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NHGRI International Genomics Education Meeting
National Institutes of Health, Lawton Chiles International House (Stone House)
Bethesda, Maryland
August 4-5, 2016

Attendees: Sarah Beachy, Kathleen Calzone, Nicky Conway*, Kate Dunlop*, Maxine Foster*, Gail Graham*, Sarah Gould, Karen Hanson, Sue Hill, Jean Jenkins, Heather Junkins, Maggie Kirk*, Bruce Kopf*, Nicki Latham*, Teri Manolio, Joseph McInerney, Donna Messersmith, Shawna Morrison*, Laura Rodriguez, Anneke Seller*, Emma Tonkin*, Jeffery Vance, and Bob Wildin.
(*via WebEx)

Welcome
Laura Lyman Rodriguez, National Human Genome Research Institute, NIH

The objectives of this meeting are to provide an overview of primary care oriented education programs; review lessons learned for meeting the changing educational needs of healthcare providers; share best practices for genomics education implementation; and identify synergies, challenges, and opportunities to share and collaborate, with a focus on physicians and healthcare practitioners. The expected outcomes of this meeting are awareness of the landscape for international genomics education, identification of synergies and opportunities for collaboration, development of an agenda for the ISCC (Intersociety Coordinating Committee) International Education Working Group to pursue, and the potential publication of the meeting summary.

Education across the Genomic Medicine Research Portfolio
Teri Manolio, National Human Genome Research Institute, NIH

The NHGRI Genomic Medicine Working Group has defined genomic medicine as, “an emerging medical discipline that involves using genomic information about an individual as part of their clinical care and the health outcomes and policy implications of that clinical use.” While the definition of genomics varies across NIH Institutes and other groups, NHGRI as a small Institute is primarily focused on DNA/RNA related research.

There are six major programs in the NHGRI’s Genomic Medicine Research Program: The Undiagnosed Diseases Network (UDN), Newborn Sequencing in Genomic Medicine and Public Health (NSIGHT), Clinical Sequencing Exploratory Research (CSER) Consortium, Electronic Medical Records and Genomics (eMERGE) Network, Implementing Genomics in Practice (IGNITE) Network, and the Clinical Genome Resource (ClinGen). There are multiple working groups within these programs that are developing tools for genomics education. One of these tools is the Genomic Report Toolkit from the CSER Consortium, which is expected to be released in the fall of 2016.

NHGRI’s education initiatives are also relevant to nurses, though they are mostly physician focused. The Genetics/Genomics Competency Center (G2C2) and Global Genetics and Genomics Community (G3C) have resources that are beneficial to nurses, and the Method for Introducing New Competencies (MINC) platform will be available fall 2016. The National

Institute of Nursing Research is developing an initiative to create a network of collaborators to improve patient care.

Moving Genomic Education Forward in Australia
Nicolette Conway, GenomePlus, Australia
Kate Dunlop, Director, Centre for Genetics Education NSW, Australia – representing AGHA

The Australian Genomics Health Alliance (AGHA) is a national network of clinicians, diagnosticians and researchers working towards the development of genomic medicine both within Australia and in collaboration with international consortia. AGHA has four key research related programs. Program 1 is a national diagnostic and translational research network developing national standards for a coordinated, sustainable implementation of clinical genomics. Program 2 is a national data repository. Program 3 focuses on the economic analysis and policy implications for the health system. Program 4 focuses on workforce education and training, patient understanding, and ethics. AGHA is seeking additional knowledge in genomic medicine before it approaches professional regulatory bodies to present new learning criteria.

Another organization involved with health care provider (HCP) education in Australia, Genome Plus, is a tailored genomic engagement and education program for healthcare professionals who are not part of the public health system. Its audience is industry employees who are involved in clinical research, sales representatives, and private-practice health professionals who need to understand the impact of genomic medicine in their practices. It is a commercial model with no government funding. Genome Plus faces challenges that include industry's limited recognition of the rapid rate of genomic technology development, its dependency on international parent companies for initiatives, and the complex reimbursement system for medicine.

