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Health Promotion through Genetic Literacy

Vicki M Park, PhD
UTHSC, Pediatrics & Preventive Medicine

CHEER Seminar, Improving Genetic Health Literacy Using Community-Based Approaches, February 11, 2011

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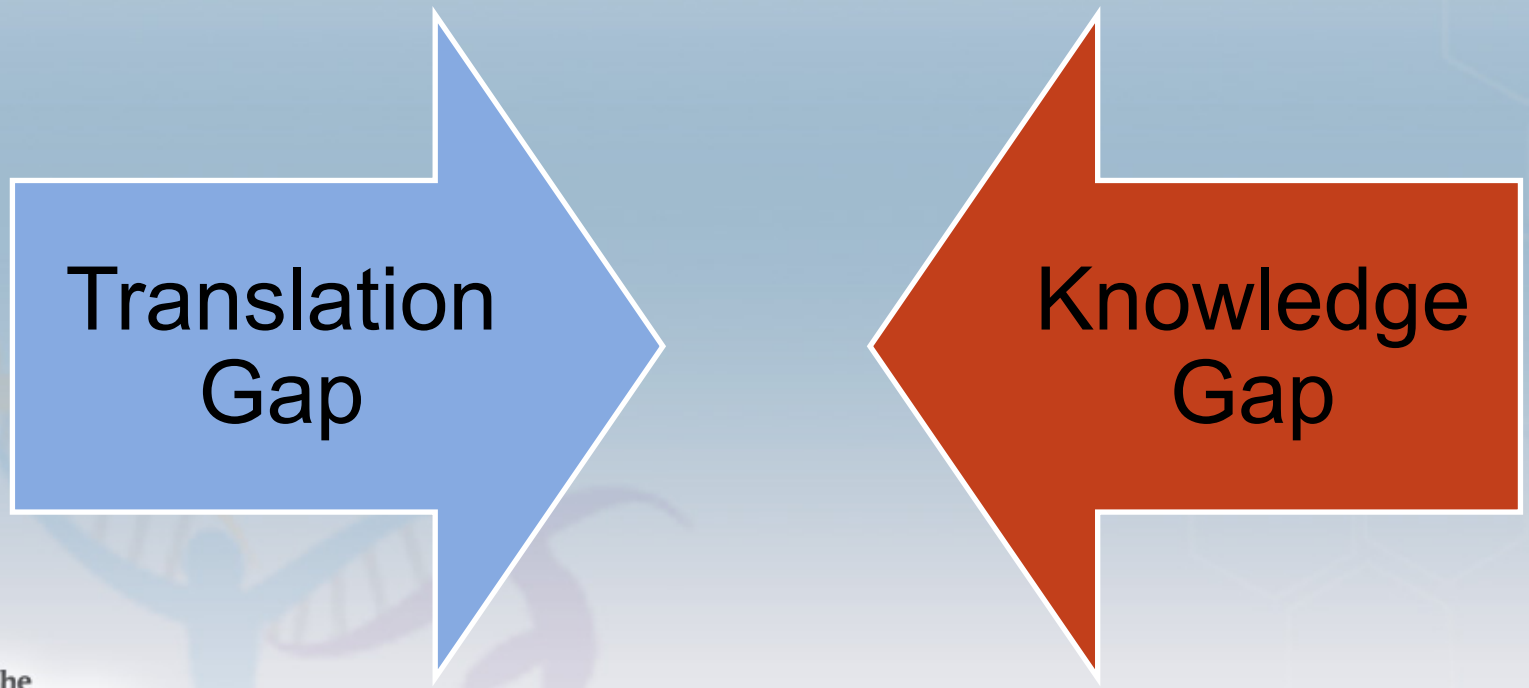
Challenges to the Implementation of Genomic Medicine

Closing the Gaps



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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

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Push & Pull Forces in Translation

Rapidly evolving technology	Consumer awareness & demand	Coverage & reimbursement
Marketing	Policy & oversight	Professional clinical practice guidelines
Differential access & disparities	Clinical practice liability issues	Industry incentives for R&D

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GAPPNet: A collaborative initiative to streamline use of genomics in clinical & public health practice

REVIEW

The Genomic Applications in Practice and Prevention Network

Muin J. Khoury, MD, PhD[1], W. Gregory Feero, MD, PhD[2], Michele Reyes, PhD[1], Toby Citrin, JD[3], Andrew Freedman, PhD[4], Debra Leonard, PhD[5]; and the GAPPNet Planning Group: Wylie Burke, MD, PhD[6], Ralph Coates, PhD[1], Robert Croyle, PhD[3], Karen Edwards, PhD[7], Sharon Kardia, PhD[2], Colleen McBride, PhD[2], Teri Manolio, MD, PhD[2], Gurvaneet Randhawa, MD[8], Rebekah Rasooly, MD[9], Jeannette St. Pierre, MPH[1], and Sharon Terry, MS[10]

