GENOMIC LITERACY, EDUCATION, AND ENGAGEMENT (GLEE) INITIATIVE
2017 STRATEGIC VISIONING MEETING

Healthcare Provider Working Group

Introduction

Genetic and genomic testing technologies are rapidly expanding, often too quickly for health care providers to become familiar with new technologies before encountering them in the clinical context or patients inquire about them. Rapid adoption has outpaced the generation of adequate evidence regarding the clinical utility (Guttmacher, Porteous, & McInerney, 2007). In its report on genetics education and training, the Secretary's Advisory Committee on Genetics, Health, and Society concluded that "...(Practitioners) cannot keep up with the pace of genetic tests [and are] not adequately prepared to use test information to treat patients appropriately..." (Secretary's Advisory Committee on Genetics, Health, and Society, 2011).

Despite a consistently positive view among health care providers about the potential importance of genetics and genomics in medicine (Mikat-Stevens, Larsen, & Tarini, 2015), many lack contemporary background knowledge in genetics and are not adequately prepared to use genetic and genomic information to treat patients (Mikat-Stevens et al., 2015; Suther & Goodson, 2003; Klitzman, Chung, Marder et al., 2013). A noted lack of confidence about their own knowledge has been one factor preventing physicians from having comprehensive discussions about genetics and genomics with their patients (Baars, Henneman, & Ten Kate, 2005). Furthermore, physicians have frequently ordered tests that are inappropriate for the clinical situation and that they do not correctly interpret, potentially leading to suboptimal patient outcomes (Bellcross et al., 2011; Brierley et al., 2010). Providers are also called upon to interpret results of direct-to-consumer tests they did not order, and therefore were unaware of the motivation or need for testing on the patient's part.

The challenge is widely recognized. In August 2014, the National Academies of Sciences, Engineering and Medicine (NASEM) Roundtable on Genomics and Precision Health (then the Institute of Medicine Roundtable on Translating Genomic-based Research for Health) convened a Workshop titled: Improving Genetics Education in Graduate and Continuing Health Professional Education. The Workshop Summary includes discussion of the urgency and "next steps." (Institute of Medicine, 2015).

The appropriate integration of genomics into routine practice stands to significantly change medicine, however, the gap in appropriate knowledge and skills among health care providers must be overcome to drive the integration of genomic technologies to clinical care. In this white paper, we explore the landscape of currently available resources, studies assessing providers' knowledge and skills in genomics practice, motivators for adopting genomic technologies, and educational resources needed to support implementation of genomics into care. We then propose a set of actions to improve the genomics knowledge and skills gaps among health care providers with the goal of appropriate integration of genomics into routine care.

In this document, the term “health care provider” refers to professionals who provide direct patient care, including physicians, nurses, physician assistants, and pharmacists, but who are not genetics or genomics specialists, such as clinical/molecular geneticists and genetic counselors.

State of the Field: Inventory of Existing Resources/Programs

A recent systematic review examined barriers to the integration of genomic services (Mikat-Stevens et al., 2015) and found that knowledge and skill deficits were among the top barriers cited by health care providers. Specifically, providers cited a lack of knowledge, including lack of confidence in their knowledge in general, appropriate family history information to collect, and how and when to make a referral to a specialist. Commonly cited confidence barriers were cited in their ability to counsel patients about risk, use variant information in management decisions, order and interpret tests, and conduct risk assessment. Providers also reported that it is difficult to keep up to date with evidence, they lack access to information, and they are unaware of existing resources. These findings are consistent with several other studies assessing knowledge and skills barriers (Mikat-Stevens et al., 2015; Suther et al.; 2003, Klitzman et al, 2013; Baars et al., 2005; Houwink et al., 2011; Vig et al., 2009). The growing plethora of testing options (arrays, panels, exome, genome, cell-free, etc.) is likely also a daunting challenge.

