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FEATURES

BRIDGING THE GAP

In a bid to ease a history of mistrust, a summer workshop trains Indigenous scientists in genomics

By **Lizzie Wade**, in Seattle, Washington

When Ripan Malhi started graduate school in anthropology in 1996, his lab at the University of California (UC), Davis, housed what he saw as a valuable scientific resource: a freezer of Native American blood samples. Burgeoning genetic tools offered a chance to study the population history of these groups, especially the still-mysterious timing of their ancestors' arrival on the continent. Malhi began to extract and sequence DNA from the samples, which his adviser had collected over many years. As his research went on, however, Malhi realized there were few other Native American samples to compare with those on hand. So, he decided to collect more.

He kicked off his effort with a lecture at a reservation in Northern California. It was the first time he had spoken with a Native American community, despite years of studying their genetics. Expecting to gather dozens of DNA samples, "I brought a bunch of cheek swabs with me," he recalls. But at the end of his talk on DNA variation and the importance of filling in sampling gaps, the room fell uncomfortably silent. "Then one person stood up and said, 'Why should we trust you?'" Malhi remembers. "That's a formative memory. I had not learned about anthropologists going to communities, taking samples, and just leaving."

He got no samples that day.

Malhi's experience was one small manifestation of the ongoing tensions between Western scientists and Indigenous communities around the world. ("Indigenous" is an internationally inclusive term for the original inhabitants, and their descendants, of regions later colonized by other groups.) Scientists have used Indigenous samples without permission, disregarded their customs around the dead, and resisted returning samples, data, and human remains to those who claim them. Indigenous communities have often responded by severely restricting scientists' sampling of their bodies and their ancestors, even as genomics has boomed, with increasing relevance for health.

But today, more than 2 decades after his wake-up call in California, Malhi, now a molecular anthropologist at the University of Illinois (UI) in Urbana, is part of an effort to change the relationship between these communities. On a recent

In 2010, members of the Havasupai Tribe look at DNA samples taken years before in an episode that fueled mistrust.

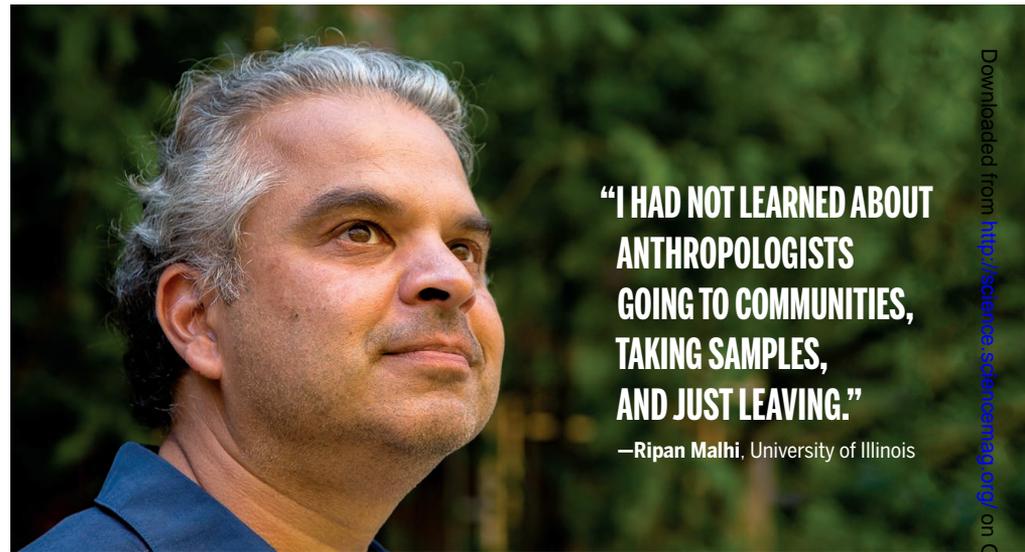
morning, Malhi listened as about 40 students and faculty introduced themselves at the Summer Internship for Indigenous Peoples in Genomics (SING), a weeklong program funded

by the National Institutes of Health and the National Science Foundation (NSF), and held this year at the University of Washington (UW) here. About half of participants spoke in Indigenous languages spanning the globe from Alaska to New Zealand.

