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Enhance Diversity Among Researchers to Promote Participant Trust in Precision Medicine Research

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The underrepresentation of research participants from diverse backgrounds is a major obstacle in pursuing the goals of precision medicine research. Insufficient data from minority populations can result in medicine that is increasingly precise for certain segments of the United States population, but not for others. Researchers in the U.S. have traditionally had difficulty recruiting participants from minority populations (Kraft et al. 2018). This should come as no surprise, in part, because of the history of research misconduct against minority populations (e.g., Tuskegee syphilis study, Henrietta Lacks, Havasupai Tribe genetic studies (Garrison and Cho 2013), the testing of contraceptives in Puerto Rican women (Vargas 2017), and the infection of Guatemalans with sexually transmitted diseases (Rodriguez and García 2013)). In addition, minority populations may exhibit a collective mistrust toward research institutions because they do not see themselves or their interests sufficiently represented. Here, we argue that an important way to promote trust and diversity among participants in precision medicine research is to have a diverse pool of researchers with whom participants can identify. We also discuss what are some of the obstacles that need to be addressed to enhance diversity among researchers.

Why increase diversity among researchers?

Participants in Kraft and colleagues (2018) raised an issue that supports how having more diversity among researchers could help promote trust toward precision medicine research and, ultimately, more precise medicine for all. First, participants' perceptions of trustworthiness in biomedical research was related to their personal or group experiences with racism. Ideally, experience with racism would not play a role in individuals' willingness to participate in research, and participants would trust researchers who do not look or sound like them as much as they trust those that do. Unfortunately, however, that does not seem to be the case. As discussed by Kraft et al., participants would feel more comfortable with researchers with whom they can identify, or as a participant described: "*I think that people relate to people that look like them. They trust people that look like them more.*" Researchers who share similar ethnic, racial, or cultural backgrounds as potential participants, may share similar life experiences, like racism and discrimination. This common history or experiences could help those researchers better understand participants concerns and build rapport when interacting with them. Rapport between researchers and

potential participants would help build trust towards precision medicine research and likely increase participation rates among minority populations.

How to increase diversity among researchers?

Increasing diversity among researchers would not only promote participation rates among minority populations, but empirical evidence demonstrates that research is of higher quality when performed by diverse groups (Campbell et al. 2013). However, achieving the goal of more diversity among researchers may be more complex than it seems at first glance. The proportion of researchers from minority racial and ethnic groups such as African Americans, Hispanics/Latinos, and Native Americans in U.S. academic institutions is significantly less than expected based on their share of the U.S. population (National Science Foundation 2012). In order to increase diversity among researchers we must address multiple obstacles at different stages of academic and scientific career development. Below, we discuss some of these obstacles and ideas to help increase the representation of underrepresented minorities (URMs) in the sciences.

Increasing URMs in Science: Starting Early

Exposure to science at early stages of academic preparation is a decisive factor to increase motivation to pursue science-related careers (Cruz-Bermudez et al. 2017). Thus, a good starting point is to incorporate meaningful research opportunities for K-12 students from minority populations. Unfortunately, minority students often attend schools that do not have the resources to provide these experiences and many teachers lack the skills to incorporate scientific method into the classroom setting (Boelter et al. 2015). A first low-cost step is to enhance teachers' training in science, technology, engineering and mathematics (STEM) by establishing partnerships between research universities and schools. Researchers could invite teachers to spend a day in the lab. This would allow teachers to see how specific experiments are performed and discuss the hypothesis and design of these studies with researchers.

Researchers can also help train teachers to design research projects and inquiry-based activities in schools (Sierra-Mercado and Cruz-Bermúdez, IBNS Newsletter, Dec 2017). For example, in the midst of a deep economic recession, neuroscientists from Puerto Rico have partnered with high school teachers to design and conduct low-cost experiments. In these experiments, students examine the impact that substances such as alcohol, nicotine, and artificial sweeteners on fruit fly development and behavior (Cruz-Bermudez et al. 2017). Furthermore, students learn the science of how the brain controls the body using hands-on kits that are commercially available at low cost (e.g., Backyard Brains) (Sierra-Mercado et al. 2017). This approach allows students from underrepresented groups in science to interact with scientists and have rich research experiences. These experiences can also help minority populations feel more comfortable and familiar with research institutions and researchers. Thus, in the future, if they are ever recruited to participate in research they may be more likely to trust the research enterprise and agree to participate.

Increasing URM in Science: Once in Academia

Promoting interest in science from an early age is necessary, but not sufficient to help enhance diversity among precision medicine researchers. URM individuals who pursue careers in scientific research face numerous obstacles. URM individuals are proportionally less likely to transition from graduate school and postdoctoral training to roles as independent researchers (e.g. Assistant Professorships) compared to well-represented (WR) groups in science (Gibbs et al. 2016). Alarming, members from certain URM groups are significantly less likely to obtain funding from the National Institutes of Health (NIH) compared to those from WR groups, even after controlling for variables like educational background, previous research awards and publication record (Ginther et al. 2011). Moreover, there is a scarcity of diverse faculty with high visibility research and underrepresentation in leadership positions (e.g., full professors, department chairs, principal investigators) (Nelson and Brammer 2010).

