Data Sharing Partnerships to Promote Lead Screening and Follow-up Through an Integrated Child Health Information System

November 1, 2017
Nashua, NH
Session Overview

★★★Brief review of RI lead data
★★★Overview of KIDSNET, Rhode Island’s integrated child health information
★★★Describe how KIDSNET is used by community partners to promote lead screening and follow-up
★★★Discussion of partnerships with other state agencies
RI Elevated Lead Prevalence Rates

RI Prevalence >=5 ug/dL for Children aged <=72 months from 2006 to 2016

2006: 17.5%
2007: 14.4%
2008: 13.8%
2009: 16.9%
2010: 9.8%
2011: 7.5%
2012: 6.4%
2013: 5.5%
2014: 5.2%
2015: 5.3%
2016: 4.8%
Percent of Children Statewide Screened for Lead in Compliance with Guidelines, 2007-2016

- At Least one Lead Screening by 18 Months
- At Least two Lead Screenings, a minimum of 12 months apart, by 36 months
What is KIDSNET?

⭐⭐⭐ A Public Health Program – not an electronic medical record

⭐⭐⭐ Integrated Child Health Information System for maternal and child health programs

⭐⭐ Facilitates the collection and appropriate sharing of health data by authorized users for the provision of timely and appropriate preventive health services and follow up
Vision: All RI children receive appropriate and timely preventive healthcare as a result of access to and utilization of comprehensive data on preventive health services by authorized users.

Mission: KIDSNET facilitates the collection and appropriate sharing of health data with healthcare providers, parents, MCH programs and other child service providers for the provision of timely and appropriate preventive health services and follow up.
<table>
<thead>
<tr>
<th>Universal:</th>
<th>Targeted:</th>
</tr>
</thead>
<tbody>
<tr>
<td>★★★Newborn Developmental Risk</td>
<td>★★★WIC</td>
</tr>
<tr>
<td>★★★Newborn Bloodspot Screening</td>
<td>★★★Early Intervention</td>
</tr>
<tr>
<td>★★★Newborn Hearing Assessment</td>
<td>★★★Home Visiting</td>
</tr>
<tr>
<td>★★★Immunization</td>
<td>★★★Birth Defects</td>
</tr>
<tr>
<td>★★★Childhood Lead Poisoning</td>
<td>★★★Cedar (Medicaid care coordination)</td>
</tr>
<tr>
<td>★★★Vital Records</td>
<td></td>
</tr>
<tr>
<td>★★★Child Outreach</td>
<td>★★★Healthy Weight</td>
</tr>
<tr>
<td></td>
<td>★★★Asthma</td>
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<td></td>
<td>★★★Early Childhood Developmental Screening</td>
</tr>
<tr>
<td></td>
<td>★★★Foster Care</td>
</tr>
<tr>
<td></td>
<td>★★★Head Start</td>
</tr>
</tbody>
</table>
KIDSNET Users

- Medical Care Providers
- Maternal & Child Health Programs
- Head Start and Child Care Agencies
- Schools/Child Outreach
- Home Visitors
- Certified Lead Centers
- Audiologists
- Managed Care Organizations
- Early Intervention
- WIC
- CEDARR Centers
Who can access what data?

Access is granted on a need to know basis

Programs, not KIDSNET, determine who can access their program data

Parents are informed at several time points and may “opt out” of display of their child’s information

Display is blocked if parental notification letter is returned as undeliverable

Signed consent is not obtained except at the program levels where the program is required or prefers to get signed consent
KIDSNET Data Capture

- Births from January 1, 1997 and later
- Records initiated at birth or first contact with KIDSNET Program

Hybrid data model (warehouse vs. complete)

- Lead data are warehoused
- Files uploaded to KIDSNET from Lead Database

- Records are updated after services are received from direct data entry or electronic file submission from programs and providers
What about HIPAA?

