

Genetics Education and Training Task Force Progress

Barbara Burns McGrath, R.N., Ph.D.
Secretary's Advisory Committee on
Genetics, Health, and Society
June 11, 2009

Session Outline and Goals

- Status of draft report
- Update on data gathering activities
- Discuss workgroup policy directions

Education and Training Task Force Roster

SACGHS Members

- Sylvia Au, M.S., C.G.C.
- Barbara Burns McGrath, R.N., Ph.D., (Chair)
- David Dale, M.D.
- Gwen Darien
- James Evans, M.D., Ph.D.
- Marc Williams, M.D., F.A.A.P., F.A.C.M.G.

SACGHS Ex Officios

- Denise Geolot, Ph.D., R.N.
- Muin J Khoury, M.D., Ph.D.
- Gurvaneet Randhawa, M.D., M.P.H.
- Paul Wise, M.D., M.P.H.

Education and Training Task Force Roster

Ad Hoc Members

- Judith Benkendorf, M.S., C.G.C.
- Vence Bonham, J.D.
- Joann Boughman, Ph.D.
- Kathleen Calzone, R.N., M.S.N.
- W. Gregory Feero, M.D., Ph.D
- Sarah Harding, M.P.H
- Jean Jenkins, Ph.D.
- Katherine Johansen, Ph.D.
- Katie Kolor, Ph.D.
- Emma Kurnat-Thoma, M.S., R.N.
- Scott McLean, M.D.
- Kate Reed, M.P.H., Sc.M., C.G.C
- Joseph Telfair, Dr.PH, M.P.H., M.S.W.

Education and Training Task Force Structure

- Core members from SACGHS
 - Barbara Burns McGrath, R.N., Ph.D., Chair
- Consumer Workgroup
 - Vence Bonham, J.D., Chair
- Health Care Provider Workgroup
 - Greg Feero, M.D., Ph.D, Outgoing Chair
 - David Dale, M.D., Incoming Chair
- Public Health Provider Workgroup
 - Joseph Telfair, Dr.PH, M.P.H., M.S.W, Chair

...at our most recent meeting

- March 12, 2009
 - Provided background on formation of E&T Task Force
 - Gave overview of each workgroup and their activities
 - Health Care Provider WG had completed surveys of health professional organizations and Federal agencies
 - Public Health Provider WG had developed competencies in preparation for development of survey
 - Consumer and Patient WG had completed structured interviews to inform the development of a survey

Task Force Report Timeline

- Today's meeting--*Discussion of workgroup policy directions*
- June 30--*Complete data collection*
- August 30--*Complete data analysis, finalize rough draft*
- September 15--*Mail draft report to SACGHS members*
- October 8-9 meeting--*Review public consultation report*
- ~November 1--*Release draft report for public comments*
- ~March 2010 SACGHS meeting--*review final draft report*
- ~June 2010--*transmit report to the Secretary*

Consumer and Patient Workgroup

Consumer and Patient Workgroup

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



Consumer and Patient Workgroup Charge

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

Consumer and Patient Workgroup Specific Tasks

- Report on federal agencies' and organizations' activities regarding genetics education for consumers and patients
- Provide recommendations for:
 - health related genetic information for the public
 - how, what, where, and when to communicate genetics information to the public and patients
- Review best approaches to consumer- and patient-level genetics education.
- Provide an appendix of consumer- and patient-level education resources

Data Gathering Methods

- Environmental Scan
 - Expert Interviews over the phone with 11 individuals
 - Clinical genetics, molecular genetics, health communications, advocacy, policy expertise, industry
 - 2 experts participated in most interviews
 - Transcribed and analyzed for overall themes
 - Informed next step--written survey

Experts Interviewed

- Health communications and genetics education:
 - Kimberly Kaphingst, Sc.D. Investigator, NHGRI/NIH
 - Celeste Condit, Ph.D. Professor, University of Georgia
- Molecular genetics and science education:
 - Louisa Stark, Ph.D., Director, Genetic Science Learning Center at the University Of Utah
 - David Micklos, Executive Director, Dolan DNA Learning Center
- Clinicians:
 - Mimi Blitzer, Ph.D., Professor, University of Maryland
 - Cindy Prows, M.S.N., R.N., Cincinnati Children's Hospital Medical Center

Experts Interviewed (cont)

- National lay advocacy outreach:
 - Sue Friedman, Executive Director, FORCE
 - Andy Imparato, President, CEO, American Association of People with Disabilities
- Industry:
 - Erin Cline Davis, Ph.D., 23andMe
 - Trish Brown, M.S., C.G.C., DNA Direct
- Policy:
 - Kathy Hudson, Ph.D., Director, Genetics and Public Policy Center

Data Gathering Methods (cont)

- Targeted Web-based Survey
 - ~1000 organizations representing “seekers of genetic information related to health”
 - 71 organizations representing health care advocacy and community based organizations
 - Oversampled for organizations representing minority and underserved communities
 - Asks for prioritization of topics related to genetics education that were identified in expert interviews
 - 301 responses (29 partials) as of June 9, 2009

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Department of Health and Human Services

Page 2 % Completed

3. Please rank the importance of the following topics that may have special relevance for seekers of genetic information as it relates to health. (Rank 1-4, 1 being the highest priority. Enter integers only.)

