

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

February 7, 2019

National Human Genome Research Institute (NHGRI)
National Institutes of Health (NIH)
Natcher Conference Center
Bethesda, Maryland



Attendees: 65 registrants (46 external; 12 from NHGRI; 7 from other NIH institutes)

Welcome and Introductions: NHGRI Division of Policy, Communications and Education Director, Laura Lyman Rodriguez, Ph.D., Co-chairs Carla Easter, Ph.D., NHGRI, and Rich Haspel, M.D., Ph.D., Beth Israel Deaconess Medical Center

Dr. Laura Rodriguez, Director of the Division of Policy, Communications and Education welcomed all ISCC members, both in-person and those on WebEx ([participants](#)), to the 8th Inter-Society Coordinating Committee for Practitioner Education in Genomics In-Person Meeting and provided an overview of NHGRI's support of ISCC over the years. Dr. Carla Easter, NHGRI Co-Chair, and Dr. Rich Haspel, External Co-Chair, welcomed and thanked all attendees for their participation. Dr. Haspel thanked Dr. Teri Manolio for her service as ISCC Co-Chair; as of 2019, Dr. Easter now serves in that role. Dr. Haspel reviewed the current membership and growth of ISCC and provided an [overview](#) of the day's upcoming meeting ([agenda](#)). He highlighted and welcomed the new ISCC members and introduced the newly updated [Compendium](#).

NHGRI Education Updates - Division of Policy, Communications, and Education

Carla Easter, Ph.D., Branch Chief, and Donna Messersmith, Ph.D., Provider Education Specialist, provided an [overview](#) of recent updates in the Education and Community Involvement Branch, including new [resources](#) and initiatives.

Extramural Programs and Medical Education

Representatives from NHGRI's Division of Genomic Medicine provided presentations on grant-funded initiatives and extramural training programs. Robb Rowley, M.D. began with a [presentation](#) on the Clinical Sequencing Evidence-Generating Research (CSER) program and Electronic Medical Records and Genomics (eMERGE) initiatives. He also pointed to the CSER Practitioner Education Working Group's "[Guide to Interpreting Genomic Reports](#)" for non-genetics providers. Heather Colley, M.S., described extramural training [programs](#), including the expectation of a new [R25](#) grant opportunity that might be of interest to ISCC members.

Comments and Questions

Help with patient care requires significant expansion of the workforce to include non-geneticists.

- There's wide genetic testing available, but there are people that do not know how to do pre-genetic testing counseling, and there are people interpreting results without the necessary training.
- Supply/demand is an issue, and we need to expand training.
- There is a need for official training standards as to who should not be doing the counseling and interpretation.

Heather's response: It is always a challenge to establish proficiency; there is always something new in genomic medicine such as changes in variant interpretation. ISCC can identify what those official standards might be and encourage professional societies engaging in genetic specialties to provide a certificate. There ought to be criteria for speaking to patients about genetic results. There is a need to do a better job at the medical school/physician assistant level so that we do not have to keep backfilling with additional training.

Comment from phone: Can we consider how NHGRI can help with the education of non-physician providers? Practicing physician assistants are looking for opportunities to help.

Heather's response: At NIH, there are not a lot of opportunities below the M.D./Ph.D. levels. For example, genetic counselors can apply for RO1s. NHGRI is looking at ways to support non-Ph.D./M.D. trainees, but we are not there yet. The National Heart, Lung, and Blood Institute is interested too. During various strategic planning workshops, it has been brought to the attention of NHGRI that there is an education gap that needs to be filled. We recognize there are resources for validation and qualitative/quantitative approaches to evaluate educational strategies, which might be a research strategy for inclusion in grant applications.

Heather's response: Also to note: As part of NHGRI's current strategic planning process, the website (Genome.gov/2020) is collecting information from the public, researchers, and clinicians. For educators in our training programs, you have to demonstrate your institutional leadership, your success in previous training programs, and in evaluating feedback from students. Evaluation needs to be stringent and will go through peer review. Do you have a partnership with an educator who knows how to evaluate and execute the process. Think about the idea regarding recommendations the ISCC wants to see for criteria or in consideration with how we can make sure there's innovation/creativity and also provide standards for grants. Also, what ways can we have physician assistants with more training, and identify roles for them to practice in genetics and genomics. What are the service delivery models?

Rich: Solid educational programs require funding for development and implementation. Perhaps, as part of the strategic planning process, ISCC can draft a letter/document that could potentially carry some weight regarding what is needed in this area.

