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Viewpoint: We need a European Health Data Space to tackle COVID-19

The COVID-19 pandemic provides a stark illustration of why we need effective tools for sharing health data in Europe, say four MEPs

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In 1854, John Snow, one of the first epidemiologists, defeated a cholera outbreak ravaging London by mapping the locations where the disease showed up and carefully analysing risk factors. That provided the data he needed to demonstrate the cause was sewage pollution in drinking water.

Almost 200 years later, we are confronted with an unprecedented health pandemic that promises to shake the core of our societies. Luckily, in 2020, we are much better equipped when it comes to the volume, variety, and velocity at which we can collect, store, access, and share data. And, in a time when the EU is stepping up with several initiatives, including stockpiling equipment, devices and medicines, and coordinating EU-wide guidelines for COVID-19 clinical trials, it is high time to deliver on a key point of our Health Commissioner's mission letter: a European Health Data Space.

The idea has been floating around for some time and has been discussed in various conferences, but now more than ever, we need effective tools for sharing health data in Europe, if we are to find a quick solution in the EU's darkest hour. Establishing a European Health Data Space is more than a case of securing competitive advantage from an economic or social point of view: it is a necessity. Given this, we are drawing attention to this idea once again, urging for it to become reality as soon as possible.

There are already many examples of how data and the artificial intelligence tools that leverage it, can be integrated and analysed to inform our response to COVID-19. BlueDot, a Canadian company that uses machine learning to track news, airline itineraries and health authority data, among other sources, was able to detect a surge in COVID-19 cases in Wuhan nine days prior to the World Health Organization's alert. Seegene, a Korean company, has created one of the most widely applied diagnostic tests for COVID-19, using a supercomputer to accelerate analyses of viral genomes provided by China, shortening the time this process usually takes from months, to three weeks.

According to a recent paper by Neil Ferguson, professor of mathematical biology at the Centre for Global Infectious Disease Analysis at Imperial College London, the two main approaches to defeating COVID-19 are suppression and mitigation. Both are needed to save lives and restart the economy. Early detection of an outbreak in communities is a key step in suppressing COVID-19 and mitigating its impact on our health systems, economy, and society.

As Ferguson notes, transmission will quickly rebound if interventions such as social distancing are relaxed. But models show that intermittent social distancing – triggered by trends in disease surveillance – may allow interventions to be relaxed temporarily in relative short time windows. However, control measures will need to be reintroduced if or when case numbers rebound.

Calibrating such a response will require widespread availability of data, and in particular secondary health data. This is even truer in an emergency scenario, such as that brought about by COVID-19, where evidence must be made available to the maximum number of people who can work with it with utmost speed. And that is where the EU can come in.

A European Health Data Space would enable pooling of the health data of EU citizens, collected under a defined and common health data standard. Such a standardised approach would allow for detailed comparisons between countries (or even regions), and underpin transnational clinical research and trials at a large scale. This would have tremendous benefits in terms of our response to the current COVID-19 crisis, but also in tackling common challenges in health policy in the future.

Of course, the idea of sharing health data raises very serious concerns about privacy and data protection, not to mention ethics. The data must be used responsibly, with due care, and kept safe. But there is a clear imperative that this data should be available for research - under strict democratic control.

In a paper examining some of the difficulties in opening up health data, published in the International Journal of Data Science and Analytics, Niels Peek of the School of Health Sciences at Manchester University and Pedro Pereira Rodrigues from the Faculty of Medicine at the University of Porto say, "The sharing of health data for research will increase our understanding of biology and medicine and thus lead to better decision-making and better health outcomes. This implies that non-sharing will, by necessity, lead to inferior decision-making and poor health outcomes, thus creating a moral imperative to share."

As this highlights, we must remember there is an opportunity cost to not responsibly sharing this data: the deadweight loss in terms of knowledge, treatments, and ultimately fatalities, is far too much to bear.

The circumstances we are facing cry out for the creation of a European Health Data Space, or at least its kick-off. One that can mobilise member states to deepen their solidarity through the sharing of

epidemiological data (for starters), so that we can tap into the potential of our researchers and universities – often ranked top in the world – and step up to the task of stopping SARS-CoV-2 and the disease it brings about: COVID-19. Our common future depends on it.