Genetics in Medicine (2009) 7:488

http://www.cdc.gov/genomics/translation/GAPPNet/

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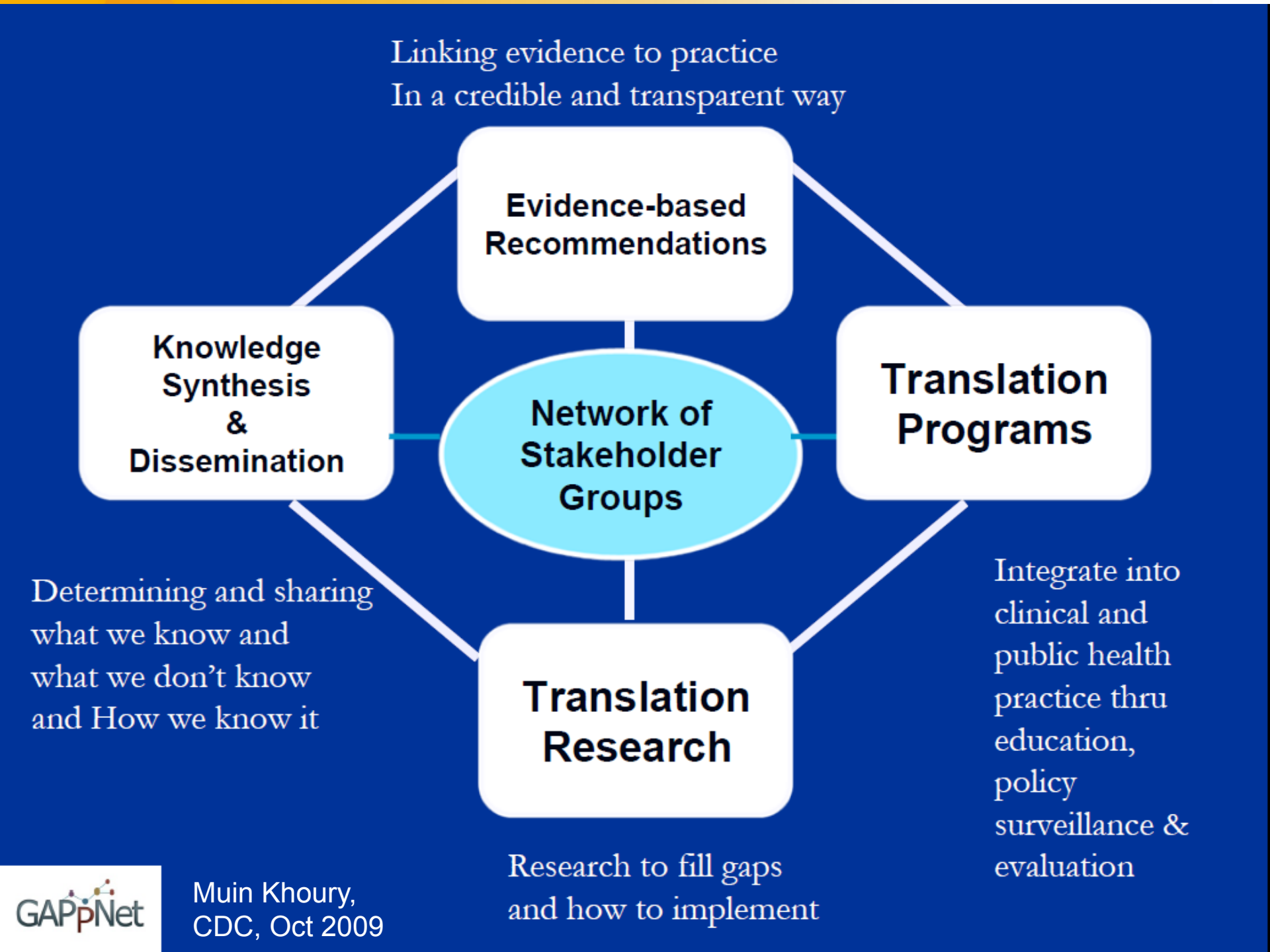

Linking evidence to practice
In a credible and transparent way
Evidence-based Recommendations
Knowledge Synthesis & Dissemination
Network of Stakeholder Groups
Translation Programs
Translation Research
Determining and sharing what we know and what we don't know and How we know it
Integrate into clinical and public health practice thru education, policy surveillance & evaluation
Research to fill gaps and how to implement
GAPPNet
Muin Khoury, CDC, Oct 2009

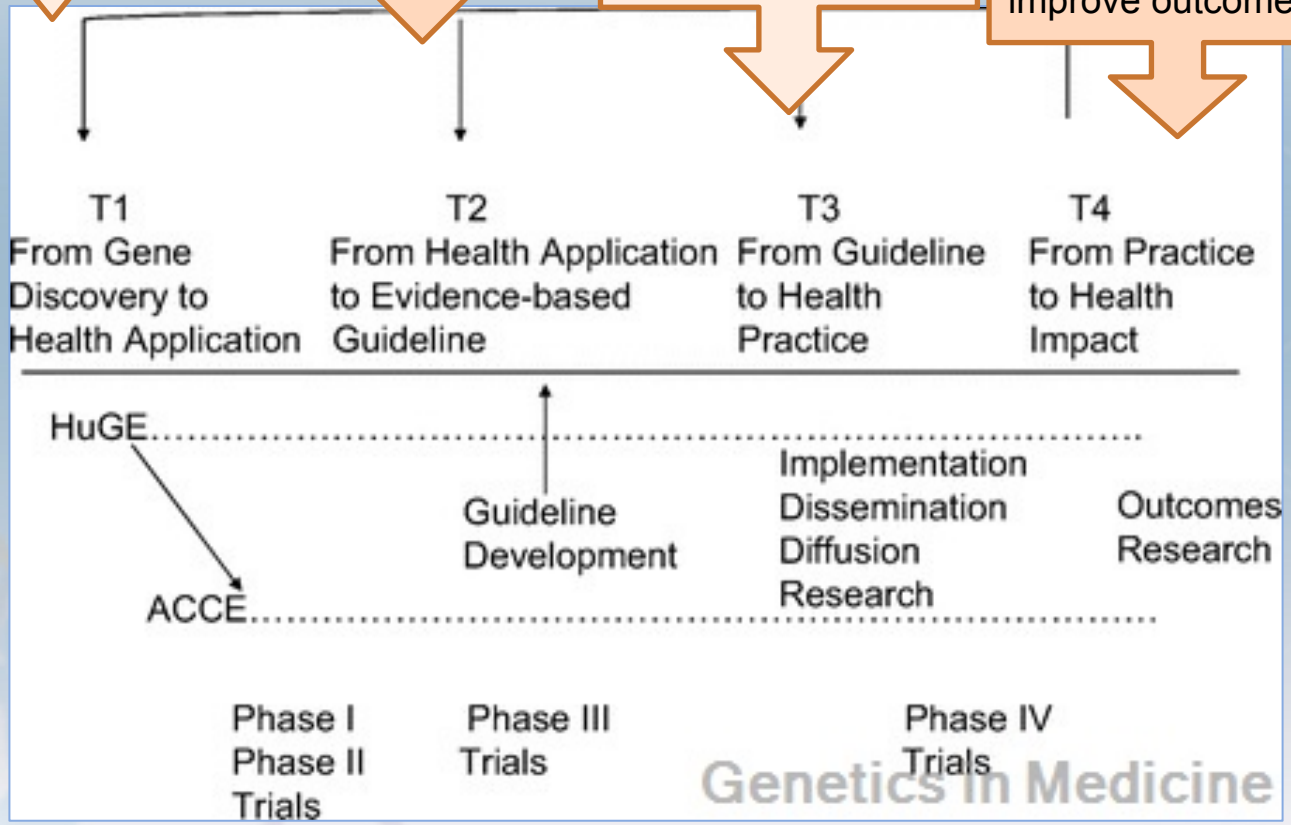
The Continuum of Translation Research in Genomic Medicine

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?



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Wolters Kluwer Health | Lippincott Williams & Wilkins

Khoury et al. Genetics in Medicine. 9 (10):665-674, October 2007.

