

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

**Barbara Burns McGrath, R.N., Ph.D.
SACGHS Task Force Chair
October 5, 2010**

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)

Overview of Session

- Review of the revised draft report
- Summary of the comments submitted by the public
- Discussion of final recommendations and transmittal to Secretary

A Brief History

("Sometimes a Great Notion")

2004 -- First SAGCHS Resolution

2007 -- Task Force Formed

2008 -- Task Force Charge Defined

- Point-of-care health professionals
- Public health providers
- Consumers and patients

2009 -- Literature review and data-gathering

2010 -- Draft Report & Public Comments

Task Force Structure

Health Care Professionals Workgroup

- David Dale, M.D., Chair
- W. Gregory Feero, M.D., Ph.D., Former 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

Draft Report Outline

- Introduction
- Background
- SACGHS Surveys
- Discussion
- Summary and Recommendations
- Appendices

Report Findings

("The Times They are A'Changin' ")

- Widespread appreciation of:
 - increased integration of genomics into health care, especially for common complex diseases
 - role of population-based applications of genomics
 - need for consumer genetic literacy and access to accurate information
- Health professionals are key to translation
- Consumers prefer to learn about genetic tests from providers
- Decreasing cost of whole genome sequencing may increase demand

Report Findings (cont.)

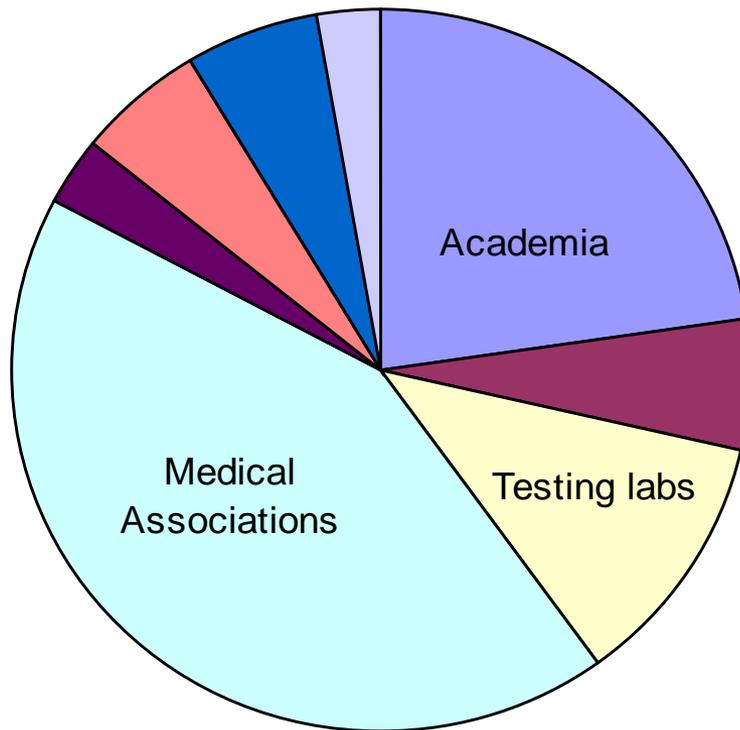
- Continuing gaps in genetic knowledge across groups
- Limited genetics education (basic and continuing) due to competing priorities
- Education not linked to accreditation, certification, licensure
- Lack of evidence of clinical utility seen as barrier to providers
- Public health workforce diverse with differing backgrounds, jobs, and educational needs
- Similarly, consumers/patients have wide range of knowledge and needs

Report Findings (cont.)

- Educational efforts should move beyond traditional models and include innovative approaches, e.g., emerging technologies (just-in-time resources), competency-based learning, and information dissemination using a variety of formats for diverse populations
- Success requires more comprehensive and coordinated efforts involving multiple stakeholders

Public Comments (n = 35)

Commenter Affiliations



- Academia
- State PH departments
- Testing labs/lab equipment co.
- Medical Associations
- Health Insurance Association
- Non-profit Associations
- Private citizens
- Federal Advisory Committee

Public Comments

These comments were grouped thematically and addressed by the Task Force:

- Clinical utility, need for evidence based guidelines
- Reimbursement for genetic services
- Consumer/public issues, K-12 education
- Public health practice
- Existing resources and models
- Larger pool of genetic health professionals

Draft Recommendations

Draft Recommendation 1

Evidence from the United States and abroad suggests inadequate genetics education of health care professionals as a significant factor limiting the integration of genetics into clinical care. Specific inadequacies include the amount and type of genetics content included in undergraduate medical school curricula and the small amount of genetics-related knowledge and skills of physicians, nurses, and other health professionals once they enter clinical practice. Modifications in medical, dental, nursing, public health, and pharmacy school curricula, and in medical residency training programs, are needed to ensure that health care professionals entering the workforce are well-trained in genetics. Innovative approaches that coordinate the efforts of entities controlling health professional education and training are needed.

Draft Recommendation 1 (cont.)

HHS should convene a workshop to identify innovative education and training approaches that will promote integration of genetics into clinical care. The workshop would build upon the findings of the June 2009 Blueprint for Genomics Education meeting—hosted by NIH, SACHDNC, HRSA, and other organizations—and newly established programs at HRSA, and would include representatives of HHS agencies and other federal departments with established programs in genetics professional education; representatives of health professional organizations engaged in accreditation, certification, and continuing education efforts; and private sector entities that provide genetics education.

