

Applying and Integrating Public Health Genomics Into Public Health Practice

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PHASE TWO: INTERPRETATION

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Poster #92 *Direct to Consumer Marketing of a Nutrigenetics Testing Product Minnesota Retail Settings*

Family History

Helps capture the effects of interactions between genes, environment and behaviors on disease risk

Family health history can be used to...

- assess risk for chronic diseases
- influence early disease detection
- target and prioritize prevention strategies

A Case of Avoidable Tragedy: *Real People, Real Situation, Real Opportunities**

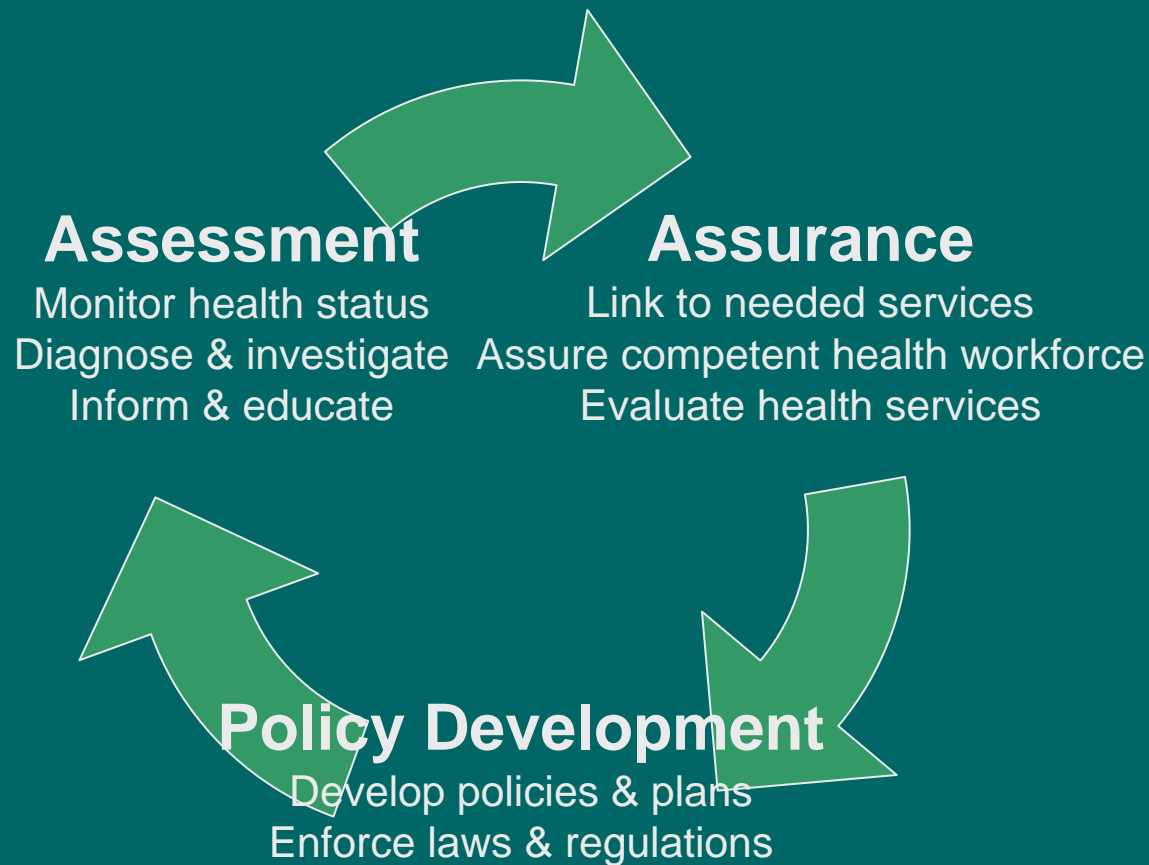
- ◆ 22 year old male presents with rectal bleeding, diagnosis of probable irritable bowel made by primary care provider
- ◆ Symptoms persist until 24 years old, when colonoscopy performed.
- ◆ Diagnosis of metastatic colon cancer at 24 years, surgery to remove most of colon
- ◆ Death at 27 years from metastatic colon cancer

* provided by Kris Peterson Oehlke, MS, CGC, Minnesota Genomics Coordinator

A Case of Avoidable Tragedy (Continued)

- ◆ Relevant Family History:
 - Brother had rectal bleeding at 29 years of age, and found to have large colon polyp (two years prior to patient's onset of symptoms)

