Improving Global Public Health through Data Sharing

[Announcer] This program is presented by the Centers for Disease Control and Prevention.

[Sarah Gregory] Hi, I'm Sarah Gregory, and today I'm talking to Dr. David Heymann in the United Kingdom. We're going to talk about strengthening global public health surveillance through data and benefit sharing. Welcome, Dr. Heymann.

[David Heymann] Thank you, Sarah.

[Sarah Gregory] Dr. Heymann is a professor of infectious diseases and epidemiology at the London School of Hygiene and Tropical Medicine.

So, let's get started. Your study is about sharing of health surveillance data and benefits. What is public health surveillance?

[David Heymann] Well, public health surveillance, in short, is data that's collected in order to inform public health action. And that data could come from many different sources. It could come from hospital records; it could come from patient records held in outpatient departments; it could come from systems which are actively looking for disease and reporting on it; and it could come from digital sources, such as scanners on the internet looking for key words that might indicate an infectious disease. So, there are many sources of public health surveillance data.

[Sarah Gregory] And who are the stakeholders?

[David Heymann] Well, the stakeholders are the people who use that data, and that could range anywhere from a district or a state health department, through to a national government, or to others who are involved in activities with, that concern people's health.

[Sarah Gregory] In your article, you use the words "equitable sharing." What does this mean?

[David Heymann] Equitable sharing means that data and benefits are shared among the stakeholders, according to whether it's an individual need, an organizational need, or a public health need. So, in short, it's defined at the time that surveillance agreements are made. So, in one instance, it may be that sharing is equitable if data is given to a pharmaceutical company, for example, to use in their assessment of their medications and if the pharmaceutical company agrees to a special price for anything that's developed using that data. That could be one extreme example of equitable sharing. Another could just be the fact that someone, some country is sharing data for a global surveillance system that contributes to a global good, such as polio eradication, and the equitable sharing would result in eradication of that disease in all countries, including the country that shared the data.

[Sarah Gregory] So, I think you sort of already touched on where the sources of data might be found, but how do these systems work and who is responsible for them?

[David Heymann] Well, these systems work in many different ways and there are many different groups that are responsible for them. For example, the World Health Organization runs an influenza surveillance network which captures information from over 121 laboratories throughout the world that are constantly attempting and isolating virus from persons with

influenza-like illness. Those viruses are then sent to WHO collaborating laboratories and groups—the CDC in Atlanta is one—and genetic sequencing is done on those viruses and that's put into global databases. Global databases are then used each year when there's a meeting at the World Health Organization in Geneva, to reexamine all the genetic sequence material and decide which sequence is the most likely the next year's influenza epidemic, therefore should be used in the upcoming season's vaccine. So, that's an example of surveillance that comes from a hard virus, into a digital system, and then is used from that system to predict what the influenza virus will be the next season, and goes into vaccine production. So, the benefit is the vaccine, then prevention of influenza, and the data comes from the laboratories.

[Sarah Gregory] Can you give us some more examples of what kind of data is being collected?

[David Heymann] Sure. There's also data that's collected on a routine basis from health facilities. For example, here in the UK, all the records that are kept in emergency departments are electronic. And there have been thresholds established of normal and non-normal syndromes. For example, a syndrome of diarrheal disease plus fever, or a syndrome of coughs plus fever, these all have thresholds. And this digitalized data in emergency departments is scanned every 24 hours and, if there's a cluster of syndrome which goes over the established baseline, then there's automatically an investigational response that occurs to see whether or not this is a serious outbreak or whether it could be an artifact. There are also less sophisticated systems which exist in developing countries, such as just reporting the number of TB cases, for example, and the number of TB cases that are on treatment. That's very important for national programs to evaluate how they're doing in finding cases and also in treating them.

[Sarah Gregory] So, you said that that was important. So, that's just sorta an overall question: How important is collecting data?

