Published in final edited form as:

Prog Community Health Partnersh. 2017 ; 11(2): 161–165. doi:10.1353/cpr.2017.0020.

A Culture of Understanding: Reflections and Suggestions from a Genomics Research Community Board

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Abstract

There has been limited community engagement in the burgeoning field of genomics research. In the wake of a new discovery of genetic variants that increase the risk of kidney failure and are almost unique to people of African ancestry, community and clinical leaders in Harlem, New York, formed a community board to inform the direction of related research. The board advised all aspects of a study to assess the impact of testing for these genetic variants at primary care sites that serve diverse populations, including explaining genetic risk to participants. By reflecting on the board's experiences, we found that community voices can have tangible impact on research that navigates the controversial intersection of race, ancestry, and genomics by heightening vigilance, fostering clear communication between researchers and the community, and encouraging researchers to cede some control. Our reflections and work provide a strong justification for longitudinal community partnerships in genomics research.

Keywords

Community-based participatory research; community health partnerships; health disparities; community health research; urban health

Community–academic partnerships[1–4] have begun to explore the burgeoning field of genomics research, particularly as it applies to diverse populations.[5,6] It can be difficult to engage marginalized communities in genomics and precision medicine research, due both to familiar barriers to community engagement (e.g., mistrust) and more genomic-specific challenges (e.g., its highly technical language).[6,7] Unfortunately, there is limited information available regarding formation of substantive collaborations to navigate the complex intersection of ancestry, race, genomics and health.

Variants of the *Apolipoprotein L1* (*APOL*1) gene are linked to a 10-fold increased risk of kidney failure among adults with hypertension.[8] This is one of the first genetic variants linked to a significantly increased risk of a serious, common, chronic disease. Because the high-risk variants thrived to protect people from sleeping sickness, found only in the African continent, they occur almost exclusively in people of African ancestry (1/7 of whom have high-risk variants).[9] In light of the prevalence, significance and ancestral history of these gene variants, the aforementioned barriers pose an important opportunity to further community engagement in research.

THE GUARDD COMMUNITY ACTION BOARD

In 2010, a genomics researcher approached a community–academic research partnership board, which advises a medical school's translational research enterprise,[10] to discuss these *APOL1* findings. The board chose to form a genomics subcommittee to discuss whether and how these findings should be shared with at-risk individuals. Because high-risk variants are found almost exclusively in people with African ancestry, the subcommittee decided that it was particularly important for this research to proceed with regular input from community members, patients, and clinicians.

The subcommittee thus transformed into a Genomics Community Board, and partnered with researchers to conceive the GUARDD (Genetic testing to Understand and Address Renal Disease Disparities) Study. In this randomized trial, intervention participants receive APOL1 genetic testing and results, clinicians receive results via their patients' electronic health records, and the impact of testing is studied through clinical measures, as well as patient and clinician surveys.[11] The board includes clinicians, patients, community leaders, and advocates, most of whom self-report as Black, African, African American, Afro-Latino, or Afro-Caribbean. For nearly four years, the board has met bimonthly to receive study updates, advise the research team on various aspects of the study including consent, recruitment, retention, and educational materials, and approve changes to study design before they are implemented.

METHODS

Board members decided to collect and reflect on our experiences. We asked a research coordinator with experience in qualitative research, who works outside the board, to attend our meetings and help us to tell our story. Using six questions regarding community partnership, genomics research and the board's work, he conducted open-ended interviews with six board members—an APOL–1–positive study patient, two community advocates,

two physicians, and a leader of a network of neighborhood health centers participating in GUARDD—and transcribed and coded the interviews using constant comparative analysis. He shared the codes and associated quotations (made anonymous) with us, and we identified common themes of our responses, built a conceptual framework, and wrote the manuscript, for which we all chose to be co-authors. Here, we share themes related to community-based research around genomics and diverse populations.

