

# NEWS IN FOCUS

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The Navajo Nation's vast reservation in the southwestern United States is home to 174,000 people.

## SOCIETY

# Navajo Nation reconsiders ban on genetic research

*Tribal leaders are developing a policy for DNA analysis and data sharing.*

BY SARA REARDON

**W**hen the Navajo Nation opens its first oncology centre next year in Tuba City, Arizona, clinicians there may be able to offer a service that has been banned on tribal lands for 15 years: analysing the DNA of Navajo tribe members to guide treatments and study the roots of disease.

That's because the Navajo, the second-largest Native American group in the United States, are considering whether to lift their long-standing

moratorium on genetic research. The tribal government banned DNA studies in 2002 to prevent the misuse of its members' genetic material. Although there is still some apprehension about allowing researchers access to Navajo DNA, the tribe's leaders increasingly see genetic research as a tool to improve medical care for the 174,000 residents of their sprawling reservation, which is roughly the size of Scotland.

As it now stands, Navajo people who live on the reservation must drive hundreds of kilometres to access specialized medical care off

tribal lands, in large cities such as Phoenix, Arizona. "We spend millions of dollars outsourcing [care] for cancer and diabetes," says Walter Phelps, a delegate to the Navajo Nation Council. As the tribe — a nation independent of the United States — tries to expand the health services it offers, he says, "the moratorium could become a barrier when blood and tissue have to be collected".

Phelps is now working on the effort to create a policy by which the Navajo Nation would approve genetic-research projects ►

► and maintain control of DNA samples. The research-ethics board run by the tribal government's department of health is working with tribal officials and traditional leaders and holding a series of public hearings to solicit opinions on the matter from tribe members. The group hopes to deliver a draft proposal by the end of October. Whatever the tribe decides could influence other Native American groups, who have tended to be wary of genetic studies because of past cases of scientists conducting research without consent.

The Navajo Nation's new oncology centre provides part of the impetus for revisiting the genetic-research ban. It will be the first such facility on Native American lands outside Alaska. Allowing some genetic testing at the centre could help physicians to identify the most effective therapies for each patient, says Lynette Bonar, chief executive of the Tuba City Regional Health Care Corporation in Arizona, which will run the facility.

Creating a repository for such genetic material on Navajo land would also enable research into the genetic and environmental factors underlying many diseases, not just cancer.

So far, Phelps says, the idea of allowing some genetic research has not drawn major opposition. Many of the tribe members consulted about lifting the moratorium have generally supported the idea after learning how physicians could use genetic data to diagnose disease and tailor treatments. And the number of Navajo tribe members who are geneticists and medical experts has grown since 2002, bolstering the tribe's ability to evaluate proposed

protocols and represent its own interests.

Still, some Navajo have lingering questions about whether the tribal government can protect the privacy of their genetic material and maintain control over its use. Such concerns helped to shape the current ban back in the early 2000s, when the Navajo Nation's department of health conducted an outreach campaign about genetics and medical research.

"In the absence of a research code and lack of expertise at the time, they decided it was not a good time to move forward with genetic research until they were able to develop a research policy," says Nanibaa' Garrison, a member of the Navajo Nation who is a geneticist and bioethicist at Seattle Children's Hospital in Washington.

The tribe had reason to be cautious. "As Native Americans, we have a problem with trust because we have been violated so much," says David Begay, a pharmaceutical scientist at the University of New Mexico in Albuquerque and a member of the Navajo Nation's human-research review board. "In the past, our data have been misused."

Native Americans in the southwestern United States want to avoid repeating the experience of the region's Havasupai tribe. In 2004, the group sued Arizona State University in Tempe over alleged misuse of tribe members' blood samples. The Havasupai said that the samples, which had been collected for diabetes research,

**"As Native Americans, we have a problem with trust because we have been violated so much."**

had later been used in studies of schizophrenia, migration and inbreeding without their consent. The university reached a settlement with the tribe in 2010, paying US\$700,000 and returning the blood samples.

Sara Hull, a bioethicist at the US National Human Genome Research Institute in Bethesda, Maryland, says the case helped to change how researchers engage with the people they study, by raising awareness of the complexities of dealing with vulnerable minority populations. For Native Americans, privacy is a pressing concern. Science-funding agencies and journals often require researchers to put the genetic data they collect into public repositories, but the relatively small size of many tribes can make it easy to identify individual members in a genetic database. In recognition of this, the US National Institutes of Health sometimes works with researchers it funds to develop methods for sharing data on a minority group without compromising its privacy.

Garrison, who is helping the Navajo Nation to develop its new policy, says that the plan is likely to include rules on what types of research will be allowed, who will have access to tribe members' genetic material and information, and who will provide oversight. It is also likely to require that the tribe maintains ownership of its members' DNA samples and data.

The policy that the Navajo Nation ultimately produces could serve as a template for other Native American groups, says Ellen Clayton, a bioethicist at Vanderbilt University in Nashville, Tennessee. "If they reach an agreement, I think it will be influential." ■

## FUNDING

# Brazil's scientists plead to save funds

*If budget levels do not increase soon, research institutions could start shutting down next year.*

BY CLAUDIO ANGELO

**A**nxity is growing in Brazil over the country's collapsing research budgets. President Michel Temer slashed funding for science by 44% in March and has proposed additional decreases for 2018 — even as some science institutes run out of money for basic needs, such as paying electricity bills. The 2017 science budget, at 3.2 billion reais (US\$1 billion), is the lowest the country has seen in at least 12 years.

On 3 October, the government announced that it will release 440 million reais to science agencies to help keep them afloat until the end of this year. But that is only about 20% of what's needed, said the Brazilian Society for the Advancement of Science in a statement.

Researchers held a march on 8 October in São Paulo — the third such demonstration this year — protesting against the shortfalls. And in late September, 23 Nobel laureates and 9 of Brazil's scientific societies warned Temer that the ongoing funding uncertainties risk dismantling

research groups and prompting a brain drain.

They hope to influence Temer's administration as it revises the 2018 budget proposal (see 'Drastic cuts'), which was submitted to Congress by the executive branch in August. It included a 16% cut to the Ministry of Science, Technology, Innovations and Communications (MCTIC). The Temer administration has promised to release a revised budget in the coming weeks.

If the 16% cut remains, it would leave about 2.7 billion reais for 22 federal laboratories, 73 National Science and Technology Institutes and Brazil's major science-funding agencies — the National Council for Scientific and Technological Development (CNPq) and the Funding Authority for Studies and Projects. "This means institutions will shut down by August next year," says Luiz Davidovich, president of the Brazilian Academy of Sciences.

His estimate is based on what happened this year. The MCTIC started 2017 with 5 billion reais. In March, after the 44% cut, the ministry was left with 2.8 billion reais, or 3.2 billion reais if money for special projects such as the Sirius synchrotron is included. As a result, institutions began running out of cash in September.

"We don't have money for electricity bills or