



Building Connections to Improve Outcomes

Amy Gaviglio, MS, LCGC

Disclaimer

- Some work presented here was completed during my employment at the Minnesota Department of Health, Newborn Screening Program.

Why NBS Needs to be More Connected

PRE-ANALYTICAL

- Accurate demographics = accurate results (*aka “Junk In, Junk Out”*)
- **Provides more accurate denominator**
- **Allows assessments of number of refusals**

ANALYTICAL

- Accurate application of cut-offs/screening protocols (*e.g., age or birthweight-based cut-offs; LBW serial screening protocols*)
- Reduce testing/interpretation delays
- Obtain accurate point-of-care screening results

POST-ANALYTICAL

- Reduce reporting errors between program and birth facility
- **Help find newborns with actionable NBS results**
- **Allows assessment of outcomes (*e.g., is NBS as effective as it can be?*)**

Vital Records

- **Matching specimens to birth certificates can help programs know who has and hasn't been screened and facilitate more timely follow-up**



Important to understand state statutory requirements re: filing of birth certificates

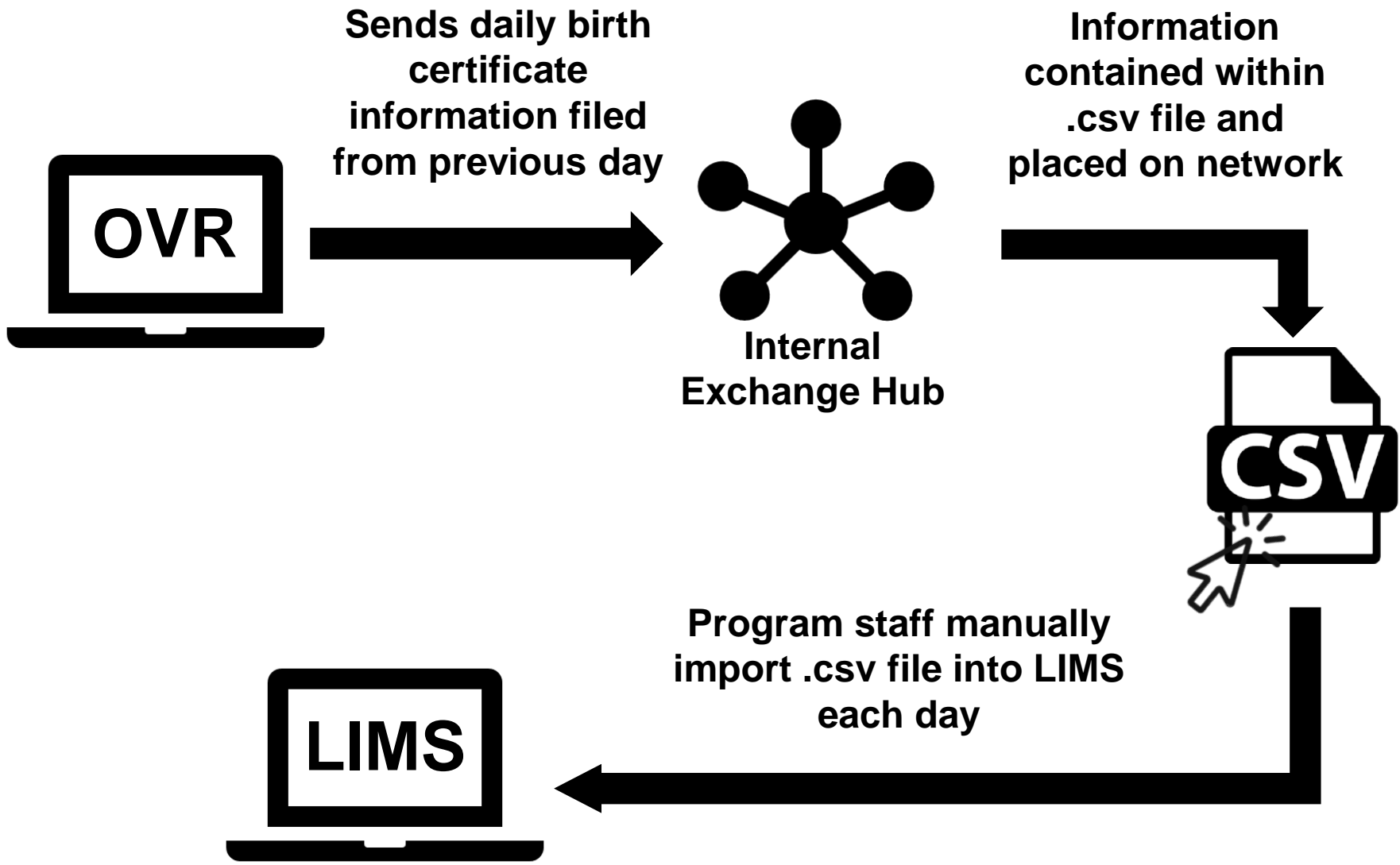


Understand limitations with out-of-hospital births and births attended by relatives

