



Engagement and
Communication in the
ClinSeq[®] Genomic
Sequencing Study:
*How much do they care
and how do we know if
they do?*

Hooker, GW¹, Koehly, LK², Lewis, KV³, Biesecker, LG³ and Biesecker, BB⁴

¹NextGxDx, Inc, Franklin, TN ²Social Network Methods Section, Social and Behavioral Research Branch, NHGRI, NIH, Bethesda, Maryland ³Genetic Disease Research Branch, NHGRI, NIH ⁴Genetic Services Research Unit, Social and Behavioral Research Branch, NHGRI, NIH, Bethesda, Maryland

**I WAS TRYING TO FIGURE OUT
WHICH IS WORSE,
IGNORANCE OR APATHY...**

**THEN I REALIZED I DON'T
KNOW AND I DON'T CARE.**

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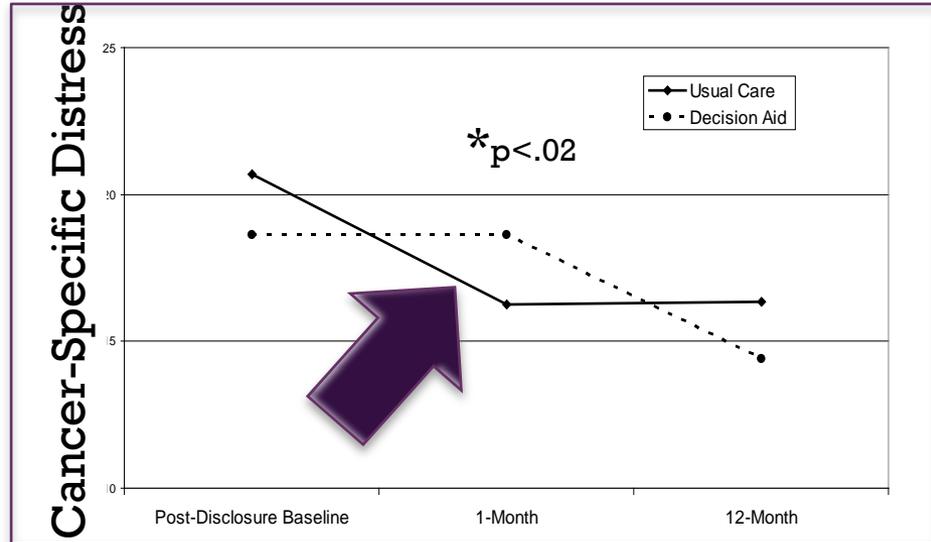
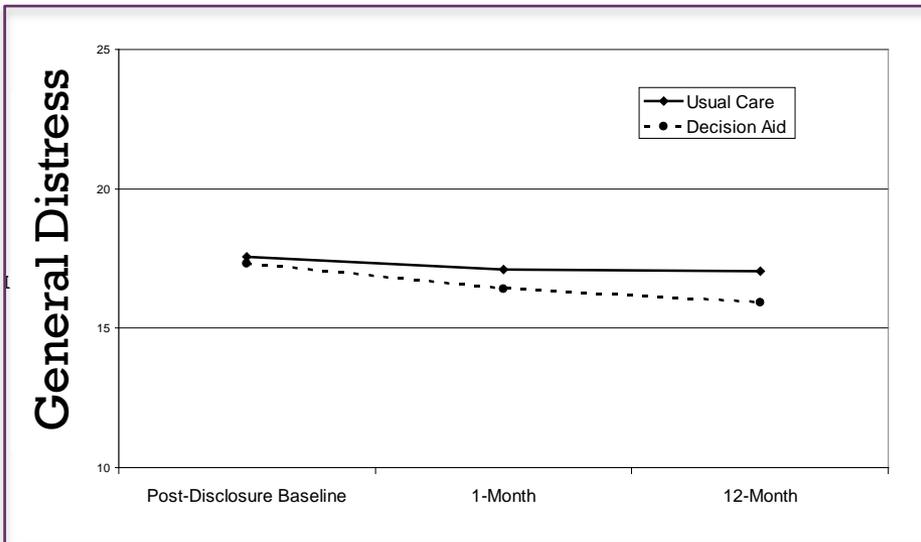
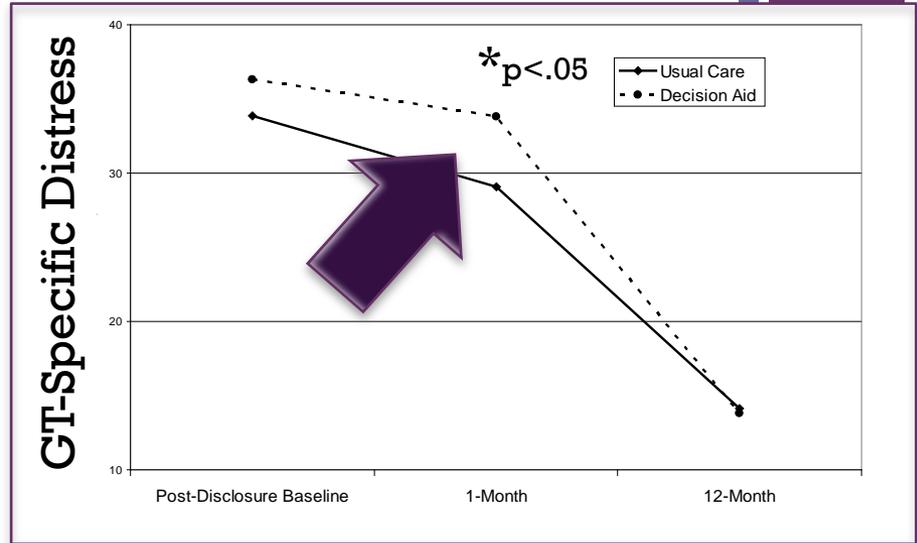
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+ A Stressful Decision Aid?