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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

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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

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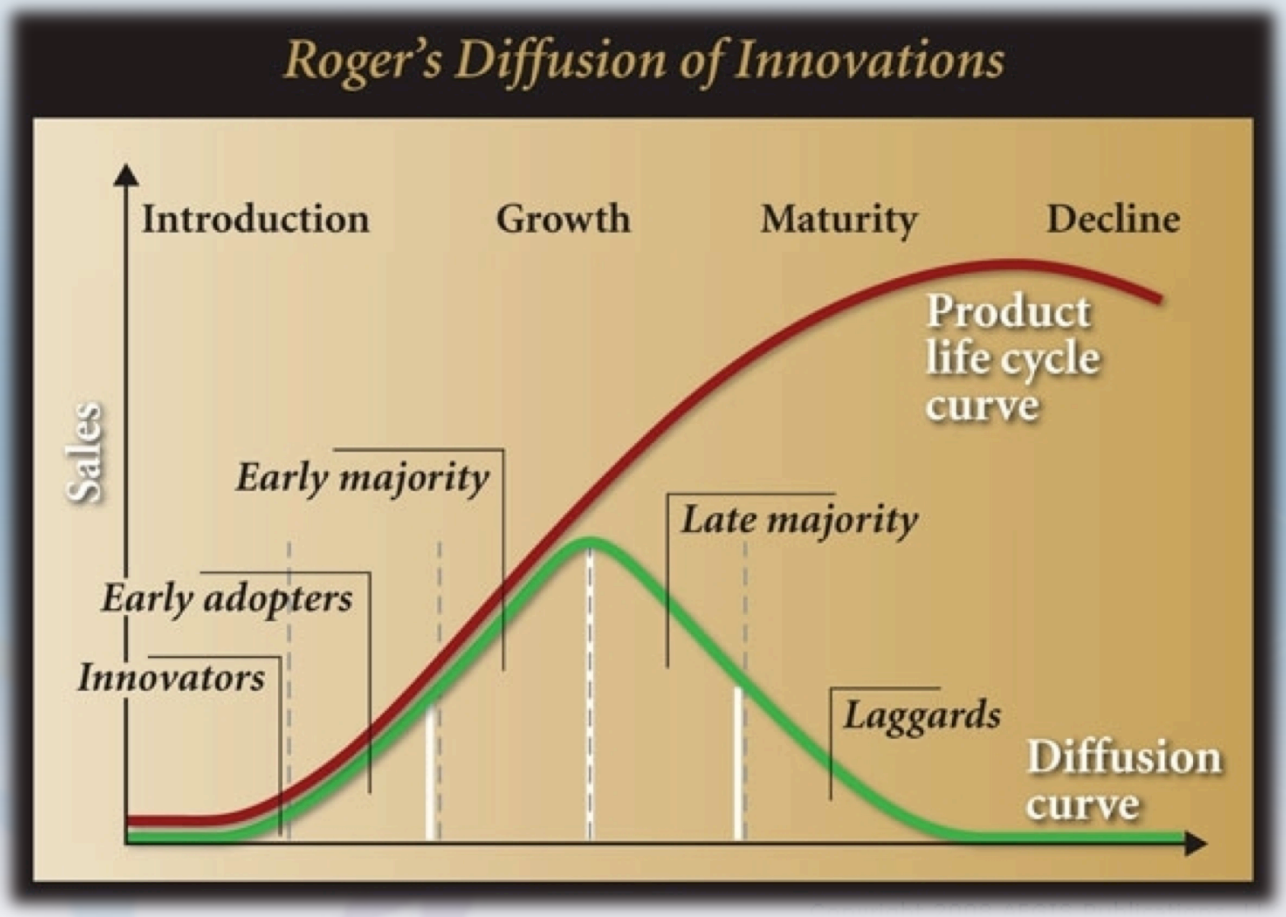
Diffusion Theory: A Framework for the Communication of Novel Practices to End Users



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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

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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

