

HighCountryNews

KNOW THE WEST

Indigenous data sovereignty shakes up research

In the COVID-19 era, tribal nations want research in service of their people.

Kalen Goodluck | Oct. 8, 2020 | *From the print edition*

As U.S. government scientists work to understand how COVID-19 affects the human body, tribal nations are still struggling with the impacts of the federal government's inadequate response to the pandemic. Now, through a National Institutes of Health program called "All of Us," tribal nations across Indian Country are pushing federal scientists to conduct disease research that serves Indigenous peoples in a meaningful way. Developing research practices in accordance with tribal consultation takes time, however, meaning that for now, tribal citizens are missing out on the program's coronavirus antibody testing.

The All of Us study aims to collect, sequence and catalog DNA representative of the United States' diverse communities. This [vast project \(https://allofus.nih.gov/protecting-data-and-privacy/research-projects-all-us-data\)](https://allofus.nih.gov/protecting-data-and-privacy/research-projects-all-us-data) will enable research such as Alzheimer's, diabetes and autoimmune diseases from across the country. But tribal nations are concerned about the ownership and control of this data, which can affect a number of things: patents and intellectual property rights, the privacy of tribes, future research and even access to basic information and health care.

"We're concerned about access to data as well as release of data without tribal permission," said Dr. Stephanie Russo (Ahtna-Native Village of Kluti-Kaah), University of Arizona public health [professor \(https://nni.arizona.edu/people/staff/stephanie-carroll-rainie\)](https://nni.arizona.edu/people/staff/stephanie-carroll-rainie). "What the pandemic has shed a light on is the need for tribes to have access to external data."



A production associate sorts through stacks of petri dishes of DNA samples. A nationwide DNA study currently will not test tribal citizens until tribes have been consulted about sharing citizens' data.

Aric Crabb/The Mercury News via Getty Images

The coronavirus pandemic has given the Indigenous data sovereignty movement a new sense of urgency. As pharmaceutical companies, researchers and governments scramble to create COVID-19 tests and vaccines, many tribal leaders and Indigenous data and public health experts are wary of participating in research that may have little benefit for their communities.

The Indigenous [data sovereignty \(https://usindigenousdata.org/\)](https://usindigenousdata.org/) movement [emerged \(https://www.maiamnayriwingara.org/projects-1\)](https://www.maiamnayriwingara.org/projects-1) in 2015, when Indigenous researchers convened in Australia to discuss research on Native peoples and Indigenous rights under the United Nations Declaration on the Rights of Indigenous Peoples. They concluded that Indigenous nations retain ownership over their citizens' data, as well as the power to decide how that data is used. All this made news earlier this year, when the U.S. was widely criticized for a major data breach that [leaked the financial data \(https://www.indianz.com/News/2020/04/20/broken-](https://www.indianz.com/News/2020/04/20/broken-)

