



SHINE Data Collection with Newborn Screening Cards



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Newborn Screening (NBS) Card

FORM EXPIRATION DATE: YY-YY-MM

T753000

To ensure timely reporting, please **PRINT** and **COMPLETE** the entire form SN

Baby's Name <small>LAST FIRST</small>		SEX: F M	Baby's Birthdate <small>MM / DD / YY</small> Time (Military)	
Baby's ID # (optional)		Baby's Physician <small>LAST FIRST</small>		
Specimen Collection Date <small>MM / DD / YY</small> Time (Military)		Physician's NPI (10 digits) ()		Physician's Phone # ()
Mother's Name <small>LAST FIRST</small>		Baby's Race Black Asian/Pacific Isle Native American White Hispanic N Y		
Repeat Specimen? N Y	Reason for repeat: 17-OHP TSH	FAO Unsat Specimen	OA Routine Other	TPN SCID
Birthweight (grams): g	Gestational age: wks	Transfusion(s) N Y Last Txn Date	Child on TPN now? N Y	
Hospital / City of birth: <small>Name of hospital City</small>		Send Report to: <small>If different from birth hospital</small>		
C.D. Brokopp, Director D. Kurtycz, Med Director WSS 253.13 HYG:213	Mothers Hep B Surface Antigen Neg Pos		Hearing Screening Date <small>If different from specimen collection date</small>	
			Right Ear <input type="checkbox"/> Pass <input type="checkbox"/> Refer	
			Left Ear <input type="checkbox"/> Pass <input type="checkbox"/> Refer	
Circle Hearing Screen Method: ABR OAE BOTH		Mark Hearing Risk Factors <input type="checkbox"/> ECMO <input type="checkbox"/> CFA <input type="checkbox"/> MED <input type="checkbox"/> Fam Hx (see tan sheet) <input type="checkbox"/> Other		
Hearing Not Screened (circle reason) NICU Deceased Refused Transferred Other		Pulse Ox Screen Date <small>MM / DD / YY</small> Time(Military)		
		Pass <input type="checkbox"/> Fail <input type="checkbox"/>		Not Screened <input type="checkbox"/>
WI State Laboratory of Hygiene 465 Henry Mall Madison WI 53706 Newborn Screening Report Submitter (2130)				

This box for Newborn Screening Laboratory use only



SHINE Data Form



SHINE Data Report

12-24-12

Reason for Report (check all applicable)

- Baby had a pulse oximetry screen out-of-hospital Baby has known/suspected congenital heart disease (CHD)
 Baby failed the newborn pulse oximetry screen Other _____
 Baby did not have a newborn blood screening card where pulse oximetry screen could be reported

1. BACKGROUND INFORMATION

Mother's First Name _____ Mother's Last Name _____
 Mother's Maiden Name (if different) _____ Mother's Zip Code _____
 Mother's DOB (mm/dd/yyyy) ____/____/_____
 Baby's First Name _____ Baby's Last Name _____
 Baby's DOB (mm/dd/yyyy) ____/____/_____
 Gender Girl Boy Birth Weight _____
 Place of Birth Hospital _____ MR Number _____
 Contact person _____ Telephone _____
 Home Birth Birthing Center Midwife Name _____
 Did the baby receive a newborn blood screen? Yes No Unknown If yes, NBS card ID _____
 Is mother part of plain clothes community (e.g., Amish or Mennonite)? Yes No Unknown

2. CLINICAL DETAILS

Was an antenatal ultrasound performed? Yes No Unknown
 Does baby have any first degree relatives with significant CHD? Yes No Unknown
 If yes, who? (Check all that apply) Mother Father Sibling(s)
 Number of siblings affected _____ Total number of siblings _____
 Comments _____
 Was baby transferred from birth place to another facility for CHD evaluation? Yes No Unknown
 If yes, to what facility? _____ City _____ State _____