SING aims to train Indigenous scientists in genomics so that they can introduce that field's tools to their communities as well as bring a sorely needed Indigenous perspective to research. Since Malhi helped found it at UI in 2011, SING has trained more than 100 graduates and has expanded to New Zealand and Canada. The program has created a strong community of Indigenous scientists and non-Indigenous allies who are raising the profile of these ethical issues and

"SING is so important," says geneticist Rasmus Nielsen of UC Berkeley, who is not involved in the program. Those who have taken part say it has equipped them with increased awareness of Indigenous concerns and how to prioritize them in research. In response to new attitudes, some communities say they might now consider working with geneticists. SING is also building what may be the best kind of bridge, one that is "the obvious solution" to the problem of mistrust, Nielsen says: creating "a new generation of geneticists within Indigenous groups."

ANY COMMUNITY DEMANDING that researchers slow down, change their questions, destroy samples, keep data private, and per-



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—Ripan Malhi, University of Illinois

developing ways to improve a historically fraught relationship.

SING grads and professors say the experience has profoundly affected their work. At SING, "you can exist as your authentic self, as both Indigenous and as a scientist, without having to code-switch all the time. It's like coming up for air," says Savannah Martin, a Ph.D. student in biological anthropology at Washington University in St. Louis, Missouri, and a member of the Confederated Tribes of Siletz Indians in Oregon.

SING participants are beginning to make waves in the broader scientific community. This year, SING alumni and faculty published ethical guidelines for genomic studies in *Science* (27 April, p. 384) and in *Nature Communications*. Echoing discussions at the workshops, those guidelines call for intense community engagement, especially in areas where Indigenous priorities may clash with those of Western science: questions of which research questions to tackle, when—or even whether—to publish, and how to handle samples and data.

Perhaps not even publish their results is bound to face skepticism from Western scientists. Some Indigenous communities, such as the Navajo Nation, decline to participate in genetic research at all. And many tribes don't permit research on their ancestors' remains. Such opposition can feel like a hostile stumbling block to Western scientists, some of whom have gone to court to gain or maintain access to Indigenous samples. Not being able to study at least some early samples would "result in a world heritage disaster of unprecedented proportions," the American Association of Physical Anthropologists said in 2007 in a debate over an amendment to the Native American Graves Protection and Repatriation Act.

To understand why so many Indigenous people distrust Western scientists, consider how intertwined science has been with colonialism, says SING co-founder Kim TallBear, an anthropologist at the University of Alberta in Edmonton, Canada, and a member of the Sisseton Wahpeton Oyate in North and South Dakota. "While the U.S.

was moving westward, stealing land, and massacring Indians, you had contract grave robbers coming out onto the battlefields and immediately picking up the dead—Native people—and boiling them down to bone, and sending their bones back east,” she says. Many of those skeletons were displayed and studied in museums by researchers who used them to argue for the biological inferiority of Indigenous people. Some of those skeletons are still there.

“Science was there, always. It’s part of that power structure,” TallBear says. Just 20 years ago, researchers sued for and won the right to study the Ancient One, also called Kennewick Man, a 9000-year-old skeleton from Washington, over the objections of Indig-

tion and the Apache in the U.S. Southwest, to see how they might be related. “When I was meeting with tribes to tell them about the project, they were very enthusiastic,” Gachupin remembers. “Every tribal community that I went to gave approval on the first visit.”

But at the same time, researchers working for the Human Genome Diversity Project (HGDP), a major international effort, were collecting samples from around the world to build a public database of global genetic variation. The project publicly emphasized the importance of collecting DNA from genetically isolated Indigenous populations before they “went extinct.”

That rationale “was offensive to Indigenous

and journals require scientists to make data public, so others can check their work. But that makes scientists the custodians of data, and it’s scientists who decide what research questions to ask and how to present the results. Many Indigenous people don’t want to cede such control to researchers they don’t know and don’t trust, let alone to the entire scientific community.

