



Genomic Literacy, Education, and Engagement (GLEE) Initiative

Strategic Visioning Meeting

**March 13–14, 2017
Natcher Conference Center
National Institutes of Health
Bethesda, Maryland**

Executive Summary

Background

Eric Green, M.D., Ph.D., Director of the National Human Genome Research Institute (NHGRI), described the rapid pace of genetics and genomics research. Genomic literacy has not kept up with these advances, and filling this gap is becoming urgent. NHGRI is therefore taking the lead in the consideration of a Genomic Literacy, Education, and Engagement (GLEE) initiative, envisioned as a public-private partnership to coordinate and augment ongoing genomic education and outreach activities.

Maria Freire, Ph.D., President and Executive Director of the Foundation for NIH (FNIH), provided an overview of FNIH and its interest in genomic literacy. She also explained that the goal of this meeting was to create a multiyear strategic vision for enhancing genomic literacy. Implementing such a vision will require several elements to galvanize funders: a vision and mission statement, a focused strategic plan, scientific heft and detail, and independent activity modules.

Robert Nussbaum, M.D., Chief Medical Officer of Invitae, and Louisa Stark, Ph.D., Director of the Genetic Science Learning Center at the University of Utah, provided perspectives on the needs for increasing genomic literacy from the genomics community's perspective. Dr. Nussbaum discussed the role of medical geneticists, the distinction between genetics and genomics, and the rationale for targeting resources to enhance genomic literacy. Dr. Stark described her experience teaching communities and educators about genetics and genomics.

Working Group Overviews

The co-chairs of each of the three established working groups summarized the white papers that their groups had drafted before this meeting.

K–16 Working Group (Presented by Bryony Ruegg, Ph.D., Bio-Rad Laboratories and Beth Tuck, National Human Genome Research Institute)

The working group's survey of K–16 educators showed that half of the teachers do not teach genomics because they are not required to do so, they lack genomics educational resources, and they are unfamiliar with or lack professional development in genomics.

The working group identified 10 actions:

- Establish a framework for basic genomic literacy for education standards implementation.
- Write a genomic literacy position paper for textbook/resource developers and policy-makers.
- Establish annual meeting(s) to convene K-16 educators, policy-makers, and others.
- Develop a genomics education resource clearinghouse.
- Disseminate genomics education resources; also address low-resource community needs.
- Develop new materials (includes new content, professional development, and mass media).
- Identify/evaluate existing genomics career resources and develop new as needed.

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- Identify/disseminate genomics-focused research experiences, internships, and competitions.
 - Create/scale-up programs for genomics professionals in education/outreach settings.
 - Further analyze survey data, and include evaluation plans for any new programs.

Recommendations from meeting participants during the discussion period included building on existing clearinghouses, broadening the focus to include proteomics and other “omics,” determining how to reach and engage teachers who are unaware of existing resources, and addressing the needs of special education teachers and middle school *versus* high school teachers. Participants also emphasized the need to address the ethical, legal, and social implications of genetics and genomics; to use students as ambassadors to teach their peers, teachers, and families; and to determine and fill gaps in undergraduate curricula genetics and genomics coverage.

Healthcare Provider Working Group (Presented by Katie Johansen Taber, Ph.D., American Medical Association and Bob Wildin, MD, National Human Genome Research Institute)

This working group focused on practicing healthcare providers who lack formal education in genomics. A trend driving the need for healthcare provider education in genomics is the rapid increase in the number of genetic/genomic tests available for providers to order. Furthermore, genetic/genomic testing uptake is low, even in fields where these tests are particularly valuable. The working group’s survey showed that only 25 percent of physicians felt comfortable integrating genetics and genomics into their clinical practice, but 75 percent had an interest in obtaining genetics and genomics education.