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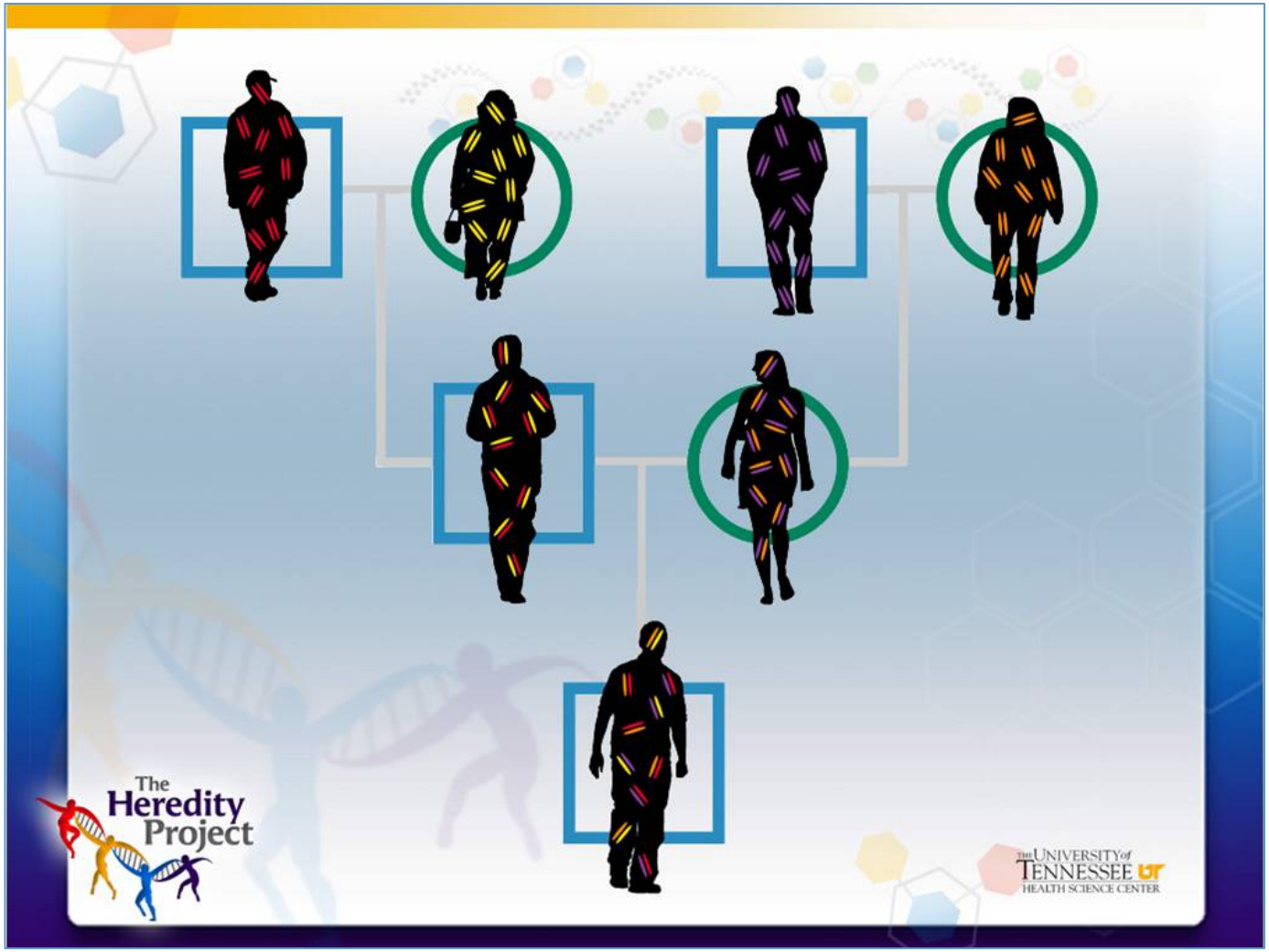
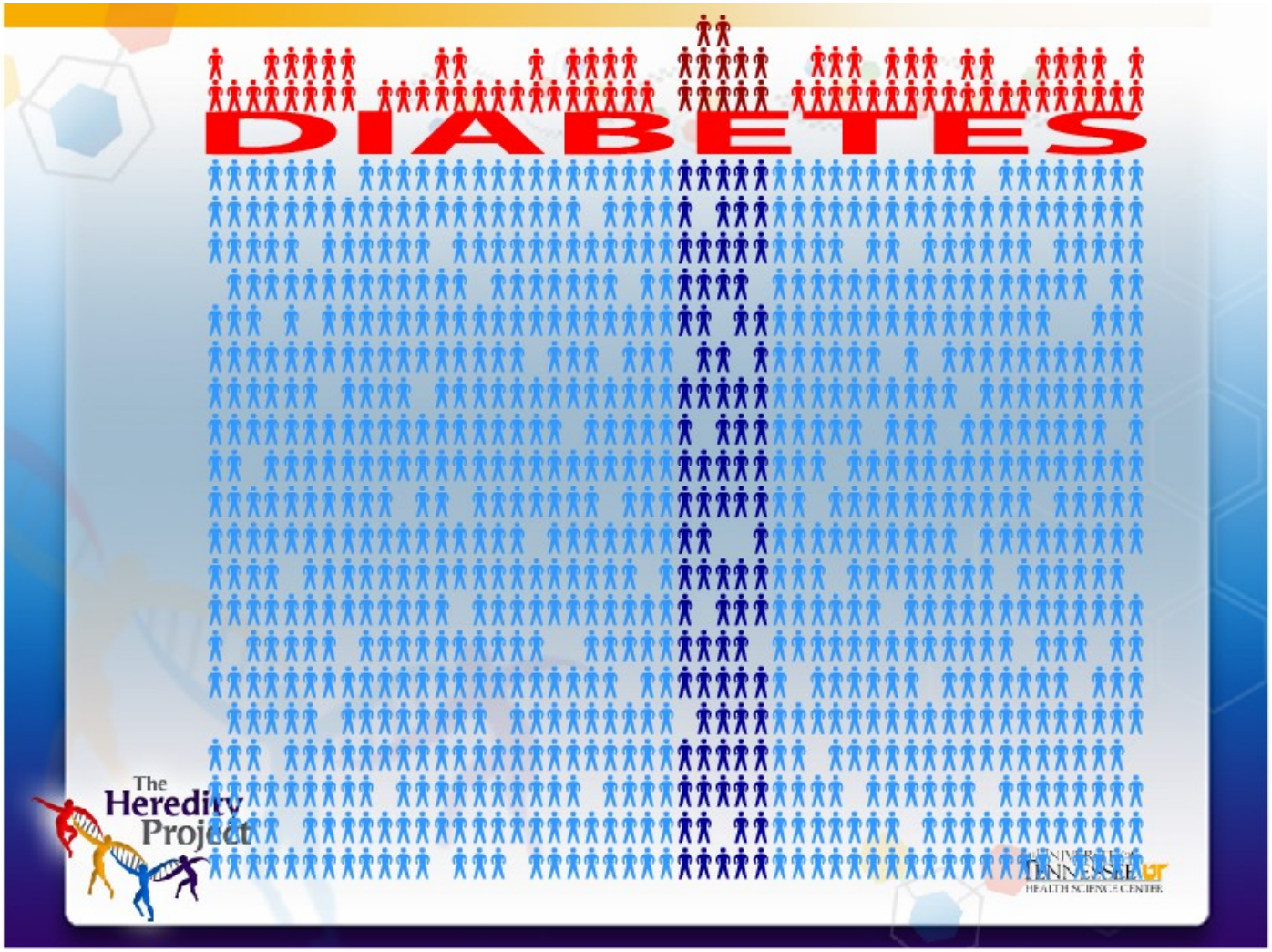


