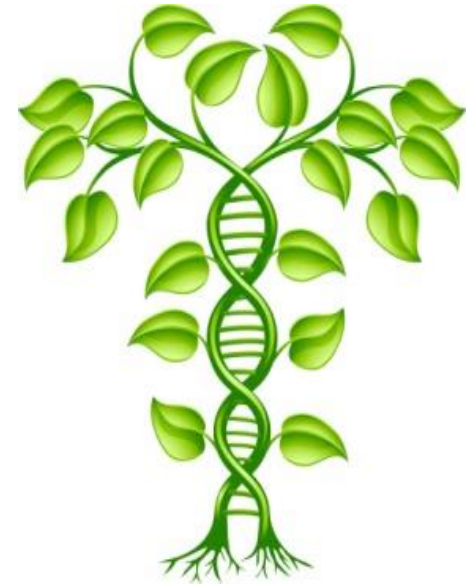


Community Voices: Knowledge and shared (mis)understandings of family health histories



Laura M. Koehly, Ph.D.
Family History Tool Meeting
June 15, 2016



Family Health History



Family Health History (FHH):

- Map family history of heritable diseases to understand risk
- Reflects genetic, behavioral and environmental factors associated with complex disease risk
- Gold Standard: 3-generation pedigree

Important clinical and social implications

Clinical risk assessment tool

- Guides genetic services referrals
- Informative in complex disease risk
- Personalized screening schedules

Familial aggregation

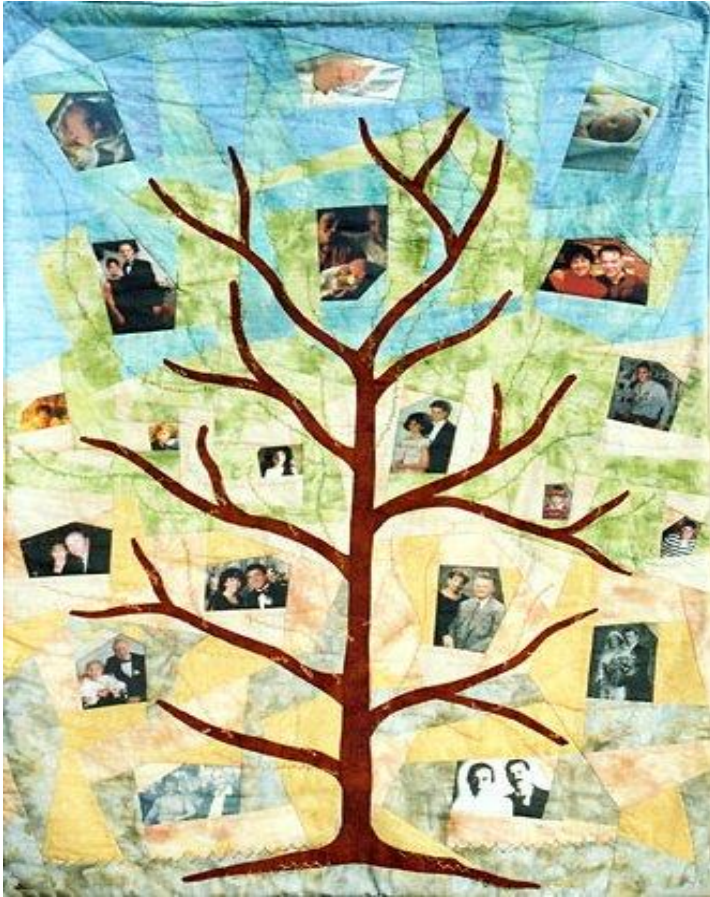
- Shared risk of disease
- Shared risk reduction recommendations

Meaning through lived experience

- Influence perceptions of risk
- Motivates engagement in preventive behaviors
- Promotes interpersonal mechanisms



Community Voices



Community samples

- Project RAMA
- Cincinnati Diabetes Family Study

Multi-informant families

Detailed family health history

- Disease Dx
- Behavioral risks

Community Samples

Project Risk Assessment for Mexican Americans (RAMA)