The working group identified actions that would help address the gaps and challenges over 5 years:

- Build up community engagement and collaboration.
- Create effective content.
- Implement best dissemination practices.
- Plan for promotion, that is, building awareness of need and of learning opportunities
- Foster engagement among learners.
- Fund quality education, including identifying beneficiary stakeholders, prioritizing projects, and facilitating partnerships
- Create sustained impact, for example, by employing methods to track impact of education efforts

Recommendations from meeting participants during the discussion period were to broaden the focus to include medical and other professional school education, to prioritize segments of the non-genetics healthcare professional population to target first, and to determine the education needs of non-physician providers. Any efforts should also provide genetics and genomics expertise to clinical guideline developers, help healthcare providers determine which genetic/genomic tests to order, determine how to reach healthcare providers at the point of care, fund clinical trials of genetic/genomic tests that might benefit patients and use the results to create demand for genomics education, and leverage knowledge of those who have recent genetics and genomics training, such as recent medical school graduates, to teach those already in practice.

Community/Public Working Group (Presented by Louisa Stark, Ph.D., University of Utah and Carla Easter, Ph.D., National Human Genome Research Institute)

The public wants to know what genetics and genomics mean, what they need to know about these topics, and when they need this information. Another question is how to get answers to those who need them ‘just in time.’ The working group’s survey found that community members are most interested in learning about disease prevention, diagnosis and treatment, disease risk, and ancestry. The most popular source of information is the internet. At the same time, the public wants safeguards to protect their genetic/genomic information.

The working group’s recommendations were as follows:

- Establish a committee to guide the any community/public initiative(s).
- Create an online repository for genetics/genomics education materials and resources.
- Collect nationally representative data about the public’s interests and needs.
- Convene an annual meeting(s) on genetics and genomics literacy.
- Hold quarterly webinars for community leaders/educators on topics pertinent to genetics and genomics education.
- Support community-initiated demonstration projects.
- Develop a network with “chapters” in each state.
- Develop a national public relations campaign.
- Promote and support research on genomic literacy, education, and engagement.

Recommendations from meeting participants during the discussion period were to develop different approaches for different segments of the community, focus on message content and strategies to deliver messages, and consider initiatives that address the needs of all audiences. Participants also suggested that any initiative determine who will vet the resources in the repository and make the repository accessible to those who lack computer access or computer literacy. They identified several potential partners, such as the *All of Us* Research Program and the Clinical and Translational Science Awards. Finally, any such effort should develop materials that clinicians can use to educate patients.

Summaries of Working Group Breakout Sessions

Each of three breakout groups spent several hours discussing the recommendations included within their working group’s white paper. The co-chairs of each working group then summarized their breakout session discussions on the second day of the meeting.

K–16 Working Group Summary

The breakout group identified five target areas of highest priority for a possible initiative:

- Establishing a basic genomic literacy framework: the first step to achieve this is to convene a diverse group of experts to determine what young adults need to know to be genomically literate, types of decisions they need to make in a world shaped by genomic information, and the genomic knowledge required to make these decisions. This would require input from each of the three working groups.
- Disseminate existing resources: participants recommended exploring options for widespread dissemination of existing resources, connecting with organizations that have

established audiences (such as science education professional societies), and determining which resources are most suitable for different grades and subjects.

- Develop new resources: activities under the initiative to develop new resources include determining priorities for new materials development, creating guidelines for developing new materials, and identifying partners and funding to support these activities.
- Authentic training and education in genomics: this action can be accomplished by determining what exists and developing guidelines, working with program owners to expand existing programs so that they serve different communities and grade levels, and working with partners to develop new resources and experiences.
- Ongoing deeper dives into survey data and evaluation needs: all projects must include provisions for ongoing evaluation (both summative and formative), and there may be important needs identified through a deeper dive into the survey data.

Recommendations from this discussion were to address the cultural context for ethnic and minority communities as well as their sensitivities and concerns; focus on under-resourced schools that lack teachers who can teach genetics and genomics; learn about effective education programs in informal settings; consider mobile laboratories for educational experiences in low-resources areas; partner with disability groups and universities to translate materials into accessible formats for students with disabilities; develop a mechanism to review and prioritize existing resources; leverage teacher leaders to disseminate information to other teachers (train-the-trainer); and partner with the technology industry to help teachers find existing resources.

