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Genomic Medicine IV

Executive Summary

The Fourth Genomic Medicine Centers Meeting was held on January 28-29, 2013 at the Hyatt Regency DFW in Dallas, Texas. The meeting focused around genomics education for health professionals and potential collaborations between various stakeholders in the field.

Education

- Introducing genomics into medical practice needs to be presented as the gradual evolution it is rather than a revolution, which may make physicians more amenable to using it. It is important to identify appropriate competencies and create educational programs tailored to developing them, rather than emphasizing a general increase in genomic knowledge. Many competencies in genomics would parallel those in more established specialties.
- Genomics education needs to be embedded at the point of care in the disease process. We also need to create appropriate technologies like clinical decision support to assist physicians at the point of care.
- Genetics is taught in the first year of medical school but is often not seen again afterwards, diminishing any initial interest.
- Many professional societies have already established online and in-person educational methods in genomics with varied success. Approval of CME credits could provide incentive for physicians to learn more about genomics. Furthermore, a higher number of physicians educated in genomics may further drive demand for these classes.
- Other educational resources include checklists, ethical guidelines, approaches to handling specific diseases, case studies, and systems to show the location of ongoing trials.
- Genomics needs to be incorporated into certifications and licensing with appropriate competencies and training developed. Review committees and boards are crucial to this.
- Those who are interested should have the opportunity to do subspecialty genomics rather than a general program in genetics, which includes pediatric syndromes and dysmorphologies of limited relevance to adult subspecialists. For example, oncologists could be trained specifically in cancer genetics.

Concerns

- Many practicing physicians do not have a complete understanding of the use of genomics, sometimes believing that it is limited to certain specialties. Sometimes genomics is not even taught because educators do not have a good foundation themselves in genomics. Some specialties place lower priority on genomics because of infrastructural changes within the discipline (e.g. takeover of cardiology practices by hospitals) or perceived small benefits (e.g. surgery specialties, little understanding of complex diseases).
- Practicing primary care physicians tend to have more gaps in genomics knowledge than those in academic medicine.

- As genomics becomes more prevalent, we will need to create standards for data storage and security. Some cancer patients find that data aggregation is preferable because more data will help more patients.
- Other concerns around genomics include litigation and liability issues and dealing with marketing from genetic evaluation companies.
- Some professional society guidelines conflict with those released by other societies, leading to confusion and inactivity.
- The role of direct-to-consumer genetic tests is still not clear, but we need to begin to address how to educate patients when a DTC test provides a result that is potentially false.
- Guidelines may be issued without sufficient supporting evidence. This can be problematic, as some variants initially thought to be pathogenic have later been found to be benign and vice versa.
- Physicians who have some confidence in their genomics knowledge still felt reluctant about their knowledge on ordering and interpreting tests and explaining the results to patients.
- Physicians who think genomics is important were still only willing to commit 1-2 hours to increase their understanding. Similarly, a minority of physicians who thought family histories were important routinely take a complete 3-generation family health history.

Collaborations

- A good starting point for professional society collaboration is shortening any delays in the issuance of guidances on genomics. Another would be to ensure uniform guidelines among societies.
- Some societies have collaborated in the past on specific disease guidelines.
- Collaborations with government agencies and other bodies have provided widespread education programs.
- NHGRI's Clinically Relevant Variant Resource would welcome collaborations with professional societies.

The possibility of establishing an Inter-Society Coordinating Committee for Genomic Physician Education was discussed at length. Goals of such a group could include:

1. Gather best practices in genomic education and clinical care.
2. Recognize genomic science about to enter the clinical arena.
3. Identify pitfalls in current practice
4. Seek optimal educational balance between competencies and basic knowledge.
5. Assist societies in jointly and severally publishing papers of common interest.

Preliminary Action Items

1. Convene society representatives by conference call in roughly one month as a nascent Coordinating Committee and invite other relevant societies and disease-specific Institutes to collaborate.

2. Send to Gene Passamani (from societies): Links for available physician education materials for posting in G2C2; individual societies' areas of interest; societies' process for developing guidelines and pseudo-guidelines; current approaches and best practices in genomic medicine.

3. Work with societies to produce a white paper from this meeting, potentially including the surveys, or will encourage the societies to publish surveys separately.

4. Consider developing a working group to address liability issues presented by genomic medicine implementation and convening societies' guideline producers to outline process and evidence needs (GM VII?).

5. If focus of GM V in May will be on coordinating federal/domestic efforts in genomic medicine, Include Health Resources and Services Administration (HRSA), Veterans Affairs (VA), possibly Office of Civil Rights (OCR) as related to HIPAA, possibly Office of Human Subjects Research Protections (OHSRP).

6. Consider setting aside 60-90 minutes in May to follow-up on payers' meeting.