Rank
1-4

How to access genetic tests

How to interpret and evaluate the credentials of a genetics professional

How to interpret results of a genetic test

Where to find reliable genetic and genomic information

If there are more important items not listed above, please specify:

4. Please rank the following barriers to genetics and genomics education efforts for seekers of genetic information as it relates to health. (Rank 1-5, 1 being the most important. Enter integers only.)

Rank
1-5

Lack of health professionals' understanding of genetics

Lack of individual health literacy in genetics

Lack of access to genetic services for consumers/patients

Direct-to-consumer marketing of genetic tests before there is evidence of their utility or benefit

Lack of patient understanding of genetic testing implications for themselves or their family (i.e. whether to share results with family members)

If there are more important items not listed above, please specify:

If you experience any technical difficulties, please contact the survey administrator at User-Centered Design at consumersurvey@user-centereddesign.com

Data Gathering Methods (cont)

- Review data collected from National Public Survey conducted by COGENT
 - “Cogent Genomics Attitudes & Trends: 2008”
 - Sample Profile: Representative of U.S. population on age, socioeconomic profile, ethnicity, region and gender
 - Data collection May 30- June 9, 2008
 - Web-based survey
 - n=1000

Data Gathering Methods (cont)

- Genetic Testing Marketing and Communications: Literature Review, 1998-2008
 - Analyze literature review report commissioned by NIH
 - Academy for Education Development (AED) conducted a search of both published and unpublished literature on the subject between October 2008 and February 2009
 - Searched multiple databases including *PubMed*, *PsychINFO*, *ERIC*, *Social Science Index (Sociofile)*, *Scopus* and *Communication & Mass Media Complete*

Workgroup Policy Directions

- Primary care providers are the first line of information for patients and consumers
- Use the internet as a source of accurate and accessible genetic information for the public

Workgroup Policy Directions

- Provide patients and consumers with tools to identify knowledgeable health care providers (genetic specialists and primary care physicians)
- Develop models to enhance genetic health literacy for the public
- Enhance K-12 science education content on the role of genetics in health
 - Probabilities and risk
 - Genetic and environmental roles in health and disease

Workgroup Next Steps

- Complete data analyses
- Identify gaps and barriers to successful genetics education efforts
- Refine proposed recommendations for the draft Task Force report

Health Care Providers Workgroup

Health Professionals Workgroup

- Outgoing Chair, W. Gregory Feero, M.D., Ph.D
- Incoming Chair, David Dale, M.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.
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 - Marc Williams, M.D., F.A.A.P., F.A.C.M.G.

Workgroup Goals

- Snapshot of Federal HP educational activities
- Compare Federal activities 2004 – 2009
- Snapshot of health professional group educational activities (M.D. primary care bias)
- Gain a sense of primary care organization plans for future genomics education

Federal Survey

- Largely duplicated 2004 survey
- Targeted agencies with SACGHS *ex-officios*
- Open ended questions on past, present and future HP educational activities
- Some questions on budgets
- Attempted to make less onerous than previous survey
- Distributed early 2009, email reminders

Federal Survey Results

- 17/20 agencies/offices responded (85%)
- 9/20 completed survey (45%)
- 6 agencies responded in both 2004 and 2009:
 - CDC, DOE, HRSA, NIH, DOC, DOD
- 3 agencies with no reply 2009
- 1 reported activities, no survey

Federal Survey Results

- 295 pages of PDF documents
- Qualitative analysis planned, with creation of data base
- Meaningful quantitative analysis is unlikely

Selected Excerpts

“.... the agency (CDC) is not currently able to fully develop this area and respond to emerging developments in genomics, due to limited available resources to assess educational needs among professionals, and to develop and disseminate training tools and curricula, in collaboration with our partners.”

“Yes, HRSA is able to fulfill this role and its' responsibilities effectively.”

Selected Excerpts

“Training and education in genetics/genomics is a key component of several CF programs and could be considered a priority area that could be expanded with additional funding.”

“National Center for Integrative Biomedical Informatics...\$ 14,767,229”

“Neurodevelopmental Toxicology...\$1,371,301”

– NIH

Workgroup Policy Direction

“The Secretary of HHS should establish, empower, and fund health professional genomics education activities within HHS.”

