NATIONAL ACADEMIES Sciences Engineering Medicine

Next-Generation Screening – The Promise and Perils of DNA Sequencing of Newborns at Birth: A Workshop

Natasha Bonhomme, Workshop Co-Chair

Cathy Wicklund, Workshop Co-Chair

JUNE 7, 2023

Goals of the Workshop

- Examine the known and expected benefits, and potential harms, of the widespread utilization of newborn DNA sequencing.
- Explore the ethical and data security and ownership issues associated with DNA sequencing of newborns at birth.
- Address issues of next-generation newborn screening equity in the United States.
- Explore the scope of recently initiated programs investigating newborn DNA sequencing as a screening tool in diverse healthy newborn populations.
- Engage families, patient advocates, and public health system representatives to provide their views on the need, impact, readiness, and risks of newborn DNA sequencing.

Planning Committee Members

Natasha Bonhomme, (*workshop co-chair*), Expecting Health

Cathy Wicklund (*workshop co-chair*), Representing National Society of Genetic Counselors, Northwestern University

April Adams, Baylor College of Medicine

Amy Gaviglio, Connetics Consulting LLC

Aaron Goldenberg, Case Western University

Alex Kemper, The Ohio State University College of Medicine

Molly McGinnis, Genome Medical, Inc.

Ryan Taft, Illumina, Inc.

Joyce Tung, 23andMe, Inc.

Karen Weck, Representing College of American Pathologists, University of North Carolina at Chapel Hill

Background and Context

The Roundtable adopted a new strategic plan in 2020.

Vision: Realizing the full potential of health for all through genomics and precision health

The idea for this workshop began with the **Innovation** working group

Scope for this workshop

- Examining sequencing in healthy newborns.
- Thinking about ethics and equity throughout the day.
- Not asking if sequencing in healthy newborns should be done, but as it is already being implemented, how can it be done responsibly and equitably moving forward?

Agenda

- Session I: Opening Remarks & Keynote
- Session II: Lessons Learned from Newborn Genomic Testing and Screening
- Session III: Implementing Newborn Sequencing at Scale – Health System Challenges & Opportunities
- Session IV: Deploying Newborn Sequencing Responsibly and Equitably
- Session V: How will Newborn Sequencing Change the Trajectory of Precision Health
- Session VI: Final Reflections

Best Practices for our Hybrid Workshop

In-Person

- Speak into a microphone, stating your name and affiliation, before asking a question
- Please be present and engaged
  - e.g. limit distractions and use of other devices in the room not related to the meeting

Remote

- Use the Slido box to share your questions for the panelists
- Please be present and engaged

Reminders

- Speaker bios can be found in the briefing book located on the workshop webpage
- We have a full agenda and will be strict with timing of talks
- A survey will be shared with you after the workshop to collect your feedback
- A Proceedings–in Brief from this workshop will be released later this year to capture the discussions
- Thank you for joining us!