ASTHO'S Genetics Program

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Who is ASTHO?

- The Association of State and Territorial Health Officials (ASTHO) is the national non-profit organization representing the state and territorial public health agencies of the United States, the U.S. Territories, and the District of Columbia. ASTHO's members, the chief health officials of these jurisdictions, are dedicated to formulating and influencing sound public health policy, and to assuring excellence in state-based public health practice.

Program Mission

- Assist states integrate genetics into public health practice as appropriate, through raising awareness, sharing information, identifying gaps, convening leadership, and developing position statements that support members.

History of ASTHO's Genetics Program

- 1998 CDC funds ASTHO's genetic program.
- 1999 ASTHO's Genetics and Public Health Workgroup is formed and work begins on the framework document.
- 1999 HRSA Funds ASTHO to work with states that have received genetics planning grants.
- 2000 ASTHO's Genetics Advisory Committee (GAC) is formed.
- 2001 GAC completes framework document and uses it as basis for ASTHO's Public Health Genetics Policy Statement.

History of ASTHO's Genetics Program

- 2001 Work on the Toolkit begins.
- 2002 ASTHO, HRSA, and NCSL sponsor Genetics Policy Forums.
- 2002 Focus groups and state site visits are conducted for the Genetics and Public Health Toolkit.
- 2002 GAC meets to identify mission and goals, set priorities, and develop action plan.
- 2002 Toolkit workgroup meets to solidify structure and contents of Toolkit, and develop rollout plan.

Genetics Advisory Committee

Mission: To provide guidance to state and local health leadership, including affiliates, on the integration of genomics into all areas of public health practice.

Genetics Advisory Committee

Goal areas:

- Policy
- Infrastructure
- Training/Workforce Development
- **Information Dissemination**
- **Leadership and Education**

Bolded items indicates priorities for the coming year.

Framework for Integrating Genetics into Public Health

Overview:

- Genetics will become a fundamental component of the policy and practice roles of public health agencies by 2010.
- Breakthroughs in human genetics provide great promise for improving the health of the public, but there are significant policy implications and resource needs.

Framework for Integrating Genetics into Public Health

Overview:

- Genetics will offer many opportunities for public and private collaboration, but state health agencies will bear the ultimate responsibility for ensuring that genetic information is integrated into the basic scientific and technical knowledge of public health appropriately.

Framework for Integrating Genetics into Public Health

Core Functions—Assessment

Surveillance of genetic information is needed to determine[1]:

- The population frequency of genetic variants that predispose people to specific diseases, both common and rare;
- The population frequency of morbidity and mortality associated with such diseases; and
- The prevalence and effects of environmental factors known to interact with given genotypes in producing disease.

1. Khoury, M., Burke, W., and Thomson, E. (Eds.) *Genetics and Public Health in the 21st Century*. New York: Oxford University Press, 2000.

Framework for Integrating Genetics into Public Health

Core Functions—Assessment, cont'd

Establishing criteria for genetic testing recommendations may involve reassessing data using additional vital statistics or other factors. Other factors include the:

- availability of quality genetics resources in the community
- appropriateness of genetics technologies offered to the community
- accessibility of clinical and genetics services
- costs and benefits of using genetics technology
- community's knowledge of the use of genetics to improve health

Framework for Integrating Genetics into Public Health

Core Functions—Policy Development

- Health agency policies underlie priorities for a public health response to identified problems, barriers, and needs. Each of these issues will need to be considered in the context of genetic screening, diagnosis, treatment, and disease prevention.
- Specific policy issues state health agencies may be asked to provide input on include discrimination issues, population screening, privacy and confidentiality, and storage and use of genetic samples.

Framework for Integrating Genetics into Public Health

Core Functions—Assurance

- State health agencies provide ongoing evaluation of the effectiveness, accessibility, and quality of health services. The impact of genetic information on the public's health and genetic tests and services will need to be incorporated into this function.
- Health agencies also may provide the necessary evaluation of health outcomes for genetics services to determine the effectiveness of these services in improving health.