Health Professional Survey

- Open ended and structured questions
- Piloted with NCHPEG board, reviewed by survey methodologist Fall 2008.
- Early 2009, email and phone call f/u to NR
- Targeted:
 - Genetics organizations (8)
 - HP education organizations (18)
 - HP organizations (28)
 - Federal Advisory Committees(3)

HP Survey Results

- Overall response rate of 58%
 - Genetics organizations (8/8, 100%)
 - HP education organizations (7/18, 39%)
 - HP organizations (16/28, 57%)
 - Federal Advisory Committees (2/3, 67%)

HP Survey Results

- 329 pages of PDF documents
- Qualitative and quantitative analysis planned, with creation of data base
- Meaningful quantitative analysis is likely

What importance does your organization place on the development and promotion of educational activities in the health area generally? (1=not at all; 5=very)

Organization Type	1	2	3	4	5	NA	Median	T Resp.
Federal Advisory Committee			1		1		-	2
General Professional Organization				<u>1</u>	<u>15</u>		<u>5</u>	16
Genetic Specific Organization		1	1		6		<u>5</u>	8
Professional Education Organization					<u>6</u>	<u>1</u>	<u>5</u>	7
All Organizations		1	2	1	28	1	<u>5</u>	33

What importance ... educational activities ... specifically related to genetics and genomics? (1=not at all; 5=very)

Organization Type	1	2	3	4	5	NA	Median	Resp.
Federal Advisory Committee			1		1		-	2
General Professional Organization	<u>1</u>	<u>1</u>	<u>3</u>	<u>4</u>	<u>4</u>	2	<u>4</u>	15*
Genetic Specific Organization					8		<u>5</u>	8
Professional Education Organization		<u>1</u>	<u>1</u>		<u>4</u>	1	<u>5</u>	7
All Organizations	1	2	5	4	17	3	5	32*

Where does genetics and genomics education fall relative to the overall priorities facing your organization?

Organization Type	Median	Resp.
Federal Advisory Committee	-	2
General Professional Organization	<u>3</u>	15*
Genetic Specific Organization	<u>5</u>	8
Professional Education Organization	<u>3</u>	7
All Organizations	<u>4</u>	32*

How proficient and comfortable would you say your organization's leadership is with genetics and genomics education? (1=low; 5=high)

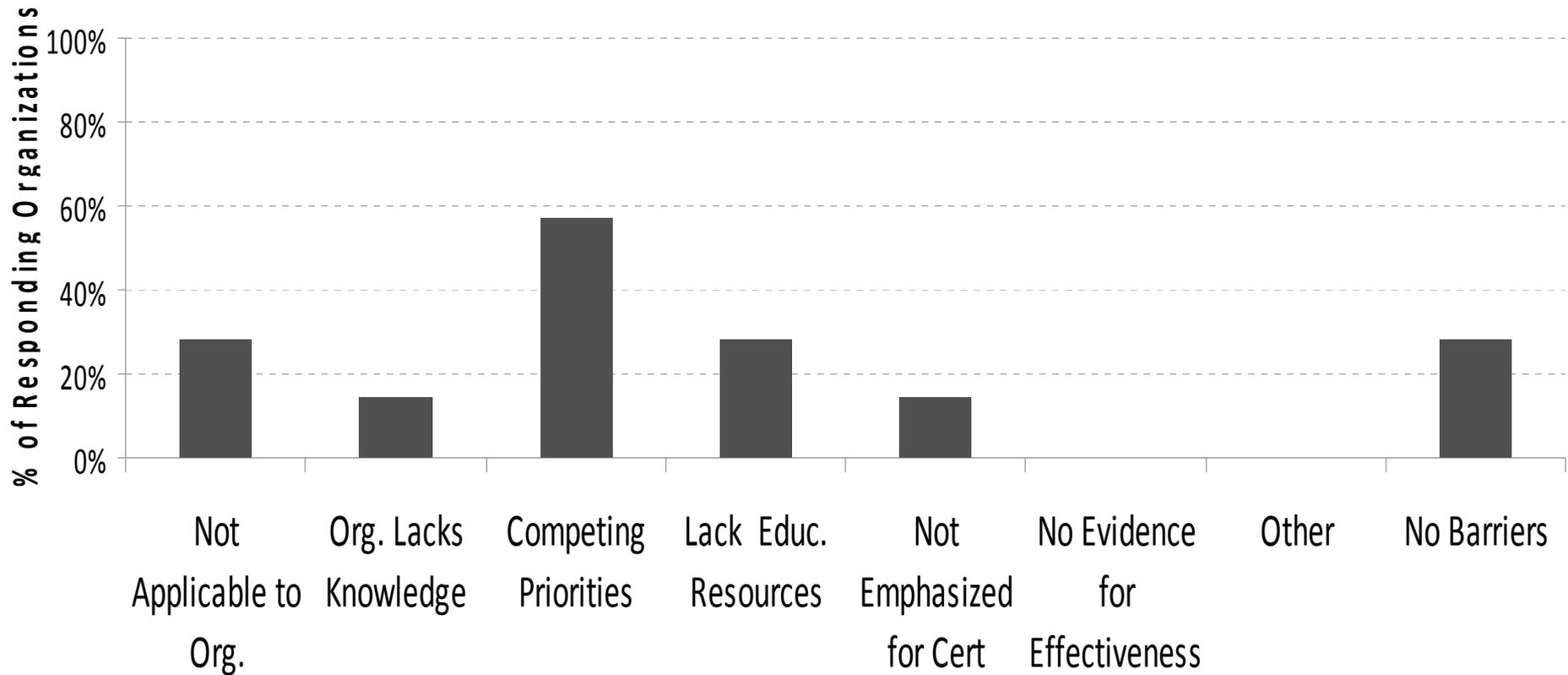
Organization Type	1	2	3	4	5	NA	Median	Resp
Federal Advisory Committee			1		1		-	2
General Professional Organization	<u>1</u>	<u>1</u>	<u>2</u>	<u>7</u>	<u>2</u>	<u>2</u>	<u>4</u>	15*
Genetic Specific Organization				1	7		5	8
Professional Education Organization		<u>2</u>	<u>3</u>	<u>1</u>		<u>1</u>	<u>3</u>	7
All Organizations	1	3	6	9	10	3	4	32*