"One Needs to be Vigilant": The Research Should Proceed, But Carefully

In the words of a local religious leader, "One needs to be vigilant when talking about medical dispositions that are associated with different races. Racial inferiority [is] a part of the ether of Western society." With this history in mind, we were cautious about studying a genetic variant that makes those of African ancestry more likely to develop kidney disease than Whites. Some scientists have suggested that racial terminology be phased out of genetics,[12] because racial/ethnic categories are social constructs, which may complicate and potentially confound research while engaging a long and problematic history of race-based and eugenics research. Although the board also views race as a social construct, we recognize that ancestry has biological/genetic components that may—as in the case of APOL1—significantly impact an individual's susceptibility to certain diseases. However, the distinction between race and ancestry is nuanced, and the risk of associating oneself with a legacy of racism and eugenics may deter even the most rigorous, well-meaning advocate or academic.

Many of us also echoed concerns about engaging marginalized communities in genomics research given limited health and genomics literacy,[6] as well as resistance within the Black community. A Black community clinician remarked that some Blacks would prefer "keeping their heads in the sand" instead of seeking out information about their own health. A person with the high risk variant said, "Blacks are mistrustful of medicine, whether they know about Tuskegee or not." However, these very barriers motivate us; as stakeholders, we should take on the challenge of ensuring that this research is done sensitively, thoughtfully and with a heightened level of vigilance. As a local religious leader explained,

> I'm not afraid of science, but one has to have good controls … how do you advance science in a good way and not take advantage of the vulnerability of a community? The statement that looking at genetic risks by ancestry works against the Black community is traditional and stereotypical…. We should not be careless, but our work illustrates that it [genomics] can be integrated into community health. This is not syphilis, eugenics, or Henrietta Lacks.

We view the GUARDD study's unique intersection of health disparities research, ancestry and genomics not as a deterrent, but as an opportunity for rigorous engagement and, ultimately, positive change.

"A Culture of Understanding": Open Discussions of Race, Racism, Ancestry, Research, and Genomics

Our partnership required all stakeholders to challenge their views about race, racism, ancestry, genomics, and research. For some, this meant thinking about how to conceptualize

race versus ancestry. For others, it meant thinking about how to ask patients whether they have any African ancestry; some community advisory board members who identify as Afro-Latino recognize that, for various reasons, their parents would not acknowledge having ancestors from Africa. For still others, particularly some White partners, discussions about race and racism were unfamiliar and sometimes uncomfortable. The difficulty of opening this dialogue demands we work with researchers to develop mutual trust and rapport. A Black community leader stated, “The culture of understanding is far more important than the culture of fear, and the culture of understanding has no color.”

Our goal as research collaborators is to spread this “culture of understanding” among researchers, community members, clinicians, and patients. Many of us discussed misconceptions of Blacks by medical professionals as being sick owing to being undereducated, noncompliant, and fatalistic. Drawing attention to the role of genetics in disease in Blacks could help to counter these stereotypes. One community leader stated that Blacks “stand to benefit [from this research] because [doctors] will be looking at them as individuals and not as a group.” Another echoed, “Now maybe White doctors won’t view Black people on dialysis as not caring enough or not being compliant. They will recognize that there’s more to sickness than bad behavior.”

We also share a priority that Blacks understand the role of genetics in health. A person with the high-risk variant recalled, “Just about every adult in my family has hypertension. So when I received the result of my APOL1 test, I thought, ‘Aha!’” A local Black leader suggested that this understanding could help participants to “operate from an empowered standpoint, [and] raise awareness of factors at work in their bodies.” We have worked to ensure that GUARDD does not merely observe participants, but also engages them as partners in disseminating health-related information throughout their communities. “They learn from us,” continued this local leader, “and we learn from them.”

“A Shared Language”: Using Our Understanding to Change Dialogue, Research Language, and Strategies

Achieving a “culture of understanding” is difficult without first establishing a “shared language” between researchers and community members. A community physician remarked, “The give and take between academics and the community is crucial.” Choosing appropriate language is a common challenge in most research, but our interviews revealed it is particularly difficult in the relatively new and unfamiliar field of genomics. Specifically, some of us acknowledged that conducting research on gene variants found almost exclusively in people of African ancestry could spark inappropriate, inaccurate, and offensive conclusions, such as that Blacks are genetically inferior. A local leader said, “Most of us are not health providers. We agonize about making sure everything we do and provide in GUARDD gives other patients the right idea. In other research and care, this rarely happens … [but] we are not the Ivory Tower.”