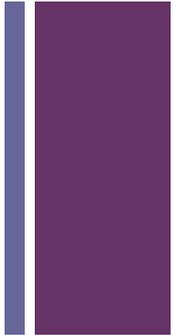
CD-rom based decision aid to help BRCA carriers make management decisions

- Prev. shown to be effective
 - ↑ likelihood of reaching a decision
 - ↓ decisional conflict
 - ↑ decisional satisfaction
- Different longitudinal patterns of distress

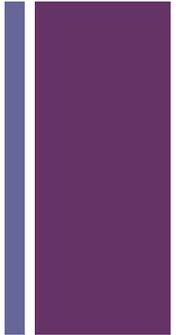


+ Engagement

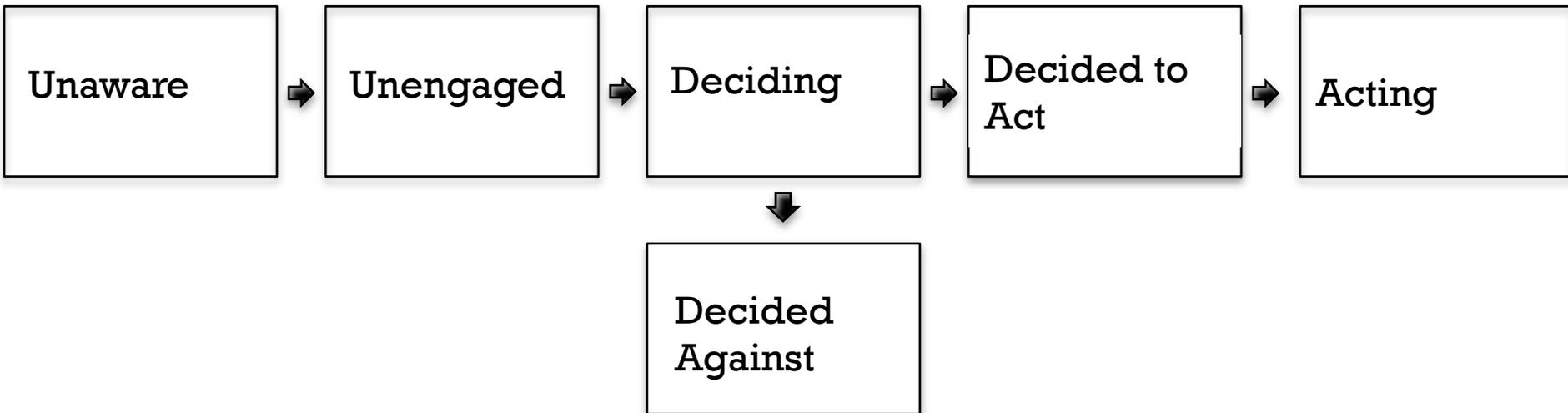
- Cognitive engagement
- How much you think and care about a particular thing
- Assumes a set amount of “thought space”
- Distinct from
 - Knowledge
 - Arousal
 - Activities stemming from engagement (e.g. “engagement *with* a website”)



