



Build the Ebola database in Africa

To build trust, capacity and utility, put local researchers in charge of planned platform, says **Brian Conton**.

When a weak, feverish person comes into a clinic in Africa, there is no quick, reliable way to know whether the illness is Ebola or one of many other diseases. This is in part why the Ebola epidemic in West Africa between 2014 and 2016 caused more than 11,000 deaths, overwhelmed infrastructure and brought so much loss.

This September, the Infectious Diseases Data Observatory (IDDO), a research network based at the University of Oxford, UK, held a meeting in Guinea to discuss plans for an information platform to share data obtained during the latest outbreaks, in hopes of improving responses in the future. It is now seeking further input on a collaborative research agenda. The team has promised to bring fellows from African institutions to work on the database and is assembling a steering group to set policies on who can access what data. The group will include representatives from countries that endured the outbreak as well as from research networks based in Africa.

The platform has yet to be established, and these preparatory efforts are well-intentioned. But in my opinion, having African scientists work on an information platform in another part of the world and at the behest of and under the jurisdiction of others does not confer the same benefits as working with local researchers to build our own tools on the ground.

As someone who has built one such database, I believe it would be more useful, and more equitable, to base the project in West Africa, at the front line of the battle against the virus. This will build capacity and trust. Once created, the platform should not become 'helicopter research', in which phenomena that occur in developing countries are studied for the benefit of foreign academic institutions. That often means that local scientists are not given authorship in publications. And worse, research can become skewed to fit the demands of Western academic careers, rather than solving the problems that the disease causes where it occurs.

During the outbreak, we had to treat people and do research at the same time. We had no vaccine and little to offer beyond rehydration. It took painful soul-searching to engage in studies while watching compatriots die. In my experience, some of the foreign institutions who came here to fight the outbreak had fewer compunctions. Even if they did not arrive with the goal of doing helicopter research, they quickly saw the need and the opportunity to gather data and patient samples. In some cases, this involved actions that would not happen in developed countries, such as unauthorized or poorly authorized taking of samples.

There were genuine reasons for circumventing bureaucracy: stocks of samples were building up that needed to be safely stored or destroyed. The outbreak countries did not have repositories of the right biosafety level to handle these. Nonetheless, many of us who

lived through the outbreak feel that data and samples from our people were used with little regard for our countries' or patients' sovereignty.

Now that we are between outbreaks, we have a chance to get this right. Those who contribute data and labour must be convinced that the final output will be relevant and usable. No one working in a field hospital in the bush will be consulting a database for help with a diagnosis. The goal of collecting and curating data is to understand incidence, distribution, prevention and control of the disease. We need to know if we will have a sufficiently large population to categorize symptoms and the efficacy of treatments. Finally, African countries should be able to develop and benefit from the bioeconomy. We need a frank conversation about who has what rights to pass results to commercial entities and who will reap any financial benefits. Before a data platform is established and contributors

of data are solicited, there must be a collaborative strategy that governs the generation of intellectual property and who will pay for analyses.

Critics of building the Ebola platform in West Africa will counter that the IDDO team, which is also working on platforms for malaria and visceral leishmaniasis, has better technical expertise and know-how. I believe local researchers have earned the right and demonstrated the capacity to lead this. Various teams including my own have already built platforms that track information from samples and medical records.

In my view, it is in the interest of science to build on these kinds of efforts rather than to assemble something new so far away. Our plan would be to function similarly to biobanks in the developed world, including charging fees to support our work. Storing samples and curating data

are expensive. The only way to make either sustainable is to carefully integrate all the data with the sample.

Whatever data platform is built, I believe that researchers in Africa can and should be building and curating it. A credible African-led initiative could convince people that the outputs of the data platform would be relevant to and usable by them. This could ease collaborations. No individual source has all the data required — organizations and research institutions from several Western nations erected Ebola Treatment Units, where samples and data were taken. An African-led initiative has a legitimacy that a third party does not, even one as prestigious as Oxford.

It would also give us researchers in Africa a better chance of establishing true collaborations that build on and acknowledge the scientific capacity we have. ■

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