The Provider Education Working Group identified a large number of currently available education resources, covering topics such as cancer, family history, risk assessment, pharmacogenomics, testing, and clinical specialties. Many of these resources are inventoried on the NHGRI’s Genetics and Genomics Competency Center (G2C2). The resources comprise a number of different formats (e.g., published textbooks and online resources) and are designed for several health care provider audiences. We were not able to collect utilization statistics for most of the identified resources, but personal communication with the developers of many of the resources confirms that participation is often low, especially for those intended to reach large audiences, such as online resources. We believe that low participation rates are due in part to a lack of awareness of the resource in addition to a lack of time to participate. Another likely explanation is a lack of motivation to engage in education on the topic of genomics, either because the learner may believe that it is not relevant to his/her practice or is unconvinced that sufficient evidence supports its use in practice, or a combination of both.

To understand more completely the interest of health care providers in learning more about genomics, their educational preferences, and relevant barriers to participating in genomics education, the Provider Education Working Group conducted a brief survey of physician, nurse, physician assistant, and pharmacist registered members of Medscape; approximately 230 members responded. About 26% of respondents reported not having previously accessed genetics/genomics education or information; of those who had, 40% had participated in self-directed/self-paced activities, 38% read journal review articles, 31% attended professional meeting workshops and sessions, 20% had consulted with colleagues, and 18% had participated in interactive real-time webinars. Preferred methods for obtaining genetics/genomics education were online self-directed/self-paced activities (61%), journal review articles (32.8%), interactive real-time webinars (29.5%), and professional meeting workshops and sessions (27%); 9.5% desired in-person stand-alone courses, and only 5% listed EHR-integrated information as a preferred method. 7.9% reported that they did not want to access education or information. Respondents reported that the

genetics/genomics knowledge and skills areas they most needed to learn about were ordering the appropriate genetic test (39%), interpreting genetic test results (36%), foundational knowledge (31%), knowing when and where to refer patients for genetics services (30% and 24%, respectively), counseling patients about genetic risk (23%), and knowing how to order a genetic/genomic test (20%). The top barriers faced by respondents in obtaining genetics/genomics education included lack of time (67.1%), competing educational requirements (54.2%), not knowing where to find resources (52.4%), and cost or charge for the activity (44%). Other barriers included unsatisfying educational resources (24%), lack of interest or relevance (22%), and a perception of genetics as too daunting or confusing (24%). The top motivators for seeking educational activities in genetics/genomics were CME/CEU credits (54%), relevance to practice (51%), interest in the field (46%), and opportunities to apply new learning (42%). Other motivators were convenience and accessibility (35%), MOC points (17%), and patient queries about it (12%). More detailed results are available upon request. Other, similar but smaller surveys have recently occurred and results are comparable.

It is important to note that the knowledge and skills gaps serving as barriers to implementation are occurring within the context of, and are related to, systems barriers (i.e., lack of dedicated education time, financial constraints, or misalignment with care delivery objectives). These include lack of access to a medical geneticist or genetic counselor, insufficient evidence of clinical utility for many applications, the paucity of genomics in clinical guidelines, and lack of coverage and low reimbursement for a number of genetic tests (Mikat-Stevens et al., 2015). Improved genomics knowledge and skills among health care providers will likely have limited effects on patient outcomes without concomitant improvements in these systems barriers. It is also possible that the lack of genomic literacy among non-geneticist providers hampers research efforts designed to close the clinical utility evidence gap.

Gap Analysis

Motivation and Engagement

The Provider Education Working Group identified many continuing education programs and opportunities. However, they are often underutilized, suggesting the need to address motivation and engagement. Motivation to participate in genomics education is dependent on a number of factors, including having an experience that demonstrates to the learner why and how genomics knowledge and skills will benefit their patients. In our brief survey, relevance to practice and having the opportunity to apply new learning were two of the top motivators for seeking out genomics educational activities.

A significant evidence base exists to guide adult education and education of health care providers, although factors influencing engagement in genomics education, specifically, are less well-defined. Pertinent to the “relevance to practice” motivator, we can speculate that for a subset of providers, caring for a patient that presents a direct-to-consumer genomic profile, has a clinical presentation suspicious for a hereditary syndrome, or experiences an adverse drug reaction due to a pharmacogenomic variant will motivate them to search out and engage with information resources and, possibly, education. Some also may be influenced by growing evidence for the impact of genomics on treatment decisions or clinical outcomes, such as testing of cancer cells to direct targeted therapy. We currently do not know how effectively direct exposure to the field motivates

increased interest and engagement in related education more generally. Specific attention to assessing factors and messages that motivate providers to seek out this education would help educational developers better direct their efforts.