To what extent is your organization's membership satisfied with the organization's current emphasis on genetics and genomics education? (1=not at all; 5=extremely)

Organization Type	1	2	3	4	5	NA	Median	Resp.
Federal Advisory Committee						2	-	2
General Professional Organization			3	6	2	4	<u>4</u>	15*
Genetic Specific Organization				3	3	2	-	8
Professional Education Organization			4	1	1	1	<u>3</u>	7
All Organizations			7	10	6	9	4	32*

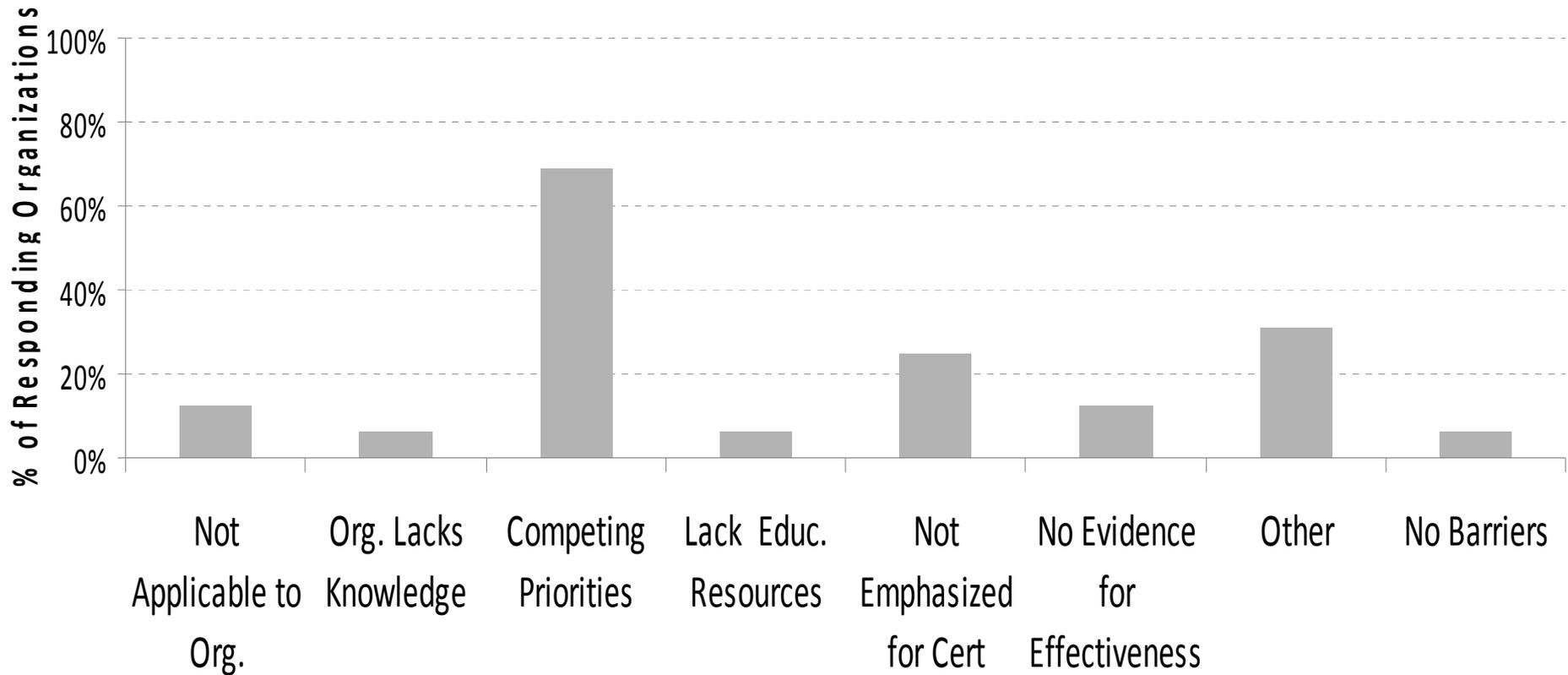
Barriers

Professional Education Organization



Barriers

General Professional Organization



Workgroup Policy Direction

“The Secretary of HHS should facilitate the development of public/private partnerships with health professional organizations to develop and implement a coordinated strategy for genomics education in the United States.”

Developing a Blueprint for Primary Care Physician Education in Genomic Medicine

- June 8-9, 2009 at NIH
- Co-sponsors: ACHDNC, CDC, HRSA, NCI, NHGRI, NHLBI, ORDR, NNSGRC
- Goal: Engage primary care physician leaders in a discussion of genomic education for the next five years
- ACP, AAP, ACOG, AAFP, STFM, SGIM, AAMC, AMA, AOA, AACOM, NMA, ACPM, NSGC, ACMG

Meeting Highlights

- **Substantial** accord on several topics:
 - Need for integration, rather than addition, of genomic education topics longitudinally in health professional education.
 - Need for better coordination mechanisms between physician groups and allied health
 - Family history is a focal point for care and education – but needs to be captured in EHRs
 - Agreement that pipeline for genetic specialists needs to be expanded – certificate programs?

Meeting Highlights

- Transitions in care are very important to genomic medicine – a team based approach in the patient centered medical home could help with this.
- Demonstration of utility and teaching using practical examples of what can be done now is key.
- RRCs and CME approval processes are key points of influence that could be approached in the near term to improve genomics integration.
- Would value a meeting again in 6 months to one year.

Public Health Providers Workgroup

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.
 - Gurvaneet Randhawa, M.D., M.P.H.
 - **Kate Reed, M.P.H., Sc.M., C.G.C,**
 - Paul Wise, M.D., M.P.H.

Data Gathering Methods

- 12 Genetic/genomic competencies were developed from available sources:
 - NCHPEG, CDC, ASTHO, TRAIN National, and U WA
- Survey instrument developed