Core Public Health Functions



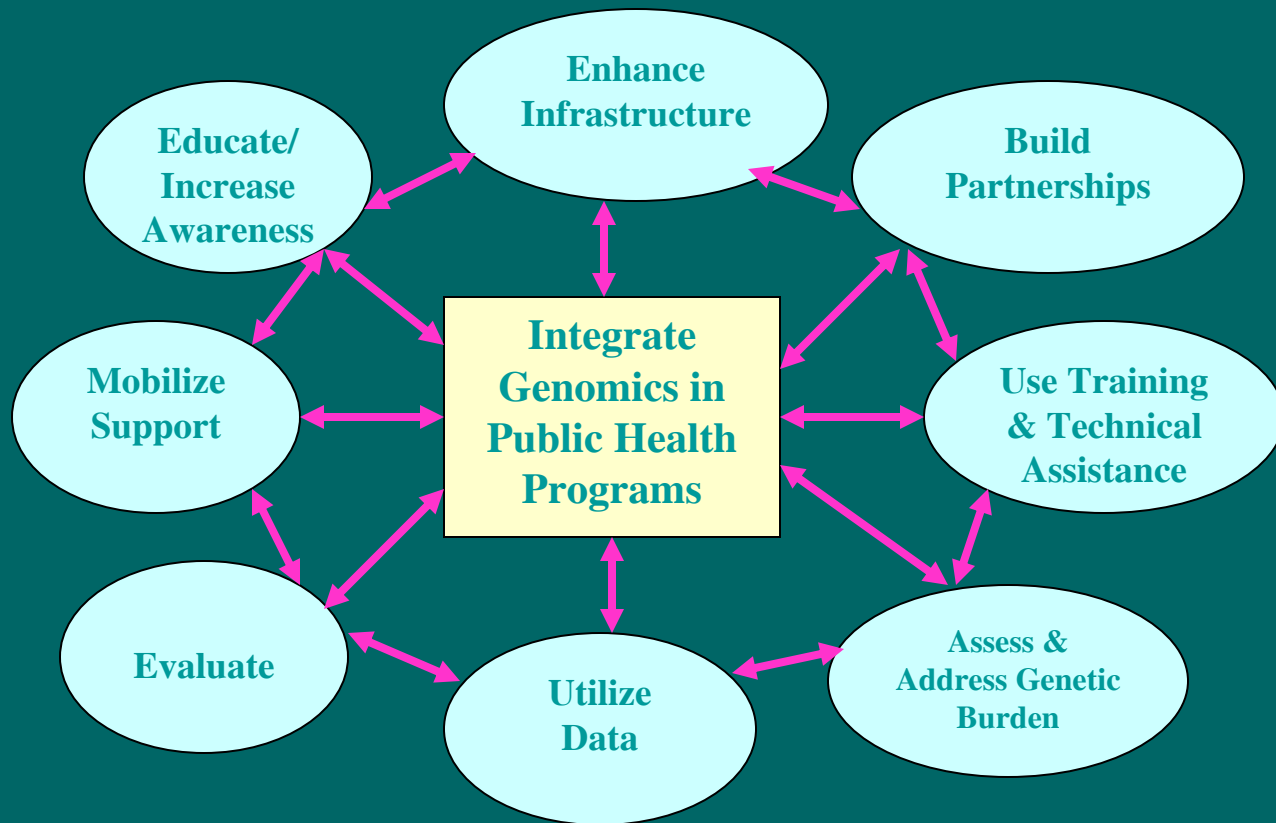
Is There a Role for Public Health Genomics in this Case?

- ◆ Assessment:
 - How often does colon cancer occur in 24 year olds? How often does death occur in 27 year olds?
 - Was the Family Health History documented in the chart?

- ◆ Policy:
 - Do professional standards exist for ordering colonoscopy before the standard of 50 years of age?
 - For families identified at risk, can their privacy be protected? Can they be protected against discrimination in insurance and at the workplace?

- ◆ Assurance:
 - Is the primary care provider, patient and family aware of the importance of Family Health History? aware of cancer genetic services in their area?
 - Can public health help to assure proper services for this patient/family?