3. PULSE OXIMETRY RESULTS

Pass Fail Not Screened If not screen, what was the reason? (Check all that apply)
 First Measurement Right Hand _____ % Foot _____ % Baby expired Parents refused
 Second Measurement Right Hand _____ % Foot _____ % Not available Other _____
 Third Measurement Right Hand _____ % Foot _____ % Comment _____
 Comments _____
 Date of screen (mm/dd/yyyy) ____/____/_____
 Age (hours) at time of first measurement _____
 Place of screen (If different than in Background Information) _____
 In NICU at time of screening? Yes No Unknown On supplemental oxygen? Yes No Unknown
 On PGE1 at time of screening? Yes No Unknown

If baby failed pulse ox screen, what was the cause for low saturation? (Check all that apply)

- Congenital Heart Disease Lung Disease
 Infection/ sepsis Pneumonia Prematurity
 Unknown Pneumothorax Diaphragmatic Hernia
 Other _____ Other Lung Disease _____

SHINE Data Report

12-24-12



4. RELEASE OF INFORMATION (IF APPLICABLE)

Does baby have a non-cardiac reportable birth defect or genetic disorder? Yes No Unknown

If yes, please list _____

Birth defects are reported to the Wisconsin Birth Defects Registry as per state statute 253.12.

Have the parents of guardians consented to release of child's information to WBDR?

Yes No Unknown N/A

5. CARDIOVASCULAR DIAGNOSTIC INFORMATION (IF KNOWN)

Was an echocardiogram performed? Yes No

If no, what was the reason? (Check all that apply) Not clinically indicated Baby expired
 Parents/guardians refused care Other _____

If yes, date of the echo ____/____/_____
 Location of echo _____

Cardiovascular Diagnosis:

- Normal
 Cardiac findings not requiring treatment (PFO, small PDA, small VSD)
 Significant Congenital Heart Disease
 Diagnosis #1 _____
 Diagnosis #2 _____
 Diagnosis #3 _____
 Diagnosis #4 _____
 Other non-cardiac diagnosis _____

If baby has significant CHD:

Was baby discharged home prior to a significant CHD diagnosis? Yes No Unknown

How was significant CHD first suspected? (Select only one)

- Antenatal ultrasound Symptoms Physical exam
 Pulse ox screening Post-mortem Unknown
 Other _____

How was significant CHD confirmed? (Check all that apply)