Awareness

Once a health care provider is motivated to seek out education, awareness of the existence of resources and the ability to find them is critical. Specialty societies may have the ability to reach their members with messages about the availability of educational resources. However, societies representing specialties that have not largely adopted the use of genomic technologies (e.g., primary care providers), may be less likely to use advertising or other awareness mechanisms to disseminate messaging about genomics education.

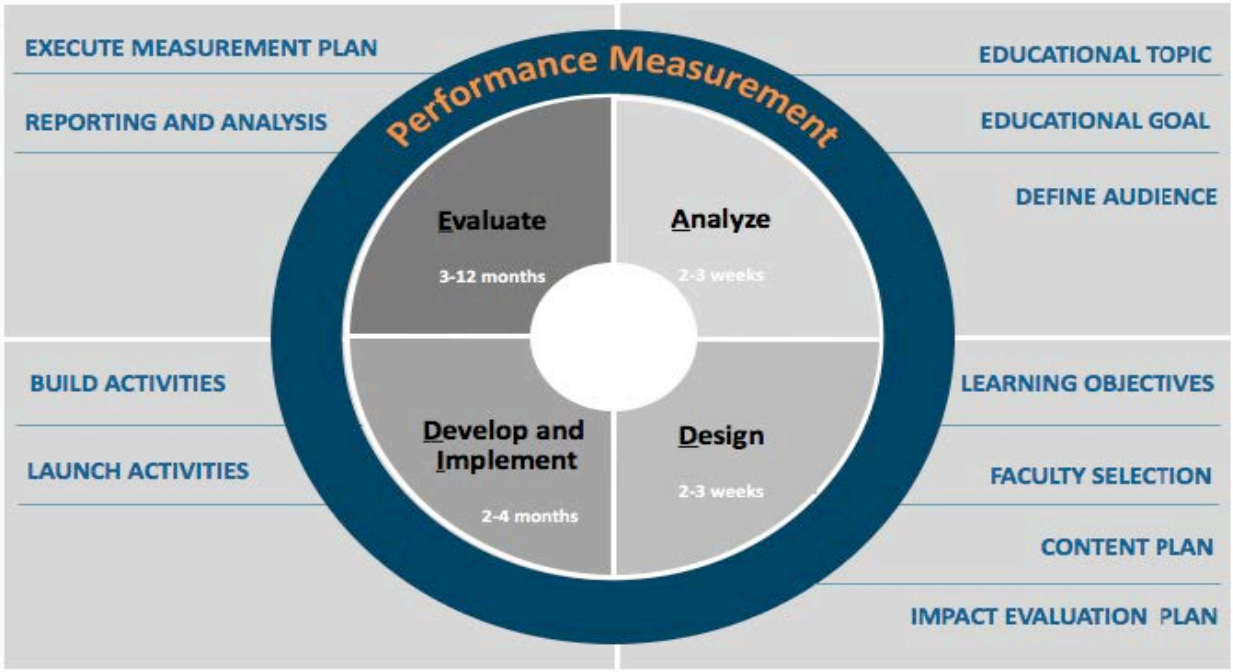
For education developers that are not part of, or do not have a relationship with, a specialty society, building awareness about the availability of resources is difficult. Reaching health care provider audiences becomes an *ad hoc* exercise of identifying personal contacts that could spread the word, and using channels that health care providers may not access or see (such as social media and press releases). Budgets for the development of educational resources are often very small, leaving little room to pay for advertising that could better target intended audiences. These activities have not traditionally been funded by NIH training programs, which focus primarily on training scientists to do research. Attention to an awareness and dissemination plan is an important task for education developers; just as important for funders is to provide appropriate funds to enable these activities.

