Summary of Atlanta Strategic Planning Town Hall – Establishing a 2020 Vision for Genomics
Wednesday, September 26, 2018

Overview:
On Wednesday, September 26, 2018, NHGRI hosted a strategic planning Town Hall to solicit feedback about genomics issues that should be considered as part of NHGRI's strategic planning process. This Town Hall was held at the Morehouse School of Medicine in Atlanta, Georgia, and was open to the public. The school is an Historically Black Colleges and Universities (*HBCUs*). Previous Town Halls have been held at the University of Washington in Seattle and Stanford University in California. Attendees were invited to provide comments on all aspects of the strategic planning effort, including scientific opportunities, challenges for the field, and the design of the strategic planning process. The day was divided into two parts: a general Town Hall for all attendees and a Town Hall specifically designed to gather input from trainees. This was the first Town Hall to also hold an evening event, which was designed to gather input from the local community.

NHGRI Director Eric Green, M.D., Ph.D. began by explaining the context for this Town Hall and providing information on the plans and timeline for the NHGRI strategic planning process. NHGRI last published a strategic plan in 2011, and the new plan is projected to be published in October 2020. Between now and October 2020, NHGRI is holding Town Halls and other in-person gatherings across the country to collect input and explore topics to consider in developing a 2020 Vision for Genomics.

Following brief introductory remarks, there was an extended question-and-answer session with Dr. Green, as well as other NHGRI representatives: Vence L. Bonham, Jr., J.D., Associate Investigator in NHGRI's Social and Behavioral Research Branch and Senior Advisor to the NHGRI Director on Genomics and Health Disparities; Dave Kaufman, Ph.D., Program Director of NHGRI's Division of Genomics and Society; Laura Rodriguez, Ph.D., Director of NHGRI's Division of Policy, Communications, and Education and Ken Wiley, Ph.D., Program Director in the Division of Genomic Medicine.

Over 150 members of the public participated in the general Town Hall. Over 70 trainees participated in the trainee-only event. Participants' organizational affiliations included members of academia, non-profit organizations and the private sector.

Session 1: Genomics from Bench to Bedside
The first session began with a discussion of applying genomics from the laboratory to clinical practice. Common themes included education for the community and healthcare workforce, patient engagement, technology development and informatics, the clinical utility of genomics, and representation of diverse participants in research.

Attendees stressed that education is important to increase genomic literacy in the community, and for physicians at the primary care level to interpret genomic results. Engaging the community, communicating a basic knowledge of genomics, employing technology and explaining what it entails for clinical treatment is paramount, especially for underserved communities where resources are limited. Correspondingly, the need for educating and training primary care providers on the front-line to provide services for genomic testing is vital.

Participants also urged that a robust, proactive approach to patient engagement will demystify genomics and turn it into personal health advantage. This will increase visibility of genomics in healthcare and facilitate the integration of genomics in clinic settings.

There was also a need to focus on technology development, particularly in front-line communities that need it most to drive genomics forward. Participants suggested NHGRI invest funding in developing informatics training programs in communities that need basic informatics and services. Challenges include awareness in the community that the technology exists followed by implementation. Participants also raised concerns of weaknesses in the literature base for the clinical utility of genomics. If there is no impact on the outcomes of genomic testing, reimbursement can be difficult. There is a strong financial interest in researching the clinical utility of genomic tests, but justifying a reason to pay for this is challenging.

Representation of diverse participants in research was mentioned several times, with an emphasis on the importance of encouraging investigators to think about diverse representation in their research to help reduce health disparities and understand gene-environment interactions. Increasing evidence in diverse communities is important as demonstrated by Clinical Sequencing Evidence-Generating Research NHGRI-funded program. The following session further discusses the importance of diversity and disparities in genomics.