Training Programs in Genomic Medicine
Heather Junkins, National Human Genome Research Institute, NIH

The Institutional Training Program in Genomic Sciences for Graduate Students and Postdoctoral Fellows (T32) seeks to develop leaders in genomic sciences. Typically, 5-year awards, Institutional T32s focus on training individuals for research careers in scientifically rich environments. T32s have a structured training program, which encompasses didactic lectures, lab-based learning, multi-disciplinary topics, mentoring, and career development.

The Institutional Training Program for Postdoctoral Fellows in Genomic Medicine (T32) aims to develop leaders in genomic medicine. There are two training paths, and participants may choose one or both: (1) a track in genomic medicine for researchers and (2) comprehensive training in genomics for clinicians. Course requirements include flexible training in quantitative approaches and Ethical Legal and Social Implications (ELSI). NHGRI tracks trainee outcomes after matriculation to evaluate these programs.

The Individual Mentored Clinical Scientist Career Award in Genomic Medicine (K08) aims to provide a mentored research experience to develop clinically-trained individuals into independent investigators. Course requirements include a defined curriculum to complement their existing expertise. Trainees pursue a research project that would provide preliminary data

for an independent research project. A new aspect of the K08 is the expansion of the program to support clinicians as eligible appointees.

Though NHGRI hosts a training meeting yearly, like many NIH programs much of the activity is located on the East and West Coasts with noticeable gaps in the middle of the country. NHGRI plans on working to educate sites about training programs to identify other locations eligible for training grants.

Moving Genomic Education Forward in the UK Part 1
Sue Hill, National Health Service England

The National Health Service (NHS) has a long-term vision which includes using precise diagnoses to improve outcomes for patients, particularly for cancer and rare diseases. One program that is aiding in this effort is the 100,000 Genomes Project. The 100,000 Genomes Project focuses on rare inherited diseases and common cancers. A private company, Genomics England, was formed to coordinate the project under an independent board, providing a 'start-up' mentality and drive.

The aims for Health Education England's (HEE) Genomics Education Program (GEP) are to embed genomics into education and the healthcare workforce, integrate whole-genome sequencing (WGS) and functional genomics into mainstream care, and continue the legacy of the 100,000 Genomes Project. A great challenge is to anticipate the mix of skills, experience and abilities that will be needed to deliver future services. NHS anticipates and prepares for new technologies by building flexibility into individuals' training. A key aspect of GEP is to identify gaps in knowledge, skills and competencies for the delivery of current and future care. GEP works closely with many professional bodies and organizations.

GEP has developed a network model with specialist diabetes nurses for sharing genomic potential and knowledge within a specialist clinical group. GEP is looking to develop and roll out this model with other specialist groups. All professionals who complete GEP training will be brought together to form a Faculty of Genomic Medicine. This will serve two key purposes: form a community to build and maintain genomic knowledge, and act as champions within the wider workforce to drive forward genomic technologies across the NHS. The HEE GEP has a three-year horizon, as they are only funded through April 2018. Despite this, they have a vision that their educational efforts will align and become mainstream for genomics in 2020.

The Master's in Genomic Medicine postgraduate curricula prepares NHS staff for the future of genomics in contemporary healthcare. The evaluation plans for the Master's program ensures content is 'fit-for-purpose' and measures the impact of the Faculty of Genomic Medicine. A key challenge is predicting the future in a fast moving area of disruptive change. Curricula need to be flexible to give staff the ability to respond as technologies and services change.

Education Tools and Programs from the Genomic Healthcare Branch
Bob Wildin, National Human Genome Research Institute, NIH

The aims of the Genomic Healthcare Branch (GHB) are to promote the effective integration of genomic discoveries into healthcare, promote the development and evaluation of tools, and promote genetics literacy among the full spectrum of healthcare providers and their patients. GHB offers a short course on genomics that is directed to nurses, nurse practitioners, physician assistants, and faculty who educate these professionals. GHB also offers public tools, like My Family Health Portrait. My Family Health Portrait allows families to enter family health information and learn about their risk for certain conditions. Another public tool is the Genetic and Rare Disease Information Center (GARD), which works to answer questions from the public and turn these questions/answers into a resource for rare disorders.

