Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC) Meeting Minutes

February 1, 2018

Bethesda, MD

Welcome, Introductions, and Framing: Co-chairs Teri Manolio, MD, PhD, NHGRI, and Rich Haspel, MD, PhD, Beth Israel Deaconess Medical Center

Dr. Teri Manolio, NIH Co-Chair and Dr. Richard Haspel, External Co-Chair opened the meeting by welcoming all participants, in person and via WebEx to the 7th Inter-Society Coordinating Committee for Practitioner Education in Genomics in Person Meeting and reviewed the goals of the meeting which included discussion of current ISCC work products and plans, reports from the projects in progress, and future opportunities for this group. Interactive discussions among attendees will aid in identifying areas for collaboration and development of future projects.

Welcome from Laura Lyman Rodriguez, PhD., Director, Division of Policy, Communications, and Education, NHGRI

Dr. Laura Lyman Rodriguez, Director of the Division of Policy, Communication and Education at the National Human Genome Research Institute, welcomed the ISCC membership to the National Institutes

of Health. She reviewed the ISCC's progress in the past year, acknowledging the departure of Dr. Bob Wildin and Dr. Ann Karty, former Co-chairs of ISCC, and recognizing the ISCC's new leaders - Dr. Teri Manolio and Dr. Richard Haspel who are now serving as ISCC's Co-Chairs. She also discussed the establishment of new working groups and collaborative project developments between the ISCC and the National Human Genome Research Institute.

NIH Addresses the Science of Diversity: Looking through a Genomic Lens: Hannah Valantine, MD, FACC, Chief Officer of Scientific Workforce Diversity of NIH and Senior Investigator, NHLBI

Dr. Hannah Valantine is NIH's first Chief Officer for Scientific Workforce Diversity and is also a principal investigator at the National Heart, Lung and Blood Institute (NHLBI), where she is exploring the genomics of organ transplantation. Dr. Valantine's talk focused on two distinct but related topics: 1) why diversity matters in the biomedical research workforce and the barriers underrepresented groups face when entering the workforce and 2) why it is important to consider race and ethnicity for genomic medicine to be successful.

On the first topic, Dr. Valantine said diversity is the foundation of creativity and innovation, and this claim has been backed by data. Dr. Valantine said that the scientific community should prioritize research to generate data on how diversity affects scientific workforce performance. U.S. demographics are rapidly changing; minority groups are becoming the majority. Drawing talent from these groups will be critical to scientific advancement as well as economic competitiveness for this country. Currently, there are significant numbers of underrepresented individuals graduating PhD/MD programs, but very few taking high-ranking positions in academia. Part of this is due to implicit bias in hiring decisions and in awarding grants.

Diversity is also specifically important to genomics. In the area of organ transplants, the data show that non-Caucasian organ transplant patients have a much poorer outcome than their Caucasian peers, even when controlling for sociological factors and medical care received. Dr. Valantine established a prospective research consortium called the Genome Research Alliance for Transplantation (GRAfT) that is investigating how genomics can inform the care of organ transplant patients. She and her collaborators consider organ transplants to be essentially 'genome transplants.' The GRAfT cohort includes a significant population of African American participants. Initial analyses show that self-reported race for African Americans and may not be sufficient to guide organ transplant treatment because this group has high admixture and mitochondrial DNA may indicate different biogeographical ancestry. Dr. Valantine and her colleagues are exploring whether high rates of transplant organ rejection in African American patients is due to mitochondrial DNA mismatch between the donor and recipient.

Discussion on Practice Gaps: Steve Singer, PhD, Vice President of Education and Outreach, Accreditation Council for Continuing Medical Education

Dr. Steve Singer facilitated an interactive activity and discussion to identify practice gaps for the integration of genomic medicine into care and ways of overcoming these gaps. He asked ISCC participants to answer a series of questions via cell phone poll, which then generated word clouds for everyone to view. First, he asked participants to identify top challenges for health care providers in the integration of genome medicine, and responses included 'time,' 'knowledge,' 'training,' 'education,' and 'resistance'. He then asked what the top concerns for patients were if integration fails to occur, and responses included, 'poor outcomes,' 'disparities,' 'misdiagnoses,' and 'trust.' Dr. Singer then facilitated a discussion about what factors promote learning and change in everyone's respective organizations. Participants noted that some of their organizations foster a culture of learning, some are driven by requirements for learning, and some achieve learning goals from strategic leadership and governance approaches.

