The Nebraska EHDI Electronic Data System and Follow-up

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Atlanta, GA
NE-EHDI Data System (ERS-II)

Learning objectives

1) List the advantages of integrating hearing records with birth records

2) Identify key data needed for adequate tracking and follow-up

3) Define important factors to construct a quality assurance report.
Goals

– Module of Nebraska Vital Records System (ERS-II)
– Create from birth record
– Collect only data needed for follow-up, quality and reports
– Minimize time and effort of reporters
– “Work in progress”
Development

– Vital records RFP, contract - 2004
– Preliminary planning - 2004
– CDC cooperative agreement – 2005
– Business analyst – 2006
– Screening module – 2007 (Rollout)
– Data edits, Audiology module – 2008
– Enhanced reports, Risk factors – 2009
– Date calculations, Case Summary – 2010
ERS-II Description

• Electronic Registration System-II (ERS-II)
  - SQL Server Database / Citrix-Internet

• QS Technologies, Inc. ->
  Netsmart Technologies, Inc

• Three tables (records) for Hearing Information
  – HINFO record (summary record)
  – HSCREENING record (detail record linked to HINFO)
  – HAUDIO record (detail record linked to HINFO)
Hearing Information (HINFO) Summary Record

(> 250 data items)

*Populated from birth record*
- Birthing facility, baby, maternal demographic information

*Data entered at hospital*
- Inpatient and outpatient hearing screening results
- Date of Hepatitis B vaccine (for immunizations)

*Data entered by NE-EHDI staff*
- “Transfer” screening results / outpatient results
- Diagnostic audiologic evaluations
ERS-II Examples

- One **HINFO** record – pass of inpatient hearing screening

Detail Records Linked to HINFO Record:

- Three **HSCREENING** records – details of inpatient events and all outpatient hearing screening events (some data copied to HINFO record)
- One **HAUDIO** record – details of audio evaluation (some data copied to HINFO record)
HINFO Record ("Quick Record")

- **Facility Name**: Alegent Lakeside Hospital
- **Type**: HOSPITAL
- **City**: Omaha
- **State**: Nebraska

**Quick Record of Passed Final Hearing Screening prior to Discharge**

**Date of Final Screening with Pass Result on Both Ears**: 01/30/2011

**Parent Educated about hearing screening, hearing loss, etc.? (Y,N)**

Y
HSCREENING Detail Record

HSCREENING (> 70 data items)
- Inpatient *Refer* hearing screening results
- Inpatient non-screening events
  - Discharge without a screening
  - Refusals
  - Expired
  - Transfers to NICU, other hospital
- Outpatient *Pass* or *Refer* hearing screening results
- Outpatient non-screening events
HSCREENING Details Screen
Inpatient Refer Right ear

<table>
<thead>
<tr>
<th>FACILITY DETAILS</th>
<th>Type of Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening Facility: Childrens Hospital</td>
<td>ABR</td>
</tr>
</tbody>
</table>

**ENTER data in SCREENING DETAILS OR SCREENING NOT GIVEN section**

--- SCREENING DETAILS --- *(If no screening, skip to "Screening Not Given" section)*

Complete INPATIENT -OR- OUTPATIENT Details:

**INPATIENT Screening Date:** 12/20/2010

- Right Ear Results (P-Pass, R-Refer, N-Not Screened): R
- Left Ear Results (P-Pass, R-Refer, N-Not Screened): P

**OUTPATIENT Screening Date:** / /

- Right Ear Results (P-Pass, R-Refer, N-Not Screened): 
- Left Ear Results (P-Pass, R-Refer, N-Not Screened): 

--- End of Screen ---
HSCREENING Details Screen
Outpatient Refer

--- SCREENING DETAILS --- (If no screening, skip to "Screening Not Given" section)

Complete INPATIENT - OR - OUTPATIENT Details:

INPATIENT Screening Date

Right Ear Results (P-Pass, R-Refer, N-Not Screened)  Left Ear Results (P-Pass, R-Refer, N-Not Screened)

--- OR ---

OUTPATIENT Screening Date 12/22/2010

Right Ear Results (P-Pass, R-Refer, N-Not Screened)  Left Ear Results (P-Pass, R-Refer, N-Not Screened)
HSCREENING – Details Screen
Transfer to Another Hospital

- SCREENING NOT GIVEN / NOT COMPLETED
  Date of internal/external transfer or other non-screening action) 12/13/2010
  Check level of care: Inpatient  ✔  Outpatient  ❌