Module 1: How genes move through families

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



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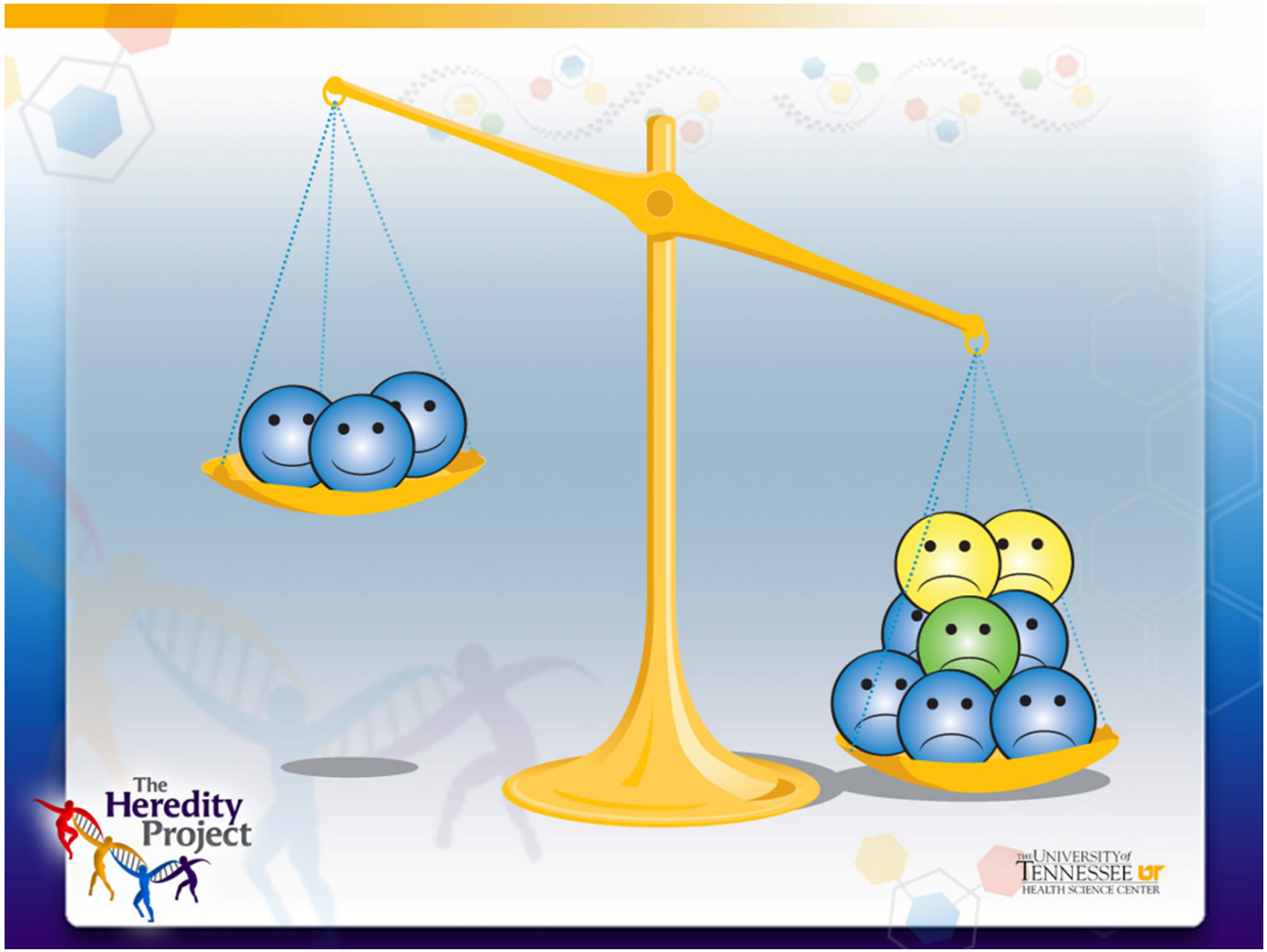
Module 2: What is a risk gene?

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

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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

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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

	Correct	Incorrect
Pre-test	26 (23.4%)	85
Post-test	50 (45.0%)	61

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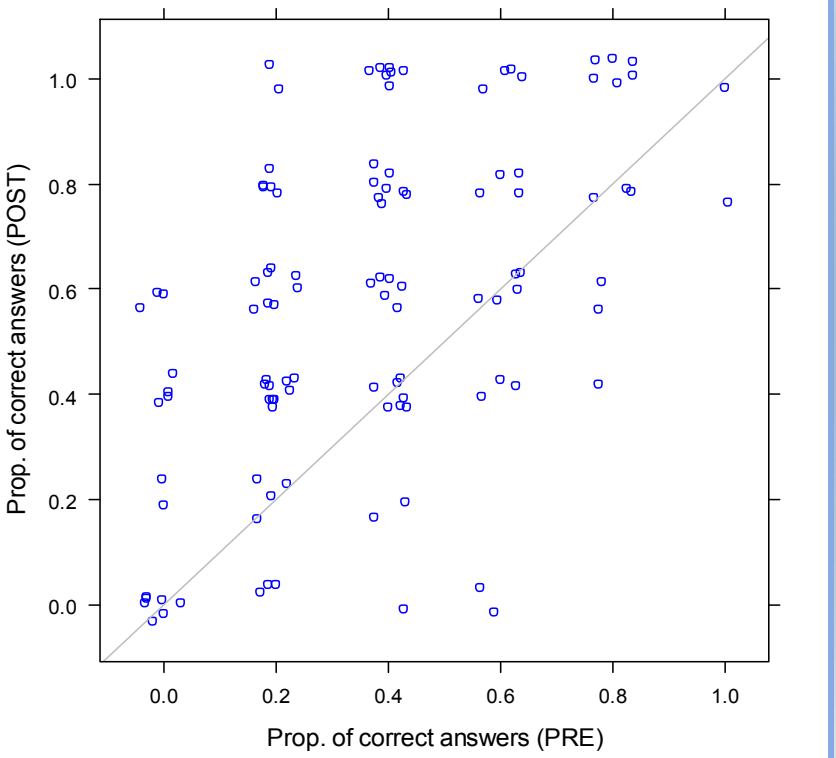
Summary Results: Pre-test/Post-test Comparison



- 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

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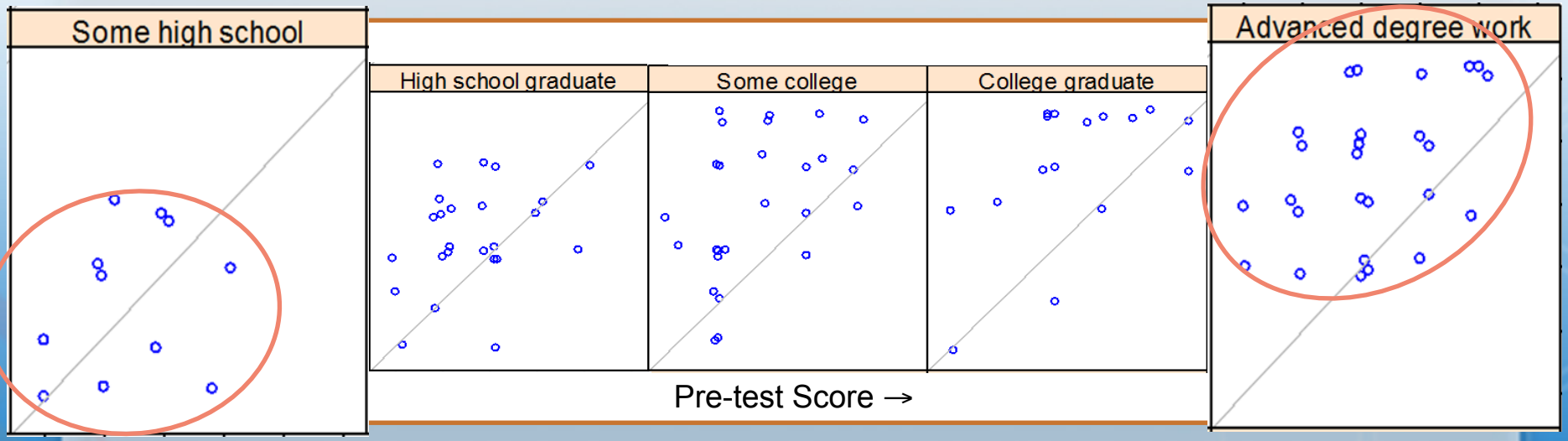
Demographic Variables:
Test Scores by Educational Attainment



- 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

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Family Health History

Clinical Practice

Genomic Tool

Public Health Practice

"Gathering your family health history really is the first step towards personalized medicine."

