

SACGHS Task Force on Genetics Education and Training Findings and Recommendations

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Task Force Roster

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

Task Force Structure

Health Care Professionals Workgroup

– David Dale, M.D., Chair

Public Health Provider Workgroup

– Joseph Telfair, Dr.PH, M.P.H., M.S.W, Chair

Consumer and Patient Workgroup

– Vence Bonham, J.D., Chair

Overview of Session

- Review findings
- Discuss and refine draft recommendations

Timeline

- Today's meeting--discuss draft recommendations
- October to January 2010--complete draft report and refine recommendations
- January 2010--transmit public consultation report to SACGHS members
- February 4-5, 2010, SACGHS meeting--review and approve public consultation report
- March 1 to April 12, 2010--public comment period
- June 15-16, 2010, SACGHS meeting--review final draft report with recommendations
- July 2010--transmit report to the Secretary

Draft Report Outline

- Executive Summary and Recommendations
- Introduction, scope of report
- Background literature review
- SACGHS data gathering
- Discussion
- Summary and conclusions
- Appendices

Good News!

Examples of Progress

- Since 2004, CDC has expanded its genetics/genomics education mission to include health care professionals and the public
- Online family history tools have become available, e.g.
 - My Family Health Portrait from the Surgeon General
 - <https://familyhistory.hhs.gov/fhh-web/home.action>
- NCHPEG has produced a number of educational products for specific groups of health care professionals
- Nurses have specialized genetic/genomic certifications
- The genetic counselor workforce has increased
- A second series of educational articles on genomics in medicine will be published in NEJM in 2010

Health Care Professionals Summary of Findings: Literature

- Integration of genetics into health care is limited by lack of, or inappropriate, genetics education for health care professionals
- The education needs are dynamic and reflect career trajectory and/or level of training (basic education, advanced training, continuing education)
- Licensure, certification and accreditation requirements are not up to date
- Based on American College of Medical Genetics data, there are currently 495 FTE medical geneticists in the U.S. workforce, 41 percent of the number needed

Health Care Professionals Summary of Findings: SACGHS Surveys

- Distributed two SACGHS surveys
 - Federal agencies with SACGHS *ex officios* were surveyed in 2004 and 2009 to help assess federal genetics education and training efforts
 - 17 surveys returned (85% response rate)
 - 6 agencies responded to both surveys (2004 and 2009)
 - Analysis ongoing
 - Health professional organizations
 - 33 surveys returned (58% response rate)

Health Professional Organizations SACGHS Survey Findings

- 70% view genetics education as part of their role, but see need for more funding, program evaluation, and interest within organization's leadership
- Organizations report moderate proficiency and comfort by their leadership in genetics and genomics education
- Competing priorities are a barrier to providing genetics and genomics education

Public Health Providers

Summary of Findings: Literature

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

Public Health Providers Summary of Findings: SACGHS Survey

- 12 competencies identified and developed as survey instrument
- Survey distributed to approximately 500 individuals
- 133 responses, but unable to calculate response rate as survey was forwarded online to unknown numbers

Public Health Providers

Summary of Findings: SACGHS Survey

- Highest competency was demonstration of basic knowledge of the role of genetics in development of disease and in screening and interventions for programs of disease prevention and health promotion
- Lowest competency was in conducting outcome evaluations
- Two thirds felt that genetic/genomic resources were inadequate for implementing competencies

Consumer and Patients

Summary of Findings: Literature

- Sources of information are media (TV, newspapers, magazines, internet) and their health care providers
- Recognize that genes and behaviors are related to health outcomes, but less knowledge of complex traits and multifactorial conditions
- Continued concern about confidentiality and disclosure of genetic information
- Most education resources have been geared to those actively seeking information

Consumer and Patients

Summary of Findings: Interviews and Surveys

- 11 semi-structured interviews with diverse individuals
- Web-based SACGHS survey distributed to more than 1,000 organizations representing “seekers of genetic information”
 - 300 responses
- Review of Cogent 2008 consumer survey analysis (N = 1000)

Consumer and Patients

Summary of Findings: Interviews and Surveys

- Wish to get information about genetic testing from primary care providers, but not confident they have adequate knowledge
- Government is seen as trusted source for information and should serve as a clearinghouse
- Family history is seen as an important tool to understand health and disease

Draft Recommendations

Health Care Professionals

1. Integrate Genetics and Genomic Content into Health Professional Education

- HHS should encourage the integration of genetics and genomic content into all levels of health professional education and training programs relevant to the needs as identified by specialty groups.