Dr. Singer noted the need for participants to harmonize educational efforts around what organizations are already doing to improve the performance of individuals, teams, and systems, and asked how individuals could 'insert a vector of improvement and learning' into everyday responsibilities. Lastly, he asked participants to complete an activity in pairs: choose a concern for patients regarding the integration of genomic medicine, identify the professional practice gap related to that concern, and identify relevant educational needs that should be targeted. One group noted that patients often do not receive appropriate genetic testing even when guidelines dictate certain tests (such as for EGFR for lung cancer) because 1) it's difficult to educate oncologists as many are widely dispersed or in small practices and 2) clinicians often do not know how and/or do not have time to collect and interpret family health histories. The session concluded with participants acknowledging that ISCC could come together as part of its coordinating work to collaborate and discuss what each organization is doing to address practice gaps.

Discussion of ISCC and the Genomic Literacy, Education, and Engagement (GLEE) Initiative Healthcare Provider Working Group: Kathleen Blazer, Co-Chair, Director, Cancer Genetics Education Program, Division of Clinical Cancer Genomics, City of Hope

Dr. Carla Easter and Ms. Beth Tuck from the Education and Community Involvement Branch (ECIB) at NHGRI introduced this session with a background on the Genomic Literacy, Education, and Engagement (GLEE) Initiative. The goal of GLEE is to promote genomic literacy nationwide. NHGRI held a GLEE Strategic Visioning meeting in March 2017 that convened three working groups to create a vision for genomic literacy: K-16, Community and Public, and Healthcare Providers. Dr. Kathleen Blazer is co-chair of the Healthcare Providers working group. Since March 2017, Dr. Easter and Ms. Tuck have engaged with existing and new stakeholders to discuss current activities, future plans, and address how to evaluate and disseminate K-16 educational resources about genomics

Since 2018 marks the 15th anniversary of the completion of the Human Genome Project, NHGRI and GLEE participants are launching a public awareness campaign called '15 for 15' that will be centered

around 15 core messages that communicate the advances made in genome science and the importance of genomics in people's lives. Core messages include cancer genomics, rare disease, pharmacogenomics, and prenatal genetic testing. 15 for 15 will also be part of this year's National DNA Day (April 25th, 2018) celebration. Each year on National DNA Day, NHGRI and organizations around the world (e.g. schools, museums, companies) celebrate DNA Day by hosting events and interacting on social media. 15 for 15 will take place between April 5th and 25th and will countdown the 15 business days leading up to National DNA Day. The campaign website can be found here once it is up.

Healthcare providers like those represented by the ISCC participating organizations are an important audience for the 15 for 15 campaign. The big picture goals are awareness, trust building, disseminating trustworthy information and resources, sharing positive impacts of genomics, and envisioning the future of genomically-informed healthcare. Dr. Blazer asked ISCC to join the 15 for 15 campaign by sharing the 15 for 15 core messages via their online presence, contributing content (e.g. videos, interviews, soundbites) for the website that fit with the 15 messages, and/or hosting events. Dr. Haspel suggested creating a unified ISCC 'voice' to contribute to and participate in 15 for 15.

Discussion of the Suggestions for ISCC Webpage

Ms. Ashley Lewis facilitated a discussion with membership about the current ISCC webpage. During this time she reviewed the current ISCC webpage (https://www.genome.gov/27554614/intersociety-coordinating-committee-for-practitioner-education-in-genomics-iscc/) and asked for input from membership about items they would like have on the webpage regarding membership, members, and projects etc. There was a lot of feedback from those present which ranged from possibly having a search engine on the webpage, to a member's section which includes a directory and a wiki that allows members to interact (an online forum). All information was noted and will be discussed in the future with The Communications and Public Liaison Branch (CPLB) at NHGRI.

Discussion on Marketing and Dissemination of Genomic Education Resources: Emily Edelman, MS, CGC, The Jackson Laboratory, Associate Director, Clinical & Continuing Education

Ms. Edelman began by stating her goal to lead a discussion on dissemination methods that we know or think work and identify possible approaches to add to this knowledge base. Ms. Edelman explained the importance of dissemination as well as the added benefits of effective dissemination to professional organizations. She asked attendees what methods do their organization currently use to market education, which many replied by saying, email, newsletter or social networks. Ms. Edelman then discussed marketing and dissemination at The Jackson Laboratory (JAX). Currently JAX is marketing an existing online education program developed for PCPs. During the marketing period of eight months, JAX will aim to engage Connecticut primary care providers through multiple marketing channels which includes having full access to all email addresses of Connecticut PCP through the Department of Health. In the future, the ISCC may be able to collaborate on a project to explore and build upon existing marketing and dissemination methods.

