Does Every Baby Get Screened?

Overhauling Birth Monitoring in Washington State

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Washington State Newborn Screening
Each year in Washington State...

- 84,300 Hospital Births
- 3,300 Out-of-Hospital Births
- 400 Out-of-State Births
- 88,000 Newborns Screened
- 170,000 Specimens Tested
OUR MISSION

Every Baby is Screened

Or has a valid parental refusal
OUR MISSION: EVERY BABY IS SCREENED
OUR MISSION: EVERY BABY IS SCREENED

Number of Babies Born?

Number of Babies Tested?
BIRTH MONITORING BEFORE

Weekly Birth Rosters
Birth Monitoring Before

Weekly Birth Rosters

Birth records are matched to specimens received
Approx. 6,000 Unmatched Specimens per year

- First specimen on out-of-hospital birth?
- Unlinked second screen?
- Adoption?
- Border baby?

Unmatched specimens created issues with program evaluation and statistics. Could not accurately account for them.
The Problem...

- Hospital Births: 84,300
- Newborns Screened: 88,000
- Specimens Tested: 170,000
- Out-of-State Births: ?
- Out-of-State Births: ?
- No monitoring for out-of-hospital births
The Problem...

Spent a lot of time considering the problem, mapped it out on white boards and discussed how we get to where we want to be
The Solution...
KEY CONCEPTS

Every birth has a birth record

Every specimen is matched to a birth record

or linked to a specimen that is matched to a birth record
Added Birth Facility Field to the card
Created generic Out-of-State birth code
Data Collection Changes

WASHINGTON STATE NEWBORN SCREENING

<table>
<thead>
<tr>
<th>MOTHER'S INFORMATION</th>
<th>CHILD'S INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>DO NOT USE THIS AREA</td>
<td></td>
</tr>
<tr>
<td>LAST NAME</td>
<td></td>
</tr>
<tr>
<td>FIRST NAME</td>
<td></td>
</tr>
<tr>
<td>Maternal Steroids</td>
<td></td>
</tr>
<tr>
<td>(within 7 days)</td>
<td></td>
</tr>
<tr>
<td>Date last___</td>
<td></td>
</tr>
<tr>
<td>MISCELLANEOUS INFORMATION</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BIRTH FACILITY</th>
<th>CHILD'S SPECIAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility ID (born at): B 1 0 0 1</td>
<td>NICU [ ] HA/TPN [ ] Steroids [ ] Antibiotics [ ]</td>
</tr>
<tr>
<td>Name of Facility: Birth Center</td>
<td>(within 24 hours)</td>
</tr>
<tr>
<td>(For home-birth, use birth attendant ID)</td>
<td>(within 7 days)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SUBMITTER ID</th>
<th>FOLLOW-UP CARE</th>
<th>CHILD'S SPECIAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collected at (facility):</td>
<td>Follow-Up Clinic ID:</td>
<td>NICU [ ] HA/TPN [ ] Steroids [ ] Antibiotics [ ]</td>
</tr>
<tr>
<td>□ Same as Birth Facility</td>
<td>□ Same as Submitter</td>
<td>(within 24 hours)</td>
</tr>
<tr>
<td>□ REFUSED: Check box if refused and sign form on reverse (required)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Created new codes for Free-Standing Birth Centers
Data Collection Changes

Created new codes for all home-birth attendant midwives
BIRTH MONITORING NOW

Hospitals

Birth Centers

Midwives

Clinics

Washington State Department of Health
BIRTH MONITORING NOW

- Hospitals
- Birth Centers
- Midwives
- Clinics

Weekly Birth Rosters

Birth Certificates

Extract birth records from birth certificate export for all out-of-hospital births
BIRTH MONITORING NOW

Birth records are matched to specimens received
93% Out-of-Hospital Births
‘LONELY’ SPECIMENS

Specimens not matched to a birth record (or linked to a previous specimen)

6,000 ‘Lonely’ Specimens/Year  3,000 ‘Lonely’ Specimens/Year

170,000 Specimens on 88,000 Newborns
‘LONELY’ SPECIMENS
Specimens not matched to a birth record (or linked to a previous specimen)

Unreported Births
Out of State Births “Border Babies”
Demographic Errors
Adoptions Foster Care / CPS

Four main causes of ‘Lonely’ specimens
UNREPORTED BIRTHS
Births not included on weekly Hospital Birth Roster

Unreported Births

Monthly Extract
Unreported Hospital Births
UNREPORTED BIRTHS

Births not included on weekly Hospital Birth Roster

Records are matched to specimens received
‘LONELY’ SPECIMENS
Specimens not matched to a birth record
(or linked to a previous specimen)

