Indigenous scholars confront the power, limitations of genomics

August 20 2019, by Diana Yates

Indigenous and non-Indigenous scholars, students and scientists participated in the SING workshop at the Carl. R. Woese Institute for Genomic Biology at the U. of I. SING alumnus Justin Lund, left, with researchers Jessica Blanchard and Yarrow Vaara, in the lab. Credit: Fred Zwicky

They traveled to central Illinois from Manitoba, Mexico City, Nova

Scotia and 18 U.S. states, bringing expertise in a variety of fields, including anthropology, biomedical engineering, ethics, health and environmental policy, law, neurobiology, and social and behavioral science.

Participants in the 2019 Summer internship for INdigenous peoples in Genomics spent a week together in the classroom and the lab, learning not only how to amplify and sequence a fragment of their own DNA, but also discussing the implications of genomics research involving their ancestors and communities.

This was the seventh SING workshop. It is offered most summers and moves to different sites in North America. Last year, participants gathered at the University of Washington in Seattle. This year, SING came back to its birthplace, the Carl R. Woese Institute for Genomic Biology at the University of Illinois at Urbana-Champaign.

The workshop is part of a broader effort to support Indigenous community members, scientists and students who want to improve their genomics education, explore the social and political ramifications of genomic tools and bring that knowledge back to their own institutions and communities. Indigenous and non-Indigenous scientists, scholars and students led the sessions and participated in the workshop.

"My goal in participating in the SING workshop is to become a better team scientist," said Jessica Elm, a citizen of the Oneida Nation, descendant of the Stockbridge-Munsee Band of the Mohicans and postdoctoral researcher at Johns Hopkins University's Bloomberg School of Public Health Center for American Indian Health.

"If a tribal community has a research question, I or somebody else should be able to assemble a team to answer those questions," said Elm, who studies how stress and trauma can affect the mental and physical

health of individuals, families and generations of Native Americans. "And tribes are starting to ask more complex questions."

One of the presenters, professor Amy Bombay of Dalhousie University in Halifax, Nova Scotia, also studies intergenerational trauma. She shared her findings on the effects of the forced relocation of tens of thousands of Indigenous children into residential boarding schools in Canada, a practice that started in the late 19th century and continued well into the 20th.

Bombay, who is Ojibway and a member of the Rainy River First Nations, presented her findings linking these traumatic experiences in parents and grandparents to substantially higher-than-average levels of depression, diabetes and suicidality in the survivors' children and grandchildren. Her research also revealed that those who rebuild their connections to their Indigenous communities and culture appear to be more resilient in the face of discrimination than those who are unable to repair those lost connections.

Some participants in the SING workshop said they sometimes struggle as they make their way in academic institutions with few other Indigenous scholars or scientists around.

Participants learn about mitochondrial DNA, which is inherited only from one's mother. Credit: Fred Zwicky

"When I was coming along in genomics, I found it really lonely," said Justin Lund, a Diné (Navajo) Ph.D. candidate at the University of Oklahoma who studies molecular anthropology and bioethics. Lund said the SING workshop offers a safe space where he and other Indigenous scholars can sort through the issues "better as a group, as a collective, rather than alone in your home institution."

In a laboratory session early in the week, participants who elected to use their own genetic samples for analysis took cheek swabs and followed a protocol that allowed them to isolate a tiny segment of their mitochondrial DNA. Then they amplified the DNA and sequenced it.

Mitochondrial DNA is inherited only from one's mother. Genetic researchers sometimes focus on one highly variable bit of mitochondrial DNA because it accumulates mutations more rapidly than other regions do, making it a better marker of recent changes in matrilineal lineages.

The science is not perfect, however, and interpreting the findings can be tricky, said laboratory presenter Deborah Bolnick, an anthropology professor at the University of Connecticut who studies ancient and contemporary DNA and is on the SING advisory board. Bolnick prompted participants to talk about the limitations of genomic science and the commercial services that claim to tell customers their ancestries or health risks.

Some participants said they were interested in the potential use of genomics in health research and personalized medicine. Traditionally, Indigenous populations are underrepresented in genetic and clinical health research, said Rene L. Begay, a Diné (Navajo) researcher originally from Salina Springs, Arizona.

In a perspective on the subject in *Nature Communications*, she and her colleagues noted that Indigenous people are thus "less likely to benefit from genomic research seeking to elucidate the biological (origins) of disease, which could aid in disease prevention and treatment and reduce future healthcare disparities." Begay is a research assistant at the Centers for American Indian and Alaska Native Health in Aurora, Colorado. She hopes to become a physician-scientist studying cardiovascular disease and genetics.

U. of I. anthropology professor Ripan Malhi, one of the originators of SING and a member of its advisory board, said the workshops are part of a larger effort to build relationships and develop better policies and protocols for anthropologists, clinicians, Indigenous scholars and others seeking to work in Indigenous communities.

"For example, at present there are inconsistent or no regulations for working with ancient ancestors," Malhi said. "And there are no requirements for working with descendant or affiliated communities, even though new scientific findings relating to their ancestors can have serious implications for them."

SING and similar initiatives build networks and knowledge among Indigenous scholars and community leaders, Malhi said, "making it that much easier for them not only to participate and collaborate, but also to take the lead in scientific research on initiatives important to the community."

More information: SING. A framework for enhancing ethical genomic research with Indigenous communities, *Nature Communications* (2018). DOI: 10.1038/s41467-018-05188-3

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