



# Participant Experience in Longitudinal Research

Elissa Z Faro, PhD  
Associate Professor, Pediatrics and Internal Medicine  
Center for Discovery and Innovation, Hackensack Meridian Health

ECHO Discovery  
Series

April 8, 2026



# Acknowledgements

- ECHO Participants, especially the Participant Action Board
- Analysis and Manuscript “Characterizing Participant Experience in Longitudinal Research: How and Why Engagement Matters in the ECHO Program”
  - Co-leads Traci Bekelman, Monica McGrath, Garrett Fuselier
  - Qualitative subgroup Amber Anderson, Constance Wilson, Fadia Chehadeh, Greta Wilkening, Haley Peele, Kathi Huddleston, Melissa Murphy, Nicole Mathews, and Paige Coyne
  - Writing Team
- ECHO Engagement Team Amber Anderson, Nina Keita, Lorraine Trim
- No conflicts of interest



# AGENDA

Overview of current landscape on participant experience in longitudinal research

EC0660: “Characterizing Participant Experience in Longitudinal Research: How and Why Engagement Matters in the ECHO Program”

- Positive research experience is multidimensional; respectful, family-centered, and crucial for maintaining engagement and satisfaction.

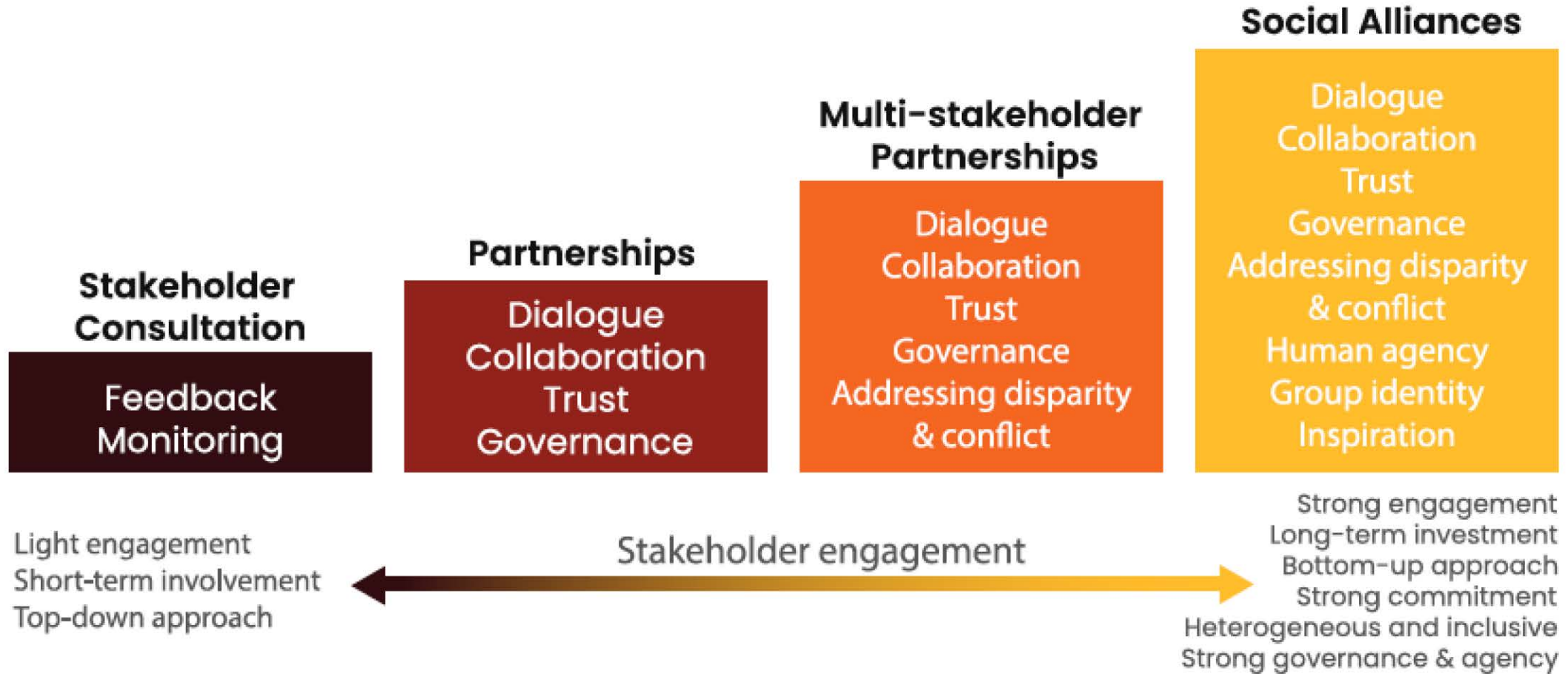
Current Participant Engagement work in ECHO Cohort Cycle 2

