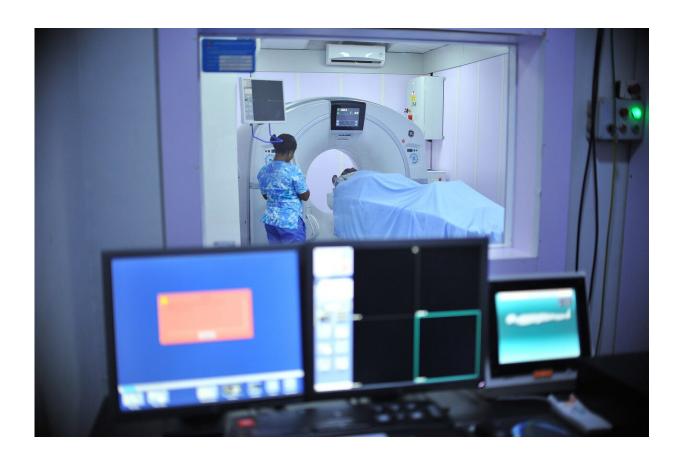# Medical Xpress

Coronavirus accelerates drive to share health data across borders

September 10 2020, by Richard Gray, From Horizon Magazine

Data-sharing can help with the next health crisis but that means privacy and technical issues need to now be addressed, say experts. Credit: Samuel Gabreil/Pixabay, licensed under the Pixabay licence

Allowing health data to flow more freely between countries in Europe could aid the fight against coronavirus while also help the region be

better prepared for future pandemics, but privacy and technical considerations need to be tackled sooner rather than later, say experts.

In the midst of a global pandemic, sharing information might seem like a mundane and rather unimportant part of the response to the health crisis.

But the willingness of national health agencies and researchers to exchange data across international borders is [a crucial element in the fight against COVID-19](#).

The SARS-CoV-2 virus was entirely new to humankind when it burst into the world in December last year, meaning scientists knew very little about how it spreads, the disease it causes and, most importantly, how to treat it.

But digital technology—combined with the will to cut through international red tape that normally restricts data sharing between countries—has meant [discoveries about the virus can be quickly shared around the world](#).

Sharing data has allowed scientists to exchange genetic sequences from the virus to track how it has spread, enabled doctors to quickly learn how to spot the symptoms of the disease, and given hospitals the ability to share the best ways of treating the virus. Pharmaceutical companies and researchers have also been able to use the information about the virus and patient immune responses to rapidly develop potential vaccines and drug treatments.

"We have seen with the COVID-19 pandemic just how successful sharing information can be in allowing collaboration across international borders," said Dr. Niklas Blomberg, director of Elixir, an intergovernmental organisation that coordinates the sharing of data and expertise in the life sciences across Europe.

Relationships

Dr. Blomberg says that relationships established as part of existing European research projects have meant some organisations were quickly able to adapt to sharing information about coronavirus. He and other experts believe, however, that greater sharing of health data between countries and organisations will be essential in the [ongoing fight against COVID-19](#), as well as helping to spot future potential pandemics earlier.

Formal, structured ways of sharing data could help make better use of the enormous wealth of health data collected across the EU to tackle other existing public health problems, adds Professor Milan Petković, head of data science at the electronics firm Philips and vice president of the industry-led non-profit Big Data Value Association.

"The creation of a common European health data space, in which health information is exchanged cross-border and which enables the participation of a vibrant ecosystem of stakeholders, should be a priority," said Prof. Petković, who also researches health data science at Eindhoven University of Technology in the Netherlands.

"This pandemic taught us some important lessons—first, about the importance and value of data sharing, and secondly that we still need to make further steps to improve."

Sensitive

Sharing the kind of data that has been so important in the response to COVID-19 is not as simple as popping it into an email and hitting send. A lot of health data contains personal and sensitive details about patients. Other important information is tied up in red tape that makes it difficult to share, while a lot of data is gathered by local hospitals or health

authorities but never shared beyond that.

"We need to unlock the value from data held by public sector bodies," said Prof. Petković, who pointed at the national portal to exchange COVID-19 patient data in the Netherlands that was set up by the Netherlands Ministry of Health in collaboration with Philips as a good example.

Elixir and a number of other pan-European projects aimed at setting up data sharing networks across Europe could also provide examples for how to overcome some of these barriers.