Comment: We are talking about extremes of training. What role is in between genomic literacy and cultural competency to ensure those conducting clinical genomics have cultural awareness to work between these two extremes to ensure better training?

Heather: Across NHGRI-funded training programs, they must talk to students about cultural competency. The new generation of scientists are more aware of this. CSER/EMERGE/IGNITE are engaging diverse groups. Mt. Sinai is thinking about how to work with community clinics and talk about genomics. The University of Illinois is working to invite in American Indian scientists to give talks.

Rich: This is the reason that the ISCC has formed a new project group that will focus on "Diversity among Healthcare Providers". Dr. Easter's branch works a great deal with diverse communities and patient advocates. In the ISCC, our focus is on healthcare providers, but we can leverage the activities within the Education and Community Involvement Branch.

Heather's follow-up [email](#).

Keynote: Eliseo J. Pérez-Stable, M.D., Director of the National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health (NIH): "Genomics Education, Minority Health and Health Disparities"

Dr. Eliseo J. Pérez-Stable provided interesting [data and comparisons](#) from published research studies within the context of health disparities, social determinants of health, and mechanisms leading to health

disparities. He highlighted the importance of including diverse participants in research studies, a concept particularly important in genomics research.

Comments and Questions

Question: Genetic counseling as a field is homogenous with white women. Regarding education and recruiting people, how does working towards a diverse workforce impact what you discussed today?

Eliseo: Twelve percent of new Ph.D graduates were from under-represented populations. The pipeline is not as empty as it was. Minority physicians are more likely to be found in underserved areas, will accept Medicaid, and see poor, uninsured patients. Their intent to serve in these areas is high. People graduate with educational debt. Genetic counseling has a number of challenges: it's difficult to refer people there without insurance. These are not insurmountable barriers. People respond to respect and humanism. Often, the distrust directed at a system and not the individual; you can overcome that.

Rich: We now have direct-to-consumer genetic testing such as Ancestry.com related to racial background --how do we navigate this? There is a slippery slope to eugenics and other problems. This is very complex.

Eliseo: We are navigating this. From the perspective of research, NHGRI and NIMHD are on same page. In September, Dr. Eric Green, Mr. Vence Bonham, and I [published](#) on this. We are dealing with a social construct that brings other things in and how you adapt to stressors, and living in a society with a white European culture. It's a fascinating approach for research purposes. Yes, groups use data to make statements about inferiority. This attitude is not as prevalent, more and more. We see people who work with biologists and clinicians and think about how to address these problems. This is not an exclusive lens of genetics. We need to use tools available to understand what's going on. Diabetes is twice as common among any minority in the U.S. independent of wealth, and outcomes for minorities are different. We end up with more end stage renal disease. White populations have more myocardial infarctions. This boils down to education about patients and trying to communicate risk is a big deal. How do people explain that the risk of cervical cancer for a 40 year old women is 1 in 10,000? It's hard for people to get their head around risk. Measles has a highly effective vaccine, and we were talking about eradication. It's about a public health consensus, shared decision making, and presenting options. Genetic ancestry should be a tool for discovery.

General Discussion, including ideas for new Project Groups:

Two New Project Groups: Accredited Continuing Education (ACE) and Diversity of Health Care Providers

Project Group Discussion and Updates ([Project Group Descriptions and Participants](#)):

1. Direct-to-Consumer (DTC) Genetic Testing (Kathy Blazer, Tracey Weiler)

This Project Group is: 1) Collecting and documenting existing DTC information resources (including educational, position statements and peer-reviewed literature and news media); 2) Assessing need, generating ideas and facilitating development for additional DTC educational resources for healthcare professionals and trainees; and 3) Identifying venues to partner in disseminating DTC educational resources appropriate to the needs of organizations needing DTC education (ISCC member organizations and others).

Kathy Blazer and Tracey Weiler [presented](#) the DTC Project Group efforts to design a survey to assess needs among healthcare providers to understand direct-to-consumer genetic testing. A PDF of the survey was distributed to ISCC members prior to the In-Person Meeting.

During the break-out session, members of the group reviewed the survey and discussed suggestions for modifications. These included:

- Deciding how similar/different questions should be for educators and practitioners.
- Putting demographics on the backend to see who is seeking information now and can they develop resources to help them?
- How many minutes would take a survey – 6 minutes.