Delivering Quality Education Within Time Constraints

Health care providers are consistently pressed for time, and taken together with state, specialty board, and institutional directives to complete education on certain topics, little time for “elective” education remains. With this time crunch in mind, special attention should be placed on the development of genomics education that is most likely to change behavior (IOM, 2015). Too often, continuing education is passive and didactic (Nissen, 2015). Programs that are grounded in evidence-based principles of adult learning and medical education have a greater impact on performance than programs that do not incorporate such principles (Grimshaw et al., 2001, Raza et al., 2009; Frenk et al., 2010). “Just-in-time” and point-of-care education (EHR integrated) are fairly recent approaches that, while promising, are supported by an immature evidence base.

Outcomes-focused continuing education requires the application of a deliberate framework to the design, development, and evaluation of educational activities (Moore, Green & Gallis, 2009). (see Figure 1, below). This includes identification of gaps to map out a thorough needs assessment, use of appropriate instructional design, and continuous assessment and refinement until the desired results are achieved. The needs assessment phase must account for the providers’ learning stage and may be determined through literature review, surveys, and testing existing learning tools. Curriculum development follows, guided by learning goals and objectives. Content plans are then developed to address the knowledge, competence, attitudes, and skills needs.

Figure 1: Framework



Single learning activities cannot address all knowledge gaps. Selection of the optimal instructional format to achieve the desired outcomes is critical. The strongest gains are seen in activities that are more interactive, use a variety of instructional techniques, involve multiple exposures, and focus on outcomes considered important by the learner (Davis et al., 1999; Cervero & Gaines, 2014). Self-assessments that lead to recommendations of targeted education are most effective as they create a sense of discomfort, motivating learners to improve and overcome the motivation barrier (Parboosingh, 1998). Consequently, educators may leverage multimedia online platforms and use self-assessments to coordinate and direct individualized learning plans. A recent workshop held by the NASEM Roundtable on Genomics and Precision Health explored these principles and discussed formats, such as clinical decision support, that can best elicit behavior change (Institute of Medicine, 2015).

Evaluation plans that measure behavior change are important so that developers of education can understand from previous activities and resources which elements lead to improvements in practice, and in addition, what educational gaps remain to be addressed. Depending on the goals of the activity or series, evaluation strategies measure change in awareness, understanding, and the ability to translate acquired knowledge into daily practice. This allows measurement of improvement in competence, performance, and, ultimately, patient and community health.

Proposed Action Plan

The Provider Education Working Group recommends the following non-exclusive actions with suggested timeframes. The “actor” is not specified as it may be different among actions, or may take the form of an independent group or groups that may arise through the initiative, or that already exists. Accordingly, some of the “actions” may be read as recommendations. The actions beginning with “Study” should be interpreted as recommendations for research.

Purpose	Actions (timeframe)
Build Community (stakeholder, educator teams) Engagement and Collaboration	1. Create a time-limited (5-year) consortium to oversee execution of the final plan actions (year 1) 2. Explore models for instantiating multi-expertise (including instructional design), institution-agnostic education teams to develop, implement, and evaluate specific projects addressing the needs and gaps in genomic medicine, and implement feasible model(s) (year 1-2) 3. Explore vertical and horizontal integration of educational programs (professional school, post-grad, and continuing ed), and engagement of educators reaching specialty (e.g. ISCC) and public health (e.g. The NASEM Genomics Roundtable) learners (year 2-5) 4. Train trainers in specialties with documented needs (years 3-5) 5. Create a plan for sustaining implementation/education work and community after the 5-year plan completes, including through development of partnerships (years 3-5)
Create Effective Content (quality educational materials and targeted to learners' needs)	1. Review and modify, if needed, core/essential common competencies (suitable for cross-specialty and interprofessional use) (year 1) 2. Identify, for each specialty, key, competencies not in the published common set, and evidence-based implementable examples of genomic medicine, and prioritize them (year 2-3) 3. Create educational programs where gaps exist using evidence-based adult learning best practices, and use existing and/or gap-filled new resources that incorporate dissemination and evaluation plans (year 2-5) 4. Facilitate development that meets CME standards in order to optimize trust and linkage to evaluation and learning through feedback (year 1-2)
Implement Best Dissemination (of suitable content via systems or platforms) Practices	1. Identify the range of suitable existing dissemination approaches (year 1) 2. Study the effectiveness of dissemination methods during pilot implementations, including in the absence of a driving research program (year 2-5) 3. Study novel dissemination approaches and compare with existing ones (year 2-5) 4. Where possible, use existing platforms that are proven to engage target learners, facilitate evaluation, and to scale effectively (year 1-5)
Plan for Promotion (building awareness of need and of learning opportunities)	1. Plan and execute an awareness campaign to publicize the need, recruit team members, highlight high-impact opportunities, and make educators and learners aware of relevant learning opportunities and incentives in a targeted fashion (year 1-5) 2. Study and model other high-impact health advances that transitioned quickly and successfully to implementation (year 1-5) 3. Study newer vs. older approaches for gaining priority among competing interests (year 1-5)
Foster Engagement Among Learners (learner incentives and validation for genomics education, and	1. Routinely include target learners in instructional design (year 1-5) 2. Study needs of and decision-making in providers and patients (year 1-3) 3. Study novel and existing methods for engaging providers in genomic learning, and for overcoming competing demands (year 1-5) 4. Study frameworks that support capture, evaluation, and translation-to-education of existing and future relevant genomic medicine topics by specialty (year 2-4)