Conclusion & Discussion



**BACKGROUND**

# Continuum of Engagement



# The Landscape of Participant Engagement Research

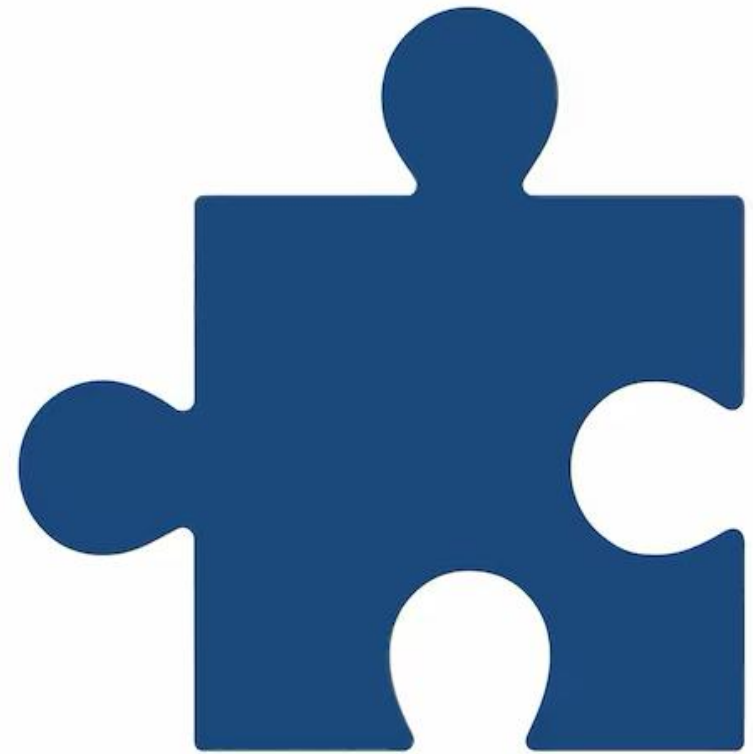
- Potential of longitudinal research frequently undermined by participant attrition and lack of engagement over the long-term, which can reduce statistical power, introduce bias, and limit generalizability.
- A better understanding of participant experiences can improve retention, enhance representativeness, and strengthen the overall quality of longitudinal research.
- Existing work has conceptualized participant experience as complex and highly varied, multidimensional, and existing along a spectrum
  - Recurring domains include: sense of belonging, motivations to continue, perceived benefits, consequences of participation, meaning derived from participation, trust, and the level of personal investment in the study