Conceptual Model* of Genomics Integration



*adapted from CDC, Conceptual Model of Comprehensive Cancer Control Planning

Establishing State Public Health Genomics Infrastructure

- ◆ Michigan Department of Community Health
 - 2 Project Co-Directors
 - ◆ Chief Administrative Officer
 - ◆ State Genetics Coordinator
 - Genomics Coordinator
 - Genomics Educator
 - Genomics Epidemiologist
 - Gene-Environment Specialist
- ◆ Utah Department of Health
 - Genomics Coordinator
 - Genomics Educator
 - Genomics Epidemiologist
- ◆ Minnesota Department of Health
 - MD Internist
 - Genomics Coordinator
 - Educator
 - Webmaster
 - Student Intern
- ◆ Oregon Department of Human Services
 - Genetics Manager
 - Genetics Program Coordinator
 - Genomics Epidemiologist
 - Public Health Genetic Specialist

Raising Awareness of Public Health Genomics at the State Level

All four genomic state grantees:

- ◆ Internal Genomics Work Groups
- ◆ Websites
 - Michigan: <http://www.migeneticsconnection.org/>
 - Minnesota: <http://www.health.state.mn.us/divs/hpcd/genomics/>
 - Utah: <http://health.utah.gov/genomics/>
 - Oregon: <http://egov.oregon.gov/DHS/ph/genetics/index.shtml>
- ◆ Participate in a variety of State Chronic Disease Committees and State Plans to integrate genomics

Creating New and Analyzing Old: Using Data for Genomic Epidemiology

- ◆ Examples of Analyzing Old
 - Identify existing Family Health History questions within chronic disease programs and registries
 - ◆ Importance of quality of questions asked
 - ◆ Evaluation of family history elements
 - WISEWOMAN (see poster #76)
 - Utah Population Database
 - Evaluating Provider Practices
 - ◆ Chart Reviews
 - Cancer Registry (see poster #16)
 - Health Plans
 - Health Systems
 - ◆ Focus Groups

Possible Sites for Inherited Cancer Surveillance System

Appendix C

Type of Cancer	Usual age @ Dx	Ca Registry Data Age at Diagnosis <50 ^Δ				Ca Registry Data for Age at Death <50 ^Δ				Associated Hereditary Cancer Syndromes
		<20	20-29	30-39	40-49	<20	20-29	30-39	40-49	
Breast (based on cell type)	Postmenopausal (After age 50)	8	331	3459	1,163	0	44	555	1692	BRCA1* & BRCA2* Li-Fraumeni Syndrome* Cowden's Syndrome Peutz-Jeghers Syndrome* MEN1* Ataxia Telangiectasia*
Ovary (based on cell type)	Postmenopausal (After age 50)	102	242	569	1228	6	21	94	304	BRCA1* & BRCA2* HNPCC* Familial Ovarian LI-Fraumeni Syndrome* Basal Cell Nevus*
Colorectal	After age 65	30	186	872	2891	4	34	237	795	HNPCC* FAP* LI-Fraumeni Syndrome* Peutz-Jeghers Syndrome* BRCA1* & BRCA2* Bloom Syndrome*
Pancreas	60 - 80 Yrs	5	19	120	611	0	14	82	450	HNPCC* BRCA2* Hereditary Pancreatitis* Ataxia Telangiectasia* Peutz-Jeghers Syndrome* MEN1* FAMMM*
Type of Cancer	Usual age @ Dx	Ca Registry Data				Ca Registry Data for				Associated Hereditary

^Δ Data Source - Michigan Resident Cancer Incidence and Death Files, Michigan Department of Community Health, Vital Records and Health Data Development Section 1992 - 2001

* Genetic Testing is Available

Genetic Testing available only to those families in which a CDH1 mutation has been identified through research studies

4/1/04

Michigan Cancer Registry Chart Audit

- ◆ 853 charts reviewed from Dec 2003 to Oct 2004
- ◆ **82.5%** of charts documented the presence or absence of any family history of cancer
 - 89% were gender-specific in identifying the affected relative
 - 82% were site-specific in the relative's diagnosis
- ◆ Among charts with a documented family history of cancer:
 - 94.3% were missing information on the relative's age at diagnosis
 - 99.5% were missing information on the relative's date of diagnosis

Creating New Data for Genomic Epidemiology

- ◆ State BRFSS questions on genomics (poster #17)
 - Technical assistance provided by Centers for Genomics and Public Health and CDC National Office of Public Health Genomics
 - ◆ Questions Compiled by University Of Washington Center for Genomics and Public Health website at <http://depts.washington.edu/cgph/centergoals/subhead.php?fid=54?fid=52>
- ◆ Creating and Adding Questions to Community-Based Programs
 - Diabetes, Cardiovascular and Renal Disease Family History Questions
 - ◆ Beauty Salon Initiatives (Healthy Hair, Dodge the Punch)
 - ◆ Head Start (new National Kidney Foundation of Michigan project)
 - Asthma Genomics
 - ◆ Healthy Homes University
 - Assistance provided by University Of Washington Center for Genomics