Gachupin, now an epidemiologist at The University of Arizona in Tucson and a SING faculty member, represents tribes when scientists want to work with them, to make sure the tribes’ wishes are respected.

Another such pioneer is Nanibaa’ Garrison, a member of the Navajo Nation. She was in college when her tribe passed its moratorium on genetic research. (According to an article in *Nature* last year, the tribe may lift the ban.) But Garrison went on to earn a Ph.D. in the field. “I wanted to find a way to do it better. To do things right,” she says. She’s now a bioethicist at UW and the Seattle Children’s Research Institute, developing ethical approaches to research with Indigenous communities. When Malhi got in touch about SING, she signed on right away. “I wanted to see more people like me,” in genetics, she says. “And I wanted to change the story.”

AT SING THIS YEAR, each day’s activities began and ended with Indigenous stories, songs, and prayers. In between, participants spent 6 days extracting and analyzing their own mitochondrial DNA, getting a crash course in bioinformatics, critiquing informed consent forms, and talking about the questions DNA can and can’t answer. Students spanned the educational spectrum, from undergraduates to public health professionals.

“We’re not trying to shelter [anyone] from Western mainstream thought,” Malhi says. The bioinformatics workshop even uses the HGDP reference panel—once so controversial—because it allows students to learn about both its uses and its fraught history. But this year’s program ended with an exercise that reminded participants of the complex social backdrop of such research: a drama about a fictional project to look for genetic links to suicide in an Indigenous community.

As students and faculty adopted roles such as researcher or at-risk youth, conflicts quickly arose: At-risk teens refused to offer blood samples for research that might stigmatize them. Public health workers pressed for holistic programs. Pharma reps gave proforma lectures. Before long, the university researchers who proposed the study quietly disappeared. Overwhelmed, they decided to go back to their labs and work on something easier, they admitted at the end of the exercise. Laughs of recognition rang through the

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—Kim TallBear,
University of Alberta



enous groups. (The Ancient One was eventually returned to five tribes who claimed him in 2017, after DNA testing suggested a genetic link between him and living tribal members.)

Many Indigenous communities see echoes of this painful history reverberating in the 21st century. In 2003, the Havasupai Tribe in Arizona discovered that samples taken for a study on diabetes had been used for research projects they had never consented to, including on population genetics and schizophrenia. They sued Arizona State University in Tempe, which eventually returned the samples and paid \$700,000 to the tribe (*Science*, 30 April 2010, p. 558).

Missteps by Western researchers have even hampered work by Indigenous scientists. For example, in the 1990s, Francine Gachupin, a member of the Pueblo of Jemez in New Mexico, was working on a Ph.D. in anthropology at The University of New Mexico in Albuquerque. She wanted to collect genetic samples from speakers of Athabaskan languages, who range from some Alaska Native groups to the Navajo Na-

populations worldwide,” Gachupin says. “Resources for infrastructure and for the well-being of the community were not forthcoming, and yet now here were these millions and millions of dollars being invested to ‘save’ their DNA.” The message from the scientific establishment was, she says, “We don’t care about the person. We just want your DNA.” Some activists dubbed the HGDP “the Vampire Project,” believing the only beneficiaries would be Western scientists and people who could afford costly medical treatments.

In the United States, Native American support for genetic research “changed overnight,” Gachupin says. She put her research on hold because tribes became so worried about data protection. She eventually finished her work, but the tribes “were not going to give permission for anything more.”

Meanwhile, the HGDP database, which includes more than 1000 samples from 51 populations worldwide, went on to become a key genetic reference panel.

What happens after data are collected can also lead to conflict. Many granting agencies



Participants in the Summer Internship for Indigenous Peoples in Genomics study DNA extraction techniques at the University of Washington in Seattle this summer.

classroom, as participants noted just how complicated ethical research with Indigenous communities can be.

In real life, everyone at SING aims to be the researcher who won't disappear. Lessons gleaned from the workshop may help. One key, TallBear says: "If you're going to work with Indigenous communities collaboratively on genetics, you have to be willing to make lifelong relations."