Longitudinal (BL, 3-, 10-month)
FHH health education program

497 members,
162 multi-generational households

100% Hispanic, Mexican heritage

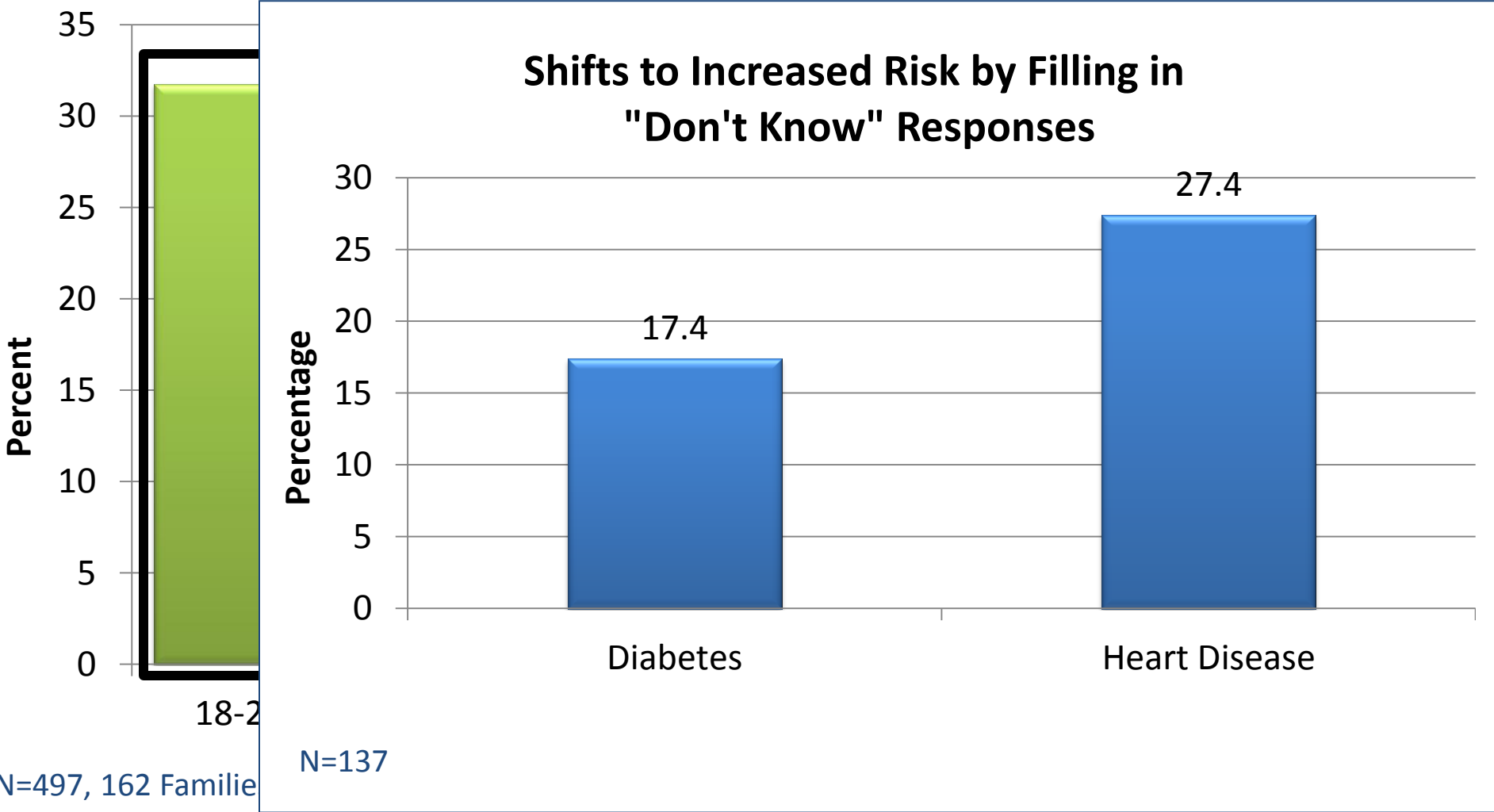
Cincinnati Diabetes Family Study

Cross-Sectional

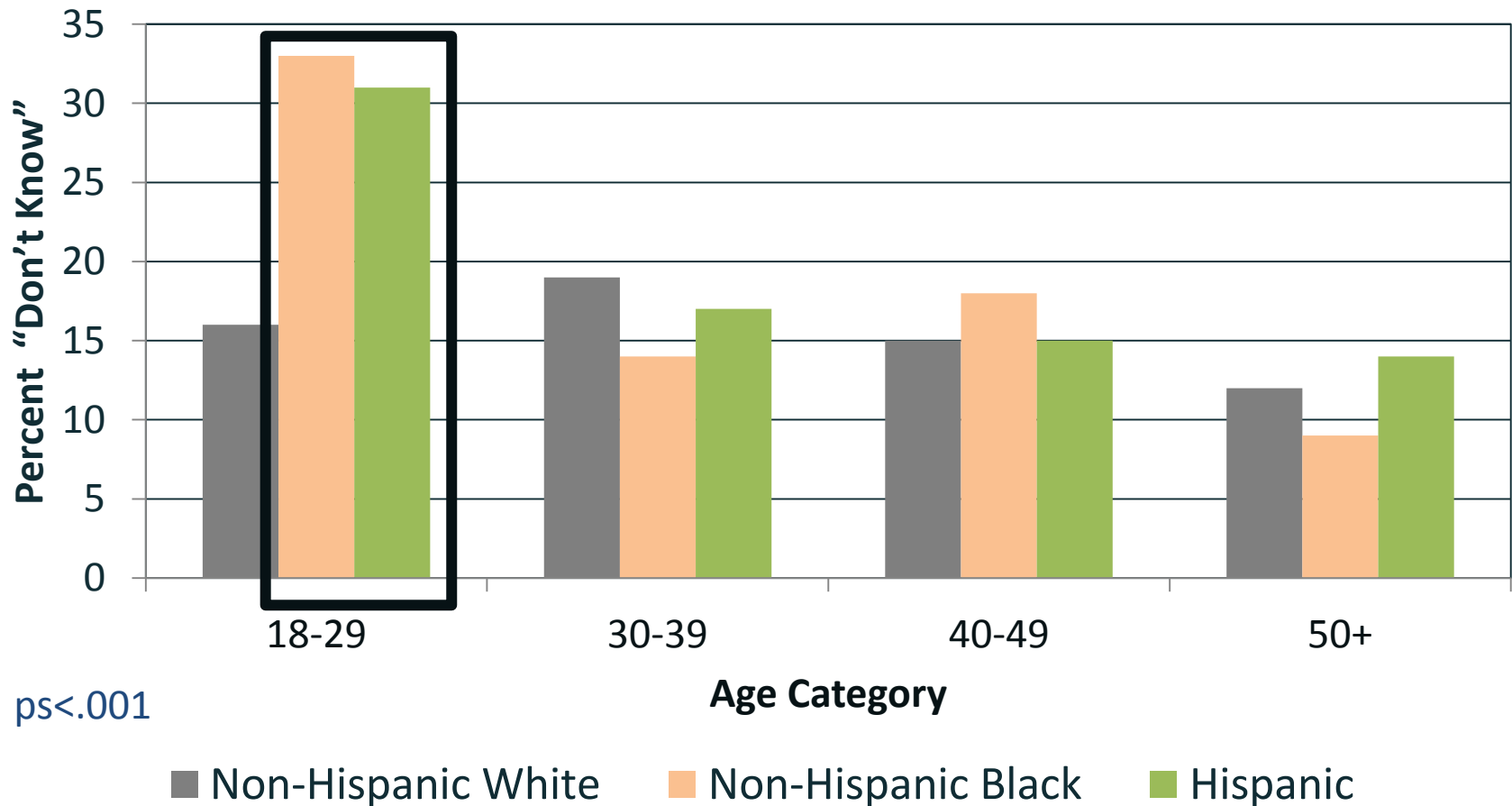
127 members,