Francis S Collins, MD, PhD,

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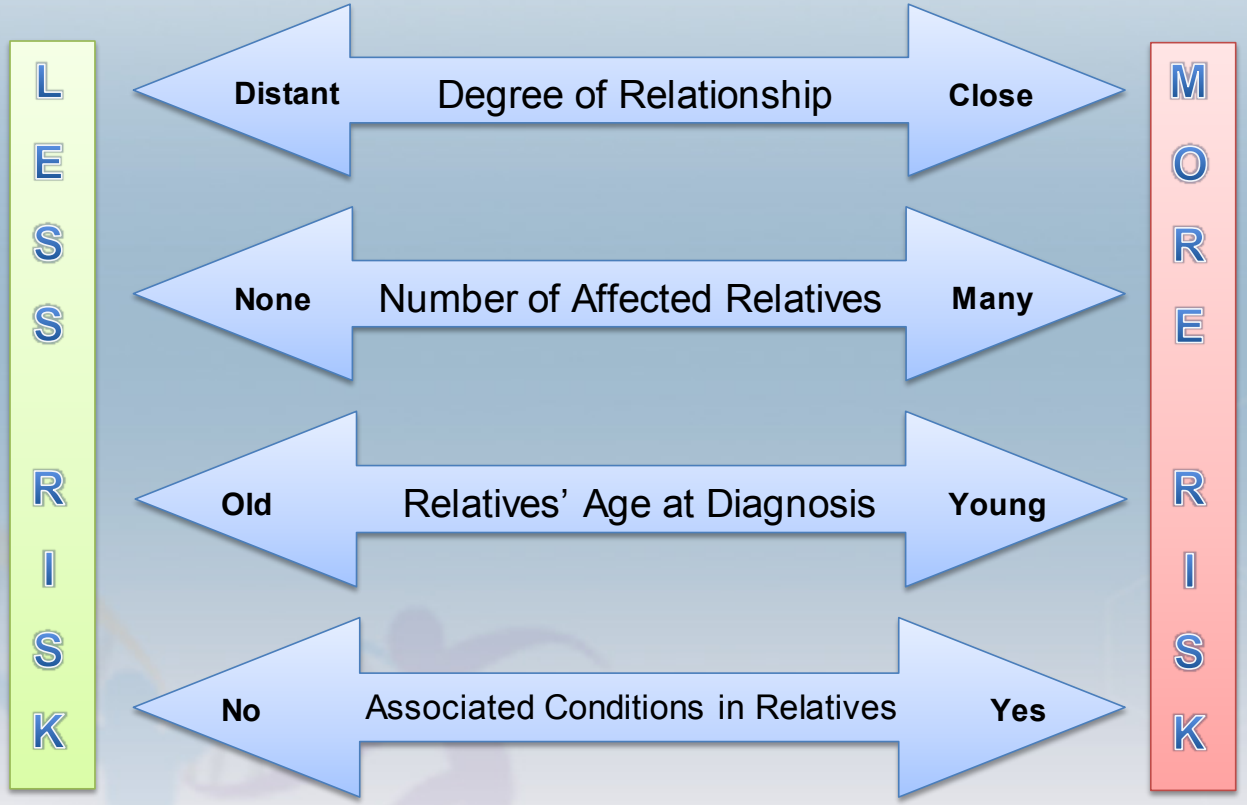
Family History & Common Diseases
A Dose-Response Relationship



From Valdez et al 2010. Annu Rev Public Health 31:69

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

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Family History in Clinical Practice

Gold standard for assessing genetic risk in medical genetics

Established use in primary care but not standardized

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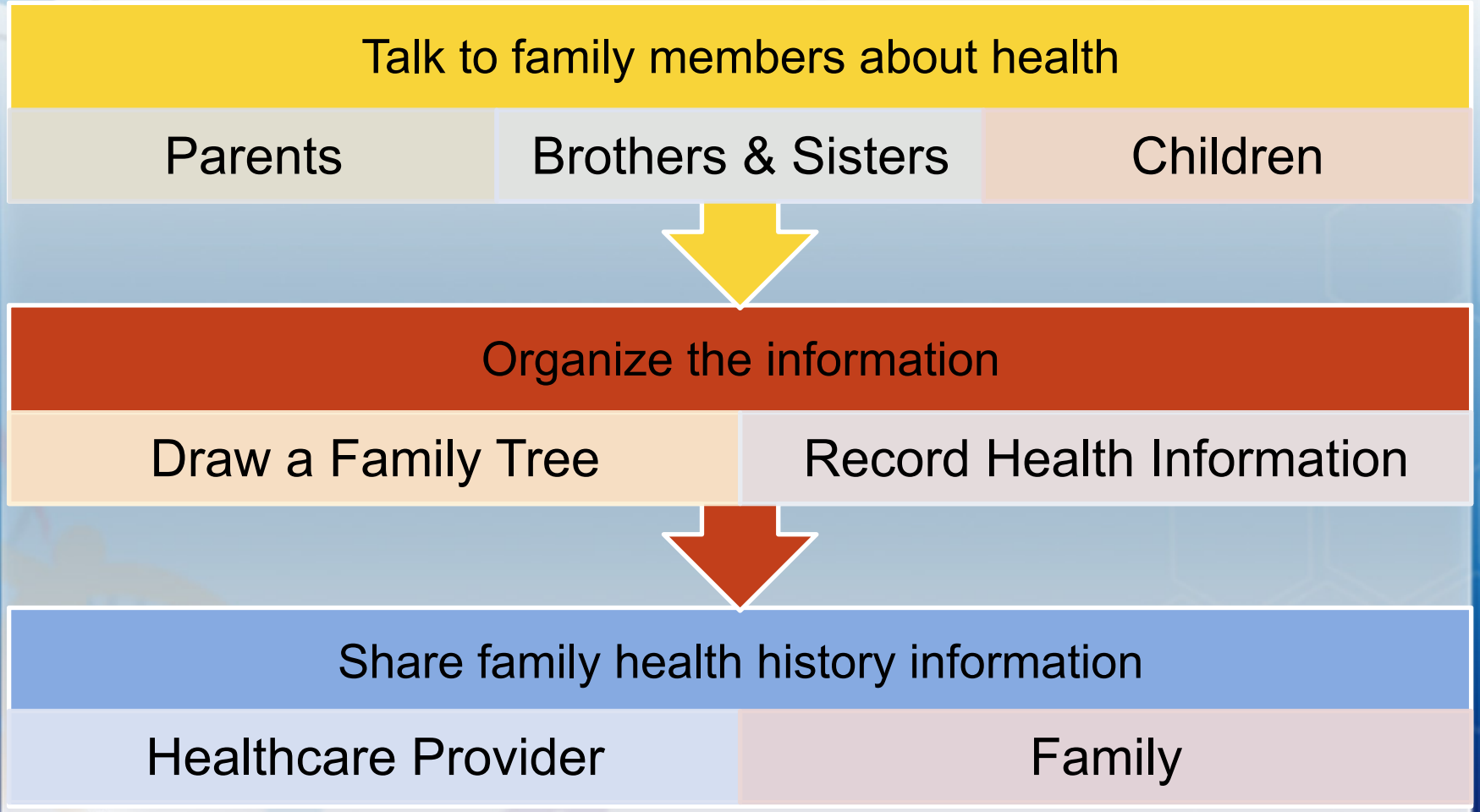
https://familyhistory.hhs.gov/

