

LISTENING SESSIONS: WHAT TO EXPECT

Newborn Screening: Current Landscape and Future Directions

OVERVIEW

The National Academies of Science, Engineering, and Medicine (National Academies) *Committee on Newborn Screening: Current Landscape and Future Directions* is hosting online listening sessions to understand various perspectives about America's newborn screening. In addition to these listening sessions, the committee is also learning from interested and impacted people through a questionnaire, and comments submitted through the project website. Learn more [here](#).

This effort is sponsored by the Department of Health and Human Services Office on Women's Health in response to a Congressional request. Supplemental funding was provided by the Chan Zuckerberg Initiative to enable enhanced community engagement.

Five listening sessions are being held in spring 2024, for the following groups:

- *Newborn screening professionals*. Wednesday May 1: noon Eastern / 9am Pacific. For lab directors and staff, follow up directors and staff, and others involved in newborn screening testing.
- *Rare disease patients, families and advocacy organizations*. Sunday May 5: 1pm Eastern / 10am Pacific. For individuals and families impacted by rare diseases, as well as people involved in organizations that advocate for people with rare diseases.
- *Health administrators, payors, and healthcare industry*. Monday May 6: noon Eastern / 9am Pacific. For those who administer state newborn screening programs, organizations that pay for health care services, and businesses that develop tests, devices, procedures, therapies, etc. for newborn screening and associated results.
- *Families (general)*. Saturday May 11: 1pm Eastern / 10am Pacific. For families whose babies did, or didn't, participate in newborn screening.
- *Healthcare providers*. Monday May 13: noon Eastern / 9am Pacific. For clinical care providers involved in newborn screening including pediatricians, neonatologists, disease specialists, and nurses.

ABOUT NEWBORN SCREENING

Each state and territory in the United States has its own newborn screening program run by the state public health department. These programs make sure babies are screened for certain conditions before they leave the hospital. The goal is to help identify treatable conditions before a baby develops problems. Finding and treating these conditions early in babies' lives can prevent brain damage, physical disabilities, costly medical care, and death.

Newborn screening involves a series of tests: tests done on blood spots, hearing tests, and congenital heart tests. These tests occur in the hospital 24-48 hours after birth. **This discussion will focus only on the bloodspot tests.**

The federal government provides advice to states on a list of conditions to consider including in routine, public health newborn screening programs. Guided by this federal list (called the "recommended uniform screening panel"), each state chooses to screen for diseases and conditions

based on the unique needs of their populations and other factors including legislative requirements, budget, workforce availability, and technological resources. These conditions tend to:

- Urgently need treatment as early in life as possible
- Likely produce serious health effects if untreated, and
- Have an available medical treatment

Newborn screening programs have to balance their mandate to screen all the infants born in the US (approximately 3.6 million a year) with the individual needs of each baby and family. Within the newborn screening program itself, public health professionals play key roles in connecting babies identified through newborn screening with diagnostic testing, parental education, and follow-up care.

Newborn screening programs also work with partners in a larger system that supports the identification, follow-up, and treatment of babies with these conditions. These partners include regulatory agencies, clinical care, advocacy groups, research, patients, parents, among others.

ABOUT THE LISTENING SESSIONS

Listening Session Format

Please plan to join for the full session. These 2.5 hour interactive discussions will invite you to share your views on key topics such as:

1. Strengths and challenges of today's newborn screening in America
2. Changes to newborn screening that might better address health inequities
3. How the system can better respond to results of newborn screening that are uncertain
4. What should guide whether new diseases are added to newborn screening
5. Advice for the NASEM committee, particularly about how to strengthen the future of newborn screening

The majority of the listening session will be held in small group discussion so you can share your views and hear from others. Facilitators and notetakers will support your discussions.

Technology Requirements

To engage with this online event, you will need a computer (laptop or desktop), tablet or smartphone, with speakers or headphones.

We recommend that you use a computer for the best experience of this event. Some interactivity and accessibility features are not available when using a smartphone or tablet.

Accessibility

The focus groups will be held online, with closed captioning available. Discussion materials will be sent in advance. If there is anything we can do to better accommodate your participation, please contact Emily McDowell [EMcDowell@nas.edu]. Advance notice is necessary to arrange for some accessibility needs.

Waiting List

If your desired session is full, please join the waiting list, and we will notify you if a registration space becomes available.

PARTICIPATION GUIDELINES

- Please plan to participate for the full duration of the listening session.
- We strive to ensure the safety of participants and speakers. There will be zero tolerance for those who promote violence against others on the basis of race, ethnicity, national origin, sexual orientation, gender identity, religious affiliation, or different ability.
- Respect the opinions of others. Every participant brings information, points of view and ideas to contribute.
- Respect the privacy of participants—do not share what is said in your listening session with other people.
- Share opportunities for airtime equally. If you've asked a question or shared a comment, ensure that new voices are heard before you contribute again.
- Practice self-care: if you need to get up or take a break, please feel free.

Your participation in this focus group activity is voluntary, and you may withdraw your acceptance at any time via an email to Emily McDowell [EMcDowell@nas.edu]. Additionally, if, for any reason, you want to leave the focus group before the scheduled finish time, please use the chat function to send an individual Zoom message.

DATA COLLECTION AND PRIVACY

You will be asked at the beginning of the listening session to consent to an audio recording of the session. Your participation is voluntary, and you can decline to comment on any topic that is put to the group for discussion. The audio recording and a transcript prepared by National Academies staff will be stored on password-protected Academies servers until the end of the calendar year. Those who will have access to this meeting recording and transcript will include National Academies staff and the engagement consultant, Susanna Haas Lyons Consulting. Your identity will be kept confidential, and you will not be identified or quoted without your express permission in any publicly available report.

Your responses will be included in a publicly available thematic summary and analysis of input on newborn screening in America, but will not attribute any response to you without your express permission. Susanna Haas Lyons Consulting will conduct this analysis and draft this summary and it will be shared with the National Academies committee examining Newborn Screening: Current Landscape and Future Directions and made publicly available.