

Update on Education and Training Task Force

Data Gathering Phase

Barbara Burns McGrath, R.N., Ph.D.
Chair, Education and Training Task Force
Secretary's Advisory Committee on
Genetics, Health, and Society
March 12, 2009

Background

- 2004 SACGHS Resolution on Genetics Education and Training of Health Professionals
- November 2007 SACGHS Education Roundtable

Scope of Task Force

- Health Care Providers
- Public Health Providers
- Consumers and Patients

Health Care Providers Workgroup

- Chair, W. Gregory Feero, M.D., Ph.D.
- Members:
 - Sylvia Au, M.S., C.G.C.
 - Judith Benkendorf, M.S., C.G.C.
 - Joann Boughman, Ph.D.
 - Kathleen Calzone, R.N., M.S.N.
 - James Evans, M.D., Ph.D.
 - Jean Jenkins, Ph.D.
 - Katherine Johansen, Ph.D.
 - Emma Kurnat-Thoma, M.S., R.N.
 - Marc Williams, M.D., F.A.A.P., F.A.C.M.G.

Goals

Survey key professional organizations to determine priorities for enhancing genetics education and training

Survey federal activities in genetics education and training of professionals

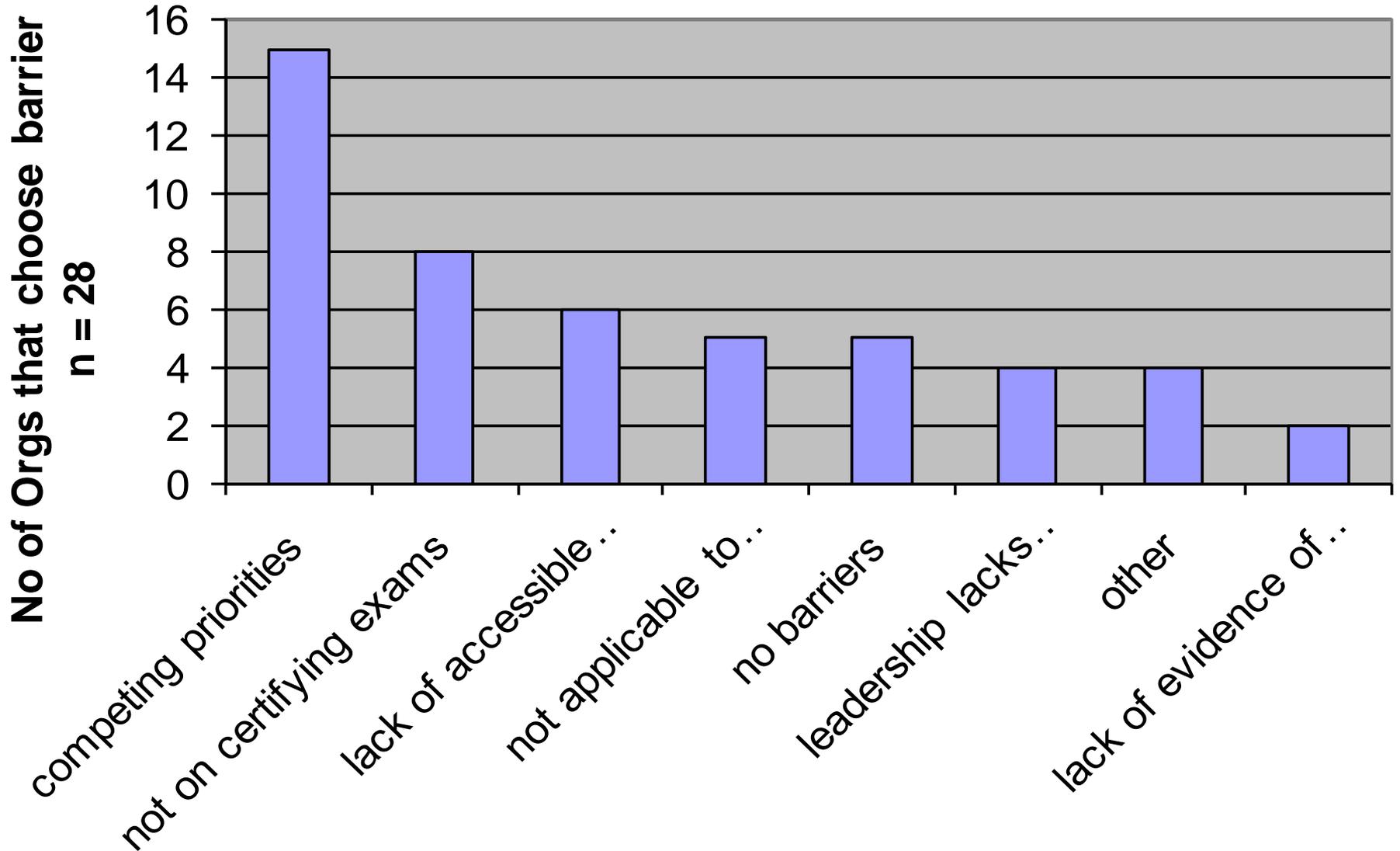
Survey Sample

- Identified 57 health professional organizations
 - 28 general professional
 - e.g., American Academy of Family Physicians
 - 8 genetic specific
 - e.g., American Society of Human Genetics
 - 18 professional education
 - e.g., American Assoc of Colleges of Pharmacy
 - 3 federal advisory committees
 - e.g., Advisory Committee on Heritable Disorders in Newborns and Children
- 32 returned (53%)

Preliminary Data

- 50% have an established committee, workgroup, or staff that deals with genetics or genomics topics
 - e.g., AMA has a full time staff person
- Barriers reported to providing genetics education:
 - competing priorities
 - not emphasized on certifying exams
 - not applicable to organization's mission
 - lack of accessible educational resources
 - leadership lacks knowledge
 - no barriers (1 was genetic specific org)
 - lack of evidence supporting clinical effectiveness of care based on genetic/genomic information

Barriers to Providing Genetics/Genomics Education Health Professional Organizations



Survey of Federal Activities

- Targeted to SACGHS *ExOfficio* agencies
 - 15 of 18 returned (83%)
 - 8 completed (5 can be compared to 2004 survey)
 - 7 reported no activities
- Data analysis underway

Next Steps for Health Care Providers Workgroup

- Continue to encourage return of surveys
- Compare 2004 and 2008 federal agency survey data
- Complete data analysis

Public Health Providers Workgroup

- Chair, Joseph Telfair, Dr.PH, M.P.H., M.S.W.
- Members
 - Sylvia Au, M.S., C.G.C.
 - Joann Boughman, Ph.D.
 - Muin J Khoury, M.D., Ph.D.
 - Katie Kolor, Ph.D.
 - Kate Reed, M.P.H., Sc.M., C.G.C.