Process of Self-Reported Family Health History



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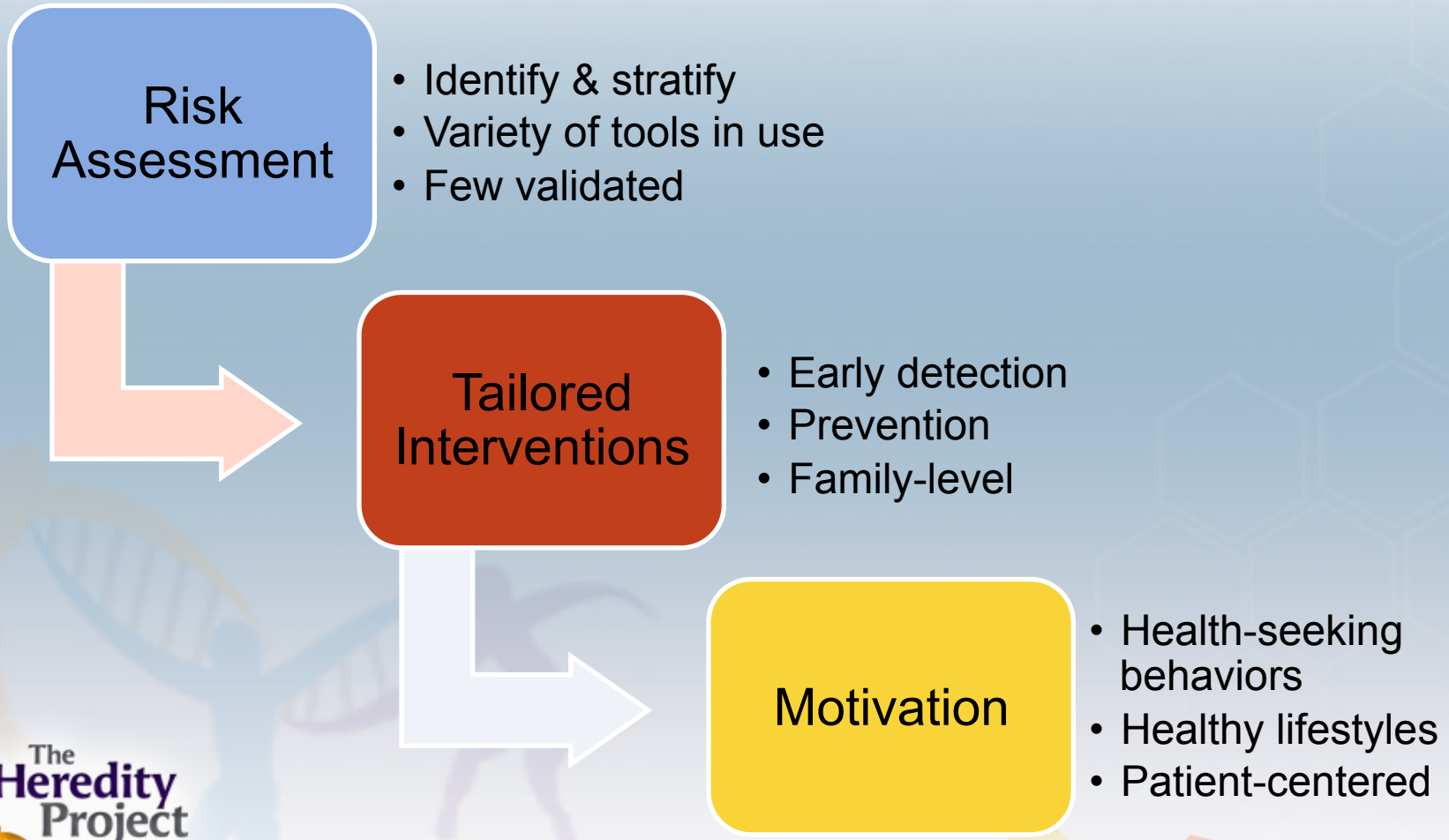
Uses of Family Health History in Public Health Practice



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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

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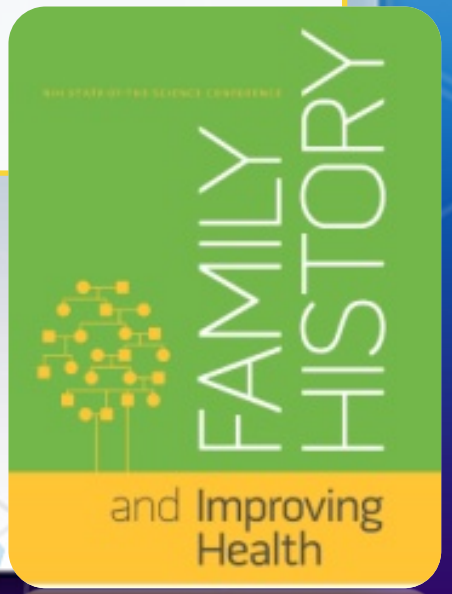
NIH State-of-the-Science Conference: Family History and Improving Health August, 2009



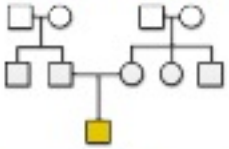
My Family Health Portrait

Structured Data + Connectivity = *Interoperability*

My Family Health Portrait

My Family Health Portrait

Structured Data



Save to...

Partners

See how you can manage your health—and that of your family—with HealthVault.

