be an important resource in slowing the spread of Covid-19, they cannot be a substitute for traditional tracing methods and require high levels of uptake to be useful. The Singapore Government has recently called for increased uptake of its contact tracing app TraceTogether, despite more than 1 in 6 citizens (1 million people) using it. There are significant concerns about reliance on smartphone apps exacerbating inequalities. And people will have lots of questions about how how data collected by these apps can be used, who gets access and how it's kept safe.

Panellists argued that due to the scale of take up required and the risks of creating a further digital divide, a global consensus on how to conduct digital contact tracing in ways that are secure and ethical should be developed. This must include measures that ensure data is used in the public interest and subject to oversight.

3. Be transparent when data practices are changing

The panellists agreed that transparency should be the key principle that governs how health data is used. This is even more important when public involvement is not feasible at the early stages of change and decisions must be made quickly.

Transparency means being open about:

1. what data will be collected
2. who will have access and for what purposes
3. how it will be protected
4. what will happen in the longer term
5. who makes these decisions and how

As much as possible, existing norms and practices around data use should be followed. However, confidential patient information may have to be shared more frequently than usual as part of public health measures, so it's especially important that the Government is open about how that data is being used. Natalie's written more about transparency, and how getting it right can be challenging - keep a look out for that next week.

Getting the balance right

Swift action is necessary in a time of crisis. But with little time to reflect or perfect, governments may be setting up norms and practices that could undermine public confidence in how health data is used in the long term. The webinar underscored that although countries are taking different approaches to data in the pandemic, issues of transparency, standards and community trust are common across all.