G2C2 is used to search for resources for the classroom or practice. G3C is a collective set of case studies. The Intersociety Coordinating Committee (ISCC) is used to help share resources, failures, successes, etc. On the ISCC website there is a template for organizing case studies to be used for educational purposes. The ISCC, a collaborative group of professional societies, hosts annual meetings, monthly calls, and working groups on topics including: Case Studies, Competencies, Educational Products, Engagement of Specialty Boards, Innovative Approaches, Insurer Staff Education, and Speaking Genetics. The ISCC has an open membership policy, but is working with very limited NHGRI funding support.

Moving Genomic Education Forward in the UK and through International Collaborations Part 2

Maggie Kirk, University of South Wales, Emma Tonkin, University of South Wales, and Kathleen Calzone, National Cancer Institute, NIH

The NHS National Genetics Education and Development Center's nursing program (2004-2012) used the Theory of Planned Behavior to inform a program of research, education, and development to engage nurses in genetics/genomics. It found that attitudes directly affected the ability to influence others (including policy makers and professional bodies), and therefore changes the feasibility of these programs. Things that were found to work included making genetics/genomics accessible and relevant, making clinical links explicit, and sharing ideas and resources. Challenges included lack of leadership from policy makers, limited awareness, and limited confidence and role models. A series of recommendations was made in 2011 to the Department of Health's Nursing and Midwifery Professional Advisory Board by an expert group on how best to take forward genetics and genomics in nursing and midwifery professional practice.

MINC strives to develop, implement, and evaluate a year-long genomic education program to train, support, and supervise institution administrator and educator dyads. It evaluates institutional nursing workforce attitudes, practices, receptivity, confidence, and competency in genomics. MINC outcomes include increased awareness of genomics and increased educational intent.

The Global Genomics Nursing Alliance (G2NA) aims for knowledge mobilization and action through sharing ideas, expertise, and resources. A G2NA roadmap will lay out how to integrate genomics into nursing education, practice and research. There is a G2NA retreat in the UK in early 2017. G2NA will benefit from sharing information with G2MC and utilizing resources within G2C2 or G3C.

Moving Genomic Education Forward in Canada
Shawna Morrison, GECKO (Genetics Education Canada: Knowledge Organization), Children's Hospital of Eastern Ontario

GEC-KO's goals include enhancing healthcare professionals (HCPs) awareness and use of genetics educational resources and ensuring up-to-date, evidence-based, high utility content on the GEC-KO website. GEC-KO also works to ensure that HCPs will be aware of the relevance and utility of genetics in primary care, have appropriate genetics knowledge, skills and confidence in those skills, and have knowledge of appropriate genetic services and genetic testing.

GEC-KO has secure funding to support a genetic counsellor/ program manager for 4 days a week. Nonetheless, to develop resources it must identify appropriate experts and rely on volunteerism. Other genetics professionals and non-genetics specialists and generalists have been very willing to share their knowledge, motivated by recognition of the importance of the relationship between genetics and other disciplines and the positive impact on health of incorporating genomics into practice in some circumstances. GECK-KO deals with the challenge of delivering genetics education to non-genetics health professionals by integrating into existing well-attended continuing education venues and involving champions within the target health professional groups to present at seminars and workshops. GEC-KO has strongly positive evaluations from workshops and seminars and evidence of continuously increasing profile from Google and Piwik analytics. Gaps that GEC-KO needs help to fill include support for more interactive electronic resources that enhance a learner's experience, and integration of family history tools, red flags and point of care tools into the electronic health record.

MD/MS Programs in Genomic Medicine
Jeffery Vance, University of Miami

In the University of Miami's MD/MS program, students can earn an MS in Medical Genetics while earning their MD. This program includes monthly didactic sessions on genomic topics, required mentored research project between 1 and 2nd year, flipped classrooms, and culminates with a "portfolio" of activities. The parallel approach of this program avoids competing for space in the MD curriculum, is a less intense course schedule (compared to doing the program separately), and is a minimal additional cost. The goal of this program is to create a qualified consumer and advocate. Some barriers for this program include managing student schedules, additional tuition costs to students of a second degree, and program capacity. Conclusions include that active learning strategies are key to program success and that laboratory data exercises with clear clinical utility improve enthusiasm.

Not many students have an advanced genetics education before entering this program. This might be a good opportunity to incorporate a fast track for medical school with increased genetics education as an undergraduate. Students in these programs can also help senior medical professionals address their gaps in knowledge. In the future this program hopes to expand to other audiences (residents, fellows). This program is also trying to integrate into the curriculum

for students not officially in the program. Though there is a recognized need for this type of program for nurses, it has not been translated into a nursing program because of logistics.

