

SACGHS Genetics Education and Training Task Force

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Session Purpose

- Report on revised draft Task Force Charge
- Provide update on Task Force activities
- Present draft Action Plan
- Reach consensus on the Task Force Charge and Action Plan

Revised Charge

At the February 2008 SACGHS meeting, suggestions made:

- Narrow scope of stakeholders
- Consider various education mechanisms/modalities
- Focus on issues specific to genetics and actionable by HHS
- Aim for measurable outcomes

Revised Draft Charge

The need

Advances in genetics and genomics are leading to a better understanding of disease processes and improved application of genetic testing to guide health decisions. With increased integration of genetics into other medical disciplines, however, health professionals—with or without training or expertise in genetics—are challenged to keep pace with this dynamic and rapidly evolving field. Education will have to address the growing importance of genetics in common disease, which likely will require more knowledge and understanding about risk assessment and communication. In addition, the accelerated growth of direct-to-consumer genetic services highlights the need for informed decision making.

...need

To realize the benefits of genetic technologies and protect against potential harms, the education of healthcare professionals, the public health workforce, and the general public is critical. For these reasons, the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) has formed a task force to build on the findings of the Committee's 2004 resolution on genetic education and training of health professionals.

Revised Draft Charge

Aims

The task force is charged with developing a plan to identify the education and training needs of health professionals, ~~lay health educators~~ the public health work force, and the general public in order to optimize the benefits of genetic and genomic services for all Americans. This plan will also outline the steps required to meet these needs and evaluate the efficacy of educational and training efforts. This plan includes, but is not limited to, the following activities:

Revised Draft Charge Goals

1. Assembling evidence to determine which recommendations from the 2004 SACGHS education resolution were implemented and which ones require additional efforts.
2. Identifying the education and training needs specific to genetics and genomics for health professionals involved in providing care for individuals and for those involved in the development of guidelines, policies, and strategies for incorporating genetics/genomics into clinical care.

...goals

- ~~3. Identifying the education and training needs of the public health work force. ~~lay health—educators, who are noncredentialed individuals from the local area trained to promote health and provide general healthcare services for a specific condition or program.~~~~
 - ~~4. Identifying the education needs specific to genetics and genomics for medical directors, administrators, and policy makers in the public and private sectors to inform policy development, legislation, coverage and reimbursement decisions, and other issues that directly or indirectly impact the provision of genetic services.~~
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...goals

5. Identifying the education needs of patients and consumers to assist them in informed decision making about the use of genetic services and enhance their understanding and utilization of results and how these results impact decisions about prevention or treatment.
 6. Identifying effective educational tools that can be incorporated into electronic health records, personal health records, and clinical decision support systems that would enhance the appropriate integration of genetic and genomic technologies throughout the healthcare system without adversely impacting privacy, access, and workflow. In addition, identify gaps where such tools do not currently exist and develop recommendations on how to address these gaps.
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...goals

7. Assessing the use of evaluative research methods to determine the efficacy of genetics and genomics education and training efforts.
8. Promoting active involvement by health-professional governing bodies that influence education and training (e.g., residency review, National Board of Medical Examiners) to be more proactive in their requirements for genetics in curricula, clinical training, licensing and certification, and continuing education requirements.

Current Activities

Conference call March 24, 2008

- Discussed limiting scope and focus of charge to 3 broad groups
- Formed workgroups to examine education & training needs for:
 1. health professionals
 2. public health providers
 3. consumers/patients

...activities

- Workgroups selected chairs:
 - ❑ Greg Feero, health professionals
 - ❑ Joseph Telfair, public health providers
 - ❑ Vence Bonham, consumers/patients
- Each workgroup drafted their action plan
- Conference call June 3, 2008 to discuss an integrated framework across groups
- Task Force action plan drafted

Task Force Draft Action Plan

GOAL

To produce a report by 2010 that identifies gaps in genetics education and training for health professionals, public health providers, and consumers/patients and provides recommendations to address those gaps.

Draft Action Plan Framework

A clinical case model will be used to provide an integrated approach that highlights the genetics education and training needs of health professionals, public health workers, and consumers/patients.

Framework will address:

- varied needs of these audiences,
- for different types of testing (e.g., screening, diagnostic, pharmacogenomic),
- at different stages of testing (e.g., pre-testing, receiving test results, follow-up consultation),
- in different settings (e.g., DTC, primary care, specialty care), and
- how education &/or training should best be provided and evaluated.

Potential case studies

- patient diagnosis of a single-gene disorder
- family history of common disease
- newborn screening
- pharmacogenomic testing
- direct to consumer testing
- population research
- media reporting of research results

Draft Action Plan

Data Gathering and Analyses

Each workgroup developed a draft action plan to identify genetics education and training needs of its target group

1. Health Professionals Workgroup

- Review and summarize the literature describing the genetics education and training needs of health professionals
- Map the existing federal ecosystem that supports and promotes health professional education and training
- Survey key professional organizations to determine priorities for enhancing genetics education and training

2. Public Health Providers Workgroup

- Identify representative subset of public health providers at the state and local levels to participate in assessment of education and training needs
- Review genetics competencies developed by professional organizations and agencies and identify a core set of competencies to use in assessment instrument
- Assess the genetics education and training needs of identified subset of public health providers

3. Consumer & Patient Workgroup

- Review and summarize research on consumer/patient genetics education
- Map existing consumer/patient genetics education activities of public and private organizations
- Consult with experts in the field of genetics education and members of the public to better understand the education needs of consumers and patients

Next Steps

- Workgroups execute action plans
- Draft findings by spring 2009
- Assemble draft report for public comment by summer 2009
- Revisions and finalize report by early 2010