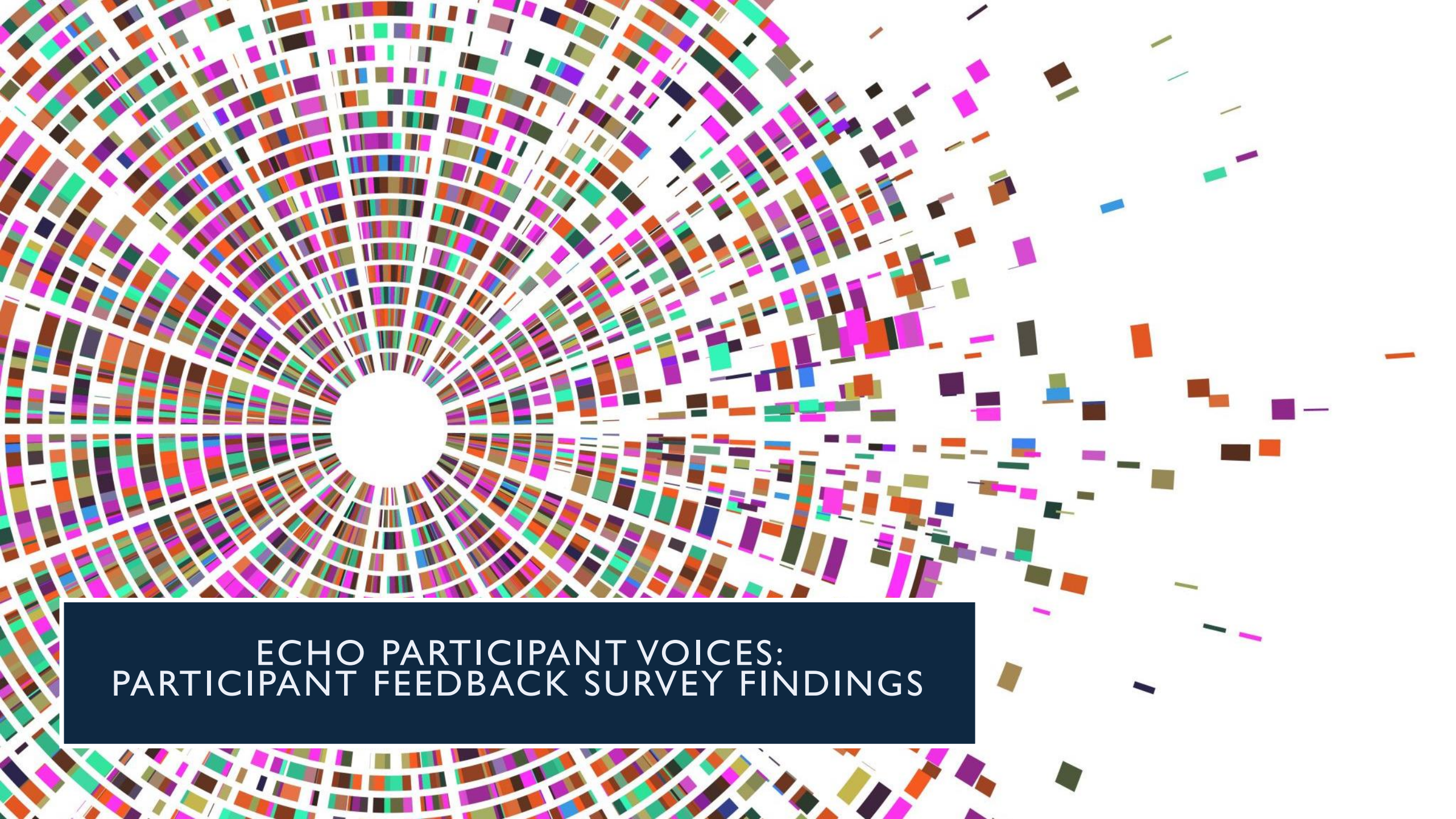
# Gaps in the Existing Literature

Research on participant experience has been:

1. predominantly assessed in clinical trials, with less consideration in other study designs
2. rarely assessed in pediatric studies or longitudinal birth cohort studies
3. often conducted outside the US
4. Infrequently multiple methods
5. Limited regarding barriers explaining low participation by minorities in biobanks

Finally, there is no standardized methodology to characterize participants' experiences in research, or even an agreed-upon definition.