Healthcare Provider Working Group Summary

The group identified many ideas and recommendations, which it grouped by purpose:

- Community building: involve many stakeholders at every stage in designing the education and developing the goals, and create a community of trainers able to adapt their training to the needs of many diverse audiences.
- Create effective content: involve the target audience and patients in designing the education and goals, use active approaches and active learning, and exploit existing high-quality content.
- Implement best dissemination practices: determine whether models with proven success can be adapted to meet the existing needs, develop plans with stakeholders who have an interest in this process, and consider using implementation science approaches.
- Build awareness of the need and of learning opportunities: use marketing principles and expertise, work with companies or academic centers with this kind of expertise, collaborate with specialty societies to build awareness campaigns, partner with stakeholders across institutions, and make clear the high priority of genomics in health and education systems.
- Foster engagement among learners: provide incentives and validation for education; identify champions at institutions to promote genetic/genomic thinking; provide incentives with requirements; and explore learning opportunities that are clear, short, “cool,” accessible, and available at the point of care.
- Fund high-quality education: create a dedicated federal funding program; develop a clearinghouse for funding opportunities; and create a central, unbiased, and funded organization to direct use of funds for high-quality educational implementation projects.

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- Create a sustained impact on provider behavior: develop outcome measures for education programs; use electronic medical process data to assess behavior change; link payment to high-quality behaviors, quality improvement programs, and continuing education quality measures; and study long-term evaluation of continuing education participants and programs.

Recommendations from the discussion were to make the patient or community the center of activities; to involve providers, genetic counselors, patients, and family members from the beginning; to understand what providers need and want; to accommodate the many demands on providers' time; and to make the training flexible. Potential partners include professional societies, the Genetics/Genomics Competency Center's clearinghouse, and the Inter-Society Coordinating Committee for Practitioner Education in Genomics. Incentives for providers to seek education include quality measures, continuing education credits, and maintenance of certification.

Community/Public Working Group Summary

The breakout group identified actions for each of the working group's recommendations:

- Support community-initiated demonstration projects that develop genetics/genomics educational methods and resources: create different "pots of money" for demonstration projects, have community members do the designing for community members, and promote sustainability for projects.
- Collect nationally representative data about the public's interests and needs: summarize existing data and datasets, use a community-based participatory approach throughout the process, and include stories and qualitative data.
- Develop a national awareness campaign to promote the importance of genetic and genomic information: choose the call to action and/or behavior change desired, link to messages currently in the media, address people's fears, work with partners, and test messages in focus groups.
- Promote and support research focused on genomic literacy, education, and engagement: partner with the other two working groups to identify research questions and conduct projects, solicit community recommendations for grant program guidelines, and provide supports for communities to build capacity for research programs.

Recommendations from the discussion were to build on genetics- and genomics-related questions from existing community programs, identify successful models of community/academic partnerships, and require meaningful community/academic partnerships. Grant programs must clearly define "community" and "community engagement" and involve community members in every aspect of the work. Other recommendations were to address aspects of communities beyond health, to conduct outreach through schools and local libraries, to use accurate terms (e.g., "genetics" and "genomics") when working with communities, to listen to tribal communities about their needs, and to survey other components of the National Institutes of Health (NIH) about their dissemination and outreach activities and relevant grant resources.

Synthesis and Visioning

NHGRI's Lawrence Brody, Ph.D. summarized themes that emerged through the strategic visioning discussions. An important and unifying chord across discussions was the overlap that exists across the various communities being discussed in each working group. The three breakout groups had agreed on the need for a survey of existing resources that could be reused for new purposes and for new resources to fill gaps. They also supported efforts to evaluate the quality of existing resources and to create a demand for information. Discussions had highlighted the value of teaching the teachers, finding funding sources to support sustainability, continuously evaluating programs, and supporting students to teach teachers.

Action Plan and Next Steps

During the final discussion, participants suggested that if a GLEE initiative proceeds, then it should maintain a focus on the three current working group domains, but ensure representation from all three target audiences in any working groups. Another recommendation was to develop a joint mission and vision statement across the three target audiences, but maintain distinct measurable goals that are linked to the overarching mission and vision. Participants differed on whether GLEE should develop a common definition of "genomic literacy," but they agreed that GLEE needs a strategic plan. NHGRI might use the 15th anniversary of the completion of the Human Genome Project as a deadline for launching GLEE publicly and promote 15 stories focusing on genomics accomplishments in the 15 years since the Human Genome Project's completion.