+ The Precaution Adoption Process Model



- A “stage” model



****Genomics****

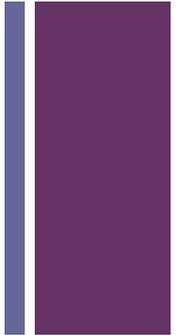
+ ClinSeq[®] - Overview

- A pilot study of large scale medical sequencing, started in 2007
- Participants brought to clinical center for consent, physical and evaluation for a common set of cardiovascular features
- Participants recruited in “bins” based on risk of cardiovascular event
- Broad consent for possible return of results, with patients given the option to learn (or not) most results



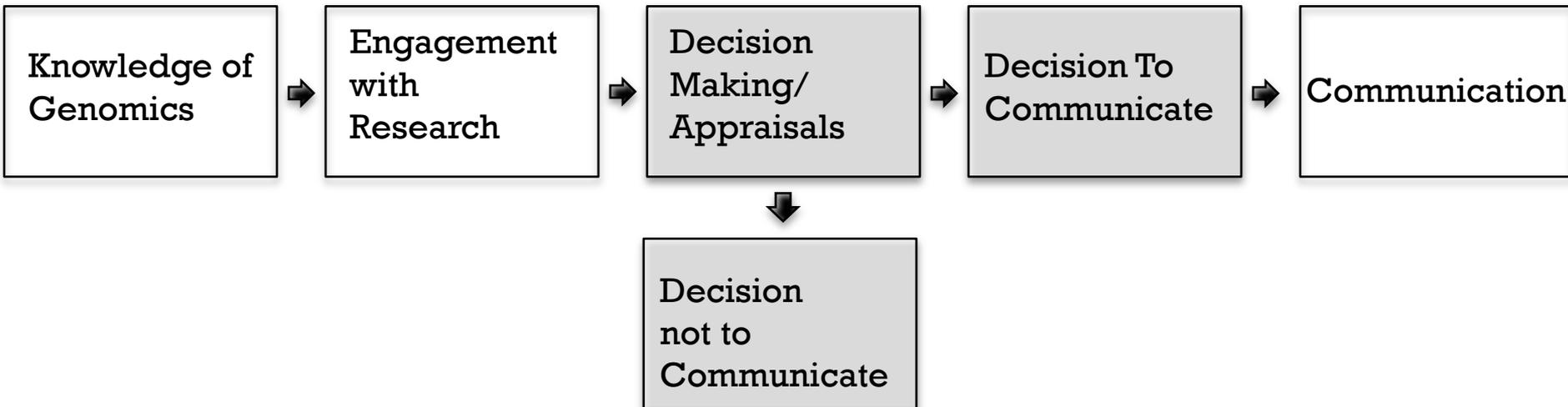
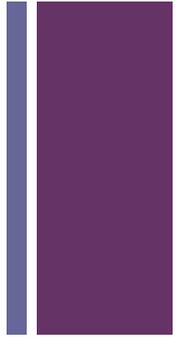
+ ClinSeq[®] BL Survey

- Contents
 - 36 Scales
 - >400 Questions
 - 45 minutes to complete
- Eligibility
 - No results yet (N=962)
 - >1 month since enrollment
- Administration
 - Online and paper
 - 3 recruitment attempts



+ Engagement Study Aims

- Describe engagement



- Test relationships predicted by PAPM, anchoring on the decision to communicate about ClinSeq participation
- Provide additional evidence for validity of engagement as a construct