ECHO PARTICIPANT VOICES:  
PARTICIPANT FEEDBACK SURVEY FINDINGS

# EC0660: Characterizing Participant Experience in Longitudinal Research: How and Why Engagement Matters in the ECHO Cohort

## Objectives

- Characterize participant experiences of those who responded to the ECHO Participant Feedback survey using both quantitative and open-ended responses,
- Examine variation in participant experience across sociodemographic characteristics including age, maternal education, race, and ethnicity.
- Explore the relationship between participant reasons for participation and how they characterize their experience with ECHO study visits across participant characteristics.
  - *Primary hypothesis:* participants who perceived the time required was appropriate, felt that their participation was valued, and were satisfied with the return of results would be more likely to recommend study participation to others.

# ECHO Cycle I\* Participant Feedback Survey

## Caregiver

- Inclusion criteria
  - Consented to ECHO data collection protocol
  - Respondent was biological mother with ECHO child less than <21 years old
  - Data available on 4 questions
- Sample size: N = 42 cohorts\* with 7,737 participants
  - Selected first completed form, if multiple forms for a family unit existed

## Adolescent

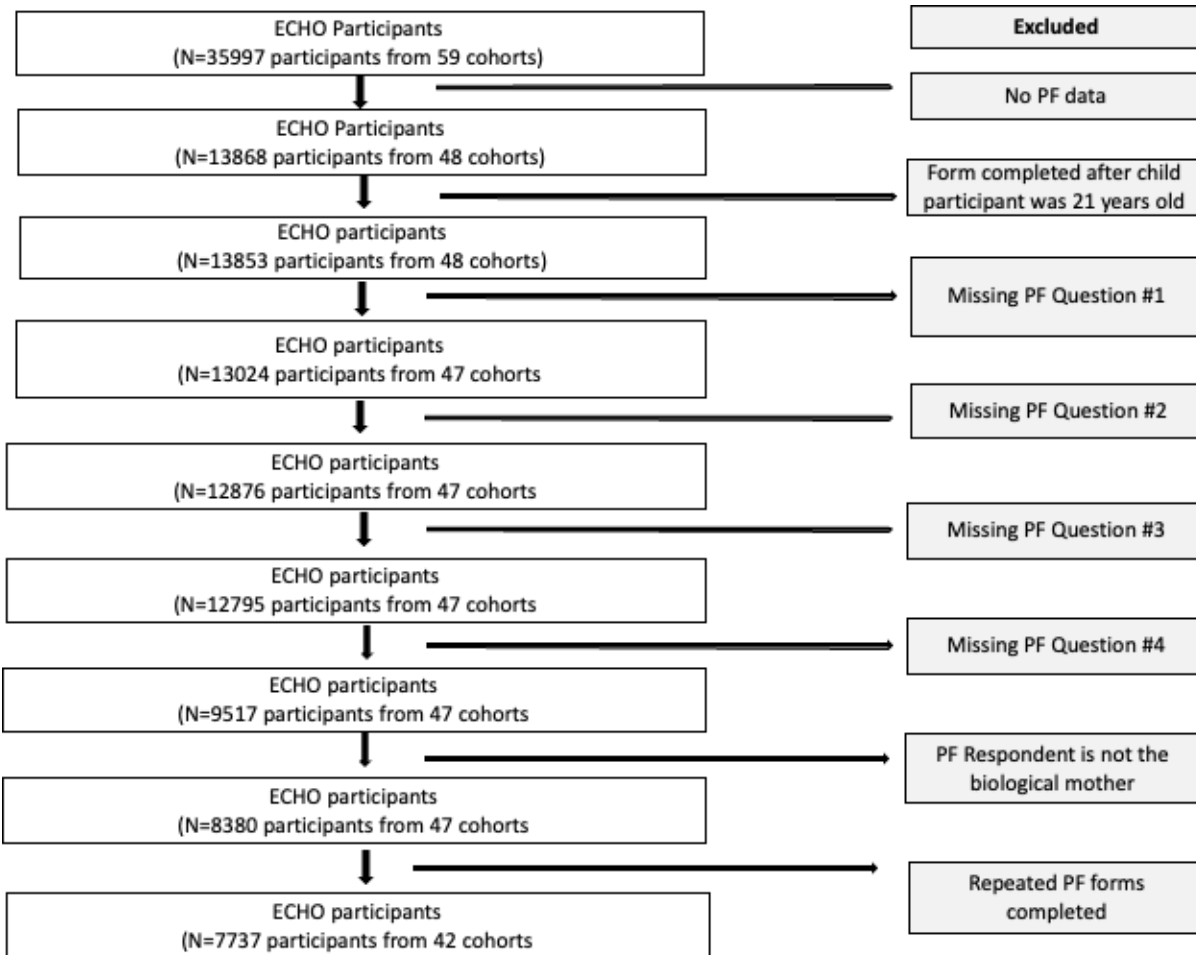
- Inclusion criteria
  - Consented to ECHO data collection protocol
  - Respondent was adolescent child
  - Data available on 4 questions
- Sample size: N = 15 cohorts with 793 participants
  - Selected first completed form, if multiple forms existed