- Echocardiogram Post-mortem
 Unknown Other _____

6. COMMENTS

SHINE personnel completing form: _____

Date: _____

2/27/14



NBS and SHINE Linkage

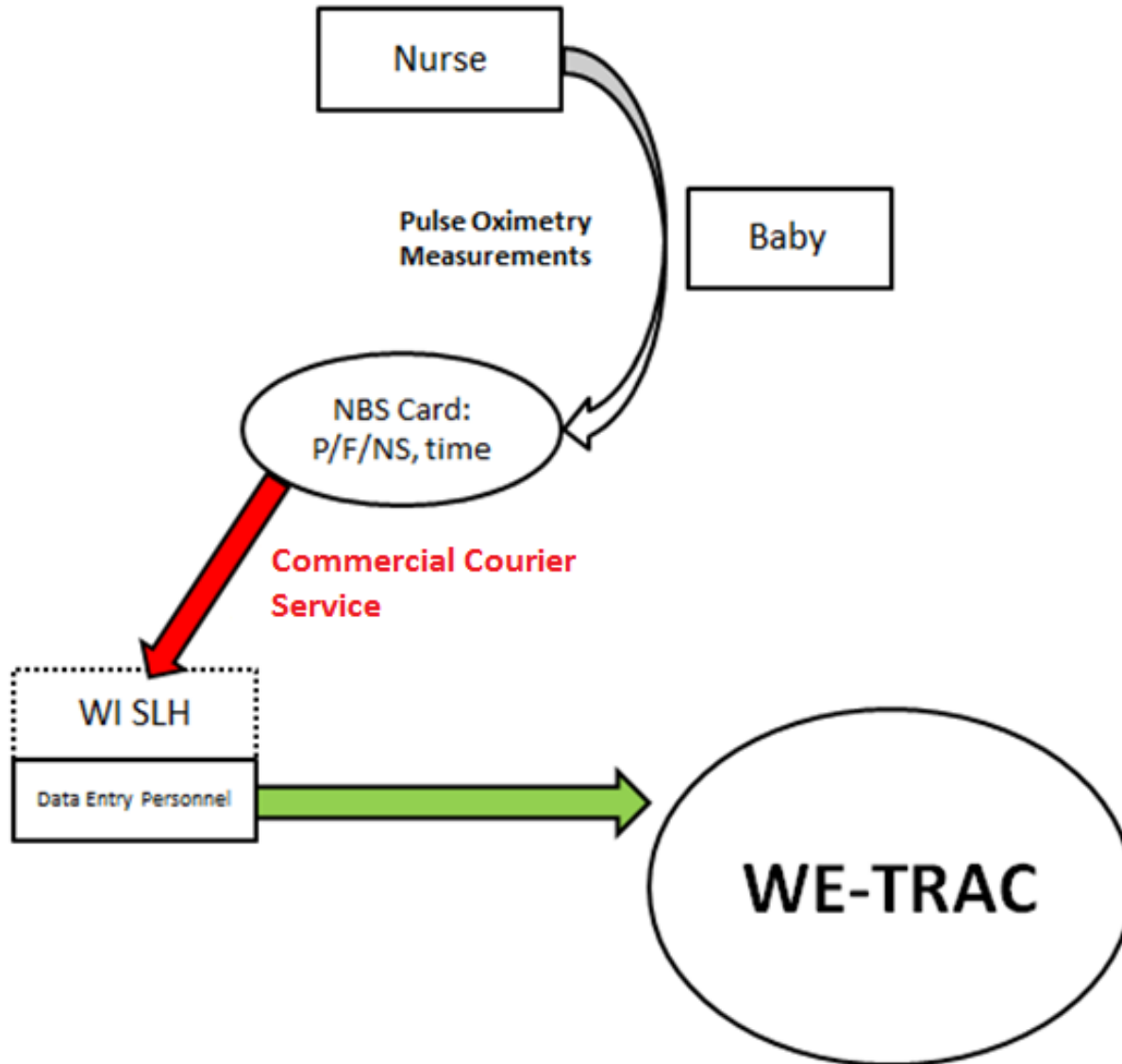
	Critical Congenital Heart Disease (CCHD)	No CCHD
Failed NBS	True Positive: <ul style="list-style-type: none">• Infants who actually have CCHD and failed NBS• Should have SHINE form• Source: NBS & SHINE	False Positive: <ul style="list-style-type: none">• Infants who do not have CCHD, but failed NBS• Should have SHINE form• Source: NBS & SHINE
Passed NBS	False Negative: <ul style="list-style-type: none">• Infants who actually have CCHD, but passed NBS• Should not have SHINE form• Source: NBS & death/hospital discharge records	True Negative: <ul style="list-style-type: none">• Infants who do not have CCHD and passed NBS• May have SHINE form if OOH• Source: NBS