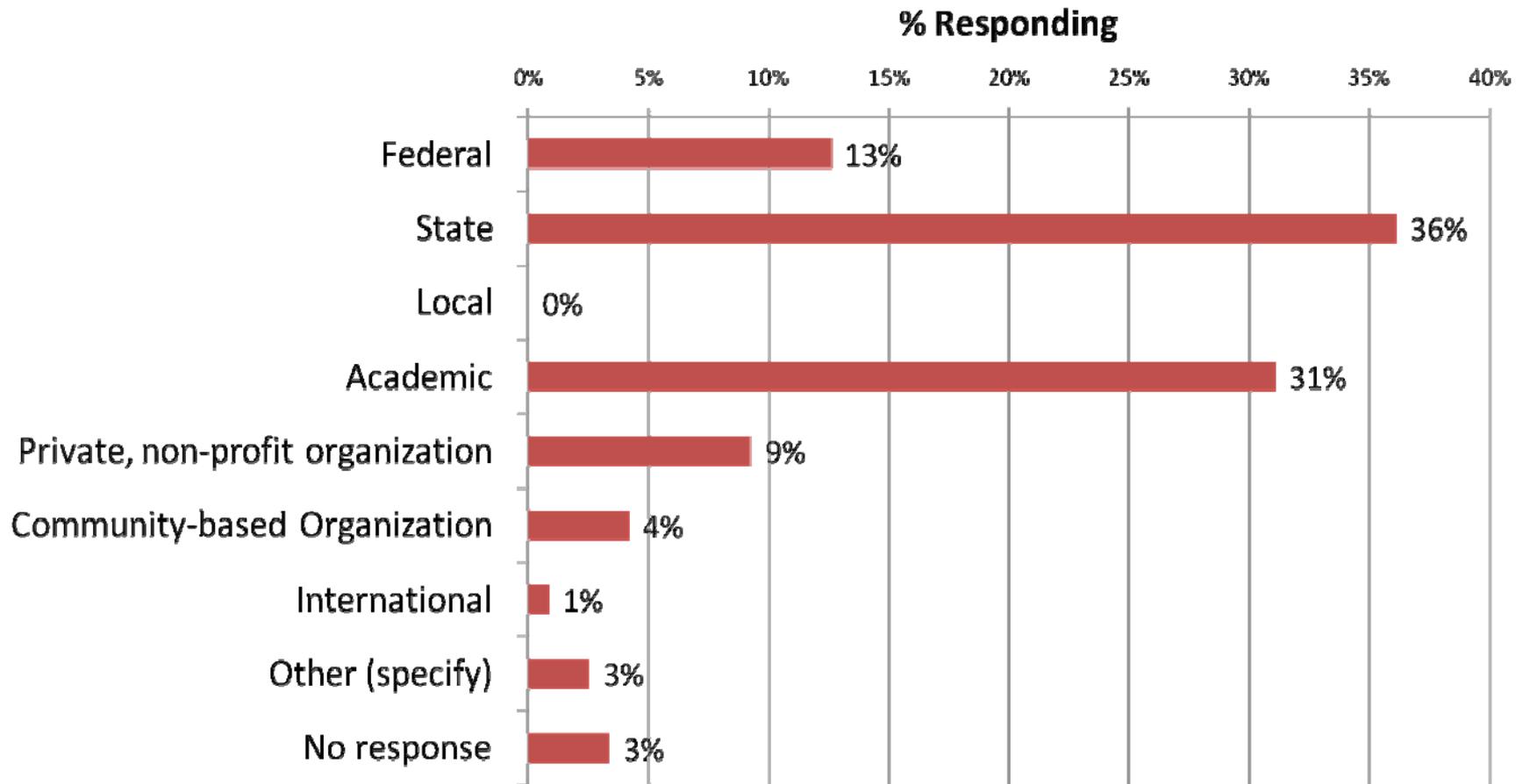
Survey Sample

- Sample
 - 96 State genetics coordinators
 - 49 APHA State affiliates addresses
 - 366 APHA Genomic Forum members
 - 58 ASTHO Health Officials (sent June 9)
- 510 email invitations sent after duplicates were removed
- 133 responses (10 partials) as of June 9

Preliminary Results

- Your role in Public Health

At what level of public health do you work?



Does not include responses from recent ASTHO health officials mailing

What is your job title?