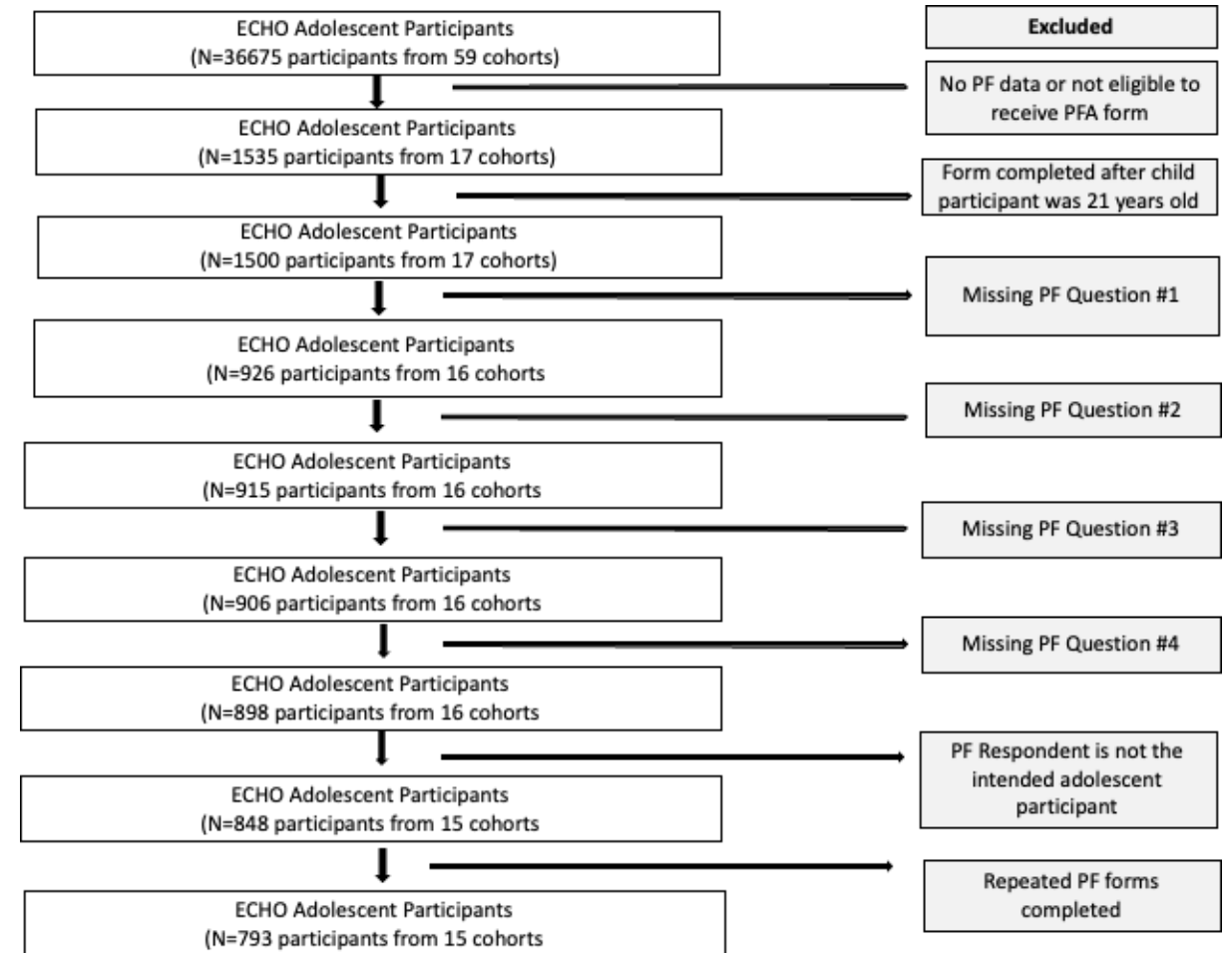
\* ECHO Program (2019 – 2023)