In the words of a community physician, our goal is to “inform people without scaring them off.” Recalling historical research abuses of Blacks,[13] it is crucial to ensure each participant’s comfort and trust in the research process and understanding of genomics research. As a local religious leader said, “People shouldn’t be signing [a consent form]

because they are scared or embarrassed." As such, we worked closely with the institutional review board to remove "boilerplate" genomics language—which we found to be confusing and potentially alarming for participants—from consent forms.

Shared language is also essential when working with GUARDD's other major community: clinicians. Through GUARDD, clinicians receive genetic test results, which they may use to encourage patients to effectively control their blood pressure. However, we suggested that research-naïve clinicians—especially those without considerable exposure to genomics—may hesitate to use their limited patient time to discuss research, for which benefits are not guaranteed. Thus, we partnered with clinicians on and outside the board to design brief, informative provider education materials made available in electronic health records. Per clinicians' requests, materials include links to further information for themselves and printable, low-literacy information for their patients.

"Let This Get Messy": Researchers Ceding Control Is a Key to Communication and Innovation

In working with the research team toward a "culture of understanding," we have been impressed by their receptiveness to our suggestions and opinions—or, as one community partner called it, their willingness to "let this get messy." Researchers sought our input from the study's planning phase, which helped to facilitate a longitudinal board–researcher dialogue. A leader from the neighborhood health center participating in GUARDD recalled a sense of openness and respect from her earliest interactions with the GUARDD team. Having been approached in the past by research teams who "just wanted access to our patients" and made her colleagues feel like they were "in the way," she appreciated the study team's receptivity to her suggestions. Researchers' willingness to "cede control" left clinical and community board members with a sense of comfort and empowerment, crucial aspects of functioning partnerships.

"This Voice Needs to be Harnessed": Future Opportunities in Research and Beyond

This receptivity allowed us to have an indelible impact on the GUARDD study. We helped to decide whether to pursue this research in the first place, and opened substantive discussions about race, ancestry, genomics, and health disparities; biological versus social determinants of health; how to discuss these concepts with patients and clinicians; and the promise and perils of pursuing this type of research. As community advocates, we have changed the study design to optimize recruitment, retention, and patient understanding; for example, a community physician's expression of discomfort with denying APOL1 testing to control participants resulted in their receiving delayed testing instead. By simultaneously engaging and representing our communities, we established a longitudinal dialogue to help reach our ultimate goals: community understanding and benefit.

To quote a community clinician, "This voice needs to be harnessed." Having recently shared GUARDD's progress at a meeting of clinicians, advocates and government leaders at the White House, a clinician said, "We have to tie our work back to where the precision medicine movement is going. This is how people will become engaged: when someone who looks like them is at the helm." As this clinician concluded, "Precision medicine can't be

about a subset of the population." It is through bona fide collaborations like ours that may we begin to fill in the gaps.

CONCLUSIONS

Our partnership has embraced research on this complex intersection of race, ancestry, genomics and disparities to ensure the fair treatment and safeguard best interests of our communities. Our work as research–community liaisons established a bidirectional dialogue that makes GUARDD more than a research study; it is a longitudinal educational experience, a shared process that challenges and shapes Board members, researchers, clinicians and patients alike as it unfolds. We hope our experience highlights the need for such partnerships and ideas for fostering them. We encourage others to consider combining vigilance, flexibility, and clear communication from researchers with regular, respected, and incorporated community input to benefit health. Until such partnerships are the status quo, perhaps our manuscript—co-authored by a diverse array of community partners and researchers—may serve as a testament to their generative potential.

Acknowledgments

Research reported in this publication was supported by the National Human Genome Research Institute of the National Institutes of Health under Award Number U01HG007278 and the National Center for Translational Sciences under Award Number UL1 TR001433. The authors thank the entire GUARDD team for their dedicated work, and GUARDD study participants for choosing to join the study.

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