For scale purposes,

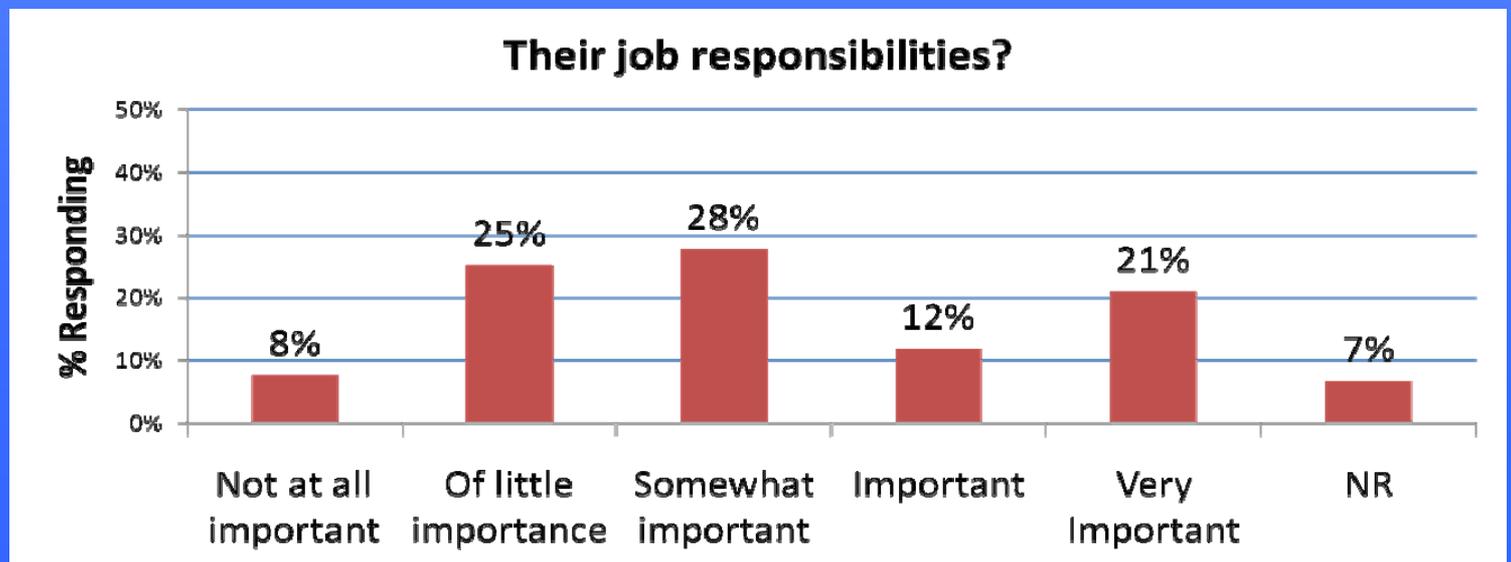
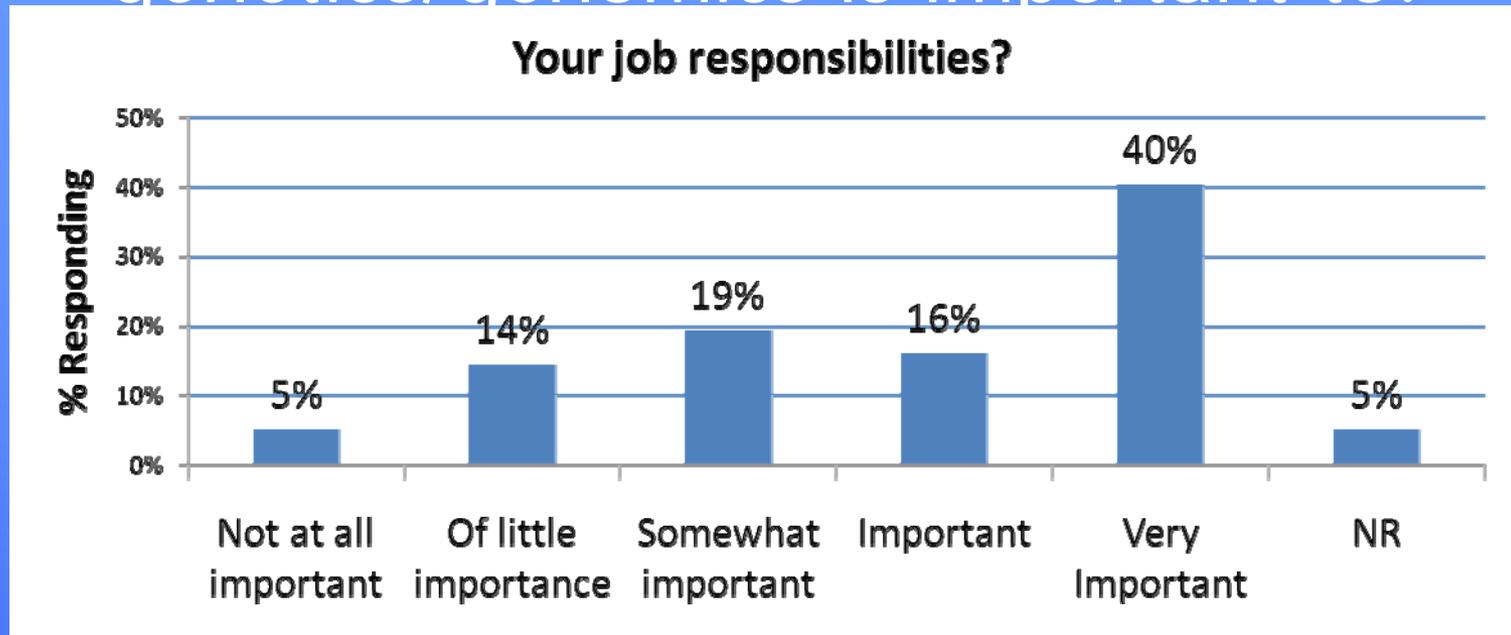
- “Professor” and “Director” each had 17 occurrences,
- “genetics” had 9 occurrences and
- “epidemiologist” had 4 occurrences