# Flow diagram for Sample with Completed Participant Feedback survey

\* ECHO Program  
(2019 – 2023)



**Caregivers Participant Feedback (PF) Form**



**Adolescent Participant Feedback (PFA) Form**

# Caregiver Survey Questions and Preliminary Analysis of Variables of Interest

Question	Responses	
What was your reason for participation in this study?		
Based on your experience with this study in the last 12 months, would you recommend participating in this study to others?	No	210 (2.7%)
	Yes	7527 (97.2%)
How do you feel about the amount of time that has been required to participate in this study during the last 12 months?	Too much	504 (6.5%)
	Less than expected/just right	7233 (93.5%)
Do you feel like your time and participation in this study are valued?	No	101 (1.3%)
	Yes	7636 (98.7%)
Does the information provided so far about your / the child's results meet your expectations?	Did not meet expectations	126 (1.6%)
	Met or partially meet my expectations	5164 (66.7%)
	No Info	2447 (31.6%)
How could we improve information provided about your/child's results?		
How important to learn results of national ECHO study?		
Suggestions to make participation easier?		

# Adolescent Survey Questions and Preliminary Analysis of Variables of Interest

Question	Responses	
What was your reason for participation in this study?		
Based on your experience with this study in the last 12 months, would you recommend participating in this study to others?	No	58 (7.3%)
	Yes	735 (92.7%)
How do you feel about the amount of time that has been required to participate in this study during the last 12 months?	Too much	18 (2.3%)
	Less than expected/Just right	775 (97.7%)
Do you feel like your time and participation in this study are valued?	No	24 (3.0%)
	Yes	769 (97.0%)
Does the information provided so far about your results meet your expectations?	Did not meet expectations	7 (0.9%)
	Met or partially meet my expectations	554 (69.9%)
	No Info	232 (29.2%)
How could we improve information provided about your/child's results?		
How important to learn results of national ECHO study?		
Suggestions to make participation easier?		

# Qualitative Analysis: Open-Ended Responses

## Sample

- 7548 caregivers provided an open-ended response
- 794 adolescents provided an open-ended response
- 8 domains/questions responded
  - Same as survey questions plus 1 open-ended question eliciting suggestions for making their participation in ECHO easier

Subgroup of this writing team met to brainstorm analytic strategies

Two approaches to summarizing findings: (1) valence and (2) themes

- **Valence:** each response was read and categorized as positive, neutral, or negative
- **Theme:** The WT subgroup read all responses and suggested potential themes/codes
  - WTL synthesized suggestions and created list of 9 themes

Subgroup members assigned one theme to each of the 8,000+ responses - THANK YOU!!