[David Heymann] Collecting data is very important, but what's even more important is to know why you're collecting that data and how it will be used. And all that must be decided before the data collection and data analysis system is developed. So, in other words, the most important thing is to plan what is necessary and then develop the system to obtain what's necessary and make sure that it's used properly.

[Sarah Gregory] You mentioned digital disease detection in your article. What role does it play in this disease surveillance?

[David Heymann] Well, digital disease detection is very important and becoming more and more important because there are actually search engines that are searching the entire world wide web, in many, many different languages, looking for clusters of disease, which might indicate an outbreak. And when that's found and the data is cleared, it's examined, and it's verified by the World Health Organization, through its country and regional offices. And if there is indeed an outbreak, then there's a response that's made either nationally, or, if it's of international concern, globally.

[Sarah Gregory] So okay, elaborating on that a little bit, how do these surveillance systems help prevent outbreaks and disease, and why is it so important for countries to share their public health data, as opposed to just keeping it within the country?

[David Heymann] Well, some data can be kept in the country, other data should not be kept in the country. For example, if a country is involved in a global elimination or eradication program, for example, malaria elimination, then countries must know what to do with that data nationally. They must use it to identify where to either increase their activities in prevention and control, or modify them in some way so that they're more effective. But then contributing globally, it helps determine the global situation of malaria, but also it helps neighboring countries understand where malaria might be occurring on the border, that would be necessary to be jointly attended to. So, surveillance data, each bit of data has a different purpose. Some needs to be shared only locally, some needs to be shared globally, and some is of no use whatsoever. But it's collected and many times not used.

[Sarah Gregory] Ah, okay. I understand that some countries are hesitant or even unwilling to share their data. Why would this be?

[David Heymann] Well, there are many reasons why countries are not anxious to share their data. And one of the most important reasons is because, sometimes when they share that data, it ends up in the wrong hands or is misinterpreted and it costs their economy money. For example, when India, back in the 1990s, reported plague, pneumonic plague, to the World Health Organization, immediately, there were trade sanctions on India, tourism dropped, and many other reactions occurred that were really not rational, but occurred just because of global panic and fear.

The same thing happened in Latin America. Cholera first entered Peru in 199… in the late 1990s, after having disappeared from the Americas for 100 years. When it entered Latin America through Peru, it caused great panic. In that year, Peru lost over seven hundred million dollars because of lost trade and tourism. So it's very important that these diseases be handled in the right way, that the reports of those diseases be handled in the right way.

Another good example is in the cholera outbreak in Haiti. The data that was collected in Haiti was then analyzed genetically and it was determined that the bacterium that was causing cholera in Haiti might have come from Nepal, through the UN services, UN peacekeeping services, in Haiti. As a result, the announcement was made that there was a link, and immediately, there was violence in Haiti and there were actually people killed because of panic and concern that this virus had come in with the forces that were trying to keep peace in Haiti, all the way from Nepal. That data was handled poorly. It could have been handled much better, in a much better way, so that these reactions did not happen, but it wasn't.

[Sarah Gregory] Can you tell me what a good example of sharing data, I mean, how could have that been handled better, I guess is what I'm asking?

[David Heymann] Well, yeah. In Haiti, the data could have been handled better if the genetic sequencing had been thought through before it was done. What was the purpose of doing the sequencing? Was it only to try to put the blame on someone else about cholera, or was it done for some other reason? If it was done just to find out where it came from to blame others, that helps no one. The problem is cholera was and still is in Haiti and it should be dealt with immediately and properly, and not worry about where it might have, how it might have come into the country.

It was the same with HIV early on in the AIDS epidemic. Countries were trying to blame each other for having contributed to their HIV problem, when the problem was present in the country

and it should have been addressed in that country and not blamed on others. So, the blame game is very important in surveillance data and that's why, many times, countries don't want to share.

