

**SACGHS Draft Report and  
Recommendations on  
Genetics Education and Training**

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# Overview of Session

- Presentation from the Advisory Committee on Heritable Disorders in Newborns and Children on its work on education and training
- Review and discuss draft report and recommendations

# Overview of Draft Report and Draft Recommendations

# Task Force Roster

## *SACGHS Members*

- Sylvia Au
- David Dale
- Gwen Darien
- James Evans
- Barbara Burns McGrath, Chair
- Marc Williams
- Paul Wise

## *SACGHS Ex Officios*

- Denise Geolot
- Muin J Khoury
- Gurvaneet Randhawa

## *Ad Hoc Members*

- Judith Benkendorf
- Vence Bonham
- Joann Boughman
- Kathleen Calzone
- W. Gregory Feero
- Sarah Harding
- Jean Jenkins
- Katherine Johansen
- Katie Kolor
- Emma Kurnat-Thoma
- Scott McLean
- Kate Reed
- Joseph Telfair

**SACGHS Staff:** Kathryn Camp, Symma Finn, Kathi Hanna (science writer)<sup>4</sup>

# Task Force Structure

## Health Care Professionals Workgroup

- David Dale, M.D., Chair

## Public Health Provider Workgroup

- Joseph Telfair, Dr.P.H., M.P.H., M.S.W, Chair

## Consumer and Patient Workgroup

- Vence Bonham, J.D., Chair

# Timeline

- June 2004: SAGCHS Resolution on Genetics Education and Training of Health Professionals
- November 2007: SACGHS Education Roundtable; Committee identifies need for Genetics Education and Training Taskforce
- March 2008: Task Force charged with identifying the education and training needs of
  - Point-of-care health professionals
  - Public health providers
  - Consumers and patients

# Timeline (cont'd)

- March 2009
  - Provided overview of activities of three Task Force workgroups
- June 2009
  - Reported on data-gathering activities
  - Discussed workgroup policy directions
- October 2009
  - Reviewed literature and survey findings
  - Discussed and refined draft recommendations

# Draft Report Outline

- Executive Summary and Recommendations
- Background and Scope
- The Status of Education and Training of Health Care Professionals
- The Status of Education and Training of Public Health Providers
- The Status of Consumer/Patient Education
- SACGHS Survey of Federal Activities
- Conclusions and Recommendations
- Appendices

# Data-Gathering Activities

- Literature review of research relevant to health professional and public education and training in genetics and genomics
- Surveys of major organizations and groups and key individuals with responsibilities in
  - health professional education
  - public health
  - consumer and patient education and/or advocacy

# Findings

- Integration of genetics into health care is limited by inadequate and/or ineffective genetics education for health care professionals
- The need for clinical genetic services has increased, but the genetic-specific workforce is insufficient to meet this need
- Health care professional organizations report that competing priorities are the primary barrier to providing genetics and genomics education

# Findings (cont'd)

- The current public health workforce is not well prepared to receive and assimilate genetic and genomic information into public health
  - **Barriers include: diverse** roles and education and training paths; out-of-date formal training; and a general sense that the utility of genetics is not clear to public health providers at this time

# Findings (cont'd)

- Consumers prefer to obtain genetic information from health care providers but also turn to the media
  - Needs:
    - Understand the concept of multiple risk factors
    - Understand the role of the environment
    - Tools to evaluate the veracity of information received
    - Concerns about direct to consumer genetic testing
- Most consumers view the government as trusted source for information and believe government should serve as a clearinghouse

# Draft Recommendations

# Draft Recommendation 1

A significant body of literature from the United States and abroad highlights the inadequate genetics education of health care professionals as a significant factor limiting the integration of genetics into health care. Genetics content is often minimal in health professional education programs, focuses primarily on single-gene disorders, and is not associated with long-term knowledge retention for clinical application. Innovative approaches that coordinate the efforts of entities controlling health professional education and training will be required to remedy this situation. These entities include but are not limited to health professional organizations, educational institutions, specialty certification boards, academic accrediting organizations, and sites of employment.

# Draft Recommendation 1

1. To promote the integration of genetics and genomics into health care, HHS should:

Two options are proposed for the first part of recommendation 1; both would address the same issues.

Option A proposes an ongoing multidisciplinary advisory panel.

Option B proposes a workshop.

# Draft Recommendation 1

## Option 1

- A. Form a multidisciplinary, public/private advisory panel to identify and promote innovative approaches to genetics and genomics education and training in the context of clinical care.