ACTION: Plan to send out a different, revised PDF for feedback on the survey.

2. Inclusion in the Practice of Genomic Medicine: Exploring the Impact of Implicit Biases Towards Disability (Shoumita Dasgupta, Tina Lockwood)

This group is developing educational resources related to studying unconscious bias for individuals with disabilities during prenatal screening. The goals are to : 1) Identify implicit and/or explicit bias held by medical students and clinicians towards individuals with physical and/or intellectual disability; 2) Determine whether these biases impact genetic counseling recommendations in a prenatal setting; and 3) Assess whether training in patient-centered counseling can positively impact subjects' ability to appropriately make unbiased prenatal recommendations.

Shoumita Dasgupta provided a [presentation](#) updating their progress. This included:

- The design of a survey and creation of modules to look at implicit bias.
- Request for ISCC members to volunteer in the near future to take the survey.
- Examination of the issue of pregnancy termination for disabilities and whether personal views of providers influence outcome.
- Looking at how physician assistant students demonstrate preference for abled patients.
- Asking the question: is it truly non-directive counseling or is there a bias in prenatal counseling scenarios?
- Creating implicit association testing in non-directive counseling modules; then re-assessing the learners.
- Requests for ISCC member reviews:
 - Provide feedback on implicit association test module.
 - Run through pilot test modules.
 - Provide comments on study design.
 - Should take 30 minutes to go through module.
 - Consider conversion to CME-granting institutes.

Question: In Genetic Counseling, there is a debate on non-directiveness and should we be a little more directive. How was the non-directive part developed?

- Shoumita Dasgupta: There are scenarios where you want to be more directive which was kept in mind during module development; an NSGC representative assisted with this aspect.
- They are currently in the pilot phase and open to edits/changes along those lines.

3. Pharmacogenomics (PGx) (Andrew Monte, Donna Messersmith)

This Project Group is working on these goals: 1) Create and/or re-purpose pharmacogenomics educational content and resources targeted to primary care providers (PCPs); 2) Prepare for presentations at professional meetings of PCPs; 3) Tailor pharmacogenomics educational content for Nurses, Pharmacists, Physician Assistants, Genomic Counselors, and other healthcare professionals; and 4) Educate the public in pharmacogenomics for improved healthcare.

Andrew Monte [presented](#) a summary of next steps for the Pharmacogenomics Project Group, focusing on the development of an educational module (CME) on the gene-drug pair CYP2C19-clopidogrel. Robert Ostrander, the current ISCC representative for American Academy of Family Physicians (AAFP), is working with the PGx Project Group to facilitate interactions with the AAFP leadership.

Discussion points from break-out session:

- Plavix (Clopidogrel) is often prescribed for patients to prevent heart attack and strokes, especially after stent procedures.
- Depending on your genetic profile, certain patients with reduced platelet function due to a mutation in the CYP2C19 gene should be on a different drug. The evidence is considered to be strong. The Clinical Pharmacogenetics Implementation Consortium (CPIC) has published [guidelines](#). The PGx Project Group is working on a collaboration with AAFP through their CME infrastructure to provide educational modules and guidelines for family physicians.
- This is the first case scenario. After interacting with other societies and defining what primary care providers need to know, the plan is to develop additional content on other gene-drug pairs. The Project Group wants to focus on the clinically important tests, what payors will cover, and also adverse drug events.

4. New! Promoting and Supporting Diverse Health Care Professionals (Patients & Caregivers) through Inclusive Outreach and Engagement (Yolanda Powell-Young and Carla Easter)

This new project group proposes to collaborate with organizations and individuals who represent and support healthcare providers, patients, and caregivers from diverse populations. This group will also assist with the dissemination of ISCC generated resources to diverse communities.

Over the next couple of months, the group will focus on:

- Authenticity and discussion of cultural awareness vs. cultural competency.
- Work with patient advocacy groups to focus on patients to help educate and help pass/change laws.
- How to define diversity because it means many things to many people; this could be accomplished by drafting a handbook/guide to help organization be more proactive regarding diversity and working with diverse populations.
- Diversity to what end? Who is it for and what are outcomes and who are communities?
- Capture data on diversity of workforce within genomics; uncertain how represented individuals who focus on genetics are (literature review).
- Creation of a case study to go on G3C to explore authenticity as a competency.
- Create scripts and disseminate. Look at what tools or models are already available.
- Connecting with Genetic Alliance and National Organization of Rare Diseases (NORD) to get an idea of what patient populations want.
- Create talking points and slide set on diversity.
- Investigate linguistic inclusion.