Project Updates: The Global Genetics and Genomics Community (G3C) Final Report: Kathleen Calzone, PhD, RN, APNG, FAAN, National Cancer Institute

Dr. Kathleen Calzone provided the final report on the Global Genetics and Genomics Community (G3C). G3C is an open access website (http://genomicscases.net/en) with simulated, diverse case studies. Dr. Calzone provided an overview of the G3C online interactive including how to login, the faculty guide with resources, and the different case studies users interact with. Users make recommendations, which feed into user outcome assessments, and expert commentary can be viewed. The most recent addition to the cases is Familial Hypercholesterolemia. ISCC played a role in advising the G3C developers about gaps and priority topics to be addressed. They assisted with case content and resources, peer review, supplemental materials and expert commentary.

In terms of analytics, the G3C website does not track what kind of clinicians utilize it, but volume is tracked using Google Analytics. Nursing schools have been very successful at integrating the interactives as supplemental activities. All educators do not use the site in the same way, and some may use a vignette question for group discussion. The ISCC appreciates Dr. Calzone's work on G3C and the opportunity to collaborate on this and hopefully future modules. A pediatric topic was suggested as a future case study.

Pharmacogenomics Universal Exercise: Kristin Weitzel, PharmD, FAPhA, Clinical Professor, Associate Director, University of Florida Health Personalized Medicine Program

Based on the previous universal exercises created by ISCC, Dr. Kristin Wetzel presented progress on developing a universal pharmacogenomics exercise. She presented the adaptation of exercise one. She described how the group approached the questions being adapted and some of the challenges they encountered in thinking about content. The ISCC provided feedback on content that was created. Dr. Wetzel mentioned that the exercises can be applied to any field, and some suggestions from the ISCC included cardiology and general medicine. Other options for expanding the use include training the trainer at pharmacists meetings.

The next steps include engaging a larger group of ISCC members to provide feedback on the draft version. Those interested should email Dr. Weitzel at KWeitzel@cop.ufl.edu. Project group members could also assist in translating the pharmacogenomics exercise to their specialty.

Project Ideas; Unconscious Bias: Shoumita Dasgupta, PhD, Associate Professor Department of Medicine, Biomedical Genetics Section, Assistant Dean of Admissions

Dr. Shoumita Dasgupta began the session by providing background information on types of bias and how implicit bias can impact outcomes, including in medical care. Then she described how the

increasing prevalence of non-invasive prenatal testing intersects with implicit biases against individuals with physical and intellectual disabilities. Data suggests that there is a disconnect between physicians' personal views and their understanding of their role in providing guidance to patients as well as misunderstanding of non-directive counseling such that they may fail to provide adequate information about the future well-being of a child with a genetic condition.

Next, Dr. Dasgupta laid out a project idea for investigating implicit biases against those with disabilities in medicine that would document how prevalent these biases are and develop interventions. The elements of the proposed project are:

- Disability implicit bias in medicine: measure implicit biases for physical and intellectual disabilities using the Implicit Association Test (IAT) or assess need to develop new metric
- Bias and counseling: examine correlation between IAT and responses to prenatal counseling scenarios in which child is at risk for physical or intellectual disability
- Non-directive counseling: develop a module to describe principles of non-directive counseling
- Impact on hypothetical counseling: after completing non-directive counseling module, assess potential impact on counseling recommendations in hypothetical cases

Some stated needs to help this project are: use/development of IAT software, case input, web designers and instructional media expertise, data pipeline and analysis, liaisons to research subjects and communities of healthcare providers, incentives to participate (e.g. CMEs)

During the discussion, Steve Murphy suggested MedScape's simulation platform could be used for case-based learning and analysis. Colleen Caleshu stated that NSGC could participate, and Melissa Parisi shared information about how inclusion of people with disabilities has made important contributions to our understanding of health and different conditions. Carla Easter mentioned she has some connections with people in the Autism advocacy community. Finally, participants discussed different models for conducting this project without additional funding available, including asking medical communities to collect data on their practice.

