

# Decision Stability among Adolescents and Young Adults Making Choices about Learning Genomic Research Results

Amy A. Blumling,<sup>1</sup> Holly Elder,<sup>1</sup> Srimayi Mulukutla,<sup>2</sup> Jessica A. Sinclair,<sup>3</sup> Madeline Mahoney,<sup>3</sup> Kristin Childers-Buschle,<sup>1</sup> Cynthia A. Prows,<sup>1</sup> Melanie F. Myers,<sup>1,4</sup> Michelle L. McGowan<sup>3,5</sup>  
<sup>1</sup>Division of Human Genetics, Cincinnati Children's Hospital Medical Center, <sup>2</sup>Medical Sciences Baccalaureate Program, University of Cincinnati, <sup>3</sup>Biomedical Ethics Research Program, Mayo Clinic, <sup>4</sup>Department of Pediatrics, University of Cincinnati, <sup>5</sup>Department of Women's, Gender & Sexuality Studies, University of Cincinnati

## BACKGROUND

- Personal genomic testing is becoming increasingly common to predict and guide treatment, including in the pediatric population, in research, clinical, and direct-to-consumer settings.
- Little is known about the factors influencing adolescents' choices and the best methods to reduce regret in genomic testing decisions.
- We conducted qualitative interviews to explore factors influencing decision-making and decision stability among adolescent (13-17) and young adult (18-21) clinical trial participants who chose to learn all, some, and no genomic research results when presented with the opportunity to undergo personal genomic testing without a clinical indication.<sup>1</sup>
- As defined by the study team:
  - High decision stability:** maintaining decisions made during T2 (Figure 1) up until participation in a study interview (up to 7 months later).
  - Low decision stability:** making a change or expressing a desire to make a change in choices after T2.

## METHODS

- Participants decide over a series of timepoints (Figure 1) which personal genomic testing results to learn for themselves using an electronic decision-making tool.
- We purposively sampled and invited interviewees from the clinical trial to maximize variation in participant age, gender, choices, and decision stability (Table 1).
- Interviews were conducted with adolescents and young adults between T3 and T4 (Figure 1) between April 2022 and August 2023.
- A codebook for qualitative data analysis was developed through an iterative process using deductive and inductive strategies. Transcripts were coded by 3 members of the study team using ATLAS.ti v.23.2.1.



Try out the demo tool here!