The proposed advisory panel should be composed of representatives from HHS agencies and other federal departments (e.g., VA and DOD) with established programs in genetic/genomic professional education as well as representatives of health professional organizations engaged in genetics and genomics accreditation, certification, and continuing education efforts. This body will:

# Draft Recommendation 1

## Option 1 (cont'd)

1. identify successful education and training guidelines and models that are outcomes based;
2. identify current funding streams for developing and promoting genetics/genomic education as well as gaps in funding;
3. recommend mechanisms for expanding and enhancing the content needed to prepare health care professionals for personalized genomic health care;
4. recommend how evolving standards, certification, accreditation, and continuing education activities might incorporate genomic content; and
5. publish findings and recommendations and develop a plan to monitor the outcome of its work.

# Draft Recommendation 1

## Option 2

- A. Convene a workshop to identify innovative approaches to genetics and genomics education and training in the context of clinical care. The workshop would include representatives of HHS agencies and other federal departments with established programs in genetic/genomic professional education as well as representatives of health professional organizations engaged in genetics and genomics accreditation, certification, and continuing education efforts. This workshop will be structured to:

# Draft Recommendation 1

## Option 2 (cont'd)

1. identify successful education and training guidelines and models that are outcomes based;
2. identify current funding streams for developing and promoting genetics/genomic education as well as gaps in funding;
3. recommend mechanisms for expanding and enhancing the content needed to prepare health care professionals for personalized genomic health care;
4. recommend how evolving standards, certification, accreditation, and continuing education activities might incorporate genomic content; and
5. publish findings and recommendations and develop a plan to monitor the outcome of its work.

# Draft Recommendation 1

- B. Act on the recommendation from the 2008 SACGHS report *U.S. System of Oversight of Genetic Testing: A Response to the Charge of the Secretary of Health and Human Services* regarding clinical decision support.

# Draft Recommendation 2

Consistent findings in the literature and SACGHS surveys indicate that health care professionals and public health providers serving underserved and underrepresented groups and populations face significant challenges. Additionally, these communities have specific needs and their involvement in development of effective education models is imperative.

# Draft Recommendation 2

2. HHS should promote the development and implementation of innovative genetic and genomic education and training models for health care professionals and public health providers serving underserved and underrepresented groups and populations. Specifically, HHS should:
  - A. target research funding to identify effective educational models for health care professionals and public health providers in underserved communities;
  - B. identify and support programs to increase the diversity of the health care workforce in general and the genetic-specific workforce; and
  - C. ensure that consumers and representatives of rural, minority, and disadvantaged communities participate in the process of developing education and training models to assure that they are culturally and linguistically appropriate and tailored to the unique needs of diverse communities.

# Draft Recommendation 3

The inherent diversity of the public health workforce makes it difficult to target educational efforts to improve genetic and genomic knowledge across the workforce. A systematic effort that evaluates the composition of the public health workforce with current job responsibilities related to genetics and genomics and identifies future needs has not been done.

# Draft Recommendation 3

3. Tapping the expertise of its agencies with relevant missions in public health (e.g., HRSA, CDC, IHS, and NIH), HHS should assess the workforce to determine the number of public health providers with responsibilities in genetics and genomics to ascertain current trends and future needs, to identify education and training needs, and to promote leadership development in the field. Based on this assessment, HHS should:
  - A. support and encourage the incorporation of relevant genetic/genomic core competencies in the knowledge base of federal and non-federal public health providers and specific competencies for those whose responsibilities require genetic knowledge; and
  - B. fund educational programs based on these competencies that promote genetics and genomics knowledge, recognize the potential impact of affordable genomic analyses, and incorporate the concepts of environmental interactions and risk assessment for population-based genomics.

# Draft Recommendation 4

Consumers have consistently expressed the desire for genetic information that is comprehensive, accessible, and trustworthy.

Two options are proposed for Committee consideration.

Option A recognizes that multiple resources already exist and recommends expanding current resources to meet the needs of consumers.

Option B requests the creation of a new, single resource center.

# Draft Recommendation 4

## Option 1

4. HHS should endorse and ensure sufficient funding for existing governmental resources (such as those developed by NIH and CDC) to provide comprehensive, accessible, and trustworthy genetic web-based information for consumers. These resources should include scientifically validated information and/or links to credible information regarding topics such as genetic contributions to health and disease, gene-environmental interactions, genetic testing, and legal protections against genetic discrimination. To reach a broad range of communities,

# Draft Recommendation 4

## Option 1 (cont'd)

- A. these genetic resources should also include links to information that are not web-based such as television and radio programs and print materials, and
- B. the availability of these resources should be promoted using a wide range of strategies from collaborating with developers of Internet search engines to working with community leaders at the local level. Mechanisms to alert interested persons to updates and new information should be developed.