Education Efforts through ASHG
Karen Hanson, American Society of Human Genetics

The American Society of Human Genetics (ASHG) is the largest genetics-based society with over 8,000 members. Its current educational programs include a cancer genetics workshop (in collaboration with the Jackson Laboratory), next generation sequencing webinars, virtual meetings, and pediatric genetic testing infographics. The free-to-participants' cancer genetics workshop is an interactive, case-based blended learning program. The workshop also has monthly emails to keep participants active, long after the workshop has ended.

Challenges of this program include the time- and staff-intensive nature of these workshops, scheduling difficulties, and that they are most practical for small audiences. To overcome these, ASHG is producing shorter and online versions. Challenges for virtual meetings include steep learning curves, funding, and reaching the target audience. ASHG plans to do more local outreach with professional organizations in the area and to expand collaborations with organizations interested in genetics education.

Resources
Jean Jenkins, National Human Genome Research Institute, NIH

G2C2 is a free online repository for healthcare provider-oriented educational resources. All resources are peer-reviewed by an editorial board and include links to identified competencies for clinical providers from nursing, genetic counseling, pharmacist, physician assistant, and physician disciplines. The resource repository site has been recently redesigned, so that the searchable educational resources for all disciplines are easier to find and their linked discipline-specific competency guidelines are more prominent.

G2C2's goal is to provide health professionals with a centralized web resource to facilitate communication, development, and dissemination of educational resources. New directions for G2C2 include expanding to other disciplines and producing nurse researcher and international resources. Though it is sometimes the same material or modules, groups often don't initially consider what's been developed for other professional groups, preferring to develop their own. Because the baseline foundational knowledge is similar, groups need to be more open to accepting these resources. G2C2 is a great resource to help groups share information, including standardizing competencies.

Metrics for Evaluating Effectiveness of Education and Training Programs/Lessons Learned
Facilitator: Jean Jenkins, National Human Genome Research Institute, NIH

Only some groups have included an evaluation component for their genomic education programs. These evaluation methods include using proxy measures and patients' stories, as well as looking at how the mode of delivery affects empathy. For one project, evaluation is a typical

survey, but also there is a headset-based patient interaction to determine if students are ordering correct tests at appropriate times. Adjustments have been made to this program based on the feedback received from the various evaluation methods. Lessons learned from these programs include acknowledging the need for more emphasis on getting people to complete the evaluations and surveys accurately, creating different evaluations for students and teachers, and beginning the evaluation process from day 1.

Though funding agencies do not want to fund evaluations because they are expensive, in reality it is more expensive not to do them. A "Trip Advisor" styled review of resources will allow for a sort of 'natural selection' to bring the best resources to the front without large investments. It would be beneficial to develop an international group to see what is working and not working, as evaluation needs vary based on educational media. When considering publishing evaluation results, it will be important to consider what should be conveyed to the audience about international genetics education programs or guidelines.

Summary of Day 1
Heather Junkins, National Human Genome Research Institute, NIH

Keys to successful implementation include changing attitudes and creating champions or ambassadors to stimulate actives at their own institutions. Nurses and physicians' assistants may be teamed up to help disseminate knowledge and interest, and accreditation standards may be used to persuade physicians and healthcare professionals who are not in the education system.

Metrics of success and evaluating workforce needs were discussed at length. How often and in what medium do these evaluations need to occur? We won't know what works unless we are effectively evaluating these programs, including instructors. Another important aspect is sharing plans of evaluation across programs. This will help others evaluate their own programs and allow for genomics educations to develop consensus on how to best implement these programs.

Global Genomic Medicine Collaborative (G2MC)
Bruce Korf, University of Alabama at Birmingham

G2MC explores synergies, redundancies, and collaborative opportunities to advance the genome sciences as a global agenda and impact global health. G2MC has several working groups, including an education working group. The education working group has developed its own case-based teaching agenda, grand rounds content, and Q&A sessions.