## Engaging Adolescents Study

# TIMELINE

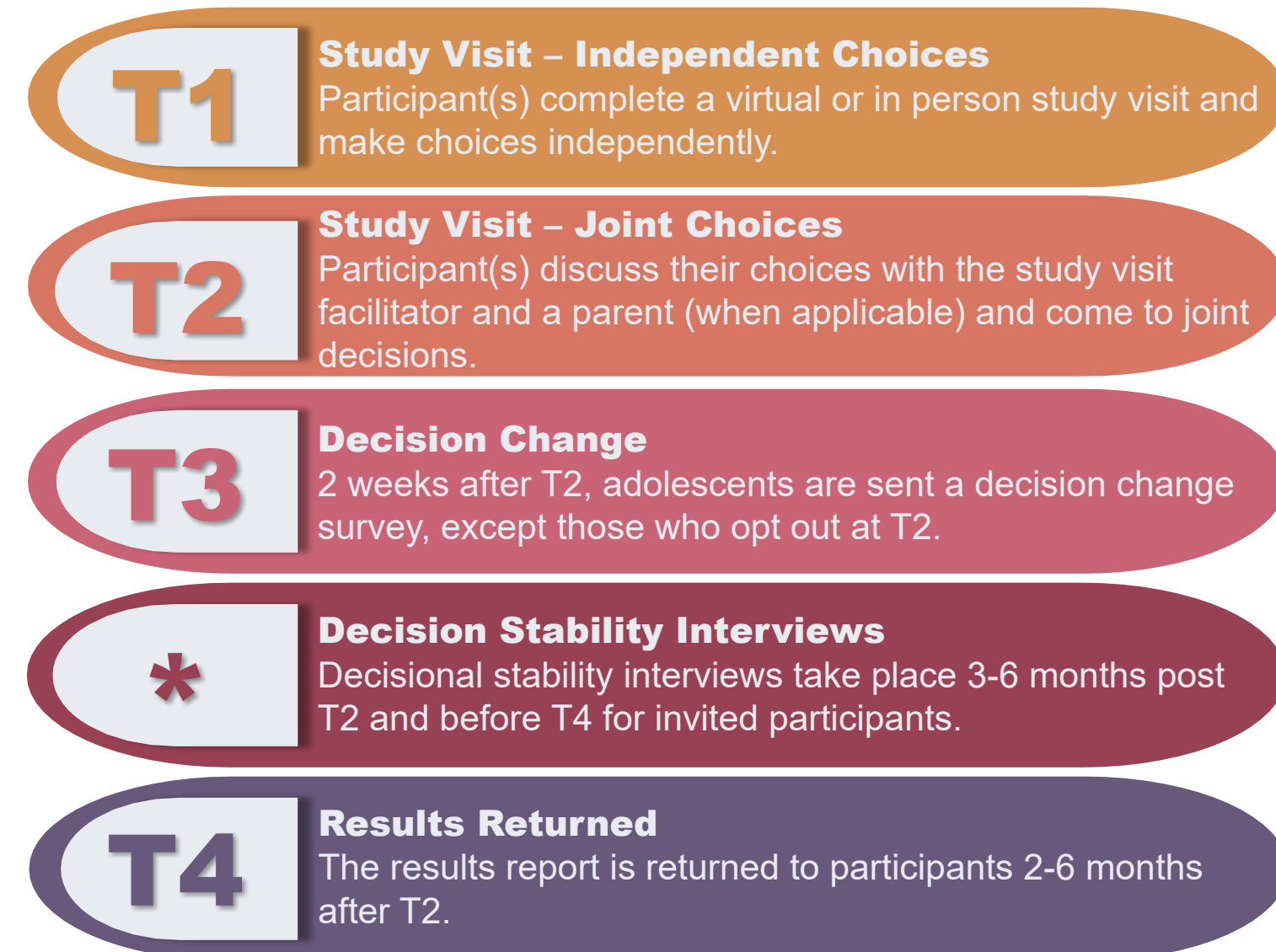
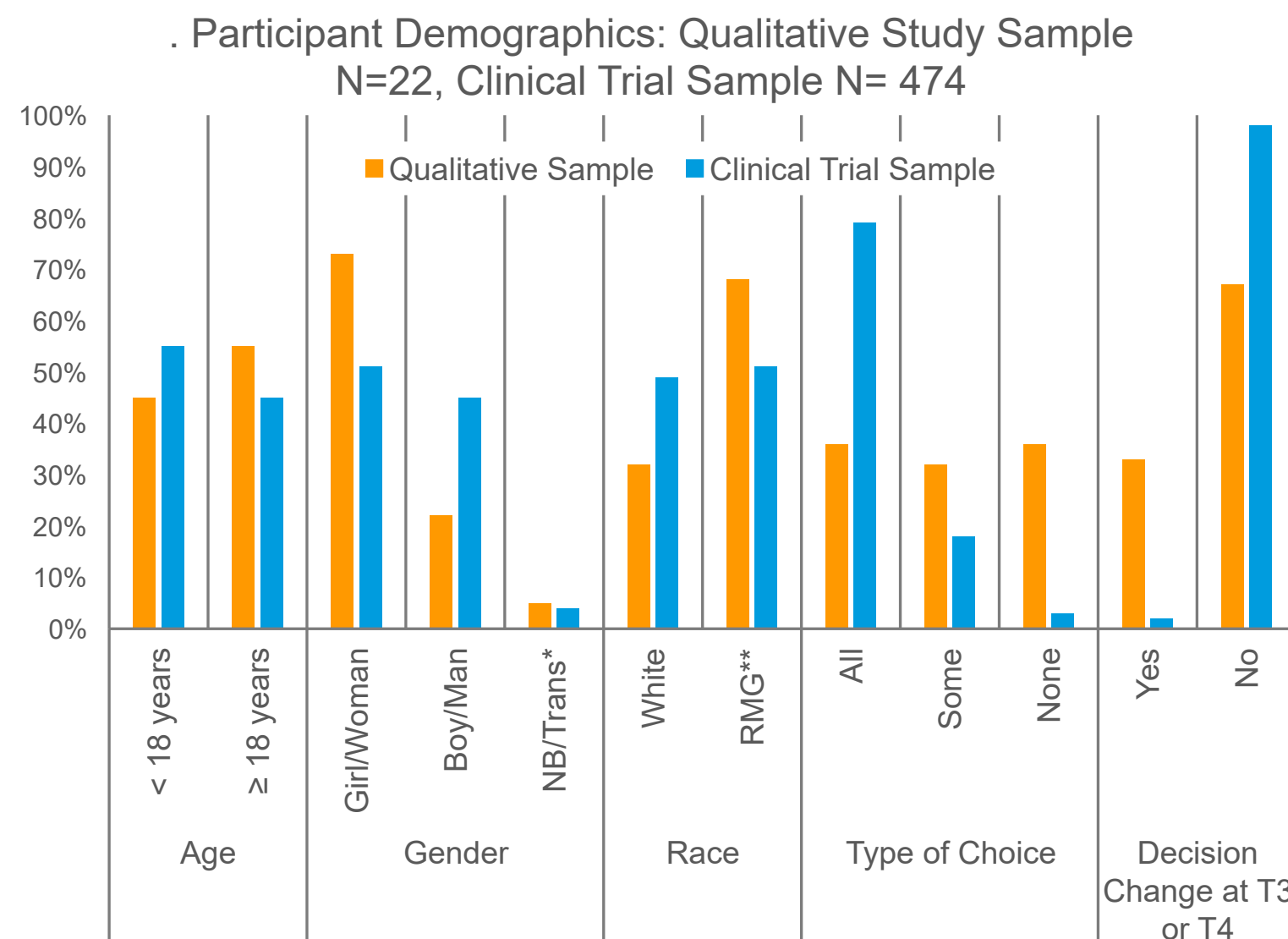


FIGURE 1 (ABOVE): Time points of intervention in the Engaging Adolescents Clinical Trial.