As young scientists from URM groups transition to junior faculty, it is imperative for research institutions and sponsors to acknowledge that there are significant obstacles that are often unique to researchers from certain racial or ethnic backgrounds. This may be uncomfortable given historical and current racial and ethnic tension in the U.S., but it is necessary in order to take steps to enhance diversity among successful grant-funded researchers. Unfortunately, there is scarce mentoring that acknowledges the obstacles URM researchers face to achieve career objectives. Furthermore, there is a need to enhance training on how to navigate institutional expectations. These challenges could be minimized by providing more mentorship, for example, matching senior investigators with junior faculty to periodically discuss challenges and progress, expanding training and support in grant writing and working to expand the professional network of URM researchers. To help achieve this, NIH and other entities have funded training programs for junior faculty, such as the Mentoring Institute of Neuroscience Diversity Scholars (MINDS) of the University of Florida, and the Broadening the Representation of Academic Investigators in NeuroSciences (BRAINS) at the University of Washington. These professional development programs are key to increasing the professional skills necessary for the success of URM researchers in biomedical research. Research institutions and sponsors should increase funding for these type of programs.

A history of research misconduct against minority groups, coupled with research institutions in which potential participants from minority groups do not see themselves or their interests sufficiently represented, can help explain why it is difficult to recruit individuals from minority populations as participants in precision medicine research. How we address the lack of diversity among researchers will be key to promoting trust and participation in precision medicine research among individuals from minority populations and achieving precision medicine for all. Efforts to ensure that URM researchers who are currently in academia are involved in precision medicine research would go a long way. However, the significant disparity between the proportion of URM in the U.S. population and scientists at research institutions conducting precision medicine research needs to be addressed. Finally, increasing diversity among researchers will enhance precision medicine research not only by increasing the participation rate of minority populations but also because the complex

thought processes necessary to conduct quality science is facilitated by having researchers from diverse backgrounds (Antonio et al. 2004).

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References

- Antonio Anthony Lising, Chang Mitchell J, , Hakuta Kenji, Kenny David A, , Levin Shana, Milem Jeffrey F. Effects of Racial Diversity on Complex Thinking in College Students. *Psychological Science*. 2004; 15(8):507–10. DOI: 10.1111/j.0956-7976.2004.00710.x [PubMed: 15270993]
- Boelter Christina, Link Tanja C, , Perry Brea L, , Leukefeld Carl. Diversifying the STEM Pipeline. *Journal of Education for Students Placed at Risk*. 2015; 20(3):218–37. DOI: 10.1080/10824669.2015.1030077 [PubMed: 28553067]
- Campbell Lesley G, , Mehtani Siya, Dozier Mary E, , Rinehart Janice. Gender-Heterogeneous Working Groups Produce Higher Quality Science. *PloS One*. 2013; 8(10):e79147.doi: 10.1371/journal.pone.0079147 [PubMed: 24205372]
- Cruz-Bermudez N, , Llerandi-Roman PA, , Ramriez-Lugo JS, , Roman-Rodriguez M, , Brown R, , Ojeda-Reyes C, , Torres-Ruiz S, , Aponte-Ramirez J, , Agosto JL. Neuroscience Research Experiences for Public School Students: Outcomes From Partnerships Between Schools and the University of Puerto Rico-Rio Piedras. *Society for Neuroscience Abstracts*, 02204SA; November; Washington, D.C. 2017
- Garrison Nanibaa' A, , Cho Mildred K. Awareness and Acceptable Practices: IRB and Researcher Reflections on the Havasupai Lawsuit. *AJOB Primary Research*. 2013; 4(4):55–63. DOI: 10.1080/21507716.2013.770104 [PubMed: 24089655]
- Gibbs Kenneth D, , Basson Jacob, Xierali Imam M, , Broniatowski David A. Decoupling of the Minority PhD Talent Pool and Assistant Professor Hiring in Medical School Basic Science Departments in the US. *eLife*. 2016 Nov.5doi: 10.7554/eLife.21393
- Ginther Donna K, , Schaffer Walter T, , Schnell Joshua, Masimore Beth, Liu Faye, Haak Laurel L, , Kington Raynard. Race, Ethnicity, and NIH Research Awards. *Science*. 2011; 333(6045):1015–19. DOI: 10.1126/science.1196783 [PubMed: 21852498]
- National Science Foundation. National Science Foundation: Federal Equal Opportunity Recruitment Program. 2012
- Nelson DJ, , Brammer CN. A National Analysis of Minorities in Science and Engineering Faculties at Research Universities 2. 2010
- Rodriguez Michael A, , García Robert. First, Do No Harm: the US Sexually Transmitted Disease Experiments in Guatemala. *Am J Public Health*. 2013; 103(12):2122–26. DOI: 10.2105/AJPH.2013.301520 [PubMed: 24134370]
- Sierra-Mercado Demetrio, Ferrer-Acosta Yancy, Colón-Mercado Jennifer, Bravo-Rivera Hector, Ramos-Medina Liorimar, Torrado-Tapias Aranza, Vega-Medina Alexis, et al. *NeuroBoricuas: Revolutionizing Education by Incorporating Neuroscience Laboratories in Schools of Puerto Rico*. *Society for Neuroscience Abstracts*, 022.08SA; November; Washington, D.C. 2017
- Vargas Theresa. Guinea Pigs or Pioneers? How Puerto Rican Women Were Used to Test the Birth Control Pill. *The Washington Post*. 2017 May 9.