[Sarah Gregory] I see. Okay, so talk to us a little bit about the seven principles of sharing public health surveillance data that you mentioned in your article, and what do they mean for public health?

[David Heymann] Well, these are very important, important principles, and the first one is articulating the value, really understanding why you want to do or need to do surveillance and what that surveillance data will do for the general public or for the public good. So, articulating the value, understanding what you're doing, is very important.

Second is making a good plan for how not only you'll collect that data, but how you'll share that data—whether or not it needs to be shared in a district, in a region, in a state, or nationally, or internationally.

Third is making sure that the data that is collected is of good quality, making sure that there are quality control measures in place.

Fourth is understanding the legal context. In some places, it's not legal to take information that has the name of a person and share it with others, even if you unlink the information from the name. So, you must understand the legal context before you develop this system, which, or as you're developing the system, to make sure that you do have the value that you're expecting.

Then, another important principle is creating a data sharing agreement. And the best ones, of course, are those that are done informally. But if they can't be done informally for some reason, then there are formal steps that can be taken, anywhere from a simple note for the record or a legal document, such as a memorandum of understanding.

And above all, the most important is building trust among those who are sharing the data and those who are creating, those who are creating the data. So, that's extremely important, as well, is to build trust.

And the final principle is to monitor and evaluation, to make sure that that value that you've articulated and the planning that you've done are really doing what they're supposed to be doing. And that can only be done by monitoring and evaluating what's going on.

[Sarah Gregory] Dr. Heymann, you're an associate editor for the EID journal. Would you tell us a bit about what that entails and also a little bit about your job?

[David Heymann] Well, the EID journal is probably the world's best journal on emerging infectious diseases and I'm very privileged to be on the editorial board of it. That involves working with the journal editor to make sure that the journal is up-to-date and meeting the needs of the people and, at the same time, it involves sometimes reviewing articles or giving an opinion when an article has been peer reviewed and has been contested, or some other need for another review of an article. So the editorial board, of which I'm a member, just serves as a reference point and as a source of help to the editor, should that be needed.

[Sarah Gregory] And the editor you mean, the editor-in-chief, Dr. Peter Drotman?

[David Heymann] That's correct. When I say "the editor," I mean the editor-in-chief.

[Sarah Gregory] Tell me about your other job.

[David Heymann] Okay. Well, I actually had a long career at CDC. And that career involved 13 years in sub-Saharan Africa as a medical epidemiologist, two years in India with smallpox eradication, and then I was assigned for a long period of time to the World Health Organization in Geneva, where I headed many different groups, including emerging infections group and, finally, a group on infectious diseases. And during that time I had the privilege, actually, first-off at CDC, my first assignment, back in 1976, was to the first outbreak of Ebola hemorrhagic fever in DRC. And after that, I was based in Africa and responded to many outbreaks of Ebola hemorrhagic fever, as well as to outbreaks of monkeypox. And I then spent time in Africa working with malaria with Emerging Infectious Diseases and a whole series of childhood diseases, and then was assigned to World Health Organization.

[Sarah Gregory] And now, your job?

[David Heymann] Presently I'm in the United Kingdom. I've just completed one job, which was chairman of Public Health England, which is the center for disease control of the United Kingdom. I was in that role for 8 years and then I stepped down from that role at the end of last year. And now I'm a professor in infectious disease epidemiology at the London School of Hygiene and Tropical Medicine, and then a senior fellow at a think tank called Chatham House, in London, where we are working with WHO and other international organizations to address technical issues that have become too political for them to handle. And so we work with them outside the WHO environment, here in London at Chatham House, and do other activities, as well.

[Sarah Gregory] Thank you, Dr. Heymann, for taking the time out of your incredibly busy schedule to talk to us.

Listeners can read the entire July 2018 policy review, Strengthening Global Public Health Surveillance through Data and Benefit Sharing, at cdc.gov/eid.

This is Sarah Gregory for *Emerging Infectious Diseases*.

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