• The Privacy Rule expressly permits public health information (PHI) to be shared for specified public health purposes….. Further, the Privacy Rule permits covered entities to make disclosures that are required by other laws, including laws that require disclosures for public health purposes.
The Confidentiality of Health Care Communications and Information Act permits release or transfer of confidential health care information without consent “between and among qualified personnel and health care providers within the health care system for purposes of coordination of health care services....”
KIDSNET Lead Data Uses

⭐️⭐️⭐️ KIDSNET can be used to look at information for an individual child

⭐️⭐️⭐️ KIDSNET can be used to look at subpopulations of children on reports
  ⭐️⭐️⭐️ Children never lead screened
  ⭐️⭐️⭐️ Children overdue for 2nd lead screening

⭐️⭐️⭐️ KIDSNET can generate files to be used by partners to match their lead screening records to focus outreach

⭐️⭐️⭐️ KIDSNET Lead data can help prioritize services
## Blood Lead Screening Information

<table>
<thead>
<tr>
<th>Test Date</th>
<th>Physician Name</th>
<th>Sample Type</th>
<th>EP</th>
<th>PbB</th>
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<tr>
<td>09/17/2014</td>
<td>JANE SMITH</td>
<td>V</td>
<td>013</td>
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<td>05/14/2015</td>
</tr>
<tr>
<td>06/18/2014</td>
<td>JANE SMITH</td>
<td>V</td>
<td>013</td>
<td></td>
<td>05/14/2015</td>
</tr>
<tr>
<td>10/16/2013</td>
<td>JANE SMITH</td>
<td>V</td>
<td>021</td>
<td></td>
<td>05/14/2015</td>
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<tr>
<td>08/21/2013</td>
<td>SMITH, MD, JANE</td>
<td>V</td>
<td>026</td>
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<td>03/18/2013</td>
<td>TEST, CLIENT</td>
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<tr>
<td>09/19/2012</td>
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<tr>
<td>09/07/2012</td>
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<td></td>
<td>05/14/2015</td>
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<tr>
<td>08/30/2012</td>
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<td>12/29/2011</td>
<td>SMITH, DORY</td>
<td>V</td>
<td>009</td>
<td></td>
<td>05/14/2015</td>
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<tr>
<td>10/07/2011</td>
<td>SMITH, DORY</td>
<td>F</td>
<td>013</td>
<td></td>
<td>05/14/2015</td>
</tr>
</tbody>
</table>

## Environmental Lead Inspection Information

<table>
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<tr>
<th>Inspection Date</th>
<th>Close Date</th>
<th>Inspection Result</th>
<th>Status</th>
<th>Inspection Address</th>
<th>Apt</th>
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<tbody>
<tr>
<td>06/16/2013</td>
<td>12/09/2013</td>
<td>NO LEAD PAINT FOUND/LEAD PAINT PRESENT</td>
<td>CLOSED, ABATEMENT COMPLETE</td>
<td>PROVIDENCE, RI 02904</td>
<td></td>
</tr>
<tr>
<td>03/21/2013</td>
<td>12/09/2013</td>
<td>LEAD PAINT HAZARD - EXTERIOR ONLY</td>
<td>CLOSED, ABATEMENT COMPLETE</td>
<td>PROVIDENCE, RI 02904</td>
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<td>09/28/2012</td>
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<td>LEAD PAINT HAZARD - BOTH INTERIOR AND EXTERIOR</td>
<td>OPEN</td>
<td>PROVIDENCE, RI 02904</td>
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</tbody>
</table>
KIDSNET Partners with Lead Reports

⭐⭐⭐ Primary care providers
⭐⭐⭐ Linked to practice when immunization is submitted

⭐⭐⭐ Other partners that submit enrollment data
⭐⭐⭐ Home Visiting
⭐⭐⭐ Early Intervention
⭐⭐⭐ WIC
⭐⭐⭐ Cedar Centers (Medicaid Special Needs Care Coordination)
⭐⭐⭐ Head Start
Practice Reports

Available Reports

1. Patient List Report
2. Developmental Screening - Due New Report
3. Lead Screening Report - Children Without a Lead Screening
4. Lead Screening Report - Children Due for Second Lead Screening
5. Lead Report - Children with results ≥ 5ug/dl
6. School Eligible Report
7. Immunization Report
8. Newborn Hearing Screening Report
9. Newborn Summary Report
10. Immunizations Submitted to KIDSNET By Other Providers
11. Immunization Coverage Report

Seasonal Reports

Seasonal Influenza - Children Due For Shot #1 Report
Seasonal Influenza - Children Due Now or Due Soon For Shot #2 Report
Head Start Reports - Lead Screening

Generate Report

A list of patients in your practice.

Children Due for Second Lead Screening

This report generates a list of patients in your practice who have been screened for lead once, with a result <5 mcg/dL, who are due for a second blood lead screening.