- Kathi Huddleston, Constance Wilson, Fadia Chehadeh, Nicole Mathews, Paige Coyne, Amber, Anderson, Melissa Murphy, and Haley Peele

Two WT members (thank you, Traci Bekelman) then reviewed the responses by theme

- developed summaries of findings by theme, and general impressions of valence
- extracted exemplar quotations or unusual sentiments
- triangulated with quantitative data together with Monica McGrath and Garrett Fuselier at the DAC

# Qualitative Findings: 8 themes reflecting participants' motivations, experiences, and expectations

## Compensation

*It is a great way to earn some money and help my child understand different ways she can contribute, learn, and be exposed to new people and career paths. (PID 2139)*

## Participant-focused

*It is easy to fill out the surveys and they make the in-person visits easy for the parent and fun for the child. (PID 4332)*

## Altruism

*All scientific research is important, especially studies that will help improve the health and well being of children now and in the future (PID 866)*

## Experience of Participation

*"I did not anticipate the LARGE volume of surveys—I have two toddlers already at home and work full time" (ID 6818)*

# Qualitative Findings: 8 themes reflecting participants' motivations, experiences, and expectations

## Time/Effort

*Some of the surveys were very lengthy and repetitive... would appreciate a 'no changes' option (PID 142)*

## Return of Results

*I would love to know everything there is to know about my kids, especially if there is something I can help with or make better. But I understand that isn't the objective of the study and the people gathering information don't have time to report back to me on everything, so I am okay to participate and hope it helps future generations. (PID 392)*

## Opportunity to Learn

*You're not only learning about you and your child and the effects of smoking long term you are not alone. You also help others by participating. Everyone can learn from one another and help us understand what we're doing to our bodies. I also love science. (PID 1675)*

## Other

*no comment*

**Other**  
*cool*



**What Does It Mean?**

# A Multidimensional Model of Engagement

- Multidimensional nature of participant experience in longitudinal studies and the importance of addressing both practical and relational aspects of engagement
  - dynamic interplay of altruism, reciprocity, and trust
  - Participants' motivations rooted in contributing to science and helping future generations
  - Desire for reciprocity including feedback, compensation, and respectful engagement
  - Need to feel contributions were acknowledged and impactful
- Importance of creating environments where children and families feel empowered to participate fully, from study design through dissemination

# KEY TAKE AWAYS

- Clear communication
- Respectful treatment
- Recognition of participant time and effort
- Reciprocity
  - material (compensation, return of results)
  - subjective (feeling valued, trust)
- Temporal dimension of engagement in long-term studies



The background features a complex network of thin, light-colored lines connecting various sized circles. The circles are primarily orange and red, with a concentration of purple circles at the bottom. The overall effect is a dense, interconnected web of nodes and edges, suggesting a network or data visualization.

# ECHO COHORT PARTICIPANT ENGAGEMENT

# ECHO Participant Engagement

## Participant Action Board

To provide insight into and represent participant interests while advising researchers on how their research goals could be attained.

## Our ECHO, Our Health Events

Build upon existing cohort study site social media presence to create a unifying forum to engage ECHO Cohort participants around research and lived experience relevant to them.

## Return of Research Results

Develop processes to return research results (both aggregate and individual) in a manner that accommodates the full spectrum of community needs and preferences.