how to compete with other demands)	5. Incentivize learning through facilitation and routine incorporation of CME/CEU credit or other rewards (year 1) 6. Incentivize learning through pervasive collaboration with specialty MOC programs (year 2-3) 7. Incentivize learning through creation or expansion of widely-accessible certificate programs (curriculum program with testing) (year 2-5) 8. Incentivize learning through systems that track outcomes and create consequences for shortcomings (year 3-5) 9. Study how best to find, develop, and support "Champions" in all specialties (year 1-3)
Fund Quality Education (making the wheels turn)	1. Identify and secure funding for early phase projects and for administrative support of teams for 5-year term (year 1) 2. Identify beneficiary stakeholders willing to co-fund collaborative education (year 1-5) 3. Prioritize funding for education using best practice principles for learning and evaluation (year 1-5) 4. Facilitate partnership development to provide post-5th-year sustainability (years 3-5)
Create Sustained Impact (on provider behavior and patient outcomes)	1. Study methods for measuring meaningful impact of education efforts (year 1-5) 2. Create and validate genomic medicine Quality Measures or other systems that track errors or failures in practice (year 1-5)

Summary

A general consensus exists among the GLEE Provider Education Working Group members and other experts regarding the urgent need to identify and deliver effective genomics education, training, and practice support, toward the goal of creating a genomically literate workforce. The slow pace of genomics implementation, however, suggests that educational barriers exist. Analyzing previous recommendations and next steps suggestions may help clarify why progress has been slow and how it can be addressed. While the subject matter is relatively new, the challenge of updating professional learners is not. Efforts to address this challenge should be informed by the methods and outcomes of successful programs, but the escalating integration of genomics information into clinical practice will also require innovative approaches that bring just-in-time learning to the point of care. Motivating providers and making learning practice-relevant, easy to access, and effective are key elements that have not witnessed wide adoption, though there are some field leaders whose work, approaches, and systems are addressing these head on and might be modeled. Research into best practices, including evaluation of learning and teaching, is needed. Dissemination and implementation will not happen on its own, but needs to be embraced - and funded - not just by genetics specialists, but by healthcare providers across the spectrum of care and by the full range of systems in which they operate. Measures of success include provider knowledge, integration of new learning into practice change, and, most importantly, quality of care and patient safety and outcomes.

Provider Education Working Group Members/White Paper Authors:

Bob Wildin, National Human Genome Research Institute (Co-chair)
Katherine Johansen-Taber, American Medical Association (Co-chair)
Katherine Blazer, City of Hope
Jim Evans, University of North Carolina, Chapel Hill Matt Ferber, Mayo Clinic
Sam Johnson, American College of Clinical Pharmacy
Esther Kim, 23andMe
Steve Murphy, WebMD
Karen Posemato, Illumina
Kate Reed, Jackson Laboratories, Clinical and Continuing Education Program

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