Microsoft HealthVault

Family Members

Care Providers

HealthVault Affiliates

MAYO CLINIC Health Manager

Aetna

American Heart Association

Healthy Circles

TrialX

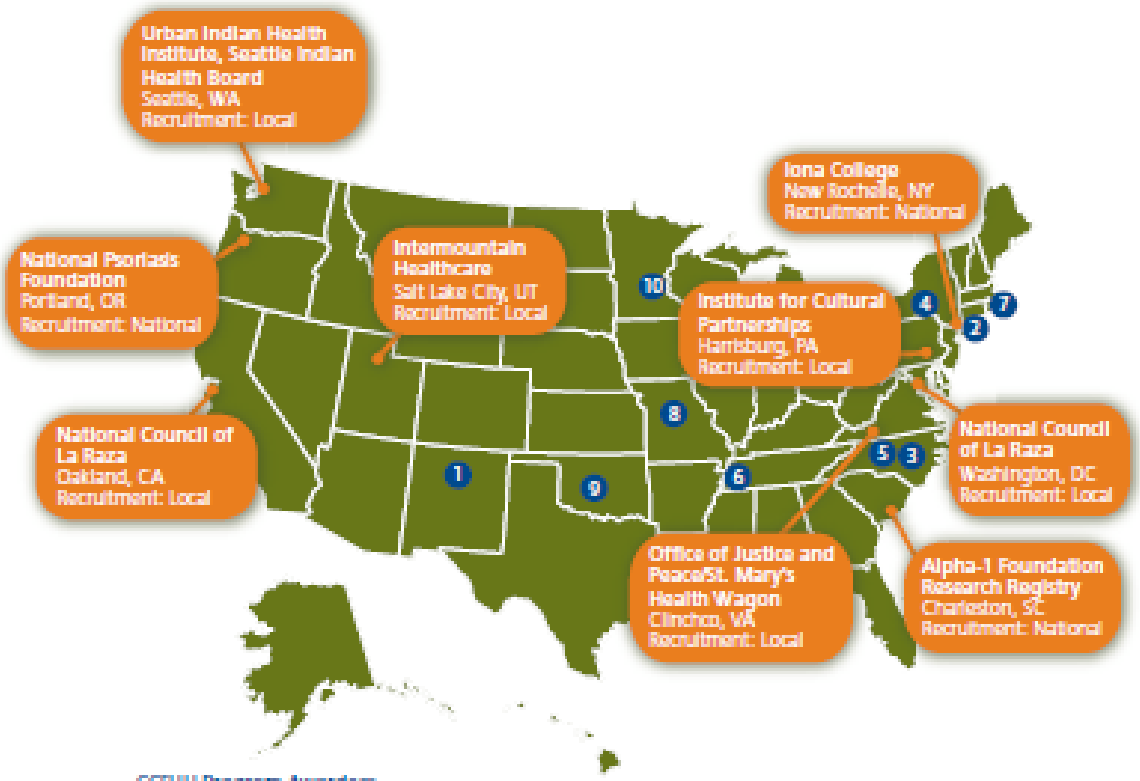
ACTIVEHEALTH MANAGEMENT

NoMoreClipboard.com

SMARTPHR

Feero, 2010

Community-Centered Family Health History Project



CCFHH Program Awardees

1. Angioma Alliance – Santa Fe, NM
2. Brookdale University Hospital and Medical Center – Brooklyn, NY
3. Duke Institute for Genome Sciences & Policy – Durham, NC
4. Fenn Institute – Binghamton, NY
5. The Genomedical Connection – Greensboro, NC
6. The Heredity Project – Memphis, TN
7. Progreso Latino – Central Falls, RI
8. Southern Missouri Telehealth Genetics Services – Columbia, MO
9. University of Oklahoma College of Medicine – Oklahoma City, OK
10. West Side Community Health Services – St Paul, MN

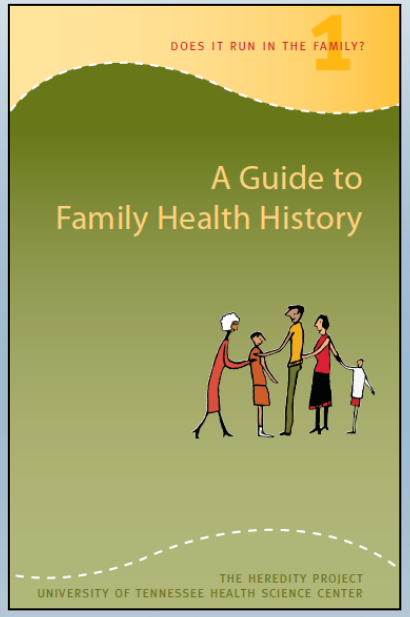
Collaboration involving diverse community partners to produce resources that increase communication about health within families

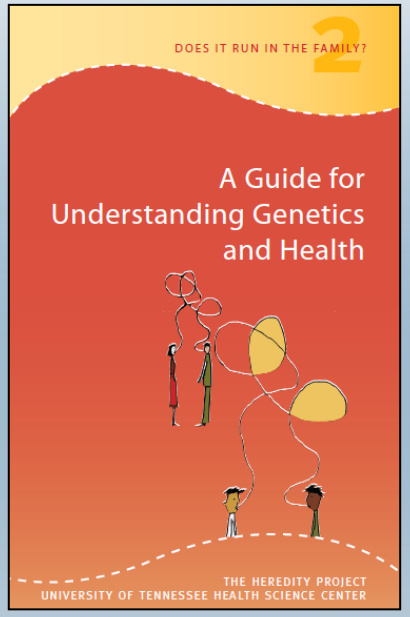
Genetic Alliance

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

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Newborn Screening

- LeBonheur-based education project
- Dr Stacy Hines-Dowell

Connecting the Dots

Community Health Enrichment

- Health science club collaborative
- HUD Neighborhood Networks

Primary Care Initiative

- Family health history tools in HRSA-funded Health Centers

Genetic Alliance

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Acknowledgements

- UTHSC
  - Maggie DeBon
  - Fridtjof Thomas
  - Bob Shreve
  - TaJuana Redmond
  - Sim Taylor
  - Larry Tague
  - Malrie Shelton

SEPA SCIENCE EDUCATION PARTNERSHIP AWARD
Supported by the National Center for Research Resources, a part of the National Institutes of Health

- Funded by NIH/NCRR

Connecting the Dots

- LeBonheur
  - Stacy Hines-Dowell
  - Jewell Ward

Genetic Alliance

- Genetic Alliance
  - Vaughn Edelson
  - Sharon Terry

- Our community partners!

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