 - Gurvaneet Randhawa, M.D., M.P.H.
 - Paul Wise, M.D., M.P.H.

Goals

- In order to identify genetics needs of public health providers:
 - Develop a core set of competencies from publically available sources to include:
 - NCHPEG, CDC, ASTHO, TRAIN National, and U WA
 - Develop and administer an assessment instrument to a subset of PHP within state and local public health agencies

Examples of the 12 Core Competencies Identified

- Maintain up-to-date knowledge on the development of genomic science and technologies
- Identify opportunities to integrate genetics/genomics into public health practice, policies or programs effectively
- Identify the political, legal, social, ethical, and economic issues associated with integrating genomics into public health
- Identify appropriate and relevant genetics/genomics research findings that can be translated into public health policies or practices

Next Steps for Public Health Providers Workgroup

- Finalize competencies
- Develop survey instrument
- Administer survey
- Data analysis

Consumer and Patient Workgroup

- Chair, Vence Bonham, J.D.
- Current Members
 - Joann Boughman, Ph.D.
 - Denise Geolot, Ph.D., R.N.
 - Sarah Harding, M.P.H.
 - Scott McLean, M.D.

Goal

To provide recommendations that address the genetic education needs of consumers and patients

Qualitative interviews

5 semi-structured interviews with professionals in

- Health communications
- Advocacy and outreach
- Clinical genetics
- Industry
- Education

Preliminary data— themes identified

- Consumers get information from health care providers and the media, and feel government has role to play
 - Needs:
 - Concept of multiple risk factors
 - Role of the environment
 - Presence of levels of expertise among health care providers
 - Tools to evaluate the veracity of information received
 - Concerns about direct to consumer genetic testing
- Reported barriers to understanding genetic information and participating in genetic research:
 - Poor health literacy/knowledge of genetics
 - Genetic determinism or fatalism
 - Fears of discrimination

Next Steps for Consumers/Patients Workgroup

- Based on identified themes, a survey has been developed
- To be administered to 30 community based organizations
- Data analysis

Report Completion Timeline

- Background, methods, data, key findings
 - on going until June 10
- Recommendation development
 - report progress at June 12 SACGHS meeting
- Rough draft completed
 - early August
- Report sent out to SACGHS members for review
 - end of August
- Present draft report to SACGHS
 - October 8-9 meeting
- Sixty day public comment period
 - Beginning in November 09
- Final Report
 - mid 2010