- Less than 24 months
- 24-28 Months Old
- 29-35 Months Old
- 36-72 Months Old

Select Age Range:

For more information or to provide feedback eMail KIDSNET

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disclaimer --- rel. 20170606
## Practice Reports - Lead Screening

**Report Criteria:** Monday, May 16, 2005 11:17:33 AM  
**Provider Id:** 9999  
**Practice:** DEMO PEDIATRICS  
**Patients 15 - 36 months**

### Lead Screening Report - Children Without Lead Screening

<table>
<thead>
<tr>
<th>Child Name</th>
<th>Date Of Birth</th>
<th>KIDSNET Id</th>
<th>Not a Patient</th>
<th>Transferred</th>
<th>Moved Out of State</th>
</tr>
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<tbody>
<tr>
<td>SANDY N BOTTOMS</td>
<td>01/09/2003</td>
<td>251592</td>
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<tr>
<td>AMANDA JONES</td>
<td>05/07/2003</td>
<td>272925</td>
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<tr>
<td>ALEX LETTY</td>
<td>02/08/2004</td>
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<td>JOHN SMITH</td>
<td>01/01/2004</td>
<td>272924</td>
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Head Start Reports - Children with results ≥ 5 µg/dl

Report Criteria: Thursday, October 19, 2017 03:34:03 PM
Agency Id: 0
Agency: XYZ HEADSTART AGENCY
Report limited to children less than 6 years of age.

### LEAD REPORT - MOST RECENT LEAD TEST > 5 µg/dl

<table>
<thead>
<tr>
<th>Child Name</th>
<th>Date Of Birth</th>
<th>KIDSNET Id</th>
<th>Most Recent Test Date</th>
<th>Lead Level</th>
<th>Test Type</th>
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<tbody>
<tr>
<td>* 1. HOME VISIT M TEST</td>
<td>02/15/2012</td>
<td>7557817</td>
<td>01/30/2015</td>
<td>013</td>
<td>V</td>
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</tbody>
</table>

Report Run: Thursday, October 19, 2017 03:34:03 PM
Partnership with MCOs

MCO sends file of members with no evidence of screening in their database

KIDSNET returns file with lead screening history from all sources

MCO can target lead screening outreach more precisely

More children screened – High National Committee for Quality Assurance (NCQA) quality ratings for RI MCOs
Partnership with Dept. of Education Child Outreach

School districts provide developmental screening for all 3-5 year old children

- Hearing
- Vision
- Speech-language
- Social Emotional
- General Cognitive

Child Outreach database was built into KIDSNET

High risk, including lead >5 µg/dL can be prioritized
### Child Outreach Screening Dashboard

**User login:** eamoreco  **User district:**

#### Screening Status Filter

- **School District:** All Districts
- **Zip Code:**

#### Screening Status 2017 - 2018

<table>
<thead>
<tr>
<th></th>
<th>District Total</th>
<th>Submitted</th>
<th>Started, Not Yet Submitted</th>
<th>Not Yet Started</th>
<th>Submitted, Awaiting Spec Ed Referral Outcome</th>
<th>Non-Residents Started, Not Yet Submitted</th>
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<tr>
<td>K</td>
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<td>0</td>
<td>1353</td>
<td>1</td>
<td>0</td>
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<tr>
<td>K - 1</td>
<td>957</td>
<td>18</td>
<td>3</td>
<td>936</td>
<td>3</td>
<td>1</td>
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<tr>
<td>K - 2</td>
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<td>1</td>
<td>1</td>
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<tr>
<td>K - 0</td>
<td>1357</td>
<td>3</td>
<td>2</td>
<td>1352</td>
<td>1</td>
<td>0</td>
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<tr>
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<td>45</td>
<td>10</td>
<td>5272</td>
<td>6</td>
<td>2</td>
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</tbody>
</table>

#### Child List Filter

- Partial last and/or first names may be used

- **Last Name:**
- **First Name:**

- [ ] DCYF
- [ ] Age 3
- [x] Lead Level
### Child Outreach Screening Dashboard

**Screening Status Filter**

- **School District:** New Shoreham
- **Zip Code:**

### Screening Status 2017 - 2018

<table>
<thead>
<tr>
<th></th>
<th>District Total</th>
<th>Submitted</th>
<th>Started, Not Yet Submitted</th>
<th>Not Yet Started</th>
<th>Submitted, Awaiting Spec Ed Referral Outcome</th>
<th>Non-Residents Started, Not Yet Submitted</th>
</tr>
</thead>
<tbody>
<tr>
<td>K</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
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<td>1</td>
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<td>K - 2</td>
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<td>1</td>
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<td>0</td>
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<td>ALL</td>
<td>18</td>
<td>2</td>
<td>2</td>
<td>14</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