Genomics and Public Health Toolkit

Purpose:

- To improve the genomics capacity in state and local health agencies by assisting them integrate genomics into public health practice and policy.

Toolkit Workgroup:

- CSTE, APHL, AMCHP, NCSL, NACCHO, CSGC, CDD, CDC, HRSA

Status:

- Needs assessment, including Focus Groups and Site Visits, completed in first half of 2002.
- In-person meetings convened in August, 2002 to clarify Toolkit structure and content.

Genomics Toolkit

Target Audience

- State Health Officials
- Directors of program areas such as Chronic Disease, Health Promotion, Maternal and Child Health, Environmental Health, Laboratory, etc.
- Entire public health workforce

Genomics Toolkit

Concept: Combination of “how-to” instruction set and tools, with hard-copy and Web-based components.

Theme: “Genomics is a marathon, not a sprint.”

Outline of Contents:

- Introduction and Purpose of Toolkit
- Why is Genomics Important to Public Health?
- What is Genomics?
- How Does Genomics Impact Public Health?
- How Do I Start?

Genomics Toolkit

How Do I Start?

- Assessment of Internal and External Resources
- Identifying Key Stakeholders
- Convening the Committee(s)
- “Genomics 101”
- Needs Assessment
- Identify Gaps and Set Priorities
- What’s Next?
- Other Resources

Genomics Toolkit

Assessment of Internal and External Resources:

- Checklist of Areas to be Assessed:
  - Review of State Public Health Plan
  - Review of Policies and Programs
  - Form to help users identify how genetics relates to Healthy People 2010 objectives

Genomics Toolkit

Identifying Key Stakeholders:

- Value/role and advantages/disadvantages of internal and external committees
- Incentives to participate
- Size of committee
- Committee structure
- State regulations regarding committee formation
- List of possible organizations to be represented

Genomics Toolkit

Convening the Committee(s):

- How to run effective meetings
- Example invitation letters
- Staff support and resource needs
- Estimated costs
- Information on ASTHO's affiliates
- Group naming exercises
- Example agendas
- Guidance on committee structure, selecting leadership, & bylaws

Genomics Toolkit

“Genomics 101”

CDC via the Centers for Genomics and Public Health is creating a “Genomics 101” course for public health professionals, an “existing tool” which will be included in the toolkit. This will include:

- Principles of public health
- CDC’s Genomics Competencies
- One-page case studies and CD-ROM on various topics, e.g., genomics and asthma, environmental health
- Self-assessment component

Genomics Toolkit

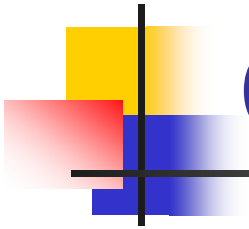
Needs Assessment:

- Areas to be addressed:
  - Community needs and education
  - Policies
  - Programs
  - Knowledge/expertise and available training
  - Surveillance
  - Technology capacity and data infrastructure
  - EPI-analysis plans
  - Availability of clinical services/providers
  - Funding sources
  - Information sharing resources
  - Staff capacity
  - Leadership involvement and commitment

Genomics Toolkit

Identifying Gaps and Setting Priorities:

- Mission Statement
- Vision Statement
- Goal Setting
- Objectives
- Work Plan
- Evaluation
- Timeline



Genomics Toolkit

Other Resources:

- Presentations on genomics
- List of key Web links
- Annotated list of resources

Genomics Toolkit Next Steps

Rollout Plan

- Marketing will be multi-step process
  - **Review**
    - Genetics Advisory Committee
    - Affiliates
    - Others
  - **Focus Groups**
    - Telephone
    - Possible in-person group
  - **Dissemination**
    - May 31, 2003

ASTHO’s Genetics Program Web site:

http://www.astho.org/?template=genetics.html