Malhi, for example, has spent years building relationships with the First Nations of British Columbia in Canada, particularly the Metlakatla and Lax Kw'alaams. He has shifted away from focusing solely on his original questions about ancient migrations to questions that matter to the communities themselves, such as their relationships with their ancestors. His study of ancient DNA published in the *Proceedings of the National Academy of Sciences* in 2017, for example, showed at least 10,000 years of genetic continuity in the region, supporting Indigenous oral traditions.

Malhi's graduate student Alyssa Bader, an Alaska Native with ancestors from British Columbia, is now studying the oral microbiome of these communities' ancestors by sequencing DNA preserved in their dental plaque. That's less destructive than sampling bones or teeth, and can reveal what these ancient North Americans ate, a subject their contemporary descendants are interested in because their traditional diets have been altered by Western foods.

SING has helped forge new research relationships. Through the program Deborah Bolnick, an anthropological geneticist at the University of Connecticut in Storrs, has established a collaborative research project with Indigenous partners in the southern United States. It took 4 years of conversation before they collected a single sample, but now they have nearly 150. One project is to see whether

maternally inherited mitochondrial DNA (mtDNA) corresponds with the communities' matrilineal clans. If so, mtDNA analyses might be able to restore clan identities to community members who had that knowledge stripped from them by colonization.

Malhi and Bolnick both say the communities they work with will always have absolute control over their samples and data, and even whether and how they publish their results. That's because many Indigenous people, still facing racism, worry that certain types of studies—such as the one on genetic risk for suicide in the SING role play—may further stigmatize them. As a non-Indigenous researcher, "You have to be willing to know that history and put in the labor to get beyond that," Bolnick says. "To do this work you have to be willing to not see yourself as the authority, but rather as somebody who is going to listen to other authorities."

THE INDIGENOUS RESEARCHERS SING aims to foster understand that history better than almost anyone. They are likely to remain a small minority, at least in the near future: In the United States, less than 1% of doctorates are awarded to American Indian and Alaska Native students, according to NSF, a statistic that has held steady since 2006. But SING offers them the chance to collectively think through whether and how they want to use genetic tools to study their own people. "If you're working with your own community, you're less likely to back out when you hit a wall," says Anežka Hoskin, a graduate student in genetics at the University of Otago in Dunedin, New Zealand, and a member of the Māori tribes Ngāti Porou and Ngāti Kahu. "And you're going to hit walls."

Martin says doing research with Indigenous people has prompted difficult reflections. She's studying the biological effects of racism and historical trauma on tribes in

the Pacific Northwest—work she hopes will include searching for epigenetic changes linked to that history. But she was wary of what might happen if a university or a granting agency demanded access to her samples. Going to SING for the first time in 2015 helped her figure out how to present data protection as a priority in grant proposals. "SING made me feel a lot more comfortable with pushing back against Western institutions," she says.

The tribes she works with have full control over their samples and data—and will decide whether the results are published. If not, "That's it, I don't get my Ph.D.," Martin says. "I've made my peace with that ... Indigenous sovereignty is more important to me than three letters after my name."

SING faculty member Keolu Fox, a postdoc in genetics at UC San Diego and a Native Hawaiian, sees a future in which genomics supports Indigenous self-governance rather than undermines it. "Our genomes are extremely valuable," he says. For example, he's starting to study a genetic variant first identified among Polynesian populations, including Native Hawaiians, that may protect against heart disease and diabetes, especially in people with high body mass indexes. It should be Polynesian communities who profit from that research, he says.

SING faculty member Rene Begay, a geneticist at the University of Colorado Anschutz Medical Campus in Aurora and a member of the Navajo Nation, is excited about her role in building this bridge. "I want to be at the table, to advocate for my people, to advocate for research," especially studies that may improve health care, she says. "I want us to ... have the advancements and the technologies that the world outside the Navajo Nation has. But I want to do it in a way that's on our terms." ■

Science

Bridging the gap

Lizzie Wade

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