2005 Michigan BRFSS

- ◆ 37% of Michigan adults actively collect health information for purpose of family health history
- ◆ 66.4% of Michigan adults thought family health history was very important to personal health
- ◆ Focus on Family History of Colon Cancer
 - 7% of Michigan adults had immediate family member diagnosed with colorectal cancer
 - ◆ 37.4% thought their chances of getting colorectal cancer was high or very high (compared to 4.6% without the family history)
 - ◆ 55.6% reported making some lifestyle changes to try and prevent colorectal cancer

Important Message For Those with Family Health History of Colorectal Cancer

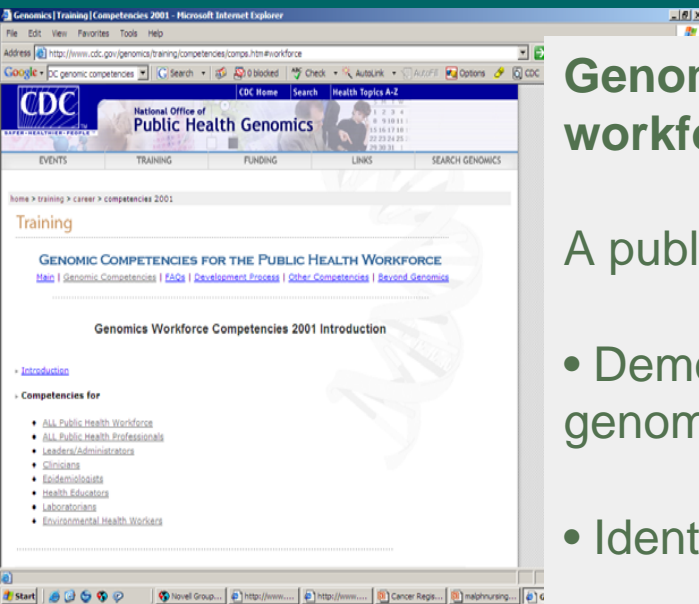
◆ **Screening for Individuals With a Family History**

- Individuals with a first-degree relative (brother, sister, parent, child) or two or more second degree relatives (grandparents, uncles, aunts, nephews, nieces, half-brothers, half-sisters) with a history of colorectal cancer should be screened with colonoscopy when they are 40 years of age or ten years younger than their relative was at the time of diagnosis, whichever is younger*

* National Comprehensive Cancer Network

Building a Knowledge Base: Increasing Genomic Literacy

CDC Genomics Competencies



Genomic competencies for the public health workforce at any level in any program

A public health worker is able to:

- Demonstrate basic knowledge of the role that genomics plays in the development of disease
- Identify the limits of his/her genomic expertise
- Make appropriate referrals to those with more genomic expertise

Building a Knowledge Base

- **An Introduction to Genomics for Public Health Professionals**
 - ◆ Presented at Michigan Department of Community Health (MDCH) DNA Day Open House in 2003
 - ◆ Created by CDC, Michigan Center for Genomics and Public Health (MCGPH) and MDCH
 - ◆ Available online since 2004 at <http://www.cdc.gov/genomics/training/GPHP/default.htm>
- **Six Weeks to Genomics Awareness**
 - ◆ Six Sessions piloted at MDCH in 2003
 - ◆ 70 MDCH staff attended one or more sessions
 - ◆ Created by MCGPH and MDCH
 - ◆ Available online since 2004 at <http://www.cdc.gov/genomics/training/sixwks.htm>
- **Cancer Genomics for Public Health** (see E02)
 - ◆ MDCH Cancer section, MDCH Genomics and MCGPH created six modules on cancer genomics to educate the entire MDCH cancer section in the spring and summer of 2005
- **Diabetes ED1 Module** (see poster #27)
 - ◆ MDCH and Michigan Diabetes Outreach Network (MDONs) created CEU approved module, *Genomics, Family History, and Diabetes*

PREVENTING CHRONIC DISEASE PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY

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TOOLS AND TECHNIQUES

Genomics and Public Health: Development of Web-based Training Tools for Increasing Genomic Awareness

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Introduction

As genomics research continues to expand and identify potential applications for disease prevention, departments of health as well as public health practitioners will need to become increasingly aware of genomics as a public health tool. In 2001, the Centers for Disease Control and Prevention (CDC) produced a set of competencies to help integrate genomics into public health practice and training (1,2). Genomic competencies were developed for all members of the public health workforce, along with specific competencies for each functional area of public health: administration, clinical, epidemiology, health education, laboratory, and environmental health (3). These competencies are described in detail and are available from www.cdc.gov/genomics/training/competencies/comp.htm (4). Based on these competencies, a public health worker in any program at any level should be able to demonstrate a basic knowledge of the role genomics plays in disease development. This knowledge is essential for public health practitioners to integrate genomics tools into public health practice and to educate the public.