FYI – Recent/Upcoming NIH Disability Rights Seminars with Tom Shakespeare
https://videocast.nih.gov/summary.asp?live=26981&bhcp=1
Sexual and Reproductive Health in Persons with Disabilities
Monday 2/5, 10:30-11:30am
Building 10 – Lipsett Auditorium

https://videocast.nih.gov/summary.asp?live=26987&bhcp=1
Prenatal genomic testing and disability rights
Thursday 2/22, 1-2pm
Building 10 – Masur Auditorium

NHGRI Short Course in Genomics for Nurses, Nurse Practitioners and Physician Assistants: Donna Messersmith, Ph.D, NHGRI

Dr. Donna Messersmith provided background on the NHGRI Short Course in Genomics for Nurses, Nurse Practitioners, and Physician Assistants, and shared that there would not be a formal course in 2018. Instead, NHGRI is taking this opportunity to re-assess the needs and opportunities for healthcare

provider education by hosting a meeting in August that will help set the course for the future. The central questions for this discussion was 'what *should* NHGRI's role be in enhancing healthcare provider education in genomics?'

Carla Easter started the discussion by explaining NHGRI's strengths in convening people and creating community, but at this moment we are not clear what NHGRI should be doing in this space. Many participants think NHGRI should have a role in healthcare provider education in genomics, and Rich Haspel suggested that because NHGRI is not specifically targeted at one provider audience, that NHGRI has a unique opportunity to support healthcare teams and collaborative learning and that ISCC could help create teaching tools and workshops to address this need. There was agreement that team-based learning is a good idea but it is important to consider carefully how we will engage the audiences and there is a need for an assessment of whether clinicians want this type of approach and consider it a high priority. It was noted that feedback from the course participants indicated an interest in learning related to the healthcare team. The National Society of Genetic Counselors had a project a few years ago in which they scored various care coordination models for specific conditions and brought teams together to address this need. NHGRI should reach out to them to get more information about that project.

Discussion of Compendium/ Other Project Ideas/Wrap-up

During this time Dr. Richard Haspel discussed the compendium, a booklet of ISCC Organizations, which describes activities and programs related to genomics education that each organization runs. There is also an area to put potential project ideas, discussions and opportunities for collaboration amongst the many organizations of ISCC. Prior to the meeting, the compendium was distributed to further promote inter-organization communication through the sharing or resources and interests. After Dr. Haspel informed attendees about the purpose of the compendium, he emphasized the importance of each organization having an entry within the book.

Lastly members referenced back to previous presentations, discussed ways they could be involved in potential projects and it was decided that during the March conference call that there would be updates of the needs for those projects and the next steps would be discussed. These projects include ISCC participation in the GLEE healthcare provider group 15 for 15 Campaign (Kathy Blazer), investigating implicit biases against disabilities in medicine (Shoumita Dasgupta), the pharmacogenomics universal exercise (Kristin Weitzel), a possible new G3C ISCC collaboration module (Kathy Calzone), and, in relation to the NHGRI genomics course, development and participation of materials to assess the needs and opportunities for healthcare provider education (Donna Messersmith).

As the meeting adjourned, Co-Chairs thanked all attendees and presenters, and staff for their participations in the 7th Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC), and reminded all attendees to please complete the survey and provide any feedback or ideas they may have for future discussions.

National DNA Day 2018

'15 for 15' Topics

DNA Sequencing: Reducing the cost of genome sequencing by a million-fold

Human Genomic Variation: Understanding what makes each of us different and what makes us the same

Cancer Genomics: Transforming the way we study, diagnose, and treat cancer

Human Origins and Ancestry: Illuminating human and family origins at the molecular level

Agriculture: Empowering farmers to improve the food supply

Genome Function: Learning how our genomes serve as the blueprint for life

Rare Genetic Diseases: Ending diagnostic odysseys for patients with rare diseases

Pharmacogenomics: Choosing the right medication at the right dose for each patient

Prenatal Genetic Testing: Revolutionizing how prenatal genetic testing is performed

Forensics: Establishing more robust methods for DNA-based forensic analysis

Microbes and Microbiomes: Advancing the study of individual and communities of microbes

Direct-to-Consumer Genomic Testing: Accessing information about your genome from your home

Natural World: Understanding biodiversity and evolution, and protecting our ecosystems

Genome Editing: Altering the genome with unparalleled efficiency, precision, and lower cost

Social Context: Considering what our DNA means to and for our health, our identities, our culture