National Human Genome Research Institute

Summary of Seattle Strategic Planning Town Hall – Establishing a 2020 Vision for Genomics

Tuesday, June 19th, 2018

Overview

On Tuesday, June 19th, 2018, the National Human Genome Research Institute (NHGRI) hosted its first, in-person, strategic-planning town hall to solicit feedback about opportunities for genomics that should be considered as part of NHGRI's strategic planning process. This town hall was held at the University of Washington in Seattle, Washington, and was open to the public. 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 event was divided into two portions: a general town hall for all attendees, and a trainee town hall specifically designed to gather input from that audience.

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 will hold 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: Lawrence Brody, Ph.D., director of NHGRI's Division of Genomics and Society; Carla Easter, Ph.D., chief of the Education and Community Involvement Branch; and Lucia Hindorff, Ph.D., program director for the Division of Genomic Medicine.

Over 150 members of the public participated in the general audience town hall. Over 70 trainees participated in the trainee-only event. Participants identified their organizational affiliations as academia, non-profits, and the private sector, and came from the Seattle, Washington, area, as well as the Portland, Oregon, and Vancouver, British Columbia, areas.

Several participants commented on the importance of investing in proteomics research and the need for developing protein technologies to study the function of cells in a manner to complement the study of nucleic acids. Participants highlighted that the study of proteomics and how proteins execute the function of genomes is critical for understanding organismal phenotypes. It was suggested that NHGRI's portfolio should include large-scale proteomics, as there is no other institute at the National Institutes of Health (NIH) with this area as a primary focus.

Several participants also highlighted the need for increased funding for model organisms research to test ideas about study designs, validate analytical methods and discover first principles. Model organisms from yeast to flies, worms, mice and others,

are needed to study complex interactions, such as gene-gene, gene-environment, and gene-age interactions. It was also suggested that NHGRI invest more in the maintenance and integration of various model organism databases to preserve data quality. NHGRI staff commented that the institute understands the value of model organism databases and is working to have better integration between them.

Complementing the discussion on proteomics and model organisms, there were several suggestions to integrate functional data at population scale. Multi -omics data could be generated in a comparable manner and scale as sequencing data is generated currently, perhaps beginning with smaller driver projects.

One of the recurring themes of the town hall was the importance of investing more in trainees for the future of genomics and the challenges of retaining trainees in the academic field. It was stated that the number of training grant slots have decreased and many trainees are choosing to work in industry instead of academia, due to a lack of well-funded positions. Several participants recommended that trainees should be a central focus of NHGRI's 2020 vision and that NHGRI should work to increase the number of postdocs in academia by increasing salaries, doubling the number of slots for NHGRI training grants, forming corporate sponsorships and expanding the funding for training programs. Additionally, NHGRI was encouraged to be nimble and explore alternate models for training, such as fellowship and internship programs for trainees who have completed post-doctoral training. These could be used to learn additional skills, especially computational biology and bioinformatics.

Several ideas related to genomic medicine were raised. First, adding functional information to available genomics data would foster stronger connections between basic and clinical research. Second, more critical examination is needed for how genetic association data are used to calculate risk scores. Finally, the broader aim of obtaining reimbursement from payers for genomic testing remains a fundamental challenge.

Another recurring theme revolved around the need for increasing diversity in genomics, at the level of workforce diversity, as well as the diversity of participants in research studies. Participants suggested that NHGRI should increase funding and training opportunities for scientists from diverse backgrounds and/or under-represented minority communities. It was also suggested that the engagement of minority communities needs to be sustainable monetarily over the long term, as it is a delicate process to build the trust and good relationships needed for these participants to feel ownership of their participation in genomics research studies.

The final theme of the Seattle town hall discussion revolved around NIH and NHGRI's move towards more open-access data portals and cloud-computing infrastructure for storing data. Participants commented on the bottleneck in academic pipelines as a consequence of publishing in closed-access journals, and the complexity of moving all data to cloud-based platforms. Although the data-sharing ecosystem is complex and includes NIH-wide and international efforts such as the NIH Strategic Plan for Data

Science and the Global Alliance for Genomics and Health (GA4GH), participants urged NHGRI to lead the call for and continue its support for broad data sharing.

During the trainee town hall session, several new comments were raised in addition to the ones discussed above. Trainees recommended that NHGRI give students the opportunity to expand their skill sets beyond the lab to be able to pursue genomics careers in interdisciplinary fields, such as genomics policy and education. One suggestion was for the institute to involve trainees in writing and reviewing scientific features, which would have the added benefit of increasing genomic literacy for the general public. There should also be an effort to legitimize these career paths so that they are not just viewed as “alternate careers.”

The topic of global genomics and inter-agency collaborations was also discussed. NHGRI was encouraged to facilitate more data sharing of human genomic and clinical data across the world. Lastly, it was recommended that NHGRI invest more in training non-geneticists such as clinicians, as there are not enough medical geneticists in the country to meet the demands, and genomics resources need to be developed for primary care providers so that they can be better informed.