- Self-identity vs. ancestry
- Synergy with Pharmacogenomics Project Group and discussions of Precision Medicine and how it will be affected by diverse populations.
- Work with minority serving institutions and colleges.
- Educational initiatives: Discuss developing a genetics track at the schools of nursing with National Coalition of Ethnic Minority Nurse Associations (NCEMNA).
- Explore K-12 initiatives.
- Discuss opportunities for connection with with Dr. Pérez-Stable and NIMHD

ACTIONS:

- Doodle poll to have first call
- Create resources on topic

5. New! Accredited Continuing Education (ACE) Project Group (Steve Singer)

This project group will provide leadership to foster coordination and evolution of accredited continuing education approaches to address genomic medicine gaps for practicing health professionals and interprofessional teams. Key activities will include developing networking and leadership insights for ISCC members to collaborate with Continuing Education (CE)/Continuing Medical Education (CME) educators, harmonizing and simplifying CE/CME planning and delivery, collaboration to address unmet educational needs, and dissemination of effective practices.

- Conduct a meta-analysis of practice gaps among ISCC organizations that:
 - is inclusive of individual, interprofessional/team, and system practice gaps
 - provides insight to the methods that ISCC member organizations are using to determine practice gaps
 - reflects the priority or urgency of practice gaps with respect to public health/care
 - includes sufficient granularity (ie, "don't understand genetics" is not sufficient)
 - includes both content and process-related gaps
- Facilitate/foster inter-organizational collaboration around mapping existing accredited continuing education to gaps to identify areas of redundancy, inefficiency and/or unmet needs.
- Disseminate insights beyond ISCC, potentially to other stakeholders and the CE community

Encourage greater collaboration within and between organizations to evolve the methodology of CE design to achieve greater impact to close identified gaps.

Goals discussed through conversation in the break-out session:

- Identify gaps across institutions and across education stage.
- Facilitate conversation across institutions on gaps to determine what are shared gaps or barriers.
- Facilitate networking across ISCC between those identifying gaps and those with expertise in education.
- Identify and share strategies for measuring if gaps are being addressed and closed.
- Improve dissemination of CME.
- Translate and disseminate the common identified gaps to CME professionals.

Themes discussed:

- Genomics CME is competing for doctors attention with subjects the doctors feel is more useful to them (e.g., latest treatment for a disease they commonly treat, etc.).
- A survey may not be the best way to assess gaps as it is subjective and, “you don’t know what you don’t know.”
- Often times, changes in CE is driven by those in volunteer roles within organizations/associations. These roles have short terms and high turn-over, so hard to make progress.
- Lack of understanding that there are gaps in genomics CE – if you asked most institutions if they have genomics and genetics education they would say yes, but this doesn’t cover the nuances.
- Need for consistent nomenclature between all health care providers to avoid confusing patients. This could stem from standard nomenclature in CE.
- General discussion for potential of identifying a recommended set of core competencies.

General discussions and suggestions for ISCC: Rich Haspel, ISCC Co-Chair, [Ideas](#)

ISCC response to [NHGRI strategic planning process](#):

- Rich Haspel has offered to take the first steps in writing a letter/manuscript reviewing the status of genomic education and recommendations for ways to help promote genomics education. This document could be submitted to the NHGRI Strategic Planning Group on behalf of the ISCC.
- NHGRI Extramural leaders have said that published papers make a difference in their planning.
- Funding is needed to study best ways to disseminate and implement resources and proposals. Need to be put together carefully with educational principles.

ACTION: Rich Haspel will follow-up on an ISCC response to the NHGRI strategic planning process.

Review of [Ideas](#) submitted by ISCC members during discussion:

- How to disseminate genomic education
- Cancer genomic testing gaps
- Networking/discussion groups, in addition to working groups, on specific topics like Learning Management Systems, cancer, genetic condition penetrance, etc.
- Nurses project group
- Awareness campaign of genomic resources
- Standards/guidelines for lay language to use in genomic reports to enhance general understanding. It would be ideal if germline, cancer, DTC, etc. used the same language.
- Development of specialty specific champions to help carry the content back to these specialties.
- Develop an “Academy of Genomic Educators”
- Association of Professors of Human and Medical Genetics (APHMG) might be a place for an academy.