Session 2: Genomics, Diversity, Disparities, & Population Health

The Town Hall at Morehouse School of Medicine drew a more diverse audience and added unique perspectives to inform the 2020 strategic plan. In this session, NHGRI solicited feedback on diversity, disparities, and ideas for how genomics can improve the health of populations who are under-represented in research. Participants discussed areas where disparities needed to be addressed across all aspects of research. They also discussed translational implementation including community engagement, recruitment and retention, study design, applicability of results, data analysis, and implementation and dissemination.

Participants stressed the need for more diversity in genomics research. Racial and ethnic ancestral diversity, as well as cultural, socioeconomic, and geographic diversity were emphasized. One participant commented on the need to look at within-group in addition to between-group differences. Engaging older populations in research was also highlighted. Several people communicated that because the current genomic sequencing evidence base represents participants primarily of European ancestry, and mainly from urban areas close to major academic research institutions, that the applicability of those studies to other populations is limited. This evidence base was also described as having a self-propagating effect across research, with later studies recruiting similar cohorts for comparison and analysis. As such, one attendee recommended that under-represented populations be regarded not as minorities, but as priorities. Strategies suggested to reach more diverse participants included recruiting from outside research centers and highly specialized health care systems and involving more community hospitals and “safety net” hospitals in research, improving collaborations with local groups across demographics, and emphasizing the need for researchers to describe plans for participant engagement and ways to improve genomic literacy in applications.

Participants discussed enhancing education about genomics across all levels as a way to increase comfort with genomics research and willingness to participate in the future. Participants urged the development of more educational curricula to improve scientific literacy at a young age, continuing educational engagement using community health workers and navigators to disseminate information, and integrating more genomics into formal medical education.

Numerous speakers stressed the importance of engaging health workers at the primary care level. Many of the barriers to participation in genomics (including mistrust of researchers, low recruitment, and retention) could more easily be overcome and strategies to build trust (such as effective communication of research consents and results and disseminating information) employed through the involvement of local health workers, including primary care physicians, nurses, advocates, and patient navigators. Participants linked the funding for the collection of research at the primary care level to better and more equitable implementation of genomic medicine in under-represented communities. The role of these community researchers was also linked to better recognition and integration of social determinants of health, and the incorporation of traditional and home-based sources of knowledge to help inform genomics research questions. Citizen science and the ability to explore research questions of importance to the local community using genomic data was connected to the use of "big computing" data programs such as the NHGRI Genomic Data Science Analysis, Visualization, and Informatics Lab-Space (ANVIL) and the ability to do outreach and training on these tools at all levels.

Finally, diverse community involvement in NHGRI's advisory bodies such as the Community Engagement in Genomics Working Group (CEGWG) and Genomics in Society Working Group can help reinforce these issues on an institutional level. The role of community voices in ELSI questions and policy beyond the Town Hall was a theme that was present throughout the session.

Session 3: Society, Education, Engagement & Research

Session 3 was moderated by Dr. Robert Meller (Associate Professor, Neurobiology, MSM) and Dr. Dave Kauffman. This was an opportunity for participants to respond to three strategies for education and engagement in research: 1) develop and deploy genomic technology to respond to community and stakeholder needs, 2) empower informed decisions on whether and how people access, use, and share their genomic information, and 3) account for and promote understanding of health-related interactions between people's environment and their genomes.

One participant commented on the challenges of returning results especially when communication is poor and suggested that research on how to return results in different languages would be helpful. Many of the comments highlighted community engagement. Examples include participatory community research, community engagement, and affirmative messaging. Participatory community research is the key to working with diverse communities, making them stakeholders with their health and research. Likewise, communities are inclined to be more involved if they have some personal ownership of data. African-American health is often perceived as a net negative, shortened life, declining health, and deficiencies. When engaging with the community, a fresh perspective on health and disease by looking at promotors of health in the African-American community and discussing resilience and factors that associate with overcoming adversity, will likely increase participation through affirmative messaging. In the application of genomics, there's a differentiation between people of African descent who came from Africa and those who live in Africa, a disconnect of first-generation Africans and African descent. Research is needed to bridge the gap between these two groups.

