

# New guidelines for genetics research focus on equity, inclusion

February 6 2024, by Henry Houston

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Researchers at the University of Oregon have come up with new recommendations designed to promote inclusive and equitable genetics research, an area where medical science has had a checkered history.

Led by UO [history](#) professor Arafaat Valiani, a research team studied the historical experiences of people of color with medical and [genetic research](#) and developed [new guidelines](#) to ensure that people of color are included in such studies on terms that are equitable. Known as precision health equity, the recommendations call on geneticists and biomedical researchers to embrace a different approach to their work.

The recommendations were [published](#) in the December 2023 issue of the *International Journal for Equity in Health*.

Precision health is an emerging approach in clinical medicine that analyzes a patient's genome and its interactions with environmental factors. The core concept of precision health centers on comparing individual genomes with a database of disease-associated genetic markers associated with chronic conditions.

Given the histories and experiences people of color have had with science and biomedicine, Valiani and his co-authors invite geneticists and biomedical researchers to consider embracing the principles of precision medicine if such studies focus on communities consenting to participate.

"One of the central social determinants of health for people of color and Indigenous people is not being able to access [primary care](#), particularly preventative care," Valiani said. "Precision medicine, and the human

genomics tools that it's based on, are thought of by a cohort of medical researchers as a way to provide preventative care to these communities in conjunction with other initiatives to improve their health access."

Valiani is an associate professor of history and an affiliated faculty member in the Global Health Program in the College of Arts and Sciences. His team of co-authors include faculty members at Arizona State University, Trent University, and Cumming School of Medicine at the University of Calgary.

The guidelines build on insights from scholarship on Indigenous data sovereignty, which assigns to First Nations peoples the right to govern how their data is used. Precision health calls on research teams to develop meaningful and collaborative partnerships with communities interested in participating in genetic research. That allows those communities to have a voice creating data stewardship practices that govern how genomic data will be accessed, used and stored.

"Some communities are interested in seeing if they have traits for common conditions, such as diabetes, hypertension, [high blood pressure](#), high cholesterol, fatty liver, certain cardiac conditions (certainly not all have these). And of course, some are not," Valiani said. "For those that are interested, community members may want to know in advance so they can consider whether they want to explore preventative care and the kinds of advocacy that requires."

When a group wants to participate in genetic studies, Valiani said it's an opportunity to practice biomedicine differently. Communities of color can be partners in the research process and participate in designing studies by incorporating their health priorities.

"They're not just [blood donors](#) who never see the research findings or are excluded from the benefits of the study, as has been the prevailing

orientation of genetic research in the past," Valiani said. "Community members can participate in the research. If designed equitably, studies designed around (precision health) principles can mobilize the many forms of knowledge within the community and among researchers for mutual benefit."

Valiani and his team developed the guidelines during the Killam Laureateship and Visiting Scholars appointment he was awarded at the University of Calgary's Cumming School of Medicine.

Valiani and his co-authors hope that medical school classes incorporate more insights from the history of the life sciences, postcolonial science and feminist technoscience into their curriculum. That would help [medical students](#) understand how indigenous communities and people of color have been affected by past practices.

"Indigenous data sovereignty and precision health equity connect with post-colonial history and indigenous science and technology studies," Valiani said. "While medical schools include modules that acknowledge these histories, their medical study needs to be incorporated into the curriculum more robustly and to be a part of the training so that medical professionals are well-versed in these histories and experiences."

**More information:** Arafaat A. Valiani et al, Precision health equity for racialized communities, *International Journal for Equity in Health* (2023). [DOI: 10.1186/s12939-023-02049-4](https://doi.org/10.1186/s12939-023-02049-4)

Provided by University of Oregon

Citation: New guidelines for genetics research focus on equity, inclusion (2024, February 6) retrieved 28 April 2024 from

<https://medicalxpress.com/news/2024-02-guidelines-genetics-focus-equity-inclusion.html>

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