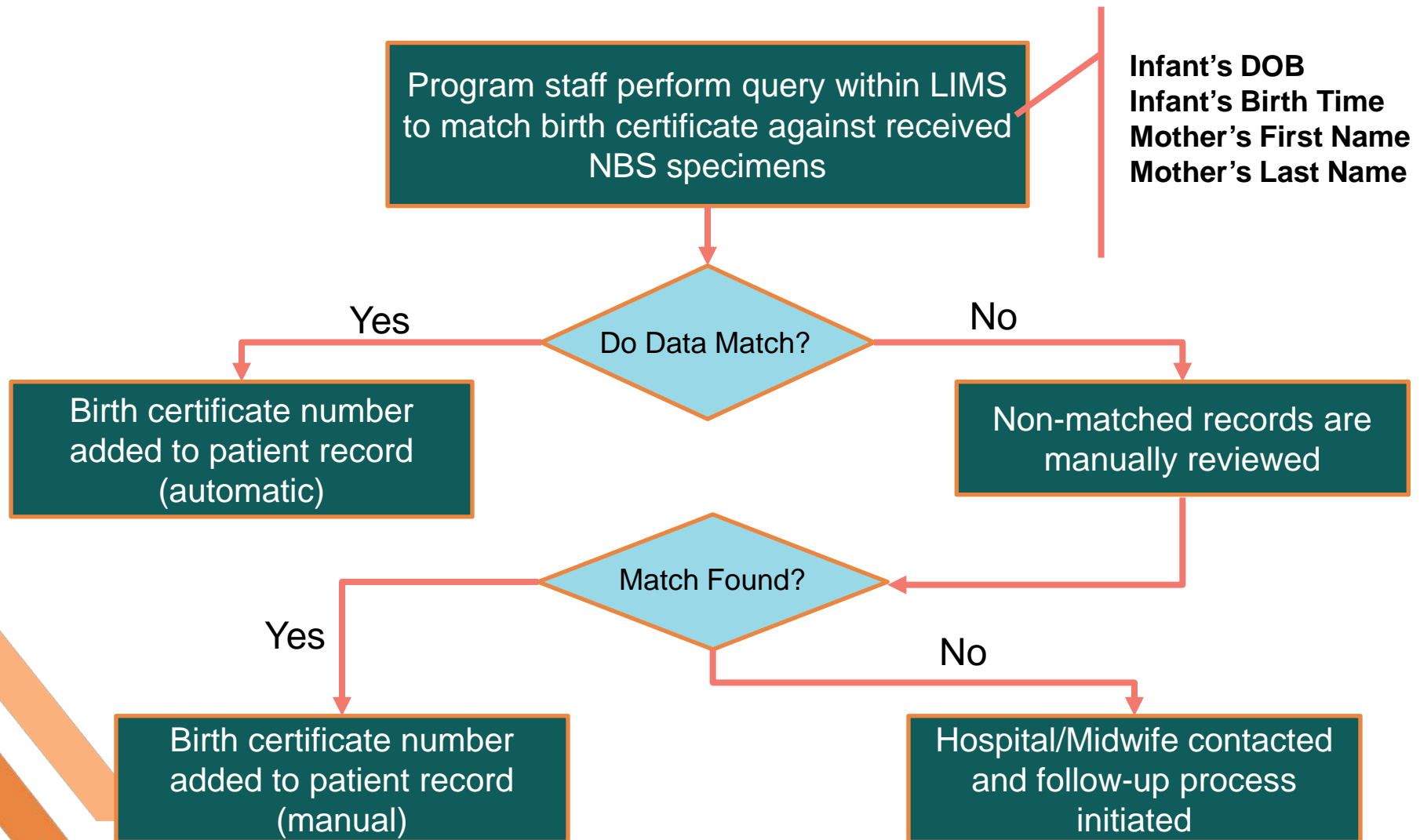


For matching to be most effective, it must be timely enough to allow for quick intervention by program staff