45 families

62% Non-Hispanic White
37% Non-Hispanic Black

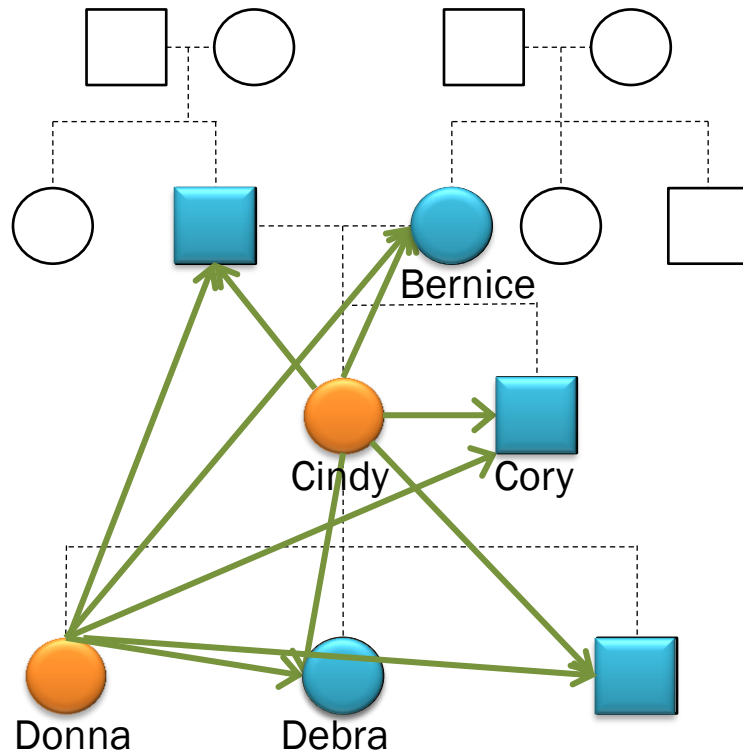
What you don't know *can* hurt you