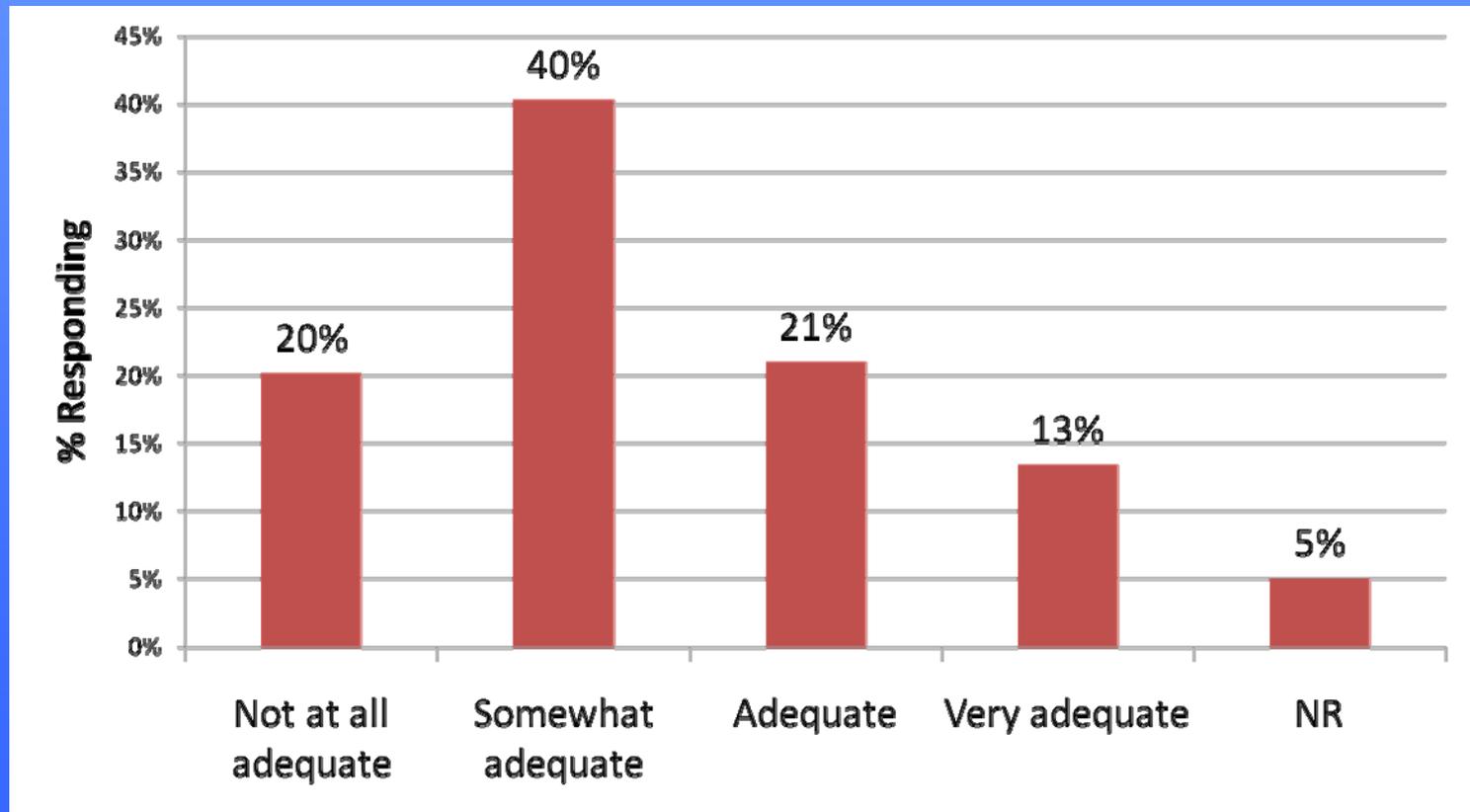
Preliminary Results

- Importance of genetics and genomics to your institution's leadership

Does your senior administration think that genetics/genomics is important to:



How adequate are your resources for implementing genetic/genomic competencies into your work/role?



Competencies



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Part I: Your Practices of 12 Competencies

% Completed

Reflecting on your current role, please check one answer from the questions below that best describes your practice for each competency statement.

A public health professional is able to:

1. Maintain up-to-date knowledge on the development of genomic science and technologies within his or her professional field and program to apply genomics as a tool for achieving public health goals.

	Not at All	Not Very	Somewhat	Very
How important is the competency?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at All	Not Very	Somewhat	Very
How confident are you in demonstrating this competency?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	1-2 Per Year	Monthly	Weekly
How frequently do you apply this competency?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Demonstrate basic knowledge of the role that genetics/genomics plays in the development of disease and in screening and interventions for programs of disease prevention and health promotion.

	Not at All	Not Very	Somewhat	Very
How important is the competency?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at All	Not Very	Somewhat	Very
How confident are you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	1-2 Per Year	Monthly	Weekly
How frequently do you apply this competency?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Analysis not yet available

Workgroup Policy Direction