# Draft Recommendation 4

## Option 2

4. HHS should endorse and ensure sufficient funding for a web-based information resource center that builds on existing government resources (such as those developed by NIH and CDC) to provide comprehensive, accessible, and trustworthy genetic web-based information for consumers. This resource center should include scientifically validated information and/or links to credible information regarding topics such as genetic contributions to health and disease, gene-environmental interactions, genetic testing, and legal protections against genetic discrimination. To reach a broad range of communities,

# Draft Recommendation 4

## Option 2 (cont'd)

- A. the genetic resource center should also include links to information that are not web-based such as television and radio programs and print materials
- B. the availability of this resource center should be promoted using a wide range of strategies from collaborating with developers of Internet search engines to working with community leaders at the local level. Mechanisms to alert interested persons to updates and new information should be developed.

# Draft Recommendation 5

With the vast increase in scientific knowledge stemming from genetic and genomic research and new technologies and the increase in direct-to-consumer genetic services, consumers of all literacy levels are challenged to understand and use this information to make appropriate health decisions.

# Draft Recommendation 5

5. HHS should support research that identifies methods that are effective for translating genetic and genomic knowledge into information that consumers and patients can use to make health decisions. HHS should also support research that identifies effective methods of patient communication. Based on this research, and to reach diverse people and communities, HHS should develop educational programs that use a wide array of media (e.g., radio, television, print, and mobile phones) and provide for translation of materials into locally predominant languages. HHS should then support the dissemination of these programs. As part of the dissemination effort, the Secretary of HHS should work with other relevant departments and agencies such as the Department of Education and the National Science Foundation to integrate effective educational programs into science and/or health education initiatives.

# Draft Recommendation 6

Family health history tools were developed as one means for individuals and families to gain health literacy and to take a more active role in preventing and managing disease, particularly inherited conditions. These tools are a powerful asset for consumers and health care professionals to use in risk assessment and health promotion, but EHRs must be capable of accepting the information provided by consumer-oriented tools (e.g., My Family Health Portrait). Otherwise, the value of family history is diminished or omitted as a factor in risk assessments.

# Draft Recommendation 6

6. HHS should support continued efforts to educate health care professionals, public health providers, and consumers about the importance of family health history.
  - A. For health care professionals, HHS should support the use of family history in clinical care through development of clinical decision support tools and mechanisms to integrate pedigrees into electronic health records.
  - B. For public health providers, HHS should promote research identifying the role of family history in public health.

# Draft Recommendation 6 (cont'd)

C. For consumers, HHS should:

1. promote research on how consumers use family history to make health care decisions;
2. assess the effects of gathering family histories within diverse cultures and communities and among individuals where family histories are unavailable;
3. expand public health awareness programs and patient information materials on the importance of sharing family history information with primary care providers; and
4. promote the embedding of educational materials in family history collection tools directed to consumers and ensure access for all by providing these tools in various formats.

# Draft Recommendation 7

Given the reality that health care professionals and the professional societies representing them are unlikely to invest significant resources in education and training in content areas for which services are only partially or not at all reimbursable, a critical step in promoting increased knowledge of genetics and genomics among health care professionals is ensuring reimbursement for time spent in direct patient care that delivers genetic and genomic services.

# Draft Recommendation 7

7. In order to increase incentives and encourage investment by public and private organizations in education and training in genetics and genomics and to increase the willingness of health care professionals to participate in educational programs, the Secretary should:
  - A. ensure reimbursement for health care professional time spent in direct patient care delivering genetic and genomic services such as interpretation of genetic tests and collecting family history;
  - B. ensure reimbursement for all members of interdisciplinary teams and for distance consultation/telemedicine; and
  - C. act on the recommendations in the 2006 SACGHS report *Coverage and Reimbursement of Genetic Tests and Services*.

# Proposed Timeline for Next Steps

- Today: review and determine readiness of draft report and draft recommendations for public comment, and if so,
- March and April, 2010: public comment period
- June 2010 SACGHS meeting: review final draft report and final draft recommendations
- August 2010: transmit report to the Secretary

# Discussion Questions

- Do the findings follow from the literature review and survey results?
- Do the draft recommendations target the issues and concerns identified in this report?
  - Are the recommendations specific enough? Do they rely to the appropriate degree on the public sector? On the private sector? On public-private partnerships?
- Overall, and with the understanding that further copy editing will be done, is the draft report ready to be released for comment?