Vital Records to LIMS Connection



Making the Match



By the Numbers

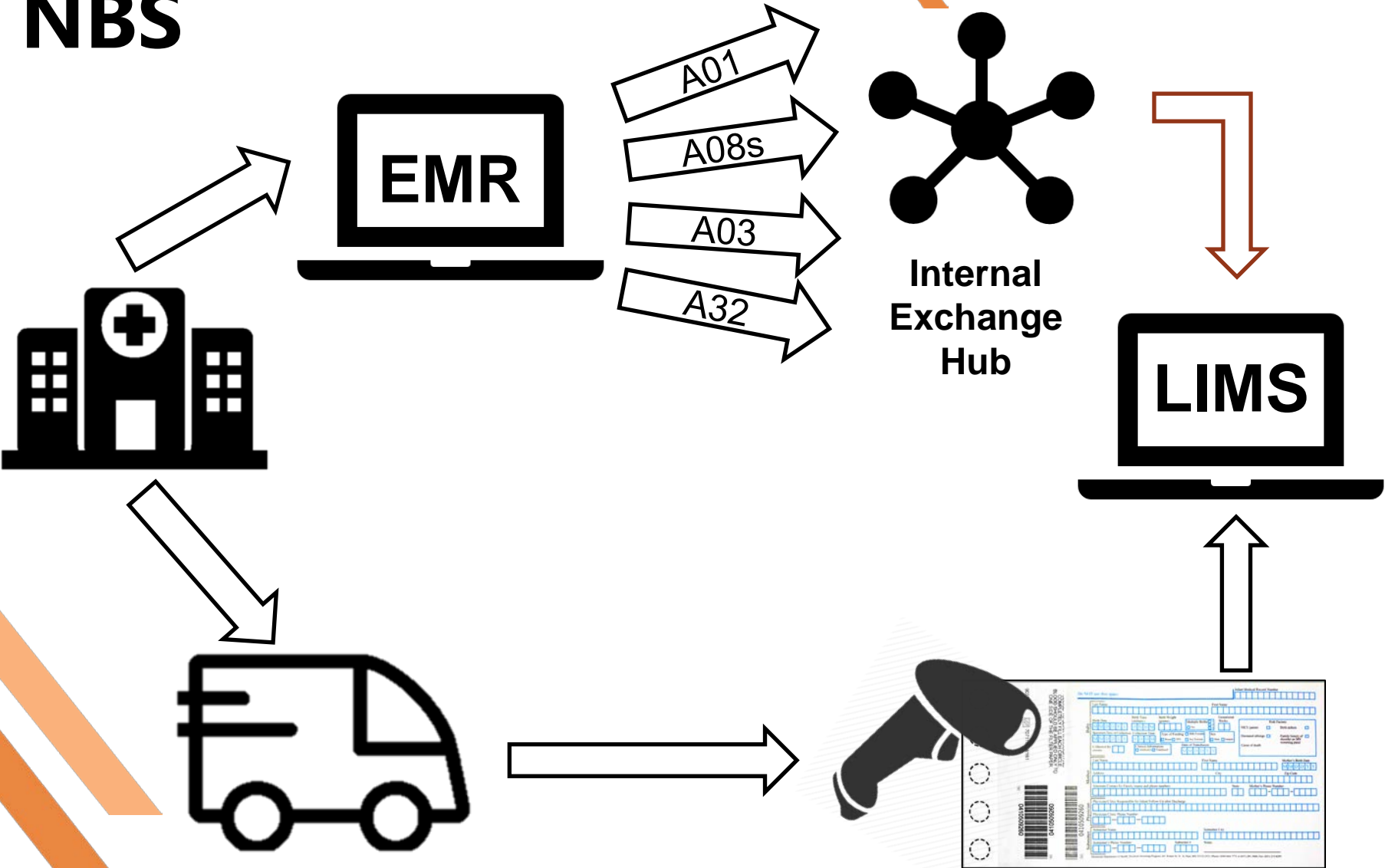
- **2018 to mid-2019:**
 - Median time from DOB to Birth Cert Match in LIMS = **5.3 days**
 - Median time from Birth Cert Filed Date to Match in LIMS = **2.3 days**
 - **Allows program to obtain specimens on missed children before most symptoms might occur**
- **What did we learn in 2018:**
 - 248 refusals
 - 158 infants born in MN, screened by border state
 - 43 infants whose specimens were “lost” and needed follow-up
 - 27 infants born to relative attendants
 - 42 infants “missed” - no refusal or specimen obtained after contact

NANI

- **Newborn Admission Notification Information (NANI)**
 - Describes information needed for timely communication of a newborn admission
 - Utilizes an HL7 ADT feed (ADT = Admission, Discharge, Transfer)
- **4 specific ADT messages are received:**
 - A01 = Patient admitted
 - A08 = Patient information updated (inpatient)
 - A03 = Patient discharged/end visit
 - A31 = Person information updated (outpatient)
- **Does not address out-of-hospital births**



