# POLICY FORUM

**GENOMICS** 

# Advancing the ethics of paleogenomics

Ancestral remains should be regarded not as "artifacts" but as human relatives who deserve respect

By Jessica Bardill, Alyssa C. Bader, Nanibaa' A. Garrison, Deborah A. Bolnick, Jennifer A. Raff, Alexa Walker, Ripan S. Malhi, and the Summer internship for INdigenous peoples in Genomics (SING) Consortium

ecent scientific developments have drawn renewed attention to the complex relationships among Indigenous peoples, the scientific community, settler colonial governments, and ancient human remains (1, 2). Increasingly, DNA testing of ancestral remains uncovered in the Americas is being used in disputes over these remains (3). However, articulations of ethical principles and practices in paleogenomics have not kept pace (4), even as results of these studies can have negative consequences, undermining or complicating community claims in treaty, repatriation, territorial, or other legal cases. Paleogenomic narratives may also misconstrue or contradict community histories, potentially harming community or individual identities. Paleogenomic data can reveal information about descendant communities that may be stigmatizing, such as genetic susceptibilities to disease. Given the potential consequences for Indigenous communities, it is critical that paleogenomic researchers consider their ethical obligations more carefully than in the past.

As Indigenous scientists and bioethicists, and allied non-Indigenous scientists, we offer needed Indigenous perspectives on ethical best practices in paleogenomic research involving the remains of our ancestors (where "ancestors" refers to all pre-Europeancontact individuals in the Americas as well as postcontact deceased Indigenous individuals

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from infants to elders). Currently, little legal structure or ethical guidance is available to help researchers determine ethical best practices for paleogenomic studies. U.S. Institutional Review Boards (IRBs) oversee human subjects research and protect research participants following the principles of the Belmont Report (5)-respect for autonomy, beneficence, and justice. However, because only living individuals are considered "human subjects," the remains of ancestors in the United States are designated legally and scientifically as "artifacts" and fall under the purview of the Native American Graves Protection and Repatriation Act (NAGPRA) (6) and the National Museum of the American Indian Act (7) (for remains held by the Smithsonian). Both laws provide guidance for consultation with federally recognized tribal nations in the context of determining the cultural affiliation of remains for repatriation. However, neither outlines research best practices nor requires consultation for research involving remains deemed culturally "unaffiliated." Further, aside from museums, ancestors uncovered on private lands or outside the United States do not fall under these laws. States like Hawai'i have additional laws regarding ancestors uncovered on private lands but do not provide ethical guidelines

With such uneven ethical terrain, community consultation and engagement practices have varied widely. Many studies have proceeded with little to no engagement. For example, a paleogenomic study of ancestors from Chaco Canyon, New Mexico (8), was recently published without tribal consultation because the remains had been deemed culturally unaffiliated. However, many Southwestern tribes have traditional knowledge and oral histories linking them to Chaco Canyon (9). Scientific studies of the Ancient One (Kennewick Man) (3) were also conducted

against the wishes of the Columbia Plateau tribes who sought repatriation of their ancestor. The results of paleogenomic analysis supported the tribes' efforts to repatriate the Ancient One, but the 20-year delay in reburial and the destructive analysis required were painful and disruptive for many community members.

#### COMMUNITY-BASED PRACTICES

To minimize harms in the future, we recommend that ancestral remains be regarded not as "artifacts" but as human relatives who deserve respect in research. As the deceased cannot give consent, present-day communities should be consulted. In this context, attention to place is paramount, as both the Indigenous peoples who reside nearby and those with ancestral ties to the region may wish to speak for the ancestor(s). Communities today are also affected by studies of ancestors, so engagement ensures that their concerns will be considered.

By adopting this approach, mutually beneficial relationships can develop between researchers and communities, leading to more robust science and productive collaborations. For example, coauthors R.S.M. and A.C.B. have partnerships with a First Nations community in British Columbia. The community is primarily interested in using paleogenomic studies to identify genetic links between living community members and ancestors in the region to corroborate oral histories and archaeological evidence of residing on the Northwest Coast for thousands of years. This genetic evidence of continuous residence may be more likely to be accepted by the Canadian government as support for treaty rights (10).