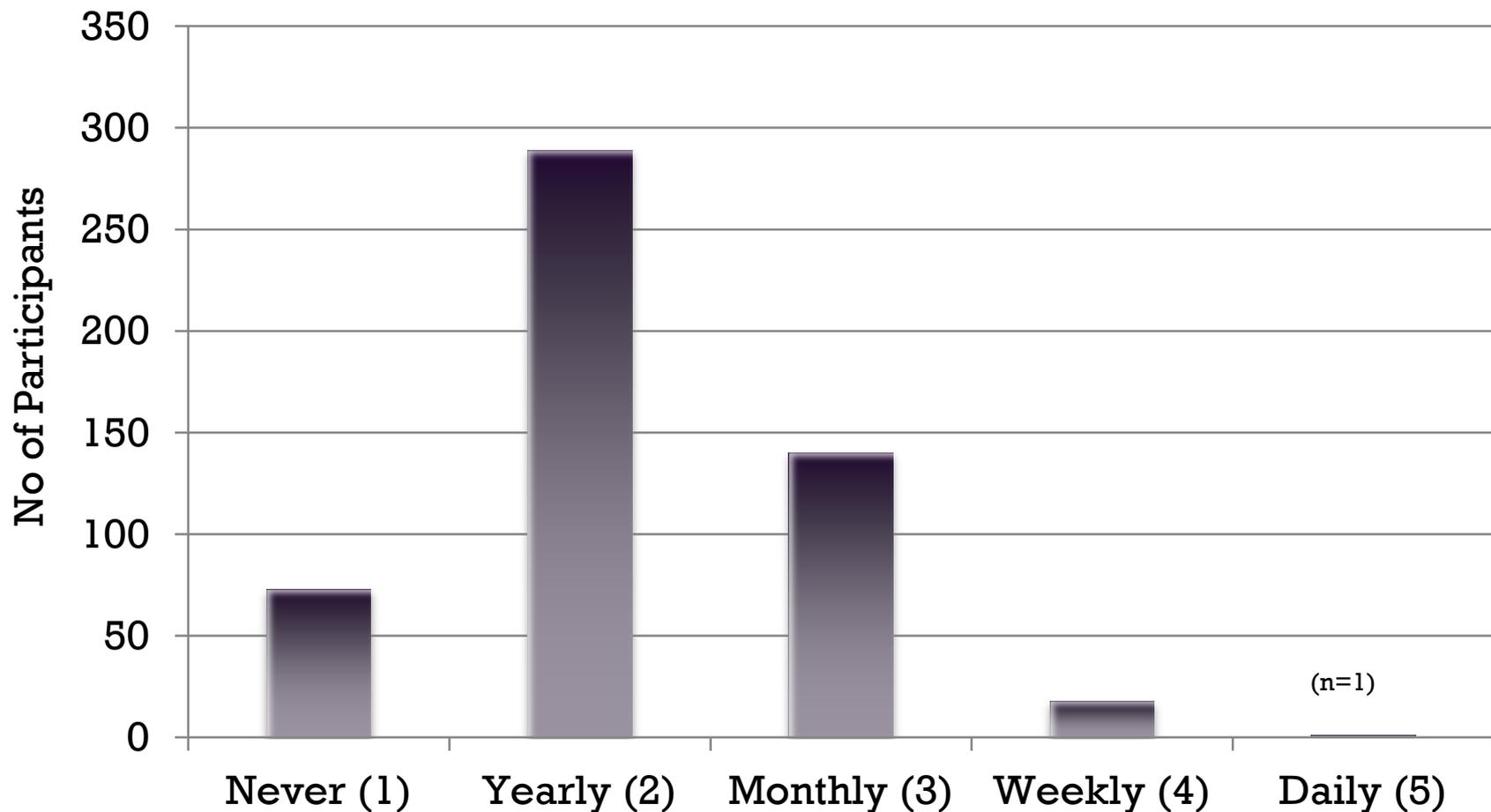
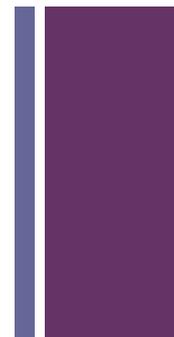
+ Response to ClinSeq[®] BL Survey