## Factors influencing participants' genomic decision-making processes included:

### Temperament/personality

"I feel like in this situation, ignorance is bliss, at least in the beginning, so that I can, you know, live a normal life up until I kind of need to face the reality of what's happening." *14 yo girl, chose to learn some genomic research results*

### Exposure to adverse health events

"And so...it was frustrating to be uncertain and to have all of these professionals around me be like, 'well, I don't know, I guess you'll just have to wait it out'. And so that frustration really made me realize that I would like to know more about myself. And I think I drew on that when I made that fully confident decision that I want to know more about myself because I don't want this to happen again." *21 yo woman, chose to learn all genomic research results*

### Reproductive Goals

"Since I was a child, it's always been a dream of mine to be pregnant and have kids. So, I thought maybe if the results came back with something negative, like me being a carrier of something, I would be very afraid of getting pregnant. What if, like it's always the what-ifs." *20 yo woman, chose not to learn any genomic research results*

### Others' Influence

"I trust my mom a lot, like I trust her opinion, so I was like, 'I think I'm going to say yes, but I wanted to check with you.' And she's like, 'yes, you should because then it would give you more information, and you might as well have more information than none, so.' ... I think I just needed reassurance that I was, rather, that my opinion was right." *18 yo woman, chose to learn all genomic research results*

FIGURE 3 (LEFT): Age category, self-identified gender and race, genomic screening choices, and decision changes of clinical trial population and qualitative interview sample. Decision Change at T3 or T4 only includes N=275 participants, as individuals who opted out completely at T2 (N=8) did not receive a 2-week decision change survey. \*Non-binary and transgender. \*\*Racial minority group (including Black/African American, Asian, Hispanic, Multiple Races, and other single groups).

## RESULTS

### Factors Influencing High Decision Stability (N=15)

- High level of decision confidence
- Others' influence on their decision making
- Fear of missing out on the opportunity to learn actionable personal health information

"I was very confident. I knew that I wanted to know as much as I can just because, one, I think like, genetics are super cool... Some of it can be devastating but might as well learn about it now rather than in the future." *20 yo woman, chose to learn all genomic research results*

"But then I slept on it for like a day or two, and I really did realize that like I do have... the anxiety about things that I can't control... So, I felt like maybe it's not the best option, after talking to [my parents], and they helped me through all these anxious worries and problems in the past." *21 yo woman, chose not to learn genomic research results*

### Factors Influencing Low Decision Stability (N=7)

- Familial influence
- Worry or anxiety about:
  - Learning positive results
  - Not knowing all results

## CONCLUSIONS

- Study participants demonstrated considerable decision stability, with increasing confidence in decision-making over time. A window of opportunity to make changes promoted confidence with final choices. Overall, most participants did not express regrets about their decision regarding learning personal genetic information.
- Individuals who experienced lower levels of decision stability (n=7) were more likely to be over the age of 18 (n=6), challenging the normative assumption that low decision stability is more likely to occur among minors when decision-making involves a parent.
- Although configuring decision-making as a process rather than a singular event may be feasible in research contexts, this decision-making model implemented in the clinical trial contradicts clinical practice norms of single point decision-making. Additional research is needed to determine feasibility and outcomes of offering patients opportunities to change their decision regarding opportunistic analysis for secondary findings genomic screening.
- Potential logistical and ethical complexities of translating approaches used to promote adolescent-engaged decision-making in genomic research to precision medicine include multiple decision-making points, opportunity for independent and shared decision-making, and the option to learn all, some, or no genomic results.

## ACKNOWLEDGEMENTS

Research reported in this poster was supported by the Mayo Clinic Center for Individualized Medicine and the National Human Genome Research Institute of the National Institutes of Health under award number R01 HG010166. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Center for Individualized Medicine or the National Institutes of Health.

## REFERENCES

- Myers, M., & McGowan, M. (2020 -). Engaging Adolescents in Decisions About Return of Genomic Research Results. National Library of Medicine (NLM) (U.S.). <https://www.clinicaltrials.gov/ct2/show/NCT04481081?term=engaging%20adolescents%20genetic&rank=1>
- Miller, D. T. et al. (2021). ACMG SF v3.0 list for reporting of secondary findings in clinical exome and genome sequencing: a policy statement of the American College of Medical Genetics and Genomics (ACMG). *Genetics in Medicine*, 23(8), 1381-1390.
- Pervola, J., Myers, M. F., McGowan, M. L., & Prows, C. A. (2019). Giving adolescents a voice: the types of genetic information adolescents choose to learn and why. *Genetics in Medicine*, 21(4), 965-971.