Health Promotion through Genetic Literacy

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CHEER Seminar, Improving Genetic Health Literacy Using Community-Based Approaches, February 11, 2011
Challenges to the Implementation of Genomic Medicine

Closing the Gaps

Translation Gap

Knowledge Gap
Practical Applications of Genomic Medicine

Newborn Screening
- The earliest genetic test

Pharmacotherapy
- The right drug, the right dose, for the right person

Reproductive Counseling
- The option of carrier testing

Disease Risk Management
- Strategies for prevention
GAPPNet: A collaborative initiative to streamline use of genomics in clinical & public health practice

The Genomic Applications in Practice and Prevention Network

Muin J. Khoury, MD, PhD1, W. Gregory Feero, MD, PhD2, Michele Reyes, PhD3, Toby Citrin, JD3, Andrew Freedman, PhD4, Debra Leonard, PhD5; and the GAPPNet Planning Group: Wylie Burke, MD, PhD6, Ralph Coates, PhD1, Robert Croyle, PhD3, Karen Edwards, PhD7, Sharon Kardia, PhD2, Colleen McBride, PhD2, Teri Manolio, MD, PhD2, Gurvaneet Randhawa, MD8, Rebekah Rasooly, MD9, Jeannette St. Pierre, MPH1, and Sharon Terry, MS10

Genetics in Medicine (2009) 7:488
http://www.cdc.gov/genomics/translation/GAPPNet/
Linking evidence to practice
In a credible and transparent way

- Evidence-based Recommendations
- Translation Programs
- Network of Stakeholder Groups
- Translation Research
- Knowledge Synthesis & Dissemination

Determining and sharing what we know and what we don’t know and How we know it

Integrate into clinical and public health practice thru education, policy surveillance & evaluation

Research to fill gaps and how to implement

Muin Khoury, CDC, Oct 2009
The Continuum of Translation Research in Genomic Medicine

- Association between BRCA mutations & breast cancer?
- Predictive value of BRCA testing in at-risk women?
- What is the uptake of testing in women meeting criteria?
- Barriers to testing?
- Does testing reduce incidence or improve outcomes?

Translate genomic knowledge and applications into public health and clinical practice programs to prevent disease and improve health

Genomics Translation Programs

Public Policy  Education  Surveillance
Heredity Project: Goals

- Develop resources to explain the role of genes in health & disease
- Allow community input to drive project content and direction
- Target education to actionable outcomes
- Align activities and objectives with national initiatives to realize the promise of genetics in health care & health promotion
Diffusion Theory: A Framework for the Communication of Novel Practices to End Users
Conceptual Model
Diffusion of Innovation

Critical elements: an innovation that is communicated over time within a social system

Level of knowledge: awareness, how-to, principles

Re-invention by community to optimize fit

Gap-narrowing strategies: build community capacity
Healthy Balance
Pilot Project on Diabetes Risk

Phase 1. Development of an educational intervention

- Developed image-based curriculum for communication of relatively complex information
- Delivered content to small groups to incorporate community feedback (n=92)
- Developed content-aligned questions for assessment of learning and project evaluation
Module 1: How genes move through families

Objectives:
- Be able to describe genes as instructions for the structure and function of the body
- Using a single gene trait as an example, be able to use the principle of segregation to track the segregation of alleles through a family
Module 2: What is a risk gene?

Objectives:
• Be able to apply the principle of segregation to track risk alleles through a pedigree
• Be able to associate risk alleles with relative risk as opposed to causation
Module 3: Healthy Balance risk model (Blue=genes, Green=environment, Yellow=lifestyle)

Objectives:
- Be able to recognize the three categories of risk that contribute to diabetes
- Be able to classify individual risk factors as components that either increase or decrease composite risk
Community-Based Health Education

- PowerPoint presentations in small group settings

- Embedded questions and use of audience response system (clickers)
  - Learning (pre-test; post-test)
  - Attitudes
  - Demographics
Healthy Balance
Pilot Project on Diabetes Risk

Phase 2. Validation Study

• Convenience sample drawn from five established community groups (n=111)
  ➢ 64% African-American
  ➢ 61% attended college
  ➢ 32% diabetic or pre-diabetic
  ➢ 46% positive family history for diabetes

• Validation study demonstrated
  ➢ Improved knowledge (p<0.0001 based on two-sided paired-data permutation test)
  ➢ Positive attitudes toward the presentation and its health-related content
Sample Question:
What are genes?