- 594 responses received (61%)
- 551 survey responses used for analysis
- Respondent characteristics
 - White & Not Hispanic or Latino (91%)*
 - Bin 1-3 (80%)
 - College Educated or Higher (87%)*
 - Income > \$100,000 (74%)
 - Married (73%)
 - At least 1 biological child (74%)

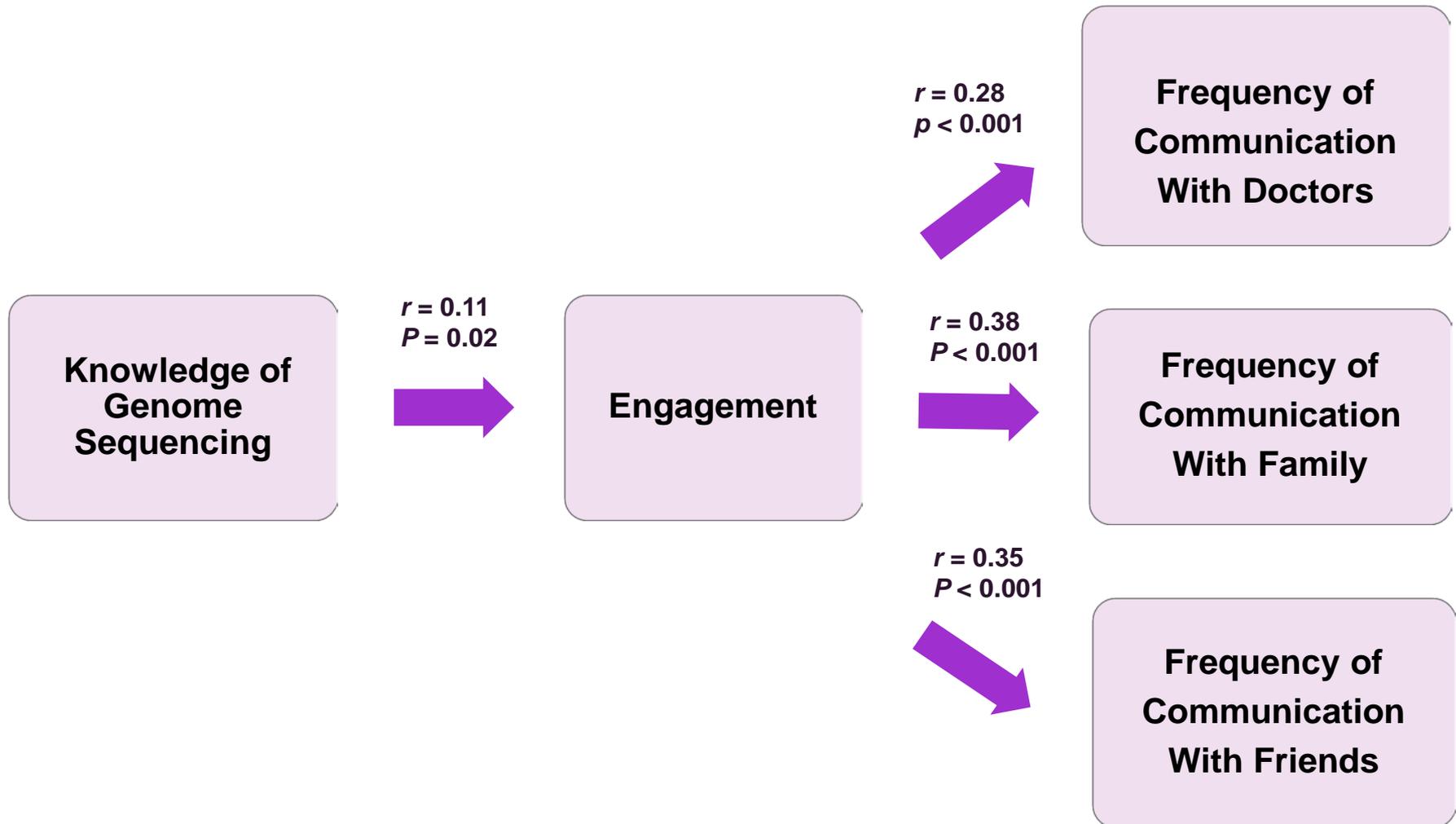
*Respondents were significantly ($p < 0.05$) more likely than the overall eligible population to have had these characteristics.