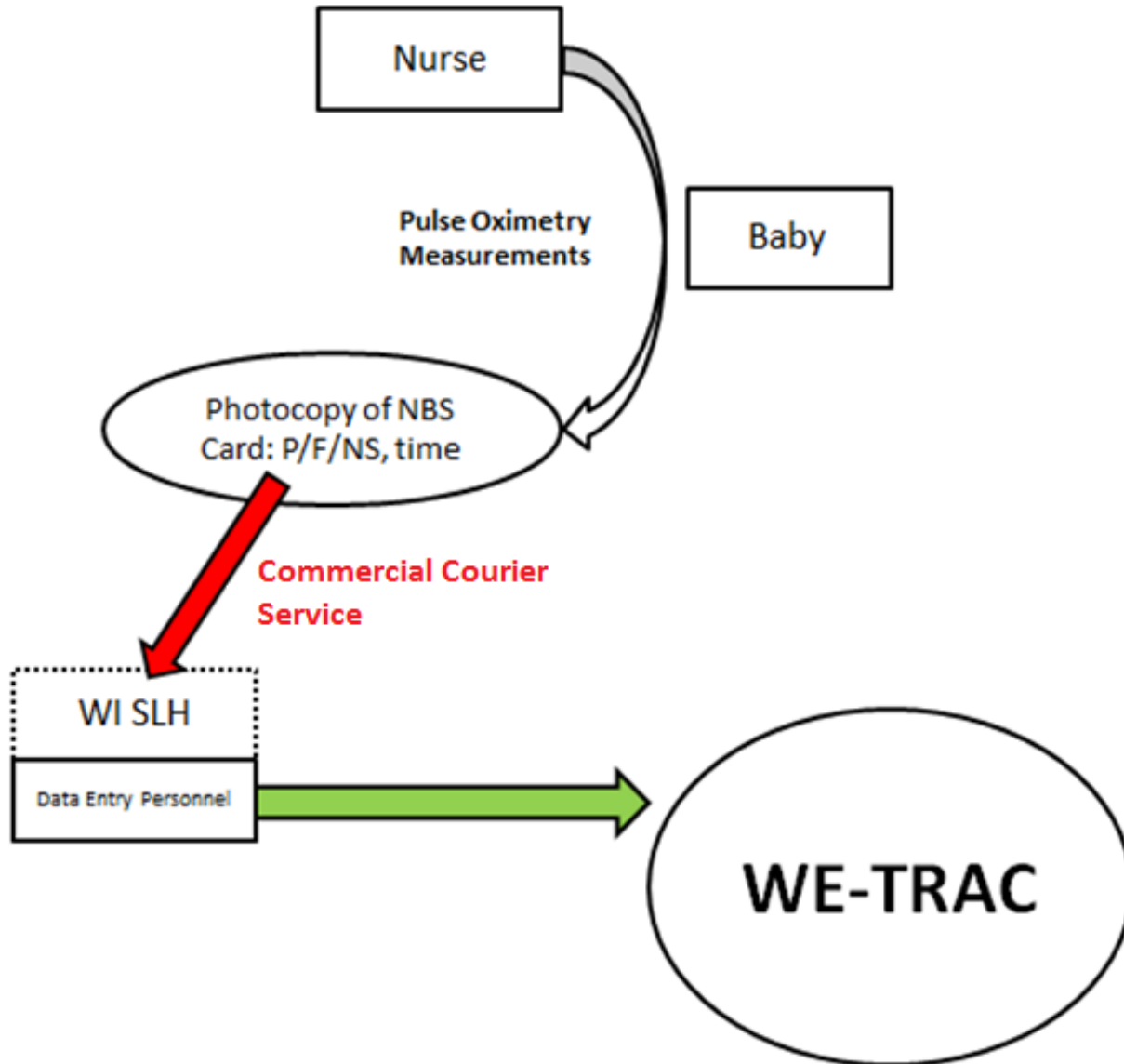
WE-TRAC Application

- WE-TRAC is a web-based data collection and tracking system that contains data on newborn hearing screenings.
- SHINE added a WE-TRAC/Heart component to this system to house the NBS and SHINE data.