A. Factors that cause serious health problems in people who have them
B. The combination of factors that determines a person’s race
C. The body’s instructions
D. Mixture of proteins & other chemicals
E. Don’t know or no opinion

<table>
<thead>
<tr>
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<th>Correct</th>
<th>Incorrect</th>
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<tr>
<td>Pre-test</td>
<td>26 (23.4%)</td>
<td>85</td>
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<tr>
<td>Post-test</td>
<td>50 (45.0%)</td>
<td>61</td>
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The Heredity Project
The University of Tennessee Health Science Center
Summary Results: Pre-test/Post-test Comparison

- Each point is 1 participant (n=111)
- X-axis: Pre-test score
- Y-axis: Post-test score
- Data points in the upper left triangle show improved scores
Demographic Variables: Test Scores by Educational Attainment

- Pre-test (X-axis): all educational levels showed range of performance
  - Content appropriate for diverse audiences
- Post-test (Y-axis): test performance improved along with education level
  - Intervention was not effective at lowest educational level
“Gathering your family health history really is the first step towards personalized medicine.”

Francis S Collins, MD, PhD,
Family History & Common Diseases
A Dose-Response Relationship

- Distant vs. Close
- None vs. Many
- Old vs. Young
- No vs. Yes

Family Health History

- Captures genetic risk component plus environment
- Low cost & high acceptability
- Organizes clinically relevant information
- Promotes conversations about health in the family & community
- Enhances health & genetics knowledge for the individual & the family
- Highlights trends & patterns of disease for potential prevention or treatment
Family History in Clinical Practice

Gold standard for assessing genetic risk in medical genetics

Established use in primary care but not standardized
Process of Self-Reported Family Health History

1. Talk to family members about health
   - Parents
   - Brothers & Sisters
   - Children

2. Organize the information
   - Draw a Family Tree
   - Record Health Information

3. Share family health history information
   - Healthcare Provider
   - Family
Uses of Family Health History in Public Health Practice

Risk Assessment
- Identify & stratify
- Variety of tools in use
- Few validated

Tailored Interventions
- Early detection
- Prevention
- Family-level

Motivation
- Health-seeking behaviors
- Healthy lifestyles
- Patient-centered
Family History as a Genomic Tool

Need for development of standardized tools tied to outcomes

Adaptation to paradigm of evidence-based medicine

Evaluation within ACCE framework

- Analytic validity
- Clinical validity
- Clinical utility
- Ethical, legal, and social implications
My Family Health Portrait
Structured Data + Connectivity = **Interoperability**

My Family Health Portrait

- Structured Data
- Family Members
- Care Providers
- HealthVault Affiliates

- Save to...
- Partners
- Microsoft HealthVault

Feero, 2010
Community-Centered Family Health History Project

Collaboration involving diverse community partners to produce resources that increase communication about health within families

www.geneticalliance.org
Funded by MCHB/HRSA
Does It Run in the Family?

• 2 booklet set written on 8th-grade level
• Community-adapted
• Non-medical
Newborn Screening
• LeBonheur-based education project
• Dr Stacy Hines-Dowell

Community Health Enrichment
• Health science club collaborative
• HUD Neighborhood Networks

Primary Care Initiative
• Family health history tools in HRSA-funded Health Centers
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  – Sharon Terry

• Funded by NIH/NCRR

• Our community partners!