The Lonely Newborn Screen 😞

A Study of Linking Algorithms and Why Two Screen State Laboratories Do Not Receive Two Appropriately Timed Screens for All Newborns
## Comparison Study
Texas Center for Health Statistics (CHS)

<table>
<thead>
<tr>
<th>Study Goal</th>
<th>Intended Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study factors influencing missing 2nd screens</td>
<td>Targeted Education</td>
</tr>
<tr>
<td>NBS Linkage vs. CHS linkage to Birth Records</td>
<td>Logic Improvements</td>
</tr>
</tbody>
</table>
Process
AutoLinking Algorithm

>= 7 Days

~ 600 links / hr

ALL specimens - previous 60 Days
## Critical Rules

<table>
<thead>
<tr>
<th>Rule #</th>
<th>Field 1</th>
<th>Field 2</th>
<th>Field 3</th>
<th>Exclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Baby DOB</td>
<td>Mom 1st Name (1st 4 letters)</td>
<td>Mom SSN</td>
<td>SSN starting with same 3 numbers</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>Mom 1st Name (1st 4 letters)</td>
<td>Mom Phone</td>
<td>Phone # all repeating digits</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td>Mom Address</td>
<td>Addresses starting with &quot;PO Box&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(1st 7 characters)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>Previous Specimen Serial #</td>
<td></td>
<td>vs. current serial #</td>
</tr>
</tbody>
</table>
## Probabilistic Scoring

<table>
<thead>
<tr>
<th>Field</th>
<th>Score</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous Serial Number</td>
<td>3</td>
<td>compared to <em>kit number</em> of potential link</td>
</tr>
<tr>
<td>Baby Last Name</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Baby First Name</td>
<td>2</td>
<td>given name matches only</td>
</tr>
<tr>
<td>Baby DOB</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Baby Birth Time</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Baby Birth Weight</td>
<td>1</td>
<td>exact birthweight matches only</td>
</tr>
<tr>
<td>Mother Last Name</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Mother First Name</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Mother SSN</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Mother Phone</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Mother Address</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Mother Zip Code</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Medical Record Number</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Mother DOB</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Mother Maiden Name</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Medicaid Number</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Father Last Name</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Physician Name</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Physician Phone</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Manual Linking

• Clinical Care Coordination
  • Case Monitoring
  • Abnormal Results
  • Access to Birth Records
• Lab Logistics Team
  • Prior to CF DNA Sampling
  • Following Autolinking
## Manual Linking

### General Linking Fields**

<table>
<thead>
<tr>
<th>Mother’s Name</th>
<th>Mother’s SSN</th>
<th>Phone</th>
<th>Address</th>
<th>Medical Record #</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Name</td>
<td>Last Name</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** Possible Twin/ Multiple***

<table>
<thead>
<tr>
<th>Baby’s Name**</th>
<th>Birth Time</th>
<th>Birth Order†</th>
<th>Birth Weight††</th>
<th>Medical Record #</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Name</td>
<td>Last Name</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Twin/Multiple Linking Fields

<table>
<thead>
<tr>
<th>Baby’s Name**</th>
<th>Birth Time</th>
<th>Birth Order†</th>
<th>Birth Weight††</th>
<th>Medical Record #</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Name</td>
<td>Last Name</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** Linking Result**

- Link
- Do Not Link

### Notes

* If possible match if found, but DOB does not match, may link if DOB is within 6 months and Mother’s Name and at least one other field match

** Slight differences in these fields should be considered matches if they appear to be misspellings, typos, or different ways of entering the same name or address

† Birth Order cannot be contradictory

†† Birth Weight can be considered a match if within 100 g

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### Field Descriptions

- **Baby’s DOB**: Date of birth
- **Mother’s Name**: Name of the mother
- **Baby’s Name**: Name of the baby
- **Medical Record #**: Medical record number

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### Twin/Multiple Indicators

- **Twin/Multiple**
- **Birth Order**: 1 or 2
- **Birth Weight**: 100 g or more

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### Matching Rules

- **Match First and/or Last Name**: At least 1 of these 4 fields must match to link.
- **Match Does not match**: At least 2 of these 4 fields must match to link.
- **Match None of these 4 fields**: No match, do not link.
Status
Linkage Rates – 2017

1st Screens
<7 Days

- % Lonely: 8.3
- % Auto: 15.6
- % Manual: 76.1

2nd Screens
>= 7 Days

- % Lonely: 10.5
- % Auto: 73
- % Manual: 82.2
Are 15% Really Lonely?

OR

• Linkage can be improved?
• Incomplete demographic data?
• 1st screens were greater than 60 days previous?
• 2nd screens collected too early?
Linkage Rates – CHS vs. NBS Lab

% 1st screens linked to at least 1 additional screen

*Preliminary data
Why so lonely?

- Birthweight
- Health Status
- Race / Ethnicity
- Payor
- Submitter Type
- Region
Limitations

- Incomplete linkage
- Data as received on NBS Card
- Single variant analysis
Birthweight

All 1st screens: 84.4%
Health Status

All 1st screens: 84.4%
Race / Ethnicity

All 1st screens: 84.4%
Payor Source

All 1st screens: 84.4%

87.7
81.9

Paid
Medicaid

%
Submitter Type

All 1st screens: 84.4%

<table>
<thead>
<tr>
<th>Submitter Type</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>84.5</td>
<td>374,401</td>
</tr>
<tr>
<td>Birth Center/Midwife</td>
<td>85.4</td>
<td>4,453</td>
</tr>
<tr>
<td>Doctor</td>
<td>48.6</td>
<td>144</td>
</tr>
<tr>
<td>Clinic</td>
<td>75.0</td>
<td>1,805</td>
</tr>
</tbody>
</table>

N=374,401   N=4,453   N=144   N=1,805
Health Region

All 1st screens - 84.4%
Border Status

All 1\textsuperscript{st} screens: 84.4%
Observations – 2 Screens

- Low Birthweight
- Premature
- Asian
- Insurance
- Central Texas
Observations – Lonely Screens

• African American
• Medicaid
• Border
Next Steps

• Refine CHS Linkage
• Analyze CHS only linked specimens
  • Determine nonlinking causes
  • Improve NBS algorithm
• Study specific sites within border region to identify direct education targets
• Identify vehicles for targeted education of underserved populations
Thank You

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Frank Gonzalez

DSHS Laboratory
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Evila Atkinson