Younger, at-risk populations “don’t know” their family health history

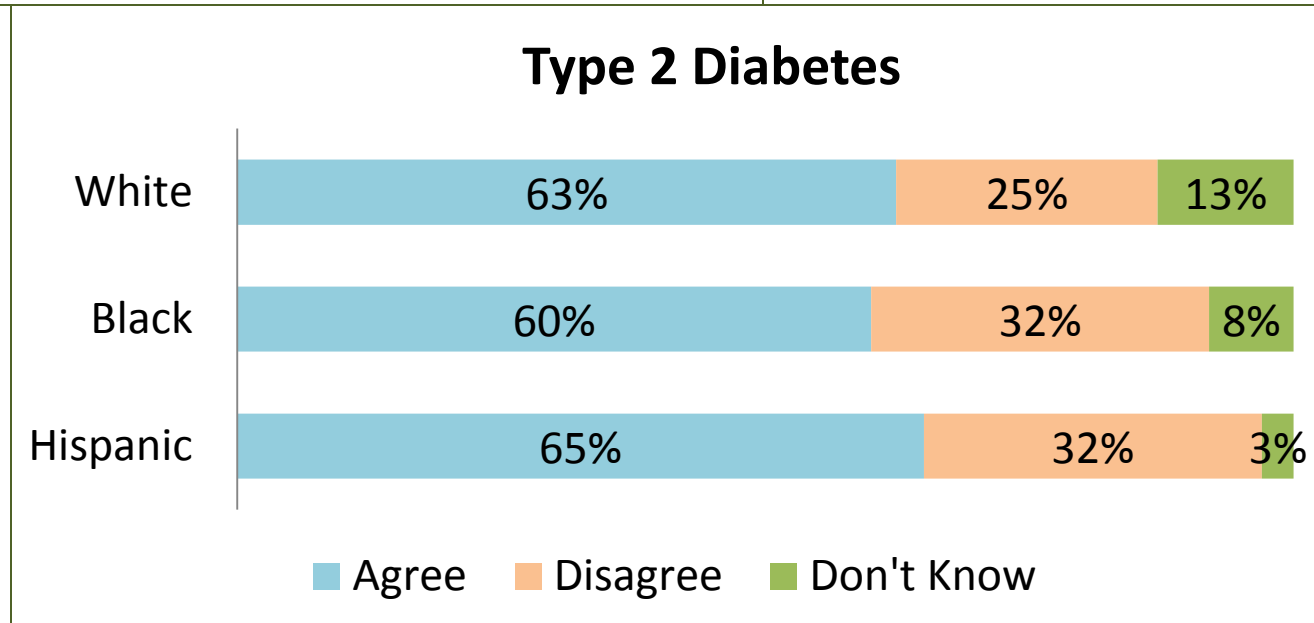
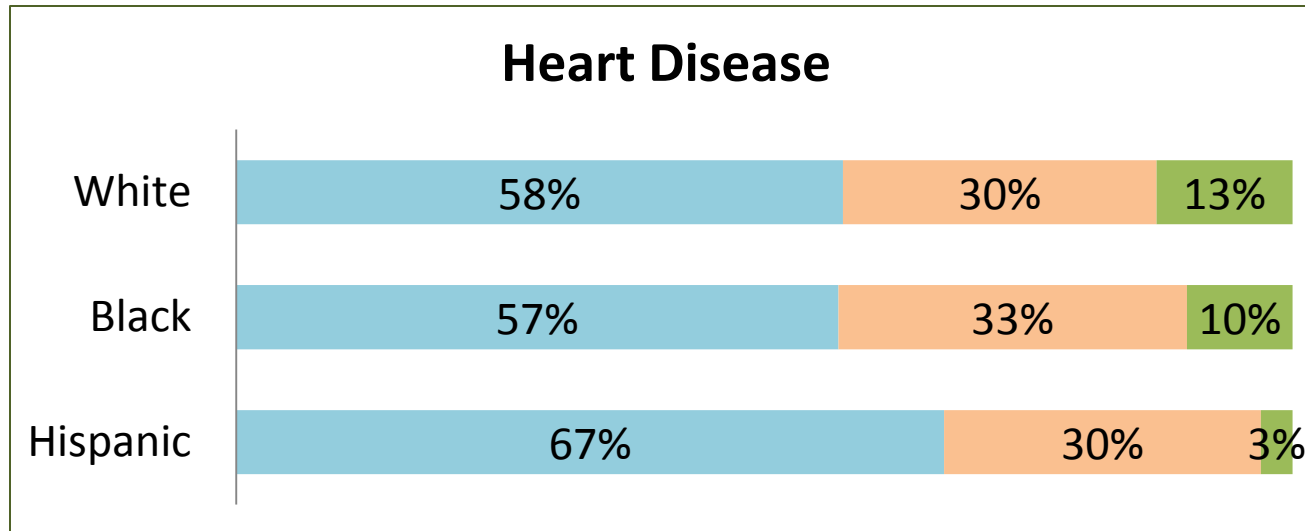


