The Wisconsin Experience
Getting In-Step with NewSTEPs Quality Indicators

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Annual Review of Patient Database

accurate count of infants screened
correctly identify first and subsequent screens

Pull all specimens by birth year (with demographics)

- Sort by:
  1. Mother’s name
  2. Date and time of birth
  3. Patient name

- Check for repeats misidentified as first specimens
- Check for missed patient merges
Elements Added to LIMS
screening specimens

- Date and time specimens received in lab
- Date and time providers notified of presumptive positive results
- Flag for out of state births
- Discrete reasons for unsatisfactory specimens
- Flags (field-specific) for missing essential information
- Documentation of not-screened status
Elements Added to LIMS
short-term follow-up

- Worklists for follow-up
  - unacceptable specimens
  - out of range results
- External confirmatory results
- Date of diagnosis
- Date treatment initiated
QI 1: Percent Specimens Unacceptable Due to Improper...

1a) ... collection
1b) ... transport

- Reason(s) for unsatisfactory specimen are designated and stored discretely to enable count of specimens in each category
QI 2: Percent Specimens Missing State-Defined Essential Information

- Essential information
  - ✓ Birth date AND time
  - ✓ Collection date AND time
  - ✓ Birth weight
  - ✓ Gestational age

- Specimens automatically flagged when any of the six fields are not initially entered (because information not provided, not legible, or otherwise problematic)

- Able to count specimens ‘missing’ information at both the specimen- and field-level
QI 3: Percent Eligible Infants Without a Newborn Screen

- Wisconsin requires a card submitted for every baby born, regardless of blood collection.
- If blood not collected, reason (*parent refusal, transferred, deceased*) is documented and stored discretely enabling tracking and follow-up.

(For details, see Poster 40)
QI 4: Percent Infants Without Recorded Resolution

4a) unacceptable specimens
4b) out-of-range results

- Upon final verification, specimens automatically drop to specific follow-up worklists
- Summary reports *(including all specimens received for patients on follow-up worklist)* allow identification of any patients lacking subsequent valid specimen
QI 5: Timeliness of Newborn Screening Activities

a) Birth to collection
b) Collection to receipt in lab
c) Receipt to reporting out results
d) Birth to reporting out results
e) Notification of out-of-range results to intervention
f) Birth to confirmation of diagnosis
g) Birth to ruling out diagnosis

added to LIMS
QI 5: Timeliness of Newborn Screening Activities

With instant of all key events in LIMS, able to calculate time intervals...

Birth | Collection | Receipt | Notification | Intervention

5a | 5b | 5c | 5e

5d

5f/g

Report | Confirmation/ ruling out
MISSING KEY INFORMATION

DEC  1 of 24 specimens were missing any of the following pieces of key information:
   BIRTH DATE and TIME
   BIRTH WEIGHT
   COLLECTION DATE and TIME
   GESTATIONAL AGE

<table>
<thead>
<tr>
<th>Period At A Glance</th>
<th>% Specimens Missing Key Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SEP</td>
</tr>
<tr>
<td>Submitter (N)</td>
<td>0</td>
</tr>
<tr>
<td>Submitter (%)</td>
<td>0.0%</td>
</tr>
<tr>
<td>State (%)</td>
<td>3.8%</td>
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</tbody>
</table>

UNSATISFACTORY SPECIMENS

DEC  2 of 24 specimens were unsatisfactory

Reason(s) For Unsatisfactory Designations:
A specimen may have more than one reason for being deemed unsatisfactory for testing
- Blood Clots 50.0%
- Filter Paper Damaged (Heel) 50.0%
- Total 100.0%

<table>
<thead>
<tr>
<th>Period At A Glance</th>
<th>% Specimens of Unsatisfactory Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SEP</td>
</tr>
<tr>
<td>Submitter (N)</td>
<td>0</td>
</tr>
<tr>
<td>Submitter (%)</td>
<td>0.0%</td>
</tr>
<tr>
<td>State (%)</td>
<td>1.3%</td>
</tr>
<tr>
<td>Additional (N) *</td>
<td>0</td>
</tr>
</tbody>
</table>

* Specimen(s) unsatisfactory for reason(s) outside of submitters' control are excluded from submitters and state %.

AGE AT INITIAL SPECIMEN COLLECTION

DEC  Initial Specimens = 22

<table>
<thead>
<tr>
<th>Period At A Glance</th>
<th>% Initial Specimens Collected Within Recommended 24-48 Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SEP</td>
</tr>
<tr>
<td>Submitter (N)</td>
<td>19</td>
</tr>
<tr>
<td>Submitter (%)</td>
<td>95.0%</td>
</tr>
<tr>
<td>State (%)</td>
<td>96.9%</td>
</tr>
</tbody>
</table>

DAYS BETWEEN SPECIMEN COLLECTION AND RECEIPT AT WSLH

DEC  Total Specimens = 24

<table>
<thead>
<tr>
<th>Period At A Glance</th>
<th>% Specimens Received Within 3 Days After Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SEP</td>
</tr>
<tr>
<td>Submitter (N)</td>
<td>20</td>
</tr>
<tr>
<td>Submitter (%)</td>
<td>100.0%</td>
</tr>
<tr>
<td>State (%)</td>
<td>96.5%</td>
</tr>
</tbody>
</table>

WSLH has a target goal of receiving 95% of specimens within three days after collection.

Included on monthly report to submitters
QI 6: Percent Infants With Out-of-Range Results (Referral to Evaluation) by Disorder

- Specimens referred to evaluation are tagged* discreetly by disorder
  *specific follow-up task(s) automatically added upon result verification
- Summary reports group tagged specimens by patient to obtain count for each disorder
QI 7: Incidence of Confirmed Disorder Detected

- Confirmatory results entered into LIMS
- Disorder-specific flag added manually to those patients confirmed through follow-up to be affected by disorder
- NewSTEPs case template populated for upload to data repository
Acknowledgements

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