The Canadian Tri-Council Policy Statement (TCPS2) (11) governing human research ethics establishes protections for living and recently deceased individuals but not indi-

#### Indigenous scientists working with DNA samples at the SING Workshop.

viduals who lived hundreds or thousands of years ago. Thus, to ensure ethical and mutually beneficial paleogenomic research, the partners signed an agreement outlining expectations of the researchers and community before samples were collected for analysis from ancestors housed at the Museum of History in Gatineau, Quebec. Research team members visit the community regularly to communicate with research participants, elders, and First Nations government representatives. They review research goals and discuss results and language for presentations, manuscripts, and press releases. Two First Nations members also participated in the SING workshop (https://sing.igb.illinois. edu) to learn about the uses and limitations of paleogenomics as well as ethical, legal, and social considerations. This collaboration has yielded insights about the community's history from population genetic analyses of ancestral skeletal remains and metagenomic analyses of diet from ancestors' dental calculus. Elders and community members inform the inferences made from paleogenomic data, helping to distinguish signals of ancestral diet from genome database biases (12).

# **RECOMMENDATIONS**

If scientists lack knowledge of Indigenous cultures and concerns, unintended cultural harm, mistrust, and/or weakened political authority may occur for communities participating in or affected by paleogenomic studies (9, 13). Community engagement helps ensure that Indigenous peoples have a voice in this research. Our aim here is not to advocate a "one size fits all" approach but to provide ethical guidance applicable to many contexts and communities.

Ideally, researchers should hold discussions with Indigenous communities before research involving ancestors begins, to address the interests and concerns of the community (e.g., incorporating community research questions or using less destructive sampling methods). This should occur regardless of whether ancestors were uncovered on public or private lands, or considered "culturally unidentified" under NAGPRA. This term reflects processes that have obscured cultural connections of ancestral remains, including historical removals of Indigenous peoples from their homelands, archaeological collection practices that disinterred individuals en masse, and settler-colonial practices of labeling Indigenous peoples in ways that merged distinct peoples or misnamed them. Often, sufficient information (e.g., geographic location, items buried with ancestors) exists to identify potential communities for consul-

tation. Many Indigenous communities are intimately connected with the land where they reside, caring for both the land and ancestors held therein, even if they are not direct biological descendants. Geographically proximate communities are therefore appropriate to contact to begin engagement. If current research lacks community input, engagement should start immediately.

Recent technological advances have also enabled paleogenomic studies of DNA from dental calculus, hair, coprolites, and even soil, providing alternatives to destructive analysis of the bones and teeth of ancestors. However, community engagement is still needed in these contexts. Indigenous perspectives on the sacredness of materials from the body and earth should be considered, and paleogenomic studies of these materials can have social, political, and legal consequences for Indigenous communities.

To aid the process of community engagement, we offer these guiding questions for paleogenomic researchers to consider:

- **1.** In the absence of known descendant or culturally affiliated communities, which Indigenous peoples, tied to land where ancestors were buried, will be consulted?
- **2.** Who is the appropriate community body (e.g., tribal council, tribal IRB, elders) or representative (e.g., tribal president, historic preservation officer) to initiate discussions with about paleogenomic analyses?
- **3.** What are potential ethical pitfalls of this research or harms that could affect the community? What cultural concerns of the community, such as destruction of ancestral remains, need to be considered?
- **4.** How will the community benefit from the paleogenomic research?
- **5.** How will the community provide input on study design and interpretation of results? How frequently does the community wish to be contacted during the project?
- **6.** When community members participate directly in the project (e.g., as advisers or laboratory technicians), will they coauthor research publications and presentations? How do communities and individuals wish to be recognized in research products?
- **7.** What happens after the project ends? Who will have access to the data generated? How will remaining samples from ancestors be handled, stored, returned, or reburied?

Because Indigenous communities have diverse practices and views on genomics, the nature and structure of engagement will vary. Although it may not always be obvi-

ous how to proceed if different potentially linked communities hold differing views, we believe engaging with Indigenous communities should be as integral to the research process as hypothesis development.

#### SHIFTING THE STATUS QUO

The ethical practices proposed here will help paleogenomics avoid perpetuating the long history of unethical and exploitative scientific research with Indigenous communities, both in the United States and Canada as well as abroad (14). Increased community engagement will produce stronger scientific interpretations and improve relationships between scientists and Indigenous peoples, particularly as the number of Indigenous scientists grows. Currently, several initiatives are focused on building capacity for genomic research in Indigenous communities, such as the Genetic Education for Native Americans program that aims to increase communities' genetic literacy (15) and the SING workshop that teaches laboratory and computational skills while facilitating discussions of culturally appropriate uses of genomics. Programs like these help dissolve barriers and distrust. Ultimately, community engagement and capacity building will produce more robust, ethical paleogenomic research. ■

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#### SUPPLEMENTARY MATERIALS

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