Abstract

In 2001, the Centers for Disease Control and Prevention funded three Centers for Genomics and Public Health to develop training tools for increasing genomic awareness. Over the past three years, the centers, working together with the Centers for Disease Control and Prevention's Office of Genomics and Disease Prevention, have developed tools to increase awareness of the impact genomics will have on public health practice, to provide a foundation for understanding basic genomic advances, and to translate the relevance of that information to public health practitioners' own work. These training tools seek to communicate genomic advances and their potential for integration into public health practice. This paper highlights two of these training tools: 1) *Genomics for Public Health Practitioners: The Practical Application of Genomics in Public Health Practice*, a Web-based introduction to genomics, and 2) *Six Weeks to Genomic Awareness*, an in-depth training module on public health genomics. This paper focuses on the processes and collaborative efforts by which these live presentations were developed and delivered as Web-based training sessions.

Currently, the public's understanding of genomics is derived primarily from the media, and the scientific information is often incomplete and/or inaccurate (5,6). As acknowledged in the 2002 Institute of Medicine report, *Who Will Keep the Public Healthy?*, "because few in the current public health workforce have the level of understanding of genomics that is required today, major continuing educational efforts must be undertaken to ready practicing public health professionals to use genomics effectively" (7).

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions. Use of trade names is for identification only and does not imply endorsement by any of the above-named entities.

www.cdc.gov/pod/issn/2005/apr04_0133.htm • Centers for Disease Control and Prevention 1

Building a Knowledge Base

◆ Professional Conferences

- *Asthma's future in Utah: How Will Genomics Play a Role (2006)*
- *Diet & DNA: The Promise and Challenges of Nutrigenomics (Michigan 2005 and 2006)*
- *Looking Back...Thinking Ahead: Applications of Family Health History in Primary Care (Michigan 2006)*
- *Cancer Genetics Moving Beyond the Basics (Minnesota 2006)*
- *Public Health Responses to Diverse Community Needs: From the Human Genome Through Health Disparities to Public Health (Minnesota 2006)*

◆ Public

- Family Health History Toolkit
 - ◆ Utah (see poster #80)
- Media
 - ◆ Press Releases
 - ◆ Television segments
- Libraries
 - ◆ *Family History and Your Health* newsletters
- Secondary Education Teachers
 - ◆ *Genetics to Genomics* (see C01)
- Genealogy Groups
 - ◆ Utah and Michigan
- Native American Tribal Colleges
 - ◆ Michigan

Genomics Policy Development: Addressing Ethical, Legal, Social Issues (ELSI)

- ◆ *Oregon Genetic Privacy Law*
 - Cross-disciplinary workgroup since 1995; Advisory Committee since 1999
 - Passed in 1995; first state with comprehensive law protecting genetic privacy
 - Multiple revisions to law to address issues of terminology, IRB, tissue banks, anonymous and coded research
- ◆ *Report on Genetic Information and How It is Currently Treated under Minnesota Law*
 - Legislature asked the Commissioner of Administration to assess how genetic information is currently protected
 - Report completed in January 2006
 - Eleven recommendations covering issues such as privacy, access, disclosure
- ◆ *Michigan Genetic Privacy Laws*
 - Michigan Informed Consent for Genetic Testing Law passed in 2000
 - ◆ Requires for predictive and pre-symptomatic testing
 - Protection against genetic discrimination in workplace and insurance

Additional Website Resources

- ◆ Centers for Disease Control and Prevention:
National Office of Public Health Genomics
<http://www.cdc.gov/genomics/default.htm>
- ◆ US Surgeon General's Family History Initiative
<http://www.hhs.gov/familyhistory/>
- ◆ National Human Genome Research Institute
<http://genome.gov>
- ◆ US Department of Energy Human Genome Project
http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml

In Conclusion...

- ◆ Genomics:
 - Is already being incorporated into public health practice, and can be applied even further to existing infrastructure as new advances occur
 - Should be part of all strategic plans to promote health and prevent disease
 - Is relevant to most clinical and public health professionals



Recently discovered "DNA nebula"
80 light years away