

Ensuring Newborn Screening in Wisconsin: Reconciling Individual Birth Certificates with Individual Newborn Screening Records

Rebecca Martin, MPH, IMH-E®(II); Elizabeth Seeliger, AuD; Gretchen Spicer, LPM, CM; Mei Baker, MD

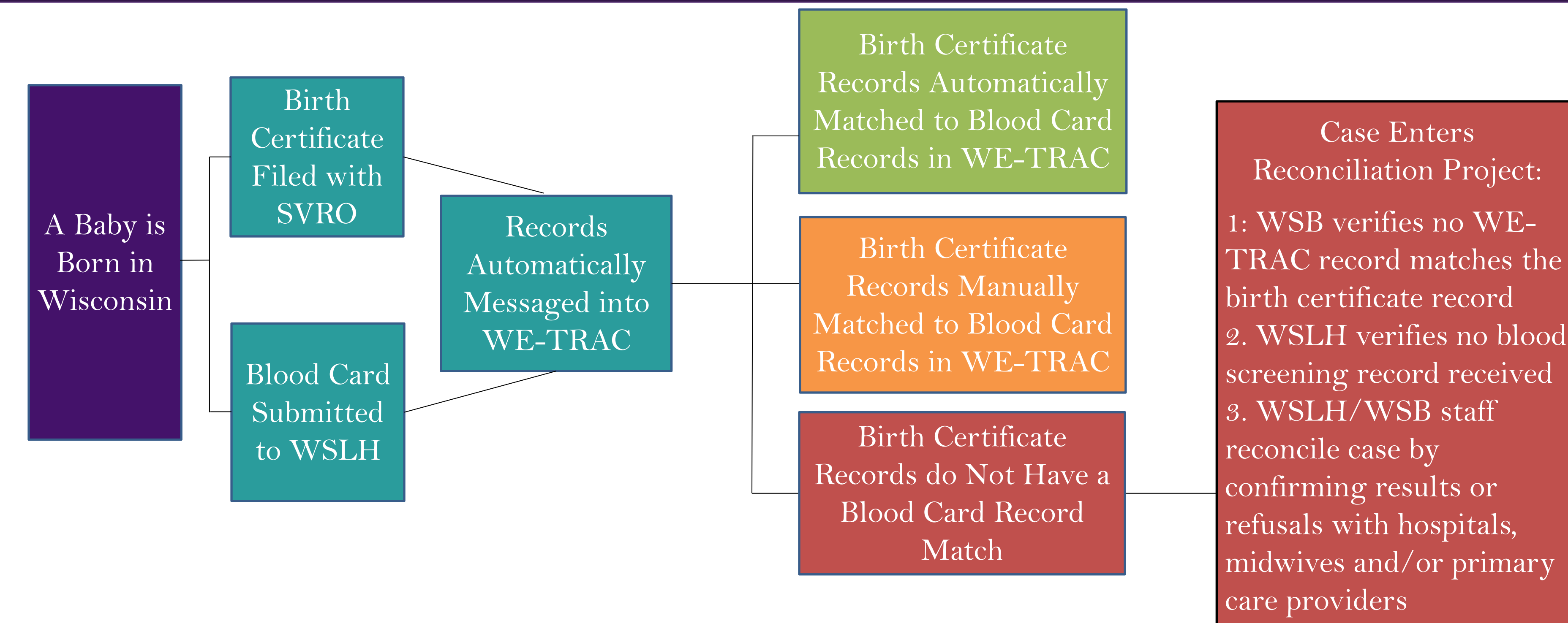
Wisconsin Sound Beginnings

Background

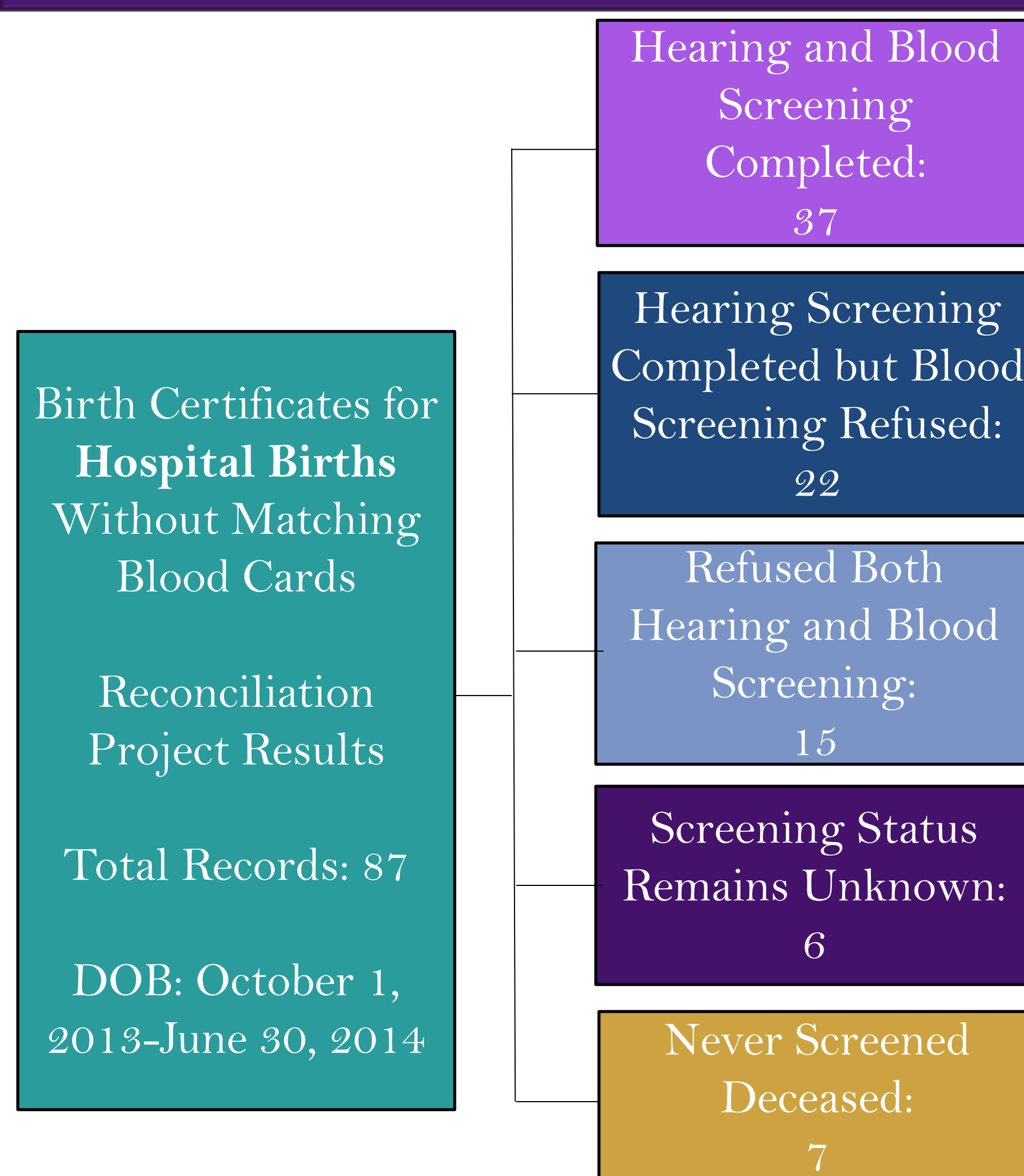
In 2012, Wisconsin Sound Beginnings (WSB) and the State Vital Records Office (SVRO) created a data exchange between WSB's data system, WE-TRAC, and the SVRO data system that allows a baby's WE-TRAC record via the newborn screening blood card from the Wisconsin State Laboratory of Hygiene (WSLH) to be matched with that baby's birth certificate record.

This blood card-birth certificate reconciliation project is part of an overarching quality assurance project for the integrated newborn screening program to document that all children born in Wisconsin receive newborn screening or have documented refusal.

This collaboration and data exchange provided, for the first time ever, the opportunity to evaluate whether the number of babies born (via birth certificates) and the number of babies screened (via WE-TRAC records) match on a baby-specific level.



