



The Life Rope: Engagement of Diverse Populations for Recruitment and Representation in Genetics

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The Mountain States Genetics Regional Collaborative Center (MSGRCC) represents and serves eight states in the mountain west – Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah and Wyoming. The region is home to a large number of diverse communities and underserved populations. Arizona, Nevada, New Mexico, and Texas have larger concentrations of Hispanic/Latino populations than the United States' average. The Mountain States region also has a higher percentage of Native Americans than the US, and in the four states along the US-Mexico border, a language other than English is spoken at home in one quarter to one third of all households. As a result, clinical and community providers in the Mountain States region are challenged to deliver genetic services to unique populations of Americans, many of whom are culturally and linguistically distinct from the majority population.

Nevertheless, these racial and ethnic groups are underrepresented in the MSGRCC. Recruiting minority individuals to participate in planning, implementation and sustainability for genetic services is a persistent problem for the MSGRCC. This dilemma also persists in other genetic fields. For example, only 11.0% of all medical geneticists and 7.0% of genetic counselors are minorities.¹ This implies that only a limited number of minority genetics patients are able to see a clinical provider of their same race or ethnicity. This becomes especially important for treatment of diseases that disproportionately affect certain minority populations.

Given these data and the geographic and population diversity in this region, the MSGRCC is working to identify new methods for genetics professionals to approach and effectively serve the vast diversity of individuals in our country. There are three primary issues that arise when attempting to engage minority populations in collaborative activities in genetics: knowledge and understanding of genetics, relationships with professionals, and access to information and resources.

This white paper will explore these issues in the context of the Native American community and, in particular, the people of the Navajo Nation, whom we will refer to as "The People." However, the principles of recruitment outlined will apply to many minority populations and should be considered when trying to engage them. This is not a step-by-step process but, rather, a guide to the issues that professionals should consider. Appreciation for the uniqueness of minority groups will only enhance clinical and public health outcomes.

¹ Mittman, I.S., & Downs, K. (2008). Diversity in genetic counseling: past, present and future. *Journal of Genetic Counseling*, 17, 301-313.

Knowledge and Understanding of Genetics

The general public has a limited understanding of genetics, genetic services, and the genes that make up their bodies.² Many minority populations are not even comfortable with the term “genetics”. The word can imply several different definitions and can be perceived negatively. Evaluation data obtained during the April, 2009 Community Conversation on Genetics with the Navajo Nation indicate that some participants were not aware of newborn screening or the genetic diseases that affect their community. Several responses also spoke to the incongruous relationship between culture, genetics, and scientific research:³

Navajo philosophy and creation story make it difficult to fully accept genetic research.

Many Navajos are tired of research and many do not understand the importance; genetic studies may be confused with cloning.

As implied in the comments above, it is inherently difficult to overcome perceptions of genetic research and genetics generally. As such, genetics professionals and collaborators must take into account the belief systems and culture that exist in minority communities. This is especially true when undertaking recruiting activities in collaborative projects and genetics programs.

Recommendation 1: Adequately assess stakeholders that are missing from the program and why they are not participating.

Recommendation 2: Research the community from which new participants are being recruited and identify their perceptions of genetics.

Recommendation 3: Prepare to talk about genetics using terminology, language and examples that are familiar to the community. For instance, demonstrating genetics to The People is easier when using examples such as corn farming or “rez dogs” that are mixed breed. This demonstrates that The People have actually been involved with genetics for a long time. Furthermore, it is important to note that not all languages have words for common English words such as DNA (described by The People as “the life rope”) or cancer (“the sore that does not heal”).

Recommendation 4: Develop a description of why individuals from the community would benefit from participating in genetics projects and collaboratives and their expected role in the project.

Relationships with Professionals

[We need to identify] how service providers who are either non-Navajos or Navajos [and are] unaware of cultural taboos/feelings/concerns, can still discuss genetics with families

² Lanie, A.D., Jayaratne, T.E., Sheldon, J.P., Kardia, S.L.R., Anderson, E.S., Feldbaum, M., & Petty, E.M. (2004). Exploring the public understanding of basic genetic concepts. *Journal of Genetic Counseling*, 13, 305-320.

³ Mountain States Genetics Regional Collaborative Center. (May 2009). *Report of the Community Conversation on Genetics with the Navajo People*.

with respect. – Participant, Community Conversation on Genetics with the Navajo Nation, April 3, 2009

Successful recruitment to genetics projects and collaborations will depend on community perceptions of and experiences with their clinical providers and the public health system. Relationships remain a vital component to any successful medical or public health program. The connection with a local, trusted community member will help facilitate entry into a target community. For example, the MSGRCC has used current members representing underserved populations to identify new participants from the same community. This process is preferable to approaching the community without introduction or previous collaboration, which can add to the time it takes to develop the relationship. Attending special cultural and community events allows the community to recognize the professional as a partner who is interested in learning and building trust.

Recommendation 1: Research the structure, hierarchy and customs of the community in which you are trying to recruit. It is imperative that genetics professionals enter a community with an understanding and respect for the way in which decisions are made. For example, the Navajo Nation believes in a holistic approach to health and their decisions may be made within this context.

Recommendation 2: Prepare to ask questions about how the individual would prefer to interact with the system, based on their cultural preferences. Be straightforward and upfront about what the professional does not understand.

Recommendation 3: Learn to say hello, goodbye, please, and thank you in the community's primary language. This will build trust and demonstrate respect.

Recommendation 4: Develop a plan to involve providers in the learning about underserved populations. Not only will new recruits see that providers are interested in learning about their culture, but providers will also see benefit in their clinical practice.

Access to Information and Resources

When asked if they learned anything new during the Community Conversation on Genetics with the Navajo Nation, one participant wrote:

The strong testimonies provided by the parents who had children with genetic disorders reinforce the need for genetic research on the Navajos reservation.

Engaging minority individuals and families affected by a genetic disease will give them a network of support and will allow genetics professionals to learn more about underserved populations and gain credibility. In addition, these individuals are linked to local groups that can provide valuable information to the community about genetics.

Recommendation 1: Develop community partnerships. Not only do community organizations and leaders understand the local culture, they can get involved with recruiting and education

efforts. The partners will help professionals gain acceptance in the community and disseminate information and materials. Examples of partners include: Head Start programs, the Indian Health Services Community Representative Programs, faith based programs, Family to Family Health information centers, Parent to Parent, early intervention and senior citizen programs, and local cultural programs. Other partners include Genetic Alliance, Family Voices, the National Center on Cultural Competency, AmeriCorps, State Title V programs, National Head Start, Congress of American Indians, National Council of La Raza, and National Alliance for Hispanic Health, city's Chambers of Commerce including those focused on minority issues - Hispanic, Chinese, Native American, African American, Filipino Chamber of Commerce all are great resources.

Recommendation 2: Review existing program literature and resources to ensure cultural appropriateness. To the extent possible, try to provide tools in multiple languages and with culturally sensitive graphics.