Linking family pedigrees across informants



- Each informant brings a unique perspective of the familial health context
- Consider consistency in dyad participants' family history reports
- Shared mental models or understanding of their family history

Shared (mis)understandings



Challenges and Opportunities

Challenges

Limited knowledge

- Younger members
- At-risk populations

Shared (mis)understanding

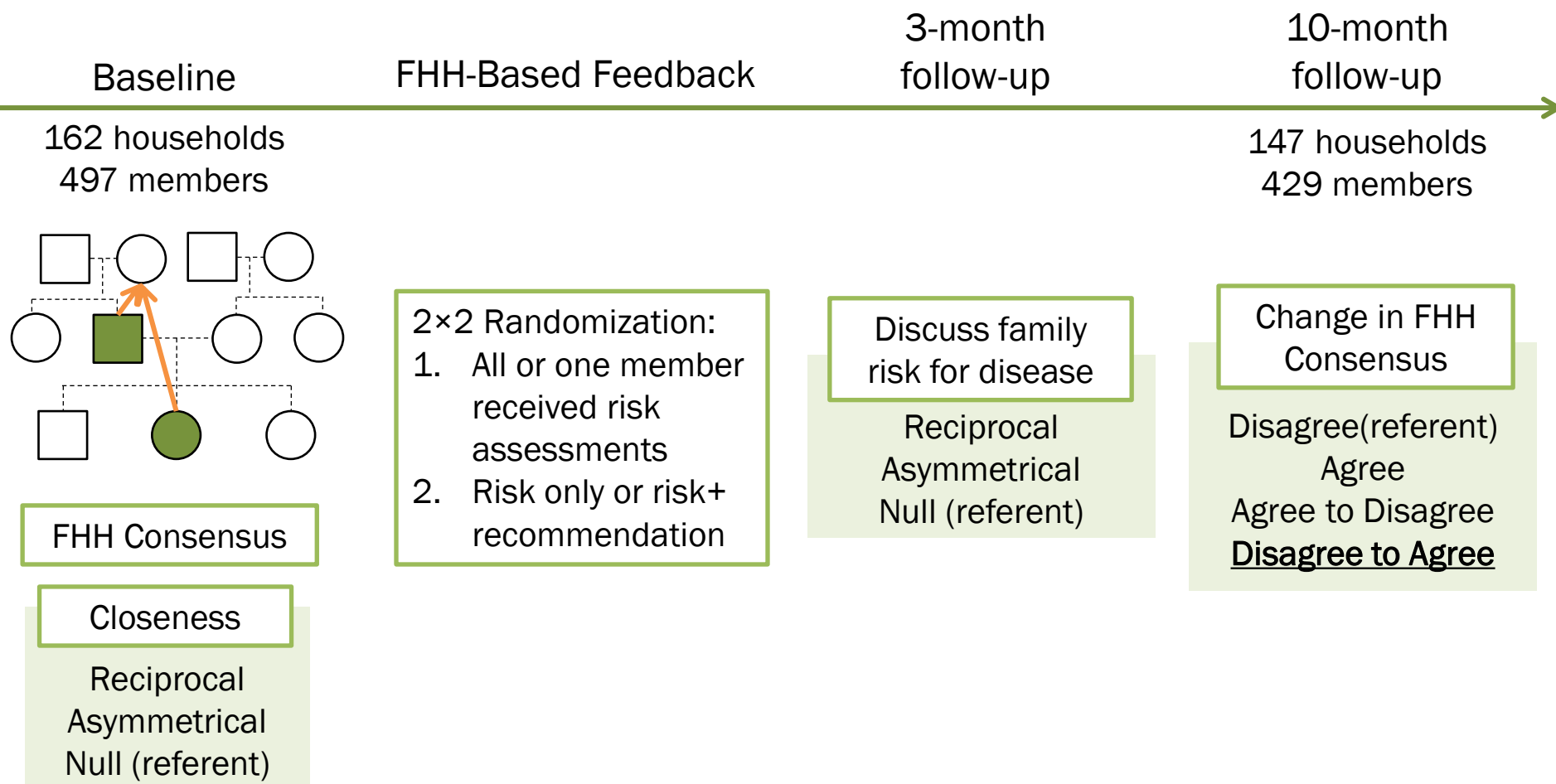
- Points of view differ
- Error prone

Opportunities

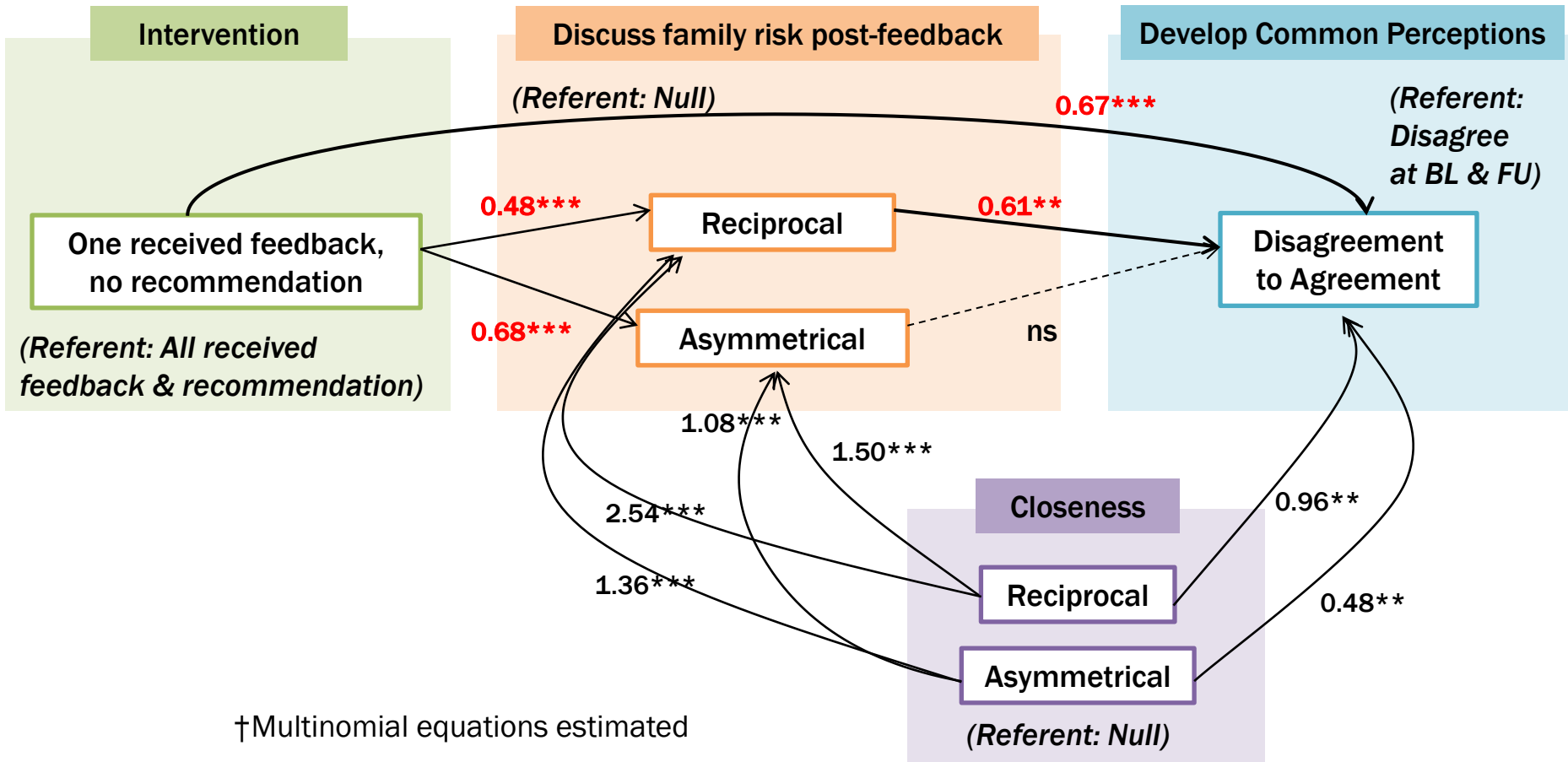
Activate pathways

Embrace the error

Activate interpersonal pathways



Family health historian can spur intergenerational transfer of family history



†Multinomial equations estimated

‡Clustering adjusted

Embrace the error

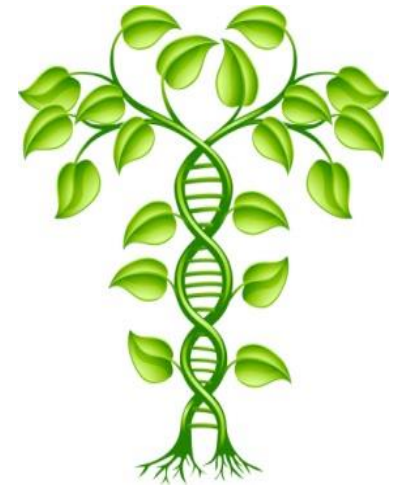