# Participant Action Board Mission, Vision, and Values



## **MISSION**

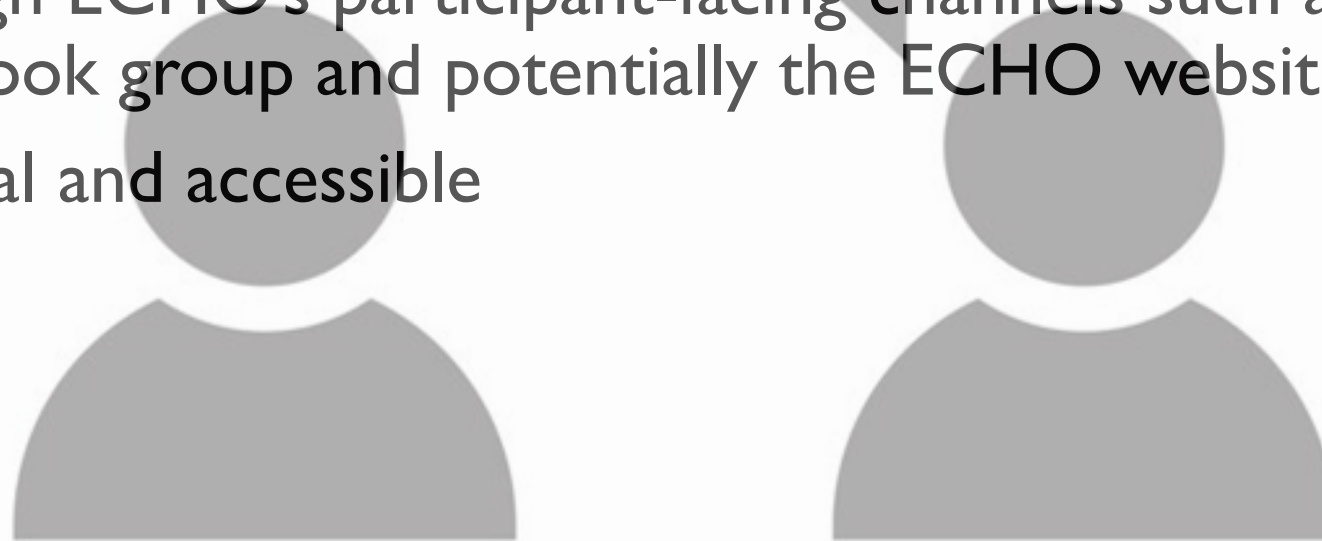
To foster ECHO partnerships by providing real life experiences as ambassadors for participants in all areas

## **VISION**

To create a space where participants' voices and lived experiences shape research

# ECHO Conversations

- Co-developed with the Participant Action Board
- Participant Action Board members are paired with ECHO Cohort investigators to have recorded conversations about topics that are important to our participant families
- Shared through ECHO's participant-facing channels such as the ECHO Facebook group and potentially the ECHO website
- Conversational and accessible



**Our Echo, Our Health**  
 Private group · 559 members

Manage

- Community home
- Overview

Admin tools ^

- Admin Assist**  
2 actions, 2 criteria
- Member requests**  
0 new today
- Badge requests**  
0 new today
- Membership questions**



## Our Echo, Our Health

Private group · 559 members



+ Invite

Share

# OUR ECHO OUR HEALTH

Periodic, live events on Facebook, co-led by investigators and participants to engage the ECHO Cohort participant, family, and community audience in real time to build community

# Return of Individual Results

- Dietary Health Questionnaire III (DHQ III) report in field as of 2025
- Height and Weight to be returned starting April 2026
- Sleep Health
  - Includes items from ECHO Sleep Health and Media Use measures
  - Reviewed by ECHO Sleep Health experts and ECHO Data Collection Form Task Force for alignment with science and existing ECHO language
- Future Return Recommendation (i.e., Accelerometry)
  - Recommended by Implementation Fidelity TF
  - Pregnant women and children
    - Data being measured: steps, sleep and heart rate





# CONCLUSION AND DISCUSSION

# Key Takeaways

1

Our participants are highly satisfied, largely thanks to the excellent work of our site staff.

2

Positive experience is multidimensional, resting on both **relational** and **practical** aspects.

3

Our research findings are not just academic; they are actively informing the strategic direction of participant engagement in **ECHO Cohort Cycle 2**.

- + •
- o •
- Based on these findings, what is one practical change or reinforcement we can implement across the ECHO Cohort to further enhance relational components of engagement?
- What are the biggest logistical challenges our cohort study sites are facing across the ECHO Cohort, and how can we address them collectively?
- How can we maximize our 'Return of Results' initiatives to not just inform, but also re-engage participants for the long term?

## DISCUSSION





# THANK YOU FOR YOUR TIME

Please feel free to reach out with  
any questions:

[elissa.faro@hmh-cdi.org](mailto:elissa.faro@hmh-cdi.org)