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Boosting consent and collaboration: Key to ethical ancient DNA research, experts assert

In a paper published in a peer-reviewed journal, <u>*Communications Biology*</u>, researchers from the University of Cape Town (UCT) and Yale University argued for the implementation of informed proxy or relational autonomy consent in ancient human DNA research, where the deceased may be represented by living people the research affects.

The ethical issues surrounding consent in ancient DNA research are a major concern within the scientific community. Preserved in human tissues that are often hundreds or even thousands of years old, ancient DNA research demands careful consideration of consent and ethical practices.

Researchers have grappled with complex considerations surrounding the ethical treatment of human bodies and their components, the impact of cultural sensitivities, the responsible use of data, and the importance of fostering collaborative efforts.

"Most ancient human DNA research is not as regulated as research on living or recently deceased individuals. The lack of oversight is at least partly because most researchers in this field do not see their work as negatively affecting living people. But it can," said <u>Professor</u> <u>Victoria Gibbon</u>, a biological anthropologist in UCT's Division of Clinical Anatomy & Biological Anthropology, who led a paper with Drs Jessica Thompson and Sianne Alves.

The authors noted that embracing the underlying principles and process of informed proxy consent can potentially transform research in ways that benefit everyone. "It encourages long-term partnership building between researchers and other interested parties, which ensures project success and can also lead to interesting new questions. It also protects all parties by setting clear expectations," they said. "If all parties have a clearer understanding of what the research involves, then there is less chance of an unexpected problem arising later in the process."

Professor Gibbon said: "The paper is a culmination of considerations and thought processes around the rights of the deceased, how data from the dead impacts the living, and our responsibility as scientists."

Gibbon said ancient DNA is important and can offer much information and understanding about the past. "The technology is incredible! As a scientist, I see and am interested in the

value of this research, but I am also thinking about my responsibility to present and future descendants. Discussing informed consent is part of that thinking."

She said that when dealing with genetic data, which can provide intimate information about a person and their history, it's important to consider protection and long-term consequences for the decedent and the living communities they may represent.

"Open access ancient DNA is standard practice; this kind of thought work makes one question whether it's the only way. Is it what descendant communities want? Do they understand the risks? And who gets to decide?" Gibbon asked.

According to the paper, the need to use specialised ancient DNA laboratories, most of which are in the Global North, increases the risk of parachute research and ethics dumping.

"Being a researcher from Africa, sadly, extractive science is a reality, and there is inherent risk when the research team is predominately from outside Africa. It's the case that ancient DNA laboratories do not exist on the continent and also that DNA from Africa is complex and interesting to understand human origins and history; for these reasons, we need to chart a path and open dialogue about how informed consent can be accomplished for this kind research. And in a manner that is not extractive, but led with and alongside community partners where everyone benefits," Gibbon said.

The team shared that structuring the consent process to invite conversation, dialogue, historical sharing, and to ensure that the knowledge is co-developed and designed, offers reciprocity to community participants, especially because knowledge transference does not have the same impact (positive or negative) on a community as it does on researchers or institutions.

<u>Dr Thompson</u>, a biological anthropologist at Yale University, commented: "When I began collaborating with ancient DNA researchers, I was expecting to gain new insights about the people who once lived in my study area. That has surely happened, but something I did not anticipate was how much I would learn from the communities where I work. Spending time listening, reflecting, and taking different perspectives seriously has reframed the way I think about many aspects of my research – not just the parts that deal with ancient remains."

<u>Dr Alves</u>, director of the Office for Inclusivity and Change at UCT, shared: "In the <u>Sutherland</u> <u>Nine Restitution</u> process in South Africa prioritising community benefit and ensuring that informed consent incorporated full disclosure about the tangible and intangible benefits to the university was a significant element of the informed consent process. As a representative for the university in this process I focused on redress, which ensures that current practices within universities do not unintentionally replicate historical injustices that were deployed by some of the sciences.

"To fulfil informed consent that favoured the research participants I held meetings with the community without anyone from the science or core research team present. This method was an attempt to provide a space that gave the participants time to consider what would be meaningful for them, without any undue influence. I was honest about how the university, researchers and pharmaceutical companies would gain financially and in intangible ways because of the information and participation of the community. Furthermore, I asked the community participants to use their own methods of writing and expression (not all community members were literate) to record how they would like the community to be acknowledged in the research and how they would like to benefit from the

research. This important document was submitted as part of the university's ethics process and as a result was implemented and honoured throughout the research, publication, and restitution process."

Alves further said: "While no process is perfect, by declaring the benefits to the university during this process, the informed consent approach was modified through the inclusion of the participants requests, which the university was obliged to abide by. By doing so the method felt ethical, more inclusive and closer to redress because the community identified what would be meaningful for them as contributors to this research process."

The authors also noted that proxy informed consent in ancient DNA research could be an important element of a discipline-wide set of standards to which we willingly commit and hold one another, even without legislated mandates. "By taking these steps, we have the potential to transform our research approach from studying people to collaborating with and learning from their successors, prioritising research integrity, and enriching ancient DNA research outcomes," they concluded.

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