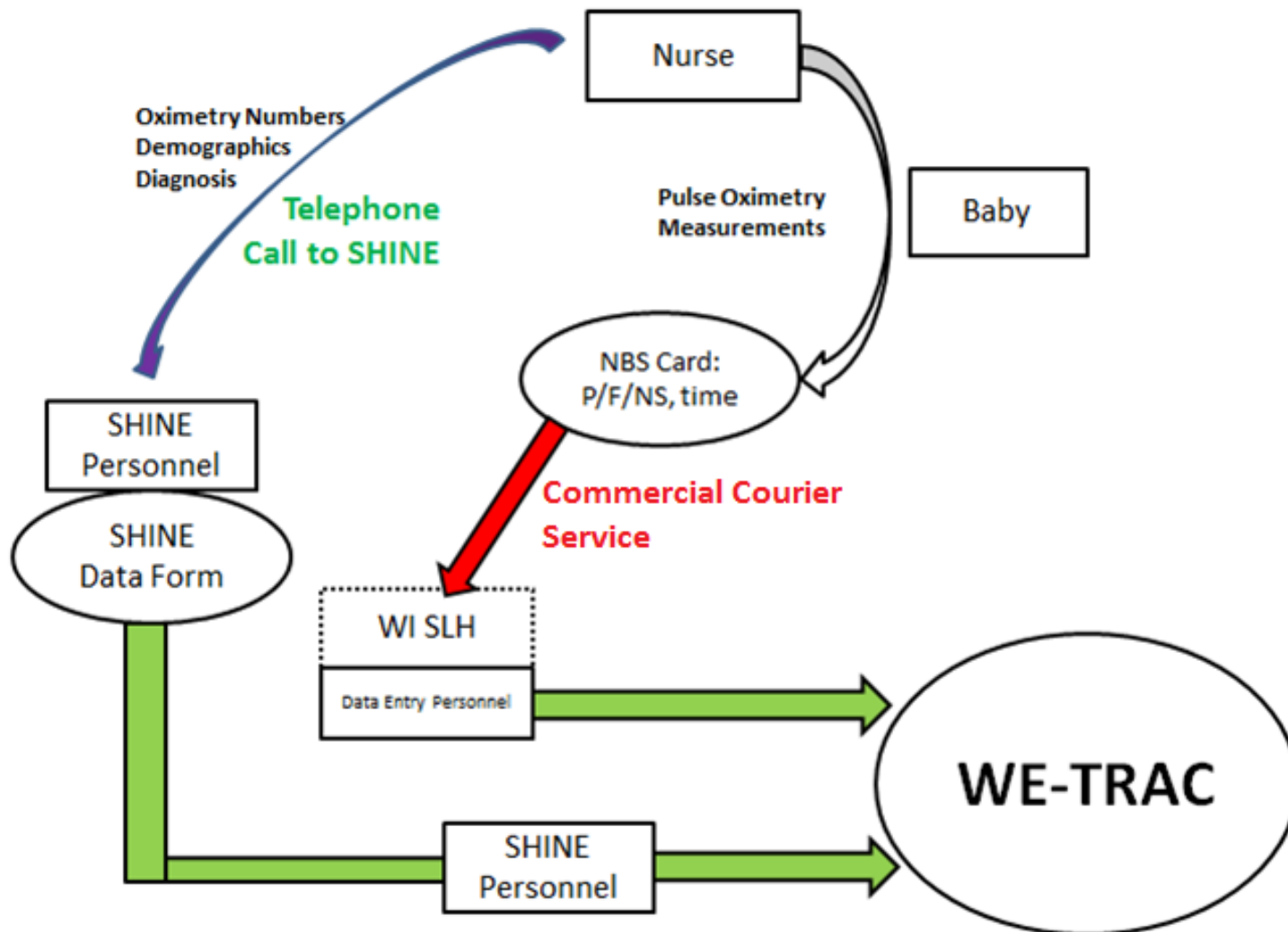
Workflow: Hospital – Pass/Not Screened



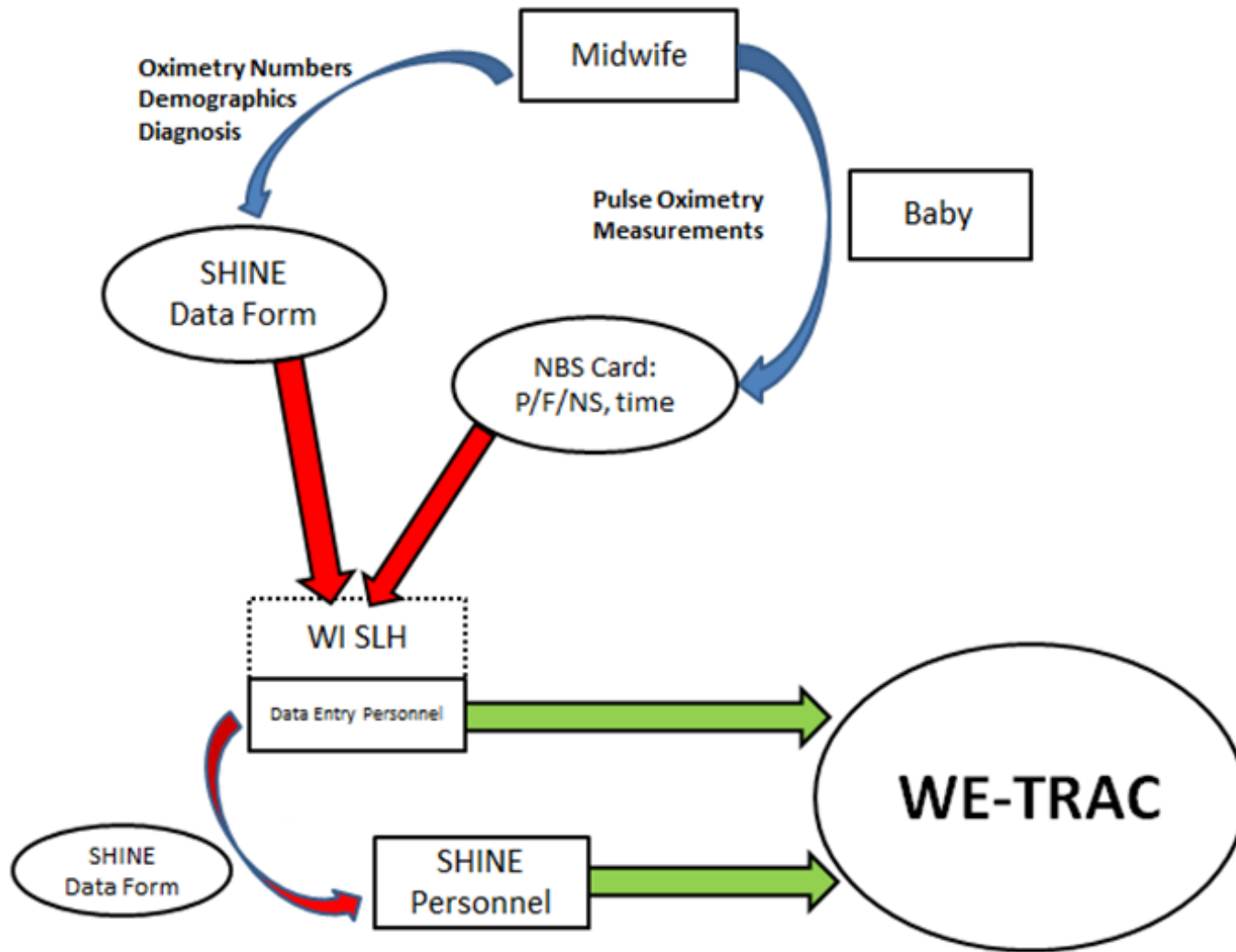
Workflow: Hospital – Baby on Oxygen



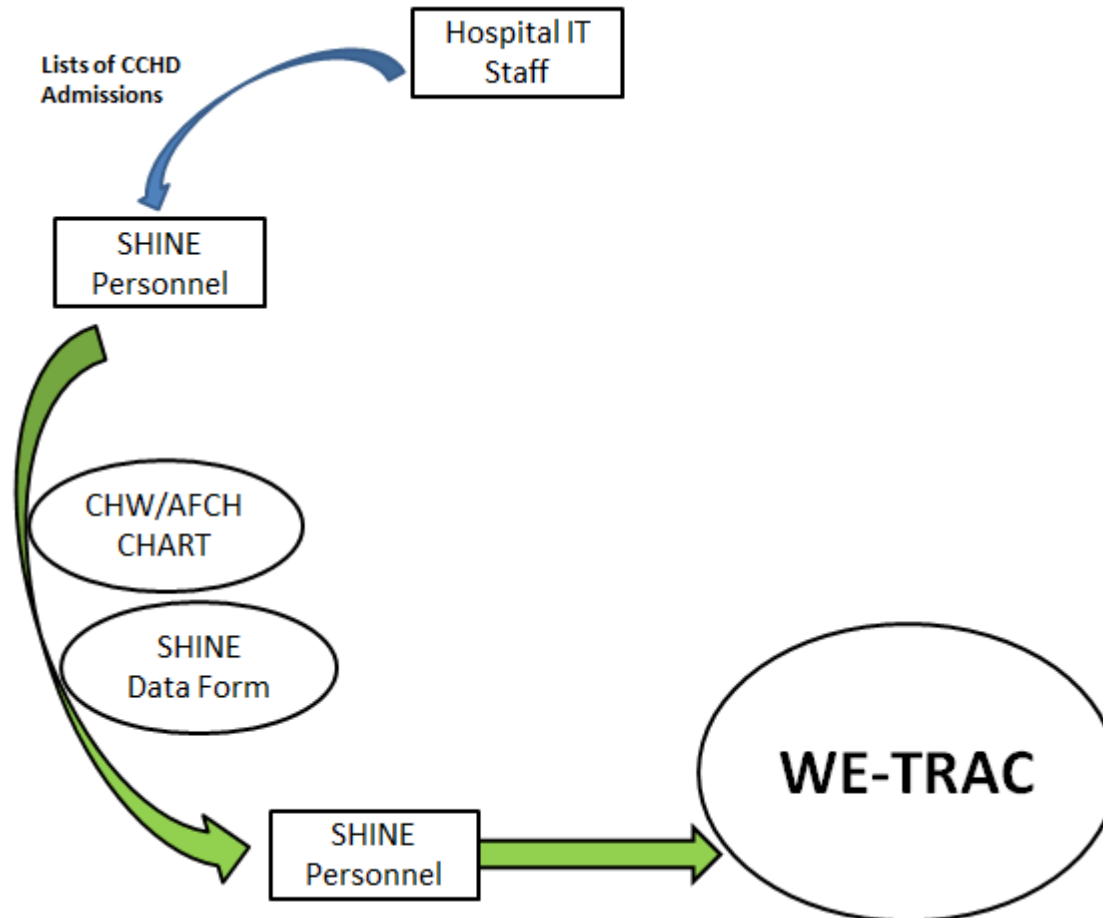
Workflow: Hospital – Fail/CCHD Diagnosis



Workflow: Home Birth



Workflow: CCHD Admissions in Children's Hospital of Wisconsin & American Family Children's Hospital





Strengths

- Uses existing infrastructure
- No additional cost at birth site
- Reinforces a unified approach to newborn screening (Blood spot + Hearing + CCHD)
- Simplifies the extension of newborn screening to Amish and other populations that previously had low rates of blood card screening.



Weaknesses

- Requires coordination of multiple tests
- Potentially delays bloodspot reporting
- Precludes real-time reporting of CCHD screening to WI Department of Health Services (DHS)



Barriers/Challenges

- Lack of communication
- Perception of large increase in staff workload



Solutions

- Arranged a meeting between clinical staff and lab staff to deal with communication issues.
- Continued in-depth talks with hospital contacts about the actual workload.
- Monitoring to evaluate whether process leads to delays in blood spot submission.



Thank you!

Any questions?

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