- Transferred to another hospital
  Receiving Hospital (Ctrl + Z to clear the field)
  Childrens Hospital

-- OR --

- Infant in birth hospital NICU > 5 days

-- OR --

- Adopted
- Could not test
- Discharge without screening
- Expired
- Homebirth
- Other
- Parent(s) refused
- Technical problems

Incomplete Test Code
HSCREENING Details Screen
(Parent Details, Disposition, Notes)

**PARENT(S) DETAILS**
- Parent(s) educated about hearing screening, etc? [Y/N]: Y
- Primary Language: English
- Phone (free form number): ###-###-####
- Other Phone: ###-###-####

**DISPOSITION**
- Primary Care Provider Name (PCP): Allison - Jay R. Allison MD
- Newborn's Primary Care Provider Notified of results.
- Recommend monitoring, intervention, and follow up care.
- Re-screen at same screening facility.
- Appointment date: / / (blank)
- Recommend re-screen/diagnostic evaluation at audiology clinic.
- Appointment date: 12/22/2010
- Audiologist/Clinic: Boys Town National Research Hospital

**NOTES**
- Baby born premature; Father has profound hearing loss;
HAUDIO Detail Record

HAUDIO (> 200 data fields)

– Facility, audiologist information
– Description of test(s): date, type
– Evaluation results: degree/type/laterality of HL
– Disposition and Recommendations
– Key data copied to HINFO record
  • Initial, most recent, confirmatory results
  • Audio summary, amplification, disposition screens
HAUDIO Record: Evaluation Screen

**Evaluation Type**
- Initial Evaluation
- Confirmatory Evaluation
- Routine Evaluation

**Hearing Loss**
- Hearing Loss
- Normal Hearing

**Right Ear**
- Not Tested
- Degree of hearing loss: PROFOUND
- Type of hearing loss: Sensorineural Hearing Loss
- Comments (e.g., configuration)

**Left Ear**
- Not Tested
- Degree of hearing loss: NORMAL HEARING
- Type of hearing loss
- Comments (e.g., configuration)
HINFO: Case Summary (all events)
HINFO – Other Screens

• Mother, Father Identifying Information
• Audiologic Evaluation – Disposition Summary
• Audiologic Evaluation – Amplification Summary
• Hearing Loss Risk Factors
• Maternal Demographics
  - Age, Marital Status, Education Level, Race, Ethnicity, Payment Source
User Groups / Work Queues

• User groups (5)
  – Super User
  – Administrator
  – Birth clerk
  – Hearing clerk (birth hospital)
  – Hearing clerk (non-birth hospital)

• Work queues
  – Automatic
  – Incomplete records needing data entry
Supplemental Data System

Microsoft® Access data system

- Letters to parents and PCPs
- Out-of-state births
- Out-of-hospital births without birth certificates
- Part C data
- Prototype for future ERS-II development
ERS-II Reports

• Birthing Facility Reports
  – Detailed reports (all births at hospital for specified date range)
  – Aggregate reports (by date range using DOB)
    • Number/percent screened
    • Number/percent pass/refers
    • Number not screened and reason
    • Number in NICU
• Administrative Reports
  – Ad hoc reports (Shazam or Report Builder)
ERS-II Data

• Delinquency reports – weekly and monthly

• Supplemental data
  – CDC’s HSFS annual survey, including all maternal demographics
  – Annual legislative report
  – Periodic reports to NE-EHDI Advisory Committee

• Quality assurance reports
  – Semi-annual reports to birthing facilities
  – Summary statistics for individual facility
    • Includes outcomes, e.g., diagnosed HL, lost to follow-up, etc.
  – Comparison with state averages
Newborn Hearing Screening Quality Assurance Report
(Upper section of report)

