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A Collaborative Community Model for Including Minorities in Genetic Research

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Genetic research has largely excluded ethnic minorities, contributing to a disparity that has far-reaching consequences for health, longevity, and quality of life in these populations. As of 2016, the percentage of genome-wide association study participants who were of African, Latino, Pacific Islander, Arab, Middle Eastern, or Native American descent was less than 3% combined. Most participants (81%) were of European ancestry.¹ Many hereditary diseases that chronically over affect minority populations, such as primary open-angle glaucoma, have mainly been studied in white patients. Primary open-angle glaucoma is 5 times more prevalent and appears 10 years earlier in African American than in European American persons,² yet the genetics of this dis-ease have been minimally studied in the most over affected group. The frequency of a condition that can cause blindness in midlife perpetuates a cycle of poverty affecting patients and their families. Excluding minorities from health research limits the ability to appropriately care for these populations and skews the scientific understanding of disease. However, organized initiatives to include minorities in health research have the potential to improve care in underserved communities.

A common belief in medicine is that the history of exploitation, most notably manifested by the Tuskegee experiments, prevents African American participants from enrolling in research projects.³ Blaming inadequate research of the African American population on their reluctance to participate reinforces health care disparities. Instead of accepting that African American persons will not enroll in research, investigators should look to the community to better understand enrollment barriers and to identify what incentives are missing. West and colleagues^{4(p1831)} argued that combining genomic research with a focus on environmental modifiers of dis-ease, community-based health initiatives, and intersectional approaches could alleviate health disparities, “if only participation by minority populations in genomic research could be increased.” Enrollment itself is an aspect of genetic research that offers opportunities for improving community health.

The process of recruiting minority patients encourages mutually informative communication between health researchers and patient communities. For example, those who enroll study

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participants in clinic and outreach settings often become additional points of contact, complementing time spent with physicians, through which patients can learn more about their disease and its prevalence in their community. Individuals who are unaware that a condition is hereditary or lack knowledge about available treatment options acquire information during conversations with enrollers and share information with family and friends. This diffusion of information can encourage at-risk community members to seek screenings and care, contributing to earlier detection of disease. Simultaneously, the enrollment process provides opportunities for health researchers to better understand the prevailing beliefs and specific needs of the community. Conversations, focus groups, and surveys can inform the development of culturally sensitive and practical methods of enrollment, as well as initiatives for increasing disease awareness and patient compliance.

While recruiting for the Primary Open-Angle African American Glaucoma Genetics (POAAGG) study, investigators at the University of Pennsylvania partnered with pastors, government representatives, leaders of community senior centers, African American media outlets, and patients to collect more than 9000 African American genotypes in Philadelphia. An important component of the enrollment process was continuously considering why patients were choosing to enroll or decline. The POAAGG investigators⁵ administered a survey to 307 patients asked to enroll in the genetics study and found that 45.9% of those who chose not to participate were uncomfortable sharing DNA, compared with 6.9% of patients who agreed to participate. Of those who participated, 36.2% said government involvement in the study would decrease their willingness to enroll. Knowledge about genetics research and educational levels did not vary between those who enrolled and those who declined.⁵

In addition to mistrust of government, mistrust of clinical research is a real factor for many patients. This fear is often rooted in experiences with the health care system that remove control from the patient.⁶ Although no quick fix to systemic inequalities affecting minority patients is available, health care professionals can create a safe environment where patients feel in control and able to make their own decisions. Physicians have the opportunity to elevate patients' feelings of agency by treating them as partners in their own care processes and in science that can ultimately provide improved screening and treatment options. The opportunity to contribute to research allows patients to take part in gaining knowledge of diseases affecting them and their families.

When patients feel a sense of mutual benefit and partnership, the sacrifices they make to participate may be outweighed by the realization that this personal sacrifice will result in a larger good for their community. According to a recent study, messages that emphasize potential benefits to others are more persuasive in influencing certain health behaviors than those focusing on the benefit to self.⁷ It is worth considering that 6.9% of patients participating in POAAGG enrolled despite their concerns with sharing genetic material.⁵ This finding suggests that fear of enrolling in studies may be overcome by a desire to contribute.

It may seem intuitive that physicians should build relationships with their patients, but these efforts can be even better supported by well-designed recruitment efforts. Initiatives to enroll

in genetic studies, especially when well-funded and community-based, have the potential to formalize systems for listening to and engaging patient communities. Health centers should maximize opportunities to integrate large-scale recruitment efforts with community outreach and care. In this way, genomics research can benefit minority groups in the short term and the long term.

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