### Child List Filter

- **Partial last and/or first names may be used**
- **Last Name:**
- **First Name:**
- **DCYF**
- **Age 3**
- **Lead Level**

= Mouse-over icons (if present) for more information

### K - 2 Not Yet Started Child List

<table>
<thead>
<tr>
<th>KIDSNET Child ID</th>
<th>Child Last Name</th>
<th>Child First Name Middle Initial</th>
<th>Date of Birth</th>
<th>Zip</th>
<th>Indicators</th>
</tr>
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<tbody>
<tr>
<td>7549662</td>
<td>EAGLE</td>
<td>BALD</td>
<td>09/19/2013</td>
<td>22222</td>
<td>Pb</td>
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<tr>
<td>7543667</td>
<td>TANAGER</td>
<td>SCARLETT</td>
<td>09/26/2013</td>
<td>22222</td>
<td>Pb</td>
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<tr>
<td>7521814</td>
<td>WINDOW</td>
<td>ORIE, L</td>
<td>04/03/2014</td>
<td>02807</td>
<td>Pb</td>
</tr>
</tbody>
</table>
Partnership with Dept. of Children, Youth and Families

⭐⭐⭐ DCYF has on-line access to KIDSNET
⭐⭐⭐ Developed a KIDSNET user guide
⭐⭐⭐ Instructions to provide lead screening page printout to foster parent and new PCP
⭐⭐⭐ Describes elevated lead and gives contact information for state lead poisoning prevention program
⭐⭐⭐ Developed on-line training for DCYF
Lead Screening

Children should be screened once a year, every year, until they are 6 years of age using the Lead "Risk Assessment Questionnaire", unless they have had two screenings at least 12 months apart, with blood lead levels below 5 mcg/dL.

Children who have, or had, elevated blood lead levels and for whom a Comprehensive Environmental Lead Inspection was ordered by the Department of Health, will have those home inspections appear on this page, with the most recent date (inspection) at the top.
Partnership with WIC - in development

WIC can access KIDSNET immunization page without leaving the WIC information system

Provide basic information regarding whether WIC Programs should screen children for Lead

Modify the immunization page made available to the WIC programs - add two indicators:

- Initial Lead Screen Due: YES would appear if they met the criteria for needing a screen
- Second Screening Due: YES would appear if the child met the criteria for needing a second screen
Welcome to KIDSNET

Immunization

Search

Enter KIDSNET ID:  

LookUp

Child Information - 10/23/2017

Name: SNEEZY D ARAGOM  
KIDSNET ID: 6124286
Date Of Birth: 02/22/2009  
Age: 8y 8m  
Gender: MALE
KIDSNET Status: ACTIVE  
PCP: TEST PEDIATRIC PRACTICE

Parent/Guardian: PARENT K ARAGOM  
Date of birth: 07/19/1979

School Requirements:  
K: ✓  
7th: ✗  
8th: ✗  
9th: ✗  
12th: ✗
(as of 8/1/2017)

<table>
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<th>Valid Doses</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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<tbody>
<tr>
<td><strong>Hepatitis B</strong></td>
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<td></td>
<td></td>
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<td>End of Series Reached</td>
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<td>3 valid doses</td>
<td>02/23/2009 HepB ped/adol 0m 1d</td>
<td>05/05/2009 DTaP-HepB-IPV 2m 13d</td>
<td>07/15/2009 DTaP-HepB-IPV 4m 23d [1]</td>
<td>08/25/2009 DTaP-HepB-IPV 6m 3d</td>
<td>04/16/2015 DTaP-HepB-IPV 6y 1m [2]</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DTaP</strong></td>
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<td>See Tdap Below</td>
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<tr>
<td>5 valid doses</td>
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<td>07/15/2009 DTaP-HepB-IPV</td>
<td>08/25/2009 DTaP-HepB-IPV</td>
<td>07/26/2010 DTaP 17m 1d</td>
<td>05/02/2013 DTAP-IPV 4y 2m</td>
<td>04/16/2015 DTaP-HepB-IPV</td>
<td></td>
</tr>
</tbody>
</table>
Questions?
Ellen Amore
KIDSNET Manager
Center for Health Data and Analysis
Rhode Island Department of Health
ellen.amore@health.ri.gov