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ENGAGING NATIVE AMERICANS IN GENOMICS RESEARCH

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Native North American groups have rarely been included in population-based genetic studies (Need and Goldstein 2009; Reich et al. 2012).³ The tumultuous history of interactions between scientists and the indigenous peoples of the Americas has likely contributed to the dearth of genomic data on Native North American peoples. For instance, researchers who have taken blood samples in indigenous communities have often not returned to report and explain research results (Wichwar 2004). This exploitation of indigenous community members has created a mistrust of scientists (Schroeder et al. 2006) that leads many Native Americans to refuse to participate in genetic studies. Genomic scientists have reacted to indigenous mistrust by using methods that favor statistical workarounds (Wall et al. 2011) or convenience sampling rather than making the necessary effort to develop strong collaborative relationships with indigenous communities. As a result, the little genetic data that has been collected from Native American communities has not been very informative. Overall, Native Americans have opted out or have been left out of major genomic efforts to understand human genetic diversity from populations worldwide such as the International HapMap Project and the 1000 Genomes Project.

Genomic scientists have begun to engage in forms of community-based participatory research that involve mutually beneficial partnerships between scientists and Native Americans. An example of a large, successful partnership between genomic scientists and indigenous communities is the Northwest-Alaska Pharmacogenetics Research Network (NWA-PRGN; Woodahl et al. 2014). This partnership, which conducts basic and applied pharmacogenomics research, includes both indigenous and nonindigenous institutions

NOTE

¹*Drapetomania* was defined by Dr. Samuel Cartwright in the 1850s as a mental illness that caused slaves to run away. It is now understood as an example of scientific racism.

²Workshop on Social and Behavioral Epigenetics, held on July 29–30, 2014, in Potomac, Maryland, and supported by the NSF (BCS-1448213), Eunice Kennedy Shriver National Institute of Child Health and Human Development, and UK Science and Innovation Network, Economic and Social Research Council (ESRC), Biotechnology and Biological Sciences Research Council (BBSRC), and Research Councils UK (RCUK).

⁵These responses may be found at the following web addresses: <http://tinyurl.com/raffwadecritique>, <http://tinyurl.com/fuenteswadecritique>, <http://tinyurl.com/markswadecritique>, <http://tinyurl.com/waderesponsecritics>, <http://tinyurl.com/raffwaderesponse>, <http://tinyurl.com/fuenteswaderejoinder>, <http://tinyurl.com/markswaderesponse>.

³NHGRI-EBI GWAS (Genome Wide Association Studies) Catalog.

throughout North America.⁴ There are also numerous smaller-scale partnerships on genomic studies. Protocols that help develop trust and clearly define expectations for all stakeholders are particularly vital in these smaller partnerships (Malhi 2009). For example, formalized research agreements between scientists and indigenous communities and timely meetings allow the expectations for each partner to be defined and, if necessary, modified. The National Congress of American Indians (NCAI), with support from the National Human Genome Research Institute (NHGRI), has created an online Genetics Resource Center with templates and models of research agreements between scientists and indigenous communities that can be used to help initiate these partnerships.

Most genomic scientists are of European descent and lack detailed knowledge of the histories, cultures, and sociopolitical concerns of indigenous peoples. Indigenous scientists may be more likely to anticipate, recognize, and navigate potentially delicate social and political issues that arise in projects with indigenous peoples as participants (McInnes et al. 2011). There are now training and internship programs that aim at both increasing the number of indigenous genomic scientists and the general knowledge of the field of genomics in indigenous communities. In 1998, GENA (Genetic Education for Native Americans) began offering workshops on genetics at national conferences. Since 2011, we have been participating in the SING (Summer Internship for Native Americans in Genomics) program of one-week workshops aimed at facilitating discussions between indigenous students and genomic researchers, dissolving barriers between indigenous communities and scientists, and providing students with access to active researchers in the field. Because most scientific research is rooted in Western thought, we examine how genomic tools can complement indigenous forms of knowledge in ways that serve Native American interests. We discuss, for example, how indigenous communities can use genomics to aid in the stewardship of nature, improvements in the health of community members, and legal claims of land and ancestral remains. Combining ethical, legal, and social discussions surrounding historical Native American encounters with science and hands-on training in the latest genomics techniques and analytical programs, the SING workshop helps prepare participants for future leadership positions in science, research, and teaching careers. Beyond the academic training component, programs like SING help to foster networks for Native students to explore potential research interests and voice concerns in a socially supportive space.

Developing and maintaining mutually beneficial partnerships is an important step in improving the quality of genomic studies. Such research requires appropriate and ethical sampling, which cannot be accomplished without mutual respect between indigenous communities and scientists. Training and supporting indigenous scientists to be leaders in their fields increases indigenous community knowledge about genomic research and diversifies scientific research perspectives. Community partnerships also require scientists to personally engage with populations of interest, contributing to a stronger, more nuanced understanding of the social context of research questions. The creation of such diverse research teams will lead to better genomic science (Paige 2008).

⁴Applied research to use biomedical data to develop drugs and appropriate dosage for patients.

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