Monthly Birth Monitoring
~90/month

Out of State Births
“Border Babies”

Demographic Errors

Adoptions
Foster Care / CPS
OUT OF STATE BIRTHS
Specimens collected on infants born in another state

BIRTH FACILITY

<table>
<thead>
<tr>
<th>Facility ID (born at):</th>
<th>X 9 9 9 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Facility:</td>
<td>Out of State Birth</td>
</tr>
</tbody>
</table>

Out of State Births
“Border Babies”

Create birth records for out-of-state births and match them to specimens
‘LONELY’ SPECIMENS
Specimens not matched to a birth record
(or linked to a previous specimen)

Monthly Birth Monitoring
~90/month

Create Out of State Birth Records
~30/month

Demographic Errors
Adoptions
Foster Care / CPS
DATABASE QUERIES
Incorrect or missing demographic information

Missing Mother’s First or Last Name

Missing Date of Birth

Mismatched Twins

Update/correct demographic errors to match and link specimens

Demographic Errors
Adoptions
Foster Care / CPS

Washington State Department of Health
‘LONELY’ SPECIMENS
Specimens not matched to a birth record
(or linked to a previous specimen)

Monthly Birth Monitoring
~90/month

Create Out of State Birth Records
~30/month

Demographic Errors
Adoptions
Foster Care / CPS

Database Queries
~20/month
MANUAL REVIEW
Incorrect or missing demographic information

Incorrect Name

Edit incorrect demographics to match and link specimens

Demographic Errors
Adoptions
Foster Care / CPS
MANUAL REVIEW
Incorrect or missing demographic information

Incorrect Name

FOSTER/ADOPTIVE MOM
LAST NAME
FIRST NAME

BABY’S NAME
LAST NAME
FIRST NAME

Demographic Errors
Adoptions
Foster Care / CPS

Edit incorrect demographics to match and link specimens
Out of Hospital Birth without a Birth Certificate

MANUAL REVIEW
Incorrect or missing demographic information

Demographic Errors
Adoptions
Foster Care / CPS

Create birth records when birth certificate is not filed on out-of-hospital birth
‘LONELY’ SPECIMENS
Specimens not matched to a birth record
(or linked to a previous specimen)

Monthly Birth Monitoring
~90/month

Create Out of State Birth Records
~30/month

Database Queries
~20/month

Demographic Errors
Adoptions
Foster Care / CPS

Manual Review
~35/month
‘LONELY’ SPECIMEN FAXES

Specimens *still* not matched to a birth record (or linked to a previous specimen)

Send faxes to the submitter to get additional information on the baby/specimen
‘LONELY’ SPECIMEN FAXES

Specimens *still* not matched to a birth record
(or linked to a previous specimen)

Use information received to edit the demographics or create a birth record
‘LONELY’ SPECIMENS
Specimens not matched to a birth record (or linked to a previous specimen)

Monthly Birth Monitoring
~90/month

‘Lonely’ Specimen Faxes
~80/month

Create Out of State Birth Records
~30/month

Database Queries
~20/month

Manual Review
~55/month
UNKNOWN BIRTHS
Specimens where the place of birth cannot be identified

Unknown Births
~3/month
IMPACT: INCREASED STAFF TIME

8 hrs / Week
Mostly spent on follow-up for out-of-hospital births that did not get screened

10 hrs / Month
Improving the process, running and creating queries
IMPACT: INCREASED STAFF TIME

More automation and improved matching algorithms should reduce overall staff time...

Giving us more time to do other important improvements
IMPACT: IMPROVED SAFETY NET

Out-of-Hospital birth monitoring
IMPACT: IMPROVED SAFETY NET

20 Babies / Year

Received screening because of birth monitoring efforts
IMPACT: IMPROVED SAFETY NET

70 Babies / Year

+50!!

20 Babies / Year

Received screening because of birth monitoring efforts
IMPACT: REDUCTION IN ‘LONELY’ SPECIMENS

6,000 Specimens/ Year
IMPACT: REDUCTION IN ‘LONELY’ SPECIMENS

6,000 Specimens/ Year

ZERO! Specimens/ Year
IMPACT: IMPROVED DATA AND REPORTING

Number of Babies Born?

?'

Number of Babies Tested?
2015 Screening Statistics

87,920 Babies Born

87,726 Eligible for Screening

266 Parental Refusals

87,401 Babies Tested

59 Babies Not Tested

All 59 received follow-up
80% are out-of-hospital births
So... Does Every Baby Get Screened?

99.9% Tested
(or had a valid parental refusal)
Thank You!!

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