Session 4: Trainee Session

In the final session, specifically for trainees, participants expressed interest in opportunities in interdisciplinary approaches to genomics research, developing bioinformatics curriculum at smaller institutions, and having resources available for cloud computing. Dr. Green encouraged being part of multidisciplinary research teams, such as the Human Genome Project (HGP) which spurred team science across multiple disciplines. Data science resources and bioinformatics is being developed at smaller institutions, and trainees inquired how NHGRI can help build these programs. NHGRI is committed to sharing genomics data information and democratize data accessibility through programs such as the ANVIL. Trainees touched upon genomics as the foundation for precision medicine and inquired in what ways NHGRI is working to educate patients on precision medicine and bridging the gap between clinicians and researchers.

Community Meeting: "What Can Your DNA Do for You?"

This was the first Town Hall to feature an evening session specifically seeking input from members of the local community who did not necessarily have a scientific background. This session, entitled "What Your DNA Can Do for You," was organized and publicized by the MSM staff with input from NHGRI staff. Approximately 40 community members attended, some representing local organizations. The session was moderated by MSM's Dr. Tabia Henry Akintobi, Director of the Prevention Research Center and Associate Dean of Community Engagement. Many of the NHGRI staff from earlier sessions were present and participated, including Dr. Carla Easter, Chief of NHGRI's Education and Community Involvement Branch.

The program was hosted in the atrium outside the auditorium from the morning's sessions, in tables of eight to facilitate dialogue. Each table was set with questions to help prompt audience discussion. In addition to facilitated discussions, the program included a role-playing skit of the *All of Us* Research Program's recruitment process, which illustrated some of the questions and concerns participants might have, a video from Rev. Leland Jones, a CEGWG member from Atlanta, on why it is important for diverse communities to participate in research, and a question-and-answer session with Dr. Easter and Dr. Kaufman.

Themes included concerns around privacy and discrimination from genetic testing, historical abuses and mistrust of research, issues of access to testing and resulting benefits of genomic medicine, and how communities can better participate in and control research that seeks to recruit their members.

Several participants were concerned about the results of genetic testing remaining private and not resulting in discrimination, stigma, or other harms. Specifically, use by insurance companies to determine benefits or pre-existing conditions, or potential unknown uses similar to a credit rating score were discussed as potential risks. Several speakers questioned how genetic information would be controlled and used, who would have access, and how potential misuses would be addressed. Analogies to past research abuses against the African-American community, including the Tuskegee Study, appropriating Henrietta Lacks' cells (HeLa cell line), and eugenics and forced sterilization, were recalled as reasons for mistrust of research. They stressed the need to address these issues through meaningful, sustained engagement by researchers, policy makers, and health workers; approach research projects with transparency and honesty; strengthen and enforce strong institutional policies around research conduct, review, and data use; and communicate the commitment to and enforcement of these strategies to everyone involved in the research process.

Access to genomic testing and to the benefits of research was another theme voiced by numerous participants. In order to participate in research, participants were concerned that the downstream benefits of that research would not be available to them and their communities because of the cost and a lack of implementation in lower-resourced settings. Speakers were also interested in the research and policy commitments to addressing health disparities, including cancers and conditions such as sickle cell disease with a higher prevalence in the African-American community. It was stressed that ensuring the benefits of genomic medicine reach all communities is an issue of social justice, which includes issues of economics and education.

A final theme was the importance of community guidance as well as individual input. Community engagement can help ensure that the benefits of participation outweigh the risks and focus research on questions that have support and value. The use of community-based participatory research (CPBR) was discussed as one way to guide and maintain control of the process and products of research.

Finally, it is worth noting that there was some confusion about the difference between NHGRI and the *All of Us* Research Program. There was also reference to an earlier community discussion with NIMHD and the need to better align discussions and engagement efforts across the NIH. However, the conversation concluded with a strong commitment to continue conversations about improving health in diverse communities and to develop future engagement opportunities. NHGRI committed to keeping MSM and the Town Hall participants informed of the strategic planning process moving forward and sharing the outcomes of that process when finalized.