

Input on Genomics in Minnesota

Focus Groups with Key People

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Focus Group Overview

- Purpose for study: Obtain input from stake holders to shape program planning and activities
- Focus groups held in May 2004
- 23 participants from public health practice, academia, clinical practice, ethnic communities, general public
- 4-6 individuals per one hour phone focus group
- Focus groups led by Dr. Richard Krueger, University of Minnesota

Discussion Questions

- What issues are important related to genomics?
- What are your concerns related to genomics?
- What role should MDH play related to genomics?
- Do you have a preference for a format for gathering stakeholders?

What Issues Are Important?

10 Issues Discussed and Ranked

Ranking Genomics Issues by Focus Group Participants (N=21)	Mean Score
1. Ethical, Legal & Social Implications (ELSI)	4.8
2. Public Policy Issues	4.3
3. Health Ed / Promotion, Disease Prevention	4.0
4. Genomics Education / Capacity Building	3.8
5. Genomics and Health Disparities	3.7
6. Genomics and Public Health Research	3.7
7. Genomics in PH Sciences and Data Collection	3.6
8. PH Systems in Genomics Capacity & Services	3.6
9. Genetic Testing in Public Health	3.2
10. Emerging & Establishing Genomics Technologies in Practice	3.1

Ethical, Legal and Social Issues (ELSI) and Public Policy

- How genomics will influence health disparities
- How resources will be allocated to genomics vs. other health issues
- How individual privacy be weighed against the collective good
- Whether adequate rules / policies / procedures are in place to address ethical, legal and social issues

Education on Genomics is Needed

- Genomics knowledge is insufficient for application or meaningful discussion
- Misinformation will inform policy
- Educational approach to encourage inquisitiveness, not fear
- Respect for different value systems
- Discusses ELSI without being alarmist

What Are Your Concerns Related To Genomics?

Education

- Decision-makers do not have the information needed to make enlightened decisions
- Practitioners do not adequately understand or know how to use genetic/genomic information
- Concerns that educating people about genomics will be difficult due to:
 - 1) the complexity of the science
 - 2) different and conflicting belief and value systems.

Resource Allocation and Access to Services

- How will / should resources be allocated?
- How will the uninsured or underinsured access services?

Privacy Concerns

- How will privacy issues be managed?
 - Weighing the needs of the one and the many
 - Who decides what is best?

What Do Practitioners Need to Know About Genomics?

The Basics

- What is genomics?
- What can / can't we do with genomics?
- What are the benefits / risks of genomics?
- What is the difference between genetic determinism vs. genetic influence?
- What are the modifiable risk factors?
- What role does environment play?

Genomics in Public Health

- Why is genomics important to public health?
- How will MDH's efforts in genomics improve the health of Minnesotans?
- Why should State put money into genomics when budgets are tight?
- How can chronic diseases be improved with genomics?

Ethical, Legal and Social Issues (ELSI)

- What are the ELSI of genomics?
- What processes, procedures, rules or regulations are needed and adequate to address ELSI?
- Who pays for screening and testing for people without insurance or resources?

Updates

- Advances in genomics and their implications

High quality education, information, coaching, and materials for practitioners

- Consistent training and useful materials
 - Materials that are adaptable to different cultures
- Guidance on integrating genomics into programs
- Coaching to respond to comments or criticism in different settings
 - How to focus on facts, be respectful of different beliefs, avoid religious or value debates
 - How to convey complex information in a useful way

What Should MDH Do?

Engage and Educate Multiple Audiences

- The public
- Public health practitioners
- Healthcare providers
- Legislators

Support Integration into Practice

- Focus on public health practice
 - Education / information
 - Coaching
 - Materials
 - Tools for practical application
 - Materials to share with relevant audiences

Collaborate and Partner to Maximize Potential of Genomics

- MDH needs to build strong collaborative relationships with partners
 - Academia
 - Local public health
 - Medical associations
 - Health Plans
 - Others

Store Genomic Data Securely

- Explain to public why genomic data collection is necessary
- Anticipate associated ELSI
- Have systems that protect privacy but also allow appropriate public health research
- Identify experts to design safeguards and guide legislators
- Advocate for issues that are important for the public's health

Advocate for Services

- MDH needs to advocate for genomics services for the public's health
 - Needed tests for public health
 - Funds for genetic services

Summary:

- ELSI and public policy are of greatest interest and concern
- Data privacy and security are important
- Primary role for MDH is engagement and education of many audiences
- Support genomics integration into public health practice through coaching and accessing tools
- Public health practitioners are interested in learning:
 1. Facts about genomics that affect their practice
 2. Information to help navigate ELSI with colleagues and constituents.
 3. Updated information as needed to stay current