How often do you think about your participation in ClinSeq[®]?



+ Engagement, Knowledge and Communication



+ Who do they tell?

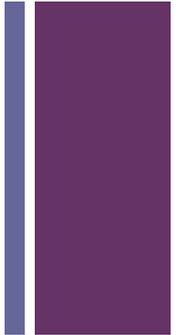
| Relationship | Percent Having at Least 1 Living Relation | Percent of Relatives Communicated to |
|------------------------|---|--------------------------------------|
| Spouse | 87% | 97% |
| Children | | |
| Biological Son(s) | 59% | 77% |
| Biological Daughter(s) | 61% | 77% |
| Parents | | |
| Mother | 41% | 63% |
| Father | 25% | 58% |
| Siblings | | |
| Biological Sister(s) | 68% | 68%* |
| Biological Brother(s) | 73% | 56% |
| Physicians | N/A | 77% |

+ Other Correlates of Engagement

| | <i>r</i> | <i>p</i> |
|--|----------|----------|
| Better Overall Health | 0.13 | 0.02 |
| More Frequent Doctor's Visits | -0.11 | 0.01 |
| More Frequent Health Information Seeking | 0.17 | <0.001 |
| Have Had Genetic Testing | 0.10 | 0.03 |
| Hold Graduate Degree | 0.09 | 0.03 |
| Time Since Enrollment | -0.19 | <0.001 |

+ Summary

- Most ClinSeq[®] participants think about their participation on a yearly basis.
- As predicted by the PAPM, Engagement is related to knowledge and communication.
- Healthier, information seekers with a history of graduate school and genetic testing are more likely to be engaged.
- Limitations
 - Response bias
 - Single item measure
 - Cross sectional data



+ Future Directions

■ Refining measurement

Engagement with ClinSeq®

Please select the answer that best reflects your experience.

How often does ClinSeq® come up in conversations with others?

Daily, Weekly, Monthly, Yearly, Never

How often do you look up information about the ClinSeq® study on the internet or in your own records?

Daily, Weekly, Monthly, Yearly, Never

How often do you wonder about results you might learn from ClinSeq®?

Daily, Weekly, Monthly, Yearly, Never

***In general, how often do you think about your participation in the ClinSeq® Study?**

Daily, Weekly, Monthly, Yearly, Never

Please rate how strongly you agree or disagree with the following statements.

If I had a question or concern about ClinSeq®, it would be easy for me to contact the study team.

Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree

I feel like I understand the goals of the ClinSeq® study.

Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree

I enjoy receiving mailed updates about the ClinSeq® study.

Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree

I feel motivated to continue participating in the ClinSeq® study.

Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree

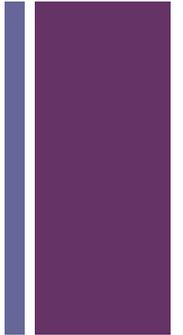
+ Future Directions

■ Testable Hypotheses

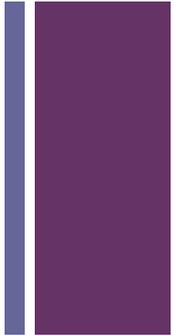
- Short-term engagement (1-month post-disclosure) with carrier results will predict cumulative communication with family members in the long term (*pending*)
- Short-term engagement with actionable, risk-associated variants will predict uptake of risk management behaviors (visiting specialists, screening, prevention)

Long-term (wildly speculative) hypothesis

Genetic counseling interventions aimed at promoting engagement among the disengaged will lead to positive health outcomes.



+ Tangential Plugs



■ Practice Guidelines Committee

- Move towards systematic evidence reviews as a prerequisite for genetic counseling guidelines
- In **GREAT** need of genetic counselors with research training
- Watch for applications in the next month or so (around the AEC)

■ Research SIG

- Aiming to increase SIG activity and visibility (engagement?)
- Move towards work groups (Research in Industry, Using Patient Portals, Qualitative Research in GC, other?)



- Barb Biesecker
- Laura Koehly
- Katie Lewis
- Les Biesecker
- The ClinSeq Social Science Team
- ClinSeq Participants