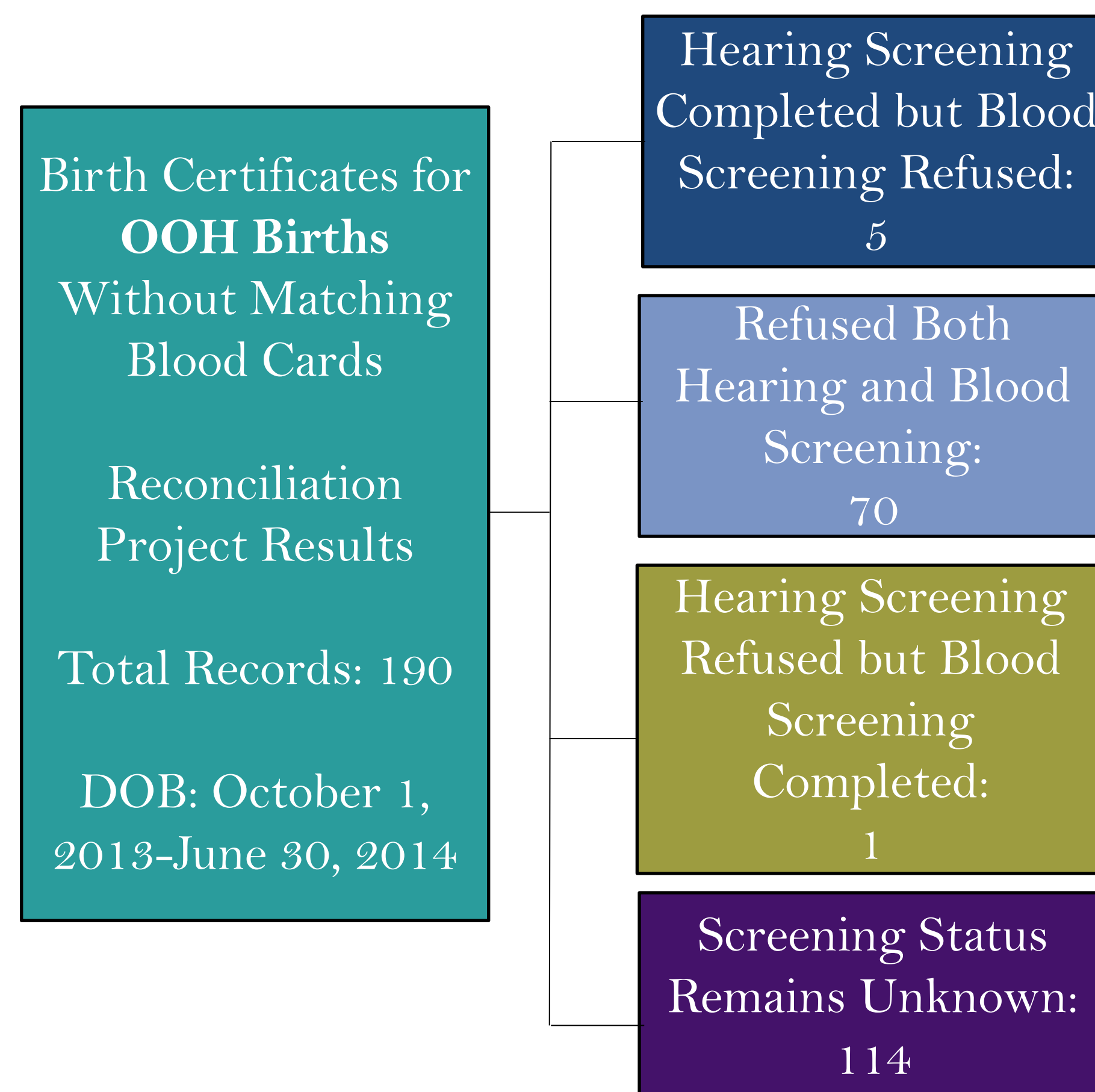
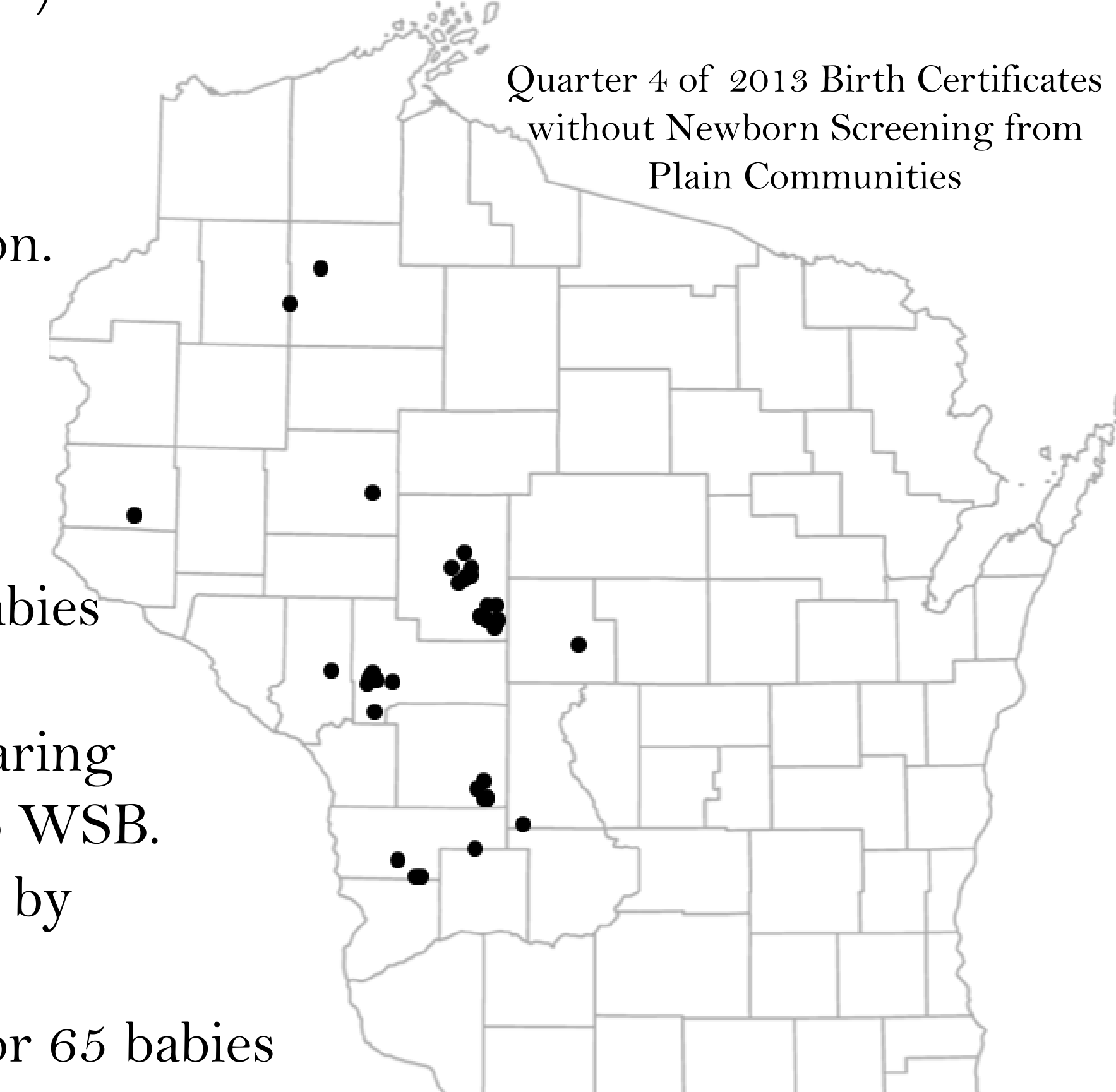
Preliminary Results