Each informant brings a unique perspective of the familial health context

Pooled family histories across multiple family informants

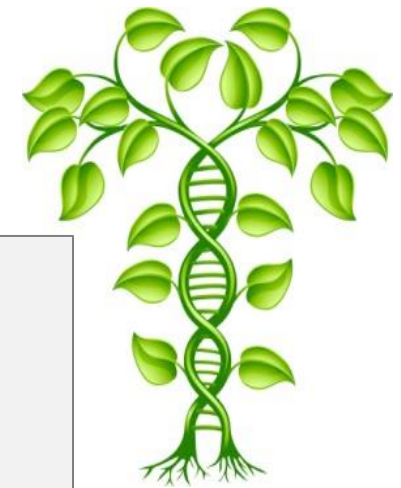
- Potential increased reliability
- Improved risk assessments

Implementation

- Electronic Health Records
- Online repositories for FHH



Bringing the Family back into Family Health History:



Personalized Risk Assessments

Improved using multi-informant (MI) family health histories.



Challenges and Opportunities

Challenges

Limited knowledge

- Younger members
- At-risk populations

Shared (mis)understanding

- Points of view differ
- Error prone

Opportunities

Activate pathways

- Family health historian
- Intergenerational transfer

Embrace the error

- Improve assessment
- Optimal reconciliation

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