<table>
<thead>
<tr>
<th>Birthing Facility (Jan-Dec 2009 DOB)</th>
<th>Comparison with State Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Hearing Screening – OAE</strong></td>
<td><strong>99.2% - state average of hearing screenings completed</strong></td>
</tr>
<tr>
<td>Number of live births</td>
<td>1377</td>
</tr>
<tr>
<td>(Percent of Nebraska births 5.1%)</td>
<td></td>
</tr>
<tr>
<td>Expired</td>
<td>1</td>
</tr>
<tr>
<td>Transfers to another hospital</td>
<td>17</td>
</tr>
<tr>
<td>Number available for inpatient screening</td>
<td>1359</td>
</tr>
<tr>
<td>Number of inpatient screenings</td>
<td>1357</td>
</tr>
<tr>
<td>Percent of screenings completed</td>
<td><strong>99.9%</strong></td>
</tr>
<tr>
<td>Number of “Passes”</td>
<td></td>
</tr>
<tr>
<td>Number of “Refers”</td>
<td></td>
</tr>
<tr>
<td>“Refer” rate</td>
<td><strong>10.5%</strong></td>
</tr>
<tr>
<td>Inpatient screenings not completed</td>
<td>2</td>
</tr>
<tr>
<td>Percent not receiving inpatient screening</td>
<td><strong>0.1%</strong></td>
</tr>
<tr>
<td>Could not screen</td>
<td>0</td>
</tr>
<tr>
<td>Discharge without screening</td>
<td>2</td>
</tr>
<tr>
<td>Technical problems</td>
<td>0</td>
</tr>
<tr>
<td>Other/Parent Refused</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td><strong>.8% - state average inpatient screening not received</strong></td>
</tr>
</tbody>
</table>
# Newborn Hearing Screening Quality Assurance Report

**(Lower section of report)**

## Birthing Facility (Jan-Dec 2009)

- **Percent of parents educated about hearing screening, hearing loss and speech-language-auditory development**: 99.9%

## Outcomes of Babies Needing Follow-up Services:

- **144 Needing Follow-up Services**
  - Normal Hearing: 131
  - Hearing Loss: 1
  - Other (in process, expired, moved, refused, etc.): 2
  - Lost to Follow-up: 10

- **Lost to Follow-up rate (10/144)**: 6.9%

## Comparison with State Statistics

- **Percent of parents educated about hearing screening, hearing loss and speech-language-auditory development**: 99.5%

## Statewide Outcome Totals:

- **1,323 Needing Follow-up Services**
  - 1,090 - Normal Hearing
  - 39 - Permanent Congenital Hearing Loss
  - 72 - Other (in process, expired, moved, etc.)
  - 122 - Lost to Follow-up

- **9.2% - “Loss to Follow-up” state average rate (122/1323)**
ERS-II Benefits

Timely, Complete and Accurate Data for All Babies

– Results entered quickly for all births: average is < 12 days

– More detail in ERS-II for all babies needing follow-up:
  • Parent phone number(s)
  • Primary language of parent
  • Primary health care provider (PCP)
  • Outpatient follow-up plans

– Letters and phone calls to PCPs and parents

– Outcomes, maternal demographics, calculation of “number of days” to screenings and evaluations
ERS-II Benefits

27,199 births in 2009
1360 newborns needed follow-up
  ▪ 209 were discharged prior to hearing screening
  ▪ 1151 did not pass hearing screening during birth admission

998 received one or more outpatient hearing screenings
152 received one or more audiologic diagnostic evaluations
  65 received a combination of outpatient hearing screenings and audiologic diagnostic evaluations
145 did not receive any hearing services or the services were not reported

1127 had normal hearing (outpatient pass, evaluation -> normal hearing)
  46 were diagnosed with permanent congenital hearing loss (PCHL)
  27 are still being evaluated
122 were lost to system (did not receive or complete services or services were not reported)
  20 families moved with no forwarding address (did not receive or complete services)
  14 parents refused prior to outpatient hearing services initiated or completed
  4 expired prior to outpatient hearing services initiated or completed
ERS-II Benefits

Lost to Follow-up by Maternal Education

Percent

% of IP Refers

% of Lost2FU

Maternal Educational Level

< HS

HS/GED

Some college; AA/AS

College Grad or above

26
ERS-II Benefits

Comparison of Percent of Births, Refers and Lost to System for Selected Hospitals

Six Hospitals with Highest Lost to System Rate

<table>
<thead>
<tr>
<th>Hospital</th>
<th>% of Births</th>
<th>% of Refers</th>
<th>% of Lost to System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital B</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital C</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital D</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital E</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital F</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ERS-II Benefits

Timeliness of Initiation of Follow-up Services - 2009

Number of Newborns

Age (in days) at Initiation of Follow-up Services

0 10 20 30 40 50 60 70 80

1 4 7 10 13 16 19 22 25 28 31 34 37 40 43 46 49 52 55 58 61 64 67 70 73 76 79 82 85 88 91
NE-EHDI PROGRAM

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