The American College of Medical Genetics and Genomics (ACMG) has also held mock genetic counseling sessions at national meetings to give people hands-on experience. The ACMG Foundation has a summer scholars program to expose medical students to genetics and genomics. To integrate genomics into clinical workflow programs will need to be funded, quality and outcomes need real world applications, and there needs to be a qualified workforce. It would be most effective to create teaching materials and allow groups around the world to customize these to their specific medical culture. Defining the elements of the educational process, so that they can be mapped to different competencies and different education approaches, allows for flexibility.

Aside from needing to educate physicians in the interpretation of genomic tests, there is also a need to insure that test reports are thoughtfully designed to facilitate their interpretation. Testing labs need to employ system engineers and designers who can develop reports and materials that are easily understandable and clear for anyone with genetics knowledge in the healthcare field.

New Directions for International Genomic Education
Facilitator: Donna Messersmith, National Human Genome Research Institute, NIH

The UK's spiral curriculum has allowed for students to explore genetics by gaining a Master's degree or through a variety of certificates leading to the Master's. Integrated modules are more reflexive and response to change, and include a core set and tailored, more specific modules. Before we can begin to educate practicing physicians, however, we need to show them why this is important.

Infrastructure is already in place for current international genomics education efforts. This infrastructure includes using industry to incorporate the new standard of care. Design and education will come together to build large online resources that allow for younger generations to get involved. We can synergize our efforts by utilizing things like case study repositories and working with industry to help doctors realize the importance of genomics education.

Potential Synergies and Collaborations
Facilitator: Teri Manolio, National Human Genome Research Institute, NIH

To make evaluation methods more standardized, with common outcomes defined similarly, there is a need to create templates for workshops, online tools, and education evaluation methods. There's a need to compare best practices, engage labs, and choose key components. Ways to improve report presentation include bringing in experts in form design and presentation, improving clinical decision support and reducing alert fatigue, and incorporating Open InfoButton (electronic health record integration).

To create a team based approach, there is a great need to engage relevant healthcare professionals including lab scientists and faculty. Professional societies have genetics committees themselves, but genetics community does not do a great job of engaging them. Presenting at their chapter or national meetings may help to engage them. There is also a critical need for continuing medical education (CME) courses. CME courses are a good place to compare requirements internationally.

Geisinger Healthcare has a 100,000 Genome Project as well. They have education modules dedicated to 27 common conditions that they would probably be willing to share. Other possible collaborations include: HEE Masters' modules, University of Miami's Masters'/MD coursework, NHGRI G2C2, insurers' webinars, AGHA Program 4, ASHG Cancer Genetics' virtual meetings, and G2MC via WebEx. When considering inter-professional collaborations, it is important to assess whether the information presented should be parallel to that presented to a physician or if different topics should have more emphasis.

One challenge in reaching non-research intensive practices is the lack of academic medical centers as leaders. To reach non-research intensive practices, the National Coalition for Health Professional Education in Genetics (NCHPEG) held grant competitions for societies to develop their own materials and disseminate them in fields such as pediatric neurology, dentistry, and speech/hearing. Museum-like programs, such as "Unlocking Life's Code," can also help reach these practices. Genomics England's eligibility materials and strong recruiting of patients allows for patients to become a network. This pushes educational resources into the hands of more patients. Programs like "The Genomic Mile" and "Pint of Science" reach out to the public *and* healthcare professionals. The Baylor College of Medicine Genomics Group has monthly exome "sign-out rounds" in which they discuss found variants, among other things. The sign-out rounds are webcast and archived. These kinds of rounds are familiar to physicians and possibly other professional groups and are a good way to engage the community.

Development of case studies involves a substantial time investment (20+ hours), but one way to decrease is to focus on elements of cases, instead of full cases. Knowing what you want people to learn or gain from any educational resource is essential; this should dictate the medium in which the knowledge is delivered. Developing case studies with professionals working in a given field will help eliminate the disparity between what people think is happening versus what is actually happening in the field.

Many potential synergies have been identified at this meeting. These include: developing training materials and programs, improving report presentation, engaging labs and systems engineers, defining educational taxonomy, creating evaluation methods, engaging relevant healthcare professionals and societies, convincing funders of the importance, reaching non-research intensive practices, and mainstreaming genomics into existing education.

