



# Innovations in Newborn Screening Interoperability

A National Resource Center

## Advancing Electronic Data Sharing for Newborn Screening Programs

Craig Newman, PhD, Altarum

ACHDNC, February 10, 2023



# Innovations in Newborn Screening Interoperability

A National Resource Center

## **No conflict of interests to disclose**

*This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The contents are those of the presenter and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov).*



# What is Interoperability?



It is the ability of different information systems, devices and applications to **access, exchange, integrate and cooperatively use data** in a coordinated manner, **within and across organizational, regional and national boundaries**, to provide timely and seamless portability of information and optimize the **health of individuals and populations**.

# Why Interoperability Matters



## **Newborn Screening Programs benefit through:**

- Timely, accurate and complete screening results
- Enhanced care coordination
- Improved quality assurance, patient safety and health equity
- Better communication and transparency with patients, providers and birthing hospitals

# The INBSI Program



Goal: to reduce morbidity and mortality associated with heritable disorders in newborns and children by enhancing connectivity between state public health newborn screening (NBS) programs and health care providers.

- Provide **technical assistance** to state NBS programs
- Access to **training and education** in data interoperability
- Promote **collaboration** between newborn screening programs

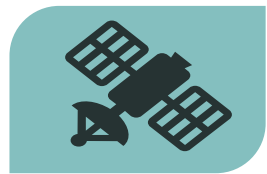
Team members:

- Altarum
- OZ Systems, PerkinElmer
- American Academy of Pediatrics
- University of Michigan Child Health Evaluation and Research Center

# Technical Assistance Program



- The collaborative Readiness Assessment process involves staff from state newborn screening programs, INSBI subject matter experts, and relevant partners
- A series of discovery sessions are conducted to document the 'current state' interoperability environment
- Leading to an Interoperability Roadmap outlining strategic approaches and recommendations for achieving goals



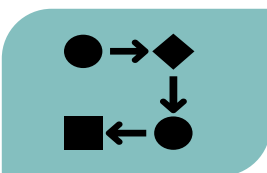
**TECHNICAL  
INFRASTRUCTURE**



**BUSINESS NEEDS  
AND GOALS**



**ONBOARDING**



**DATA FLOWS**



**PROJECT PLANNING**



**RESOURCE  
CAPACITY**

# Training and Education



## Webinars

- Happen monthly
  - Closing the CCHD gap
  - Breaking down silos
  - Hospital engagement
  - HIEs



## On-Demand

- Available on the Resource Center
  - Interoperability standards
  - Onboarding and testing
  - Logic Modelling
  - USCDI, ISA and Project US@



## Project ECHO

- Virtual learning collaborative
- Connect with subject matter experts
- Brief lectures and real-life case studies





# Outcomes: Challenges



## **Most programs are experiencing multiple challenges:**

- Competing priorities for resources within their jurisdiction
- Potential data submitters have competing priorities
- Gaps in technical and workforce capacity
- Access to sustainable funding
- Pilots for electronic data sharing losing momentum
- Siloed EHDI, CCHD and Dried Blood Spot (DBS) programs
- Lack of funding and policy for CCHD programs
- Vendor changes and antiquated information systems
- Lack of leadership buy-in (DoH and hospitals)

# Outcomes: Lessons Learned



## **Through the INBSI program we have found that:**

- Newborn screening programs thrive when collaborating with other states/jurisdictions
- Interoperability helps identify gaps in follow up care for newborns and can be a tool for addressing health equity
- Not all state programs are aiming for an HL7 specific interoperability solution (but many are)
- Synergy of sharing data and the importance of thinking about newborn screening as a whole and not just as individual programs

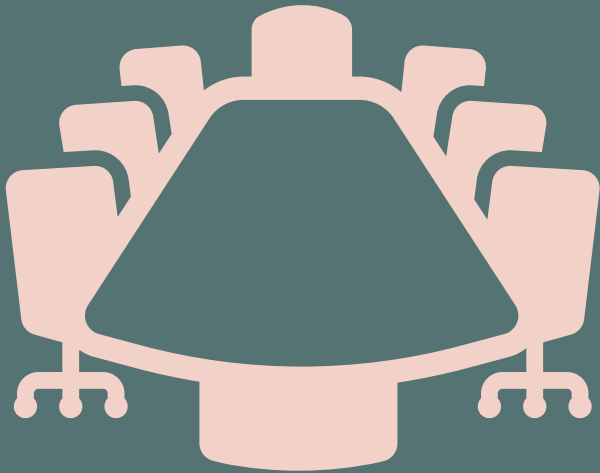
# Outcomes: Making Progress



## **Newborn Screening Programs are overcoming challenges to implementing their interoperability goals by:**

- Strengthening resources
  - Recruiting new staff
  - Identifying funding opportunities
  - Identifying participants/leaders/project champions
- Collaborating with other states/jurisdictions and subject matter experts to share tools, lessons learned and tricks of the trade
- Utilizing learning opportunities to build workforce capacity
- Utilizing INBSI roadmaps for implementing HL7 standards for newborn screening (DBS, EHDI and CCHD)

# The INBSI Advisory Board and Faculty



---

Willie Andrews

---

Amy Gaviglio

---

Brandan Kennedy

---

Rachel Lee

---

Elizabeth Mikula

---

Ashleigh Ragsdale

---

Paul Romitti

---

Dan Rutz

---

Annamarie Saarinen

---

Joe Schneider

---

Marci Sontag

---

Susan Wiley

---



# Innovations in Newborn Screening Interoperability

A National Resource Center

## Thank you

Visit [www.nbsinterop.org](http://www.nbsinterop.org) for more details

Or contact us at [nbsinterop@altarum.org](mailto:nbsinterop@altarum.org)

*This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](http://HRSA.gov).*