OZ NANI™: EMR to NBS



Implementation

- Implementation plan developed
- First hospital engaged
- Continue implementation
- Continuous monitoring



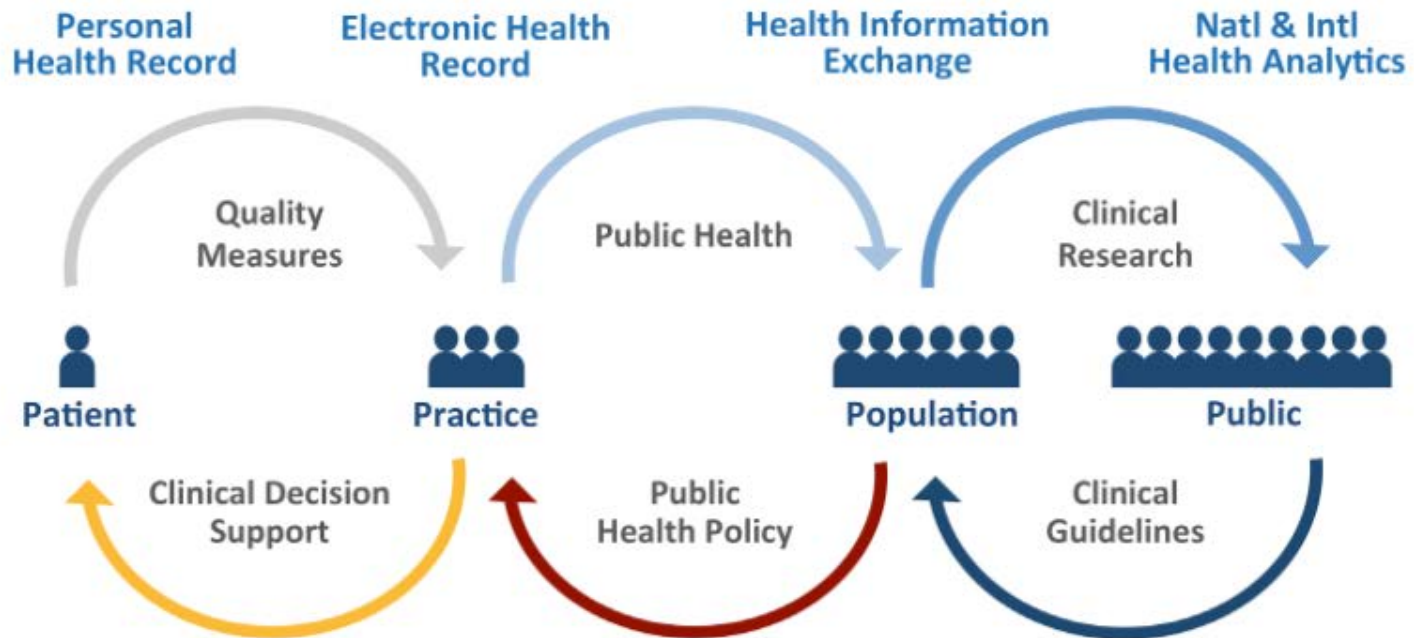
- Declared Meaningful Use/Promoting Interoperability to incentivize hospitals
- Ongoing hospital engagement

- All hospitals LIVE with NANI!

Other Connections...

- **Birth Defects Registries**
 - Understand missed cases (e.g., CCHD)
 - Understand co-morbidities and impact on screening (e.g., Down syndrome and Congenital Hypothyroidism)
- **WIC, CYSHN, and Local Public Health**
 - Ensure access to care and resources
 - Medical Foods and Formula
- **Reference/Clinical Laboratories**
 - Obtain follow-up clinical labs
- **Subspecialist EMRs**
 - Obtain post-diagnostic follow-up information
 - Alerted to new cases (e.g., false negatives)
 - Alert to change in clinical status (e.g., X-ALD now symptomatic)

Back to the Why: Health IT in Rare Disorders



Considerations

- **How does interoperability fit into other program priorities?**
 - Adding new disorders; maintaining day-to-day; providing access to treatments; long term follow-up; etc.
- **The interoperability Catch-22**
 - May save staff time and money, but need staff time and money up front to achieve this
- **There are lots of ways to become more connected – each program's starting point will be different.**

Next steps/Needs



MY GOAL IS THAT WE SET A PATH TOGETHER AND
A ROAD MAP SO THAT EVERYONE CAN BE BROUGHT ALONG.”

—KAREN B. DESALVO, MD, MPH, MSC, THE NATIONAL COORDINATOR FOR HEALTH INFORMATION
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Amy Gaviglio, MS, LCGC

agaviglio@gmail.com

MN NBS Program

Health.newbornscreening@state.mn.us