Health Care Professionals

2. Stimulate Creative, Innovative, Collaborative Care Delivery

- HHS should fund multi-disciplinary, public-private Genetics/Genomics Education Advisory Panels whose function is to prepare a model framework for education, licensure, accreditation and certification requirements in preparing for personalized genomic health care.

Health Care Professionals

3. Facilitate Interdisciplinary Collaboration

- HHS should support formal and informal genetic knowledge sharing by facilitating interdisciplinary collaborations
 - In rural or underserved areas, employ innovative technologies such as telemedicine conferencing to share knowledge and expertise
 - HHS should ensure reimbursement for interdisciplinary teams and distance consultations (see *SACGHS Coverage and Reimbursement report* with respect to coding and billing for genetic counselor services)

Public Health Providers

4. Assess Public Health Workforce

- HHS should assess the size and scope of the public health workforce that have genetic and genomic responsibilities to ascertain current trends and plan for future needs.

Public Health Providers

5. Develop Core Competencies

- HHS should facilitate the development of relevant core competencies for all federal and non-federal public health providers and specific competencies for those whose role requires such knowledge.

Public Health Providers

6. Promote Collaborative Training

- HHS should promote collaboration for genetics/genomics education and training between medical and public health professionals to benefit population health, e.g. schools of public health and medicine and American Medical Association and American Public Health Association.

Consumers and Patients

7. Improve Literacy in Genetics/Genomics

- Efforts to improve genetic/genomic literacy of consumers and patients should be based on educational theory and be coordinated with other Federal departments and agencies and community based organizations.

Consumers and Patients

8. Expand Educational Resources for the Public

- HHS should support the continued and expanded development of educational resources to enhance the public's genetic literacy.

Consumers and Patients

9. Support Family History

- HHS should support continued efforts to publicize the importance of family health history, ensure access to tools in various formats, and inform consumers about the importance of sharing this information with primary care providers.

Consumers and Patients

10. Increase Public Understanding of Genetic Research

- HHS should inform the public about the risks and benefits of participating in genetic/genomic research through national and local educational efforts.

Recommendations that Apply Across Groups

11. Fund Strategic Planning for Education and Training

- In consultation with relevant agencies, HHS should ensure funding of a national strategic planning mechanism for genetics and genomics education and training of the health care workforce.
- The planning group should include
 - Individuals who are experts in genetic/genomic content and the educational needs of specific disciplines
 - Experts outside of these traditional fields who are innovative thinkers regarding incorporation and adoption of knowledge in a technology explosive era while looking towards the future in genomics education.

12. Increase Faculty Training

- Due to the identified shortage of clinical and public health educators with formal training in genetics, HHS should facilitate increased training for academic health care educators, for example, through HRSA training grants.

13. Develop Effective Translation Methods

- HHS should support research on assessment and development of effective methods for translating genetic and genomic science to health care professionals, public health providers, and consumers and patients.

Applicable Recommendations from Prior SACGHS Reports

- Provider education and training
 - *Coverage and Reimbursement of Genetic Tests and Services, February 2006*
 - *U.S. System of Oversight of Genetic Testing, April 2003*
- Clinical validity and clinical utility
 - *Coverage and Reimbursement of Genetic Tests and Services, February 2006*
 - *Realizing the Potential of Pharmacogenomics, May 2008*
- Evaluate and regulate genetic testing
 - *Coverage and Reimbursement of Genetic Tests and Services, February 2006*
- Need for greater public awareness
 - *Coverage and Reimbursement of Genetic Tests and Service, February 2006*