Draft Recommendation 1 (cont.)

The workshop goals are to:

- A. Identify successful education and training guidelines and models that are outcomes based;
- B. Identify potential and current funding streams for developing and promoting genetics education for all relevant health care professionals;
- C. Recommend mechanisms for expanding and enhancing the content needed to prepare all health care professionals for personalized genomic health care;

Draft Recommendation 1 (cont.)

- D. Recommend mechanisms for evolving standards, certification, accreditation, and continuing education activities to incorporate genetic content;
- E. Determine the need, and if appropriate, appoint an advisory panel representing a range of educational and health care stakeholders to facilitate implementation of the approaches identified during the workshop and to re-evaluate educational needs on an ongoing basis;
- F. Publish findings and recommendations and develop a plan to monitor the outcome of these efforts.

Draft Recommendation 2

The inherent diversity of the public health workforce makes it difficult to target educational efforts that are relevant across groups. A systematic effort is needed to evaluate the composition of the public health workforce with current job responsibilities related to genetics and genomics and to identify future priorities, such as the potential impact of affordable genomic analysis.

Draft Recommendation 2 (cont.)

Tapping the expertise of its agencies with relevant missions in public health (e.g., HRSA, CDC, the Indian Health Service, 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:

Draft Recommendation 2 (cont)

- A. Support and encourage the incorporation of basic genetic and genomic core competencies in public health training programs and in the knowledge base of federal and nonfederal public health providers, and specific competencies for those whose responsibilities require specialized genetic knowledge, such as environmental interactions and risk assessment for population-based genomics; and
- B. Based on these competencies, fund development and implementation of accessible educational programs and continuing education in genetics and genomics for the public health workforce and explore incentives for the end user and for organizations that provide these programs.

Draft Recommendation 3

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.

HHS should promote the development and implementation of targeted 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:

Draft Recommendation 3 (cont.)

- A. Direct 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 explore use of incentives such as CEUs to encourage health care professionals to practice in underserved communities;

Draft Recommendation 3 (cont.)

- C. Incentivize organizations to increase the development of targeted genetic and genomic educational models (e.g., provide support for meetings where curricula are drafted); and
- D. Ensure that consumers and representatives of rural, minority, and underserved 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 these diverse communities.

Draft Recommendation 4

A significant amount of genetic-related information directed to consumers and patients exists in a variety of formats and from a number of sources, but the quality of the content is variable. Consumers have consistently expressed the desire for accessible, web-based genetic information that they can trust and consider provision of these resources as a role of the Federal Government.

Draft Recommendation 4 (cont.)

HHS should endorse, fund the development of, and maintain an Internet portal to a vetted collection of comprehensive, accessible, and trustworthy web-based genetic information and resources for consumers. This portal should utilize existing governmental resources (such as those developed by NIH, CDC, HRSA, and the National Newborn Screening Clearinghouse). HHS should assure that:

Draft Recommendation 4 (cont.)

- A. These resources 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;
- B. These resources include references to identify other types of information that are not web-based such as television and radio programs and print materials; and
- C. The availability of this portal 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 genetics research, the development of new technologies, and the increase in direct-to-consumer genetic services, educational efforts are needed to translate this information to reach consumers of all literacy levels.

HHS should support research and public-private collaborations to identify methods that are effective for translating genetics knowledge into information that consumers and patients can use to make health decisions. Specifically, HHS should:

Draft Recommendation 5 (cont.)

- A. Support research that identifies effective methods of patient and consumer communication, specifically by increasing availability of funding opportunities that call for collaboration among various disciplines (e.g., increase the number of Request for Proposals for patient and consumer education by 2015);
- B. 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 community-based learning and provide for translation of materials into locally predominant languages; and

Draft Recommendation 5 (cont.)

- C. Support the dissemination of these educational programs and materials into science and/or health education initiatives through collaboration with other relevant departments and agencies such as the Department of Education and the National Science Foundation, who can explore issues surrounding K-12 learning.
- D. Increase the availability of funding opportunities that call for collaboration among various disciplines to research.

Draft Recommendation 6

Family health history tools are a potentially powerful asset for consumers and health care professionals to use in risk assessment and health promotion.

HHS should support continued efforts to educate health care professionals, public health providers, and consumers about the importance of family health history, and to support efforts to validate family history tools for risk assessment and health promotion.

Draft Recommendation 6 (cont.)

- A. For health care professionals, HHS should, in collaboration with private sector stakeholders, 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 population health.

Draft Recommendation 6 (cont.)

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.

Proposed Points to Include in Report Cover Letter

The Committee recommends that the Secretary consider involving (or charging) other Federal agencies, such as AHQR, NIH and/or CDC, with:

1. tracking the implementation of the recommendations in the Education and Training in Genetics and Genomics report
2. establishing metrics to measure the success of genetics and genomics education and training programs instituted or funded as a result of the report's recommendations, and with
3. reassessing the state of genetics education and training within 5 years to ensure that Federal efforts continue to reflect the diverse and unique needs of health care and public health professionals and consumers.