Summary and Overview
Teri Manolio & Heather Junkins, National Human Genome Research Institute, NIH

In this meeting we discussed many lessons learned for meeting changing educational needs. Key partners are those willing to be champions for genomics education, as well as those who are early adopters of these programs. We discussed how important it is to evaluate the burdens facing instructors in these programs. Adding implementation scientists and incorporating spiral curricula with multiple entry points for subspecialists will aid in these educational efforts. To further these efforts, online formats that are attractive to millennial learners should be used. By focusing on things clinicians are likely to see soon, we can show them that these practices have real-world applications. We have to convey that although some of these technologies may not be available today, they will be soon. We need to prepare for rapid change. Identifying underlying causes of disease, through genomics, will drive trans-disciplinary approaches. Clinicians already incorporate changing technologies from other disciplines (imaging, surgery), and it should not be a big leap to incorporate new genetic technologies.

Some of the best practices heard in this meeting were the mock genetic counseling sessions offered at professional society meetings and pairing experienced sites with new adopter sites. By pairing experienced sites with sites that would like to get more involved in education, the new adopter sites will have a great advantage. Engaging institutional leaders could provide them with

direct evidence of return on investment. Creating leaders in other medical specialties could allow for the creation of a network of champions. Advocates for genomics among junior doctors and patients could help drive interest in the field.

Discussed challenges include need for evidence of effectiveness of genomics and effectiveness of training programs, and need for funding. Other challenges include how to reach non-research intensive healthcare areas and clinicians who've finished training, as well as improve clinicians' confidence, avoid over-interpretation of VUS, and improve reporting.

Common data deposition programs like ClinVar, ClinGen, and Database of Chromosomal Imbalance and Phenotype in Humans using Ensembl Resources (DeCIPHER) allow for vast collection of resources in a single place. The Genomics England Clinical Interpretation Partnership (GeCIP) on Education and Training has plans to form an international network. It will strive to identify the best pedagogic methods and best training methods. There needs to be an agreement on what should be included in disease gene panels and reportable findings.

Next Steps
Heather Junkins & Jean Jenkins, National Human Genome Research Institute, NIH

This meeting could potentially produce a white paper on genomics education for clinical care. We would have a prioritization exercise to discuss what is important to focus on and what the next steps are. There are plans to create an International Education working group of the ISCC, which would have a NIH chair and non-NIH co-chair. [Note: Following the meeting it was decided to include this component as part of the ISCC's educational products working group]. The ISCC would welcome more international members. Also, a joint research project to figure out the effectiveness of education models would be of interest to many programs.

Recommendations

- Educators should work with clinicians and laboratories to standardize clinical reports and evaluation methods. Templates should be created for workshops and online tools. Report presentations should be improved by including experts in form design and presentation. Well-designed reports should obviate the need for clinicians to be an expert when interpreting the report.
- Case studies should be developed with professionals working in the field. To reduce the time needed to prepare case studies, it is possible to use elements of case studies, rather than whole cases.
- Relevant healthcare professionals including lab scientists, professional societies, systems engineers, and faculty should be engaged. Presenting at professional societies chapter or national meetings is a good way to engage them.
- Compare continuing medical education requirements internationally.
- The genomics education community should utilize unique opportunities for engaging with all healthcare professionals such as general practitioners or nurses who don't participate in research. Mock genetic counseling sessions and pairing experienced sites with new adopter sites could be a way to increase interest in the field.
- When considering inter-professional collaborations, it is important to assess how the information will be presented to medical and non-medical professionals.

- To convince health ministries and other funders to provide funding for educational initiatives, there needs to be evidence of a need for education, since there is a glaring absence of genomics in current curricula. The trainings cost need to be minimal and proven effective. To provide evidence for the need for this education, one could look at cases of misinterpretation and inappropriate ordering and the associated costs.
- Engaging institutional leaders would provide them with direct evidence of return on investment. Creating leaders in other medical specialties would allow for the creation of a network of champions. Advocates for genomics among junior doctors and patients could help drive interest in the field.
- Setting standards for disease gene panels and subsequent laboratory reports would promote consistency of interpretation across different medical settings.
- Adopting spiral or staged curriculum programs, like those implemented through HEE, in other countries might be beneficial. Similarly, it might be beneficial to implement the University of Miami's Master's/MD program in other schools or countries.