

### **Q&A: Indigenous community-first approach** to more ethical microbiome research

September 28 2023, by Francisco Tutella



The Penn State Ancient Biomolecules Research Environment uses a mixture of ancient DNA, anthropological microbial genomics and experimental models to explore and identify mechanisms of microbial community change and adaptation. Researchers work to translate these mechanisms to improve the world around us today. Credit: Penn State

Every person hosts trillions of microorganisms, like bacteria and viruses, on their skin and in organs including those that make up the digestive tract, like their mouth, that collectively make up their microbiome.



Microbiome research can lead to medical breakthroughs to treat diseases like inflammatory bowel syndrome and diabetes.

According to Laura Weyrich, associate professor of anthropology and bioethics at Penn State, <u>microbiome</u> samples from Indigenous communities have played an important role in furthering Western medicine, but those same communities often have been excluded from the research process and may miss out on the benefits that result from their contributions to science.

Two perspectives pieces published today (Sept. 28) in *Nature Microbiology* by an international team, including Weyrich, of non-Indigenous and Indigenous researchers look to rectify the issue. The articles, linked by focus in the questions below, lay out a framework for ethical microbiome research practices that include Indigenous communities and ensure that these communities reap the benefits from their contributions.

Weyrich; Weyrich's former graduate student Matilda Handsley-Davis, R&D communications specialist at Mærsk Mc-Kinney Møller Center for Zero Carbon Shipping; and Alyssa Bader, who is Tsimshian and an assistant professor of anthropology at McGill University, discussed their research guidelines and why Indigenous communities should have ownership of their microbiome samples.

#### Why are researchers interested in studying Indigenous microbiomes?

**Weyrich:** The single biggest factor that drives global microbiome differences is whether or not someone lives in an industrialized country. Industrialized microbiomes are now linked to many <u>chronic diseases</u>, such as obesity, diabetes and rheumatoid arthritis. Today, microbiome



researchers hope that Indigenous peoples' microbiomes—as a proxy for non-industrialized microbiomes—may provide new solutions to widespread chronic disease. Sometimes these are diseases that don't impact all Indigenous communities, which can result in an extractive process, where researchers are getting samples and information from Indigenous communities to solve problems that don't impact Indigenous people. The research needs to be equitable and beneficial for all involved.

**Bader:** The microbiomes of Indigenous people have increasingly been used as a point of comparison to study industrialized populations, particularly to understand how factors like diet and our environment have influenced the composition and function of our microbiome, with consequences for our health. Microbes associated with Indigenous peoples have been framed as valuable resources to restore lost microbial diversity and treat chronic disease in industrialized populations, but these research directions often do not center the research needs or interests of the Indigenous communities that researchers rely on for microbiome data.

**Handsley-Davis:** There are several reasons, but I think one of the biggest drivers is the increasing popularity of the idea that understanding Indigenous peoples' microbiomes will somehow help to solve chronic health problems that are widespread in the industrialized world. Another reason could be a desire to better understand health problems that affect Indigenous communities and that may be linked to the microbiome.

#### In one of the papers you introduce <u>'microbiome ownership'</u> as an ethical concept. What is microbiome ownership, and why is it important?

**Weyrich:** This means that someone could own or have rights to their own bacteria. The 'next generation' of probiotics to support health are



coming from people who donate their microbes—not yogurts or fermented foods, so establishing a framework for people to own their microbes means that they could benefit or profit from the commercialization of these microbes. This framework is important for providing equal benefits for research participants, research teams and companies that may want to commercialize someone's microbes to make 'next generation' probiotics.

**Handsley-Davis:** These discussions about ownership are really important because who is seen to 'own' a microbial community plays a huge role in determining who receives both commercial and noncommercial benefits from microbiome research. At the moment, we see a lot of benefit going to non-Indigenous researchers and companies. Part of the promise we see in microbiome ownership as a concept is to help rebalance this pattern, protect Indigenous microbiomes from exploitation and ensure that Indigenous communities get meaningful benefits from research on their own microbes.

#### What are some of the best practices that researchers can follow when working with Indigenous communities in microbiome research?

**Weyrich:** A mentor of mine once suggested that I should approach communities by asking, "What can I do to be of service?" rather than going into a community and asking if they will help with my research. Research requires building meaningful relationships with communities, and that also means understanding how you can be a contributing, respected member of that community. Our paper provides a starting point for researchers wanting to work in this space.

**Bader:** Research with Indigenous communities should be deeply collaborative, which means researchers work with communities as



research partners. In this research partnership, it's critical that researchers uphold Indigenous sovereignty throughout the <u>research</u> <u>process</u>. This includes ensuring Indigenous community partners have a central role in developing research questions, establishing protocols for research consent and data management, and interpreting and communicating results.

**Handsley-Davis:** Keep an open mind and put in the time to understand and honor community perspectives and priorities. Be prepared to step outside your own culturally specific understanding. It's also important to openly discuss the risks and benefits of a research project and agree on how they will be shared early on.

## In your paper, you also discuss the <u>concept of relationality</u>. What is it and how does it apply to microbiome research?

**Bader:** Relationality is the idea that we are interconnected with each other and our world. With this relationship comes the responsibility to act with care and respect. We use relationality as a framework to emphasize how humans, our microbes and our environment exist in relationship with each other, and our research ethics must recognize this relationship. When scientists study the microbiomes of Indigenous peoples, they aren't just studying microbes, but also engaging with Indigenous communities living alongside these microbes. Microbiome scientists need to consider how to enter a research relationship with both Indigenous peoples and their microbes respectfully.

**Weyrich:** Our papers center relationality in many ways, focusing on the linkages between researchers and communities, as well as the relationship between people and their microbes. We urge researchers to build and appreciate these relationships in their research to reduce potential harms and expand the potential of what is possible today in microbiome research.



# How can the concepts and guidelines that you put forward benefit everyone?

**Weyrich:** While this framework was developed alongside Indigenous colleagues and is centered around working with Indigenous communities, its relevance is much farther reaching. Community centered approaches with shared benefits for researchers and communities should be a foundational tenet of any research program. I sincerely hope that teams doing field research will integrate some of these tenets into their programs so that scientists can do research that is impactful at all levels.

**Handsley-Davis:** In the concepts and guidelines that are laid out in these two papers, we can see microbiome research actually take the lead in establishing ethical research partnerships and benefit-sharing with Indigenous communities. As we say in one of the papers, we see an opportunity here for researchers in this field to avoid the mistakes of the past.

**More information:** Matilda Handsley-Davis et al, Microbiome ownership for Indigenous peoples, *Nature Microbiology* (2023). DOI: 10.1038/s41564-023-01470-3

Alyssa C. Bader et al, A relational framework for microbiome research with Indigenous communities, *Nature Microbiology* (2023). DOI: 10.1038/s41564-023-01471-2

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