- Develop and implement strategies to educate those who are currently being trained in PH.
 - Incorporate genetics into existing programs or develop specific programs; use structured approach
- Develop and implement strategies to educate the current public health workforce that are tailored to the various segments of the public health work force

Discussion of Workgroups' Policy Directions

Consumer and Patient Workgroup Policy Directions

- Primary care providers are the first line of information for patients and consumers
- Use the internet as a source of accurate and accessible genetic information for the public

Consumer and Patient Workgroup Policy Directions (cont)

- Provide patients and consumers with tools to identify knowledgeable health care providers (genetic specialists and primary care physicians)
- Develop models to enhance genetic health literacy for the public
- Enhance K-12 science education content on the role of genetics in health
 - Probabilities and risk
 - Genetic and environmental roles in health and disease

Health Care Provider Workgroup Policy Directions

- Establish, empower, and fund health professional genomics education activities within HHS.
- Facilitate the development of public/private partnerships with health professional organizations to develop and implement a coordinated strategy for genomics education in the United States.

Public Health Provider Workgroup Policy Directions (cont)

- Develop and implement strategies to educate those who are currently being trained in PH.
 - Incorporate genetics into existing programs or develop specific programs; use structured approach
- Develop and implement strategies to educate the current public health workforce that are tailored to the various segments of the public health work force