"We've been building this infrastructure primarily for the exchange of genomic sequencing data," said Dr. Blomberg. "There are nodes in each country that deal with the national coordination of life sciences research data and in particular genomic sequencing data. Then Elixir runs the services that allow member countries to connect and exchange that data."

Standardisation

Part of that work has involved developing standards for how genomic data should be collected, compiled and shared. Much like the standardisation of mobile communication networks that allow mobile phones to work wherever they are in the world, science and health data also needs to be shared in formats that can be used wherever they are needed.

Projects like the 1+ Million Genomes initiative, which Elixir is involved in establishing standards for, are working on agreements that will enable large amounts of genetic and health data to be shared across the borders of European countries.

"When the COVID-19 pandemic came along, we were able to use the

[foundations (Elixir) had put into place](#) to sequence the genomes of both the virus and the patients," said Dr. Blomberg. "It has been useful in helping to see how the virus is mutating and what determines why some people get sick and others don't get nearly as sick."

In April, the European Commission established a [COVID-19 Data Platform](#) to allow research data to be rapidly collected and widely shared, as part of their [ERAvsCorona Action Plan](#), and have drawn up a [manifesto](#) to make COVID-19 research results accessible. Many other pan-European projects also pivoted to find ways of tackling the pandemic and countries with strong national infrastructures to coordinate data collection responded quickly. Dr. Blomberg points to Spain, Germany, the UK, Sweden and other Nordic countries as having strong national coordination structures that allowed them to quickly share data on the virus.

"Those countries that were not already connected in established projects are requiring a lot more effort when it comes to sharing data," said Dr. Blomberg. "And we will face the same challenge in future disease outbreaks. We need to move from data sharing being something that is done in rapid response by the leading laboratories and institutions to being available to every research base in Europe."

For that to happen, he believes that data sharing needs to be built into the fabric of all European research projects so that information is collected, stored and shared in standard ways that allow it to be shared openly.

Privacy

It also needs to be easier for individuals to let the data they generate be used for the public good, added Prof. Petković. "For instance, a system could be developed at EU level to allow citizens or patients to make their health data available, if they wish so, for research without reference to a

particular research project," he said.

But this also needs to happen in a way that can guarantee the privacy of patients whose data might be collected, and that citizens can trust.

"In order for healthcare systems and the health industry to deal with a huge block of data, we need to be thinking about privacy by design and security by design," said Anett Mádi-Nátor, a senior cyber defence expert at Hungarian cybersecurity consultancy Cyber Services and a member of the strategic committee of the European Cyber Security Organisation (ECSO).

"Currently, most national healthcare systems are standing at point zero and patients don't have much control over their own data. We need to take steps to ensure that private individuals' health data is protected in a much more secure way."

Part of this may be addressed by projects such as MyHealthMyData and SHiELD, which are attempting to develop ways for sensitive health data to be shared in a more secure way. Mádi-Nátor also sees a role for artificial intelligence in helping to label health care that contains personal information.

"It can mark personal and sensitive data so that it has to be handled with special care and stronger technical support from a cybersecurity perspective," she said. "Once these sorts of services are up and running we can start discussing these with the European public to build up trust that will be needed for health data to be handled in a much more clever and useful way."

An important step along this journey was the creation of Europe's General Data Protection Regulation (GDPR) rules, but the computer systems and databases used by most health services still need to be

updated to ensure security is at the heart of their design.

"Most state-owned and managed systems are legacy systems that have no inbuilt security," added Mádi-Nátor. "Replacing these is not going to happen in one night—it will be a very long process that could take 10-15 years as they are made more secure step by step."

With global pandemics expected to be more common in the future, global sharing of health data could help the world better respond. It could also contribute to tackling other health issues such as cancers and rare diseases by allowing more information to be shared between countries.

"COVID-19 has been a really important driver for the European data spaces," said Dr. Blomberg. "But it could be leveraged further for other aspects of the health programme. It is a really important opportunity."

Provided by Horizon: The EU Research & Innovation Magazine

Citation: Coronavirus accelerates drive to share health data across borders (2020, September 10) retrieved 17 May 2024 from https://medicalxpress.com/news/2020-09-coronavirus-health-borders.html