WSB and its newborn screening partners have reconciled nine months of records. For Hospital Births, the focus has been on documenting refusals and ensuring accurate data transmission from birth hospitals to the State Laboratory of Hygiene (WSLH) and from the WSLH to WE-TRAC. For Out Of Hospital (OOH) births, along with documenting refusals and results, the focus has been on identifying areas of high-density OOH births with low screening rates, typically births attended to by Plain community (Amish or Mennonite) traditional birth attendants.

Key findings:

- Approximately 100 birth certificates per quarter do not match to a blood card in WE-TRAC.
- Plain community members represented 64% of the OOH and 7% of hospital births in reconciliation.
- Twice as many birth certificates without blood cards were from OOH births.
- Many of the birth certificates without matching blood cards for Plain community babies had a traditional birth attendant listed. Typically neither the family nor the birth attendant have phones, making the process of documenting refusal or results more lengthy.
- Many hospital cases were for babies who were transferred to NICUs out of state; most of these babies received newborn screening out-of-state.
- Families do not necessarily refuse all screenings. They might refuse blood screening but accept hearing screening. Hospitals and OOH midwives did not know they could or should report those results to WSB.
- While 57% of all the cases were successfully reconciled (93% of hospital births and 40% of OOH) by documenting results or refusals, it has been a time- and labor-intensive process.
- Without reconciliation, WSB would not have known about or received hearing screening results for 65 babies for this time period.



Ongoing Impact and Future Efforts

- Identifying geographic trends among OOH births inform targeted efforts to train birth attendants and develop options to increase access to and acceptance of newborn screening in these areas.
- WSB and its newborn screening partners drafted policy and educated hospitals and OOH midwives on how to report results and refusals for each of the newborn screenings.
- The WSLH and its newborn screening partners modified the blood card and it now includes a "not screened" field for each of the newborn screenings (blood, hearing and critical congenital heart disease) as of February 2015.
- OOH midwives are submitting a survey with a family's refusal reasons to WSB's OOH Outreach Coordinator to help providers better understand why a family might refuse.
- Beginning in 2015, every baby born in Wisconsin should have a blood card sent to the WSLH, even if the family refused the blood screening.
- In July 2014, critical congenital heart disease screening became mandatory. WE-TRAC has been modified to support direct-entry of these screening results. WSB continues to modify WE-TRAC to adapt to changes in the newborn screening program.
- WSB continues to build rapport, support and screening capacity among Plain and OOH communities in an effort to increase screening and decrease refusals. WSB continues to build rapport, support and accurate reporting among hospitals as well.

ACKNOWLEDGEMENTS

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