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Indigenous Genomics

STUDIES OF INDIGENOUS PEOPLES ARE A CRUCIAL PART OF GENOMIC RESEARCH, NOT ONLY TO DEFINE the extent of human diversity but to provide medical benefit to all people. There are more than 370 million indigenous people living in almost half the countries of the world. Exploding interest in indigenous genomics and global population structure has raised debate about issues of informed consent and community benefit. As was evident in March 2011 during the African and Southern African Society of Human Genetics Meeting in Cape Town, South Africa, the inclusion of indigenous people in future genomic research is paramount, but ethical guidelines must address local concerns. Scientific practices and values must be integrated with indigenous governance so that such genomic research can continue, with the benefits fully realized by all.

The indigenous world, composed often of marginalized and impoverished populations, has experienced social injustices for the purposes of scientific advancement for centuries. Ranging from unethical experimental testing (such as of nuclear weapons in the deserts of Aboriginal-occupied Australia), to the “biopiracy” of traditional knowledge and resources (such as of endemic plants and their medicinal properties), exploitation has produced a sense of distrust in scientific endeavors. Concerns need to be addressed before establishing protocols and seeking ethical approvals. For example, informed consent is generally overseen by an institutional review board that lacks representation by, or understanding of, the local indigenous population of interest. This is frustrating for locals, who may understand the benefits of the research but may not have a clear understanding of the facts, implications, and consequences of participation.

Language concerns range from inadequate translations to a lack of written indigenous texts. Whereas modern societies emphasize literacy skills, indigenous cultures may communicate through sensory stimulations (visual action) and description (storytelling). For example, in the Khoesan languages, a single “western” word may have multiple descriptive narratives depending on the context in which it is used, by whom it is used, and to whom the narrative is directed. By including communities early in the process, one can ensure an adequate translation and adaptation of informed consent protocols. Cultural practices also must be respected. For many indigenous communities, for example, the practice of group ownership would call for a group-based informed consent for genomic property that may require extensive community discussions, as is the case in the nonhierarchical Khoesan communities.

Going forward, the scientific community must do more to ensure the full and effective participation of indigenous communities in the research process, ranging from correct data interpretation and acknowledgment in scientific publication, to negotiating potential long-term commercial benefits, to maintaining ties after the research is completed. Access to such communities requires a long-term social obligation that considers basic community needs, such as access to water, nutrition, education, and medicines.

My own experience in sequencing the first Southern Africans’ genomes and exomes from Khoesan Namibian communities is perhaps illustrative.* The groups involved in this study have since communicated immense pride in the local and global recognition of their culture and history, and that this knowledge has had a positive impact on their youth. The project provided a platform for social empowerment by providing an opportunity for these voiceless communities to come together with local government, local media, and human rights leaders (including Archbishop Desmond Tutu) to enhance discussions about community needs. Indigenous genomic research must commit to bridging the communication and cultural differences between scientists and indigenes, creating additional knowledge-based capacities through bidirectional learning, while ensuring continued and sustained community benefit.

– Vanessa Hayes

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*S. C. Schuster *et al.*, *Nature* **18**, 943 (2010).



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