Integrating Child Health Information Systems

Alan R. Hinman, MD, MPH
All Kids Count
May 5, 2004
Basic premise

• Health and health services can be improved by assuring timely provision of accurate and comprehensive information

• Currently, information is often not timely and usually fragmented
Newborns screened for hyperphenylalaninemia – 1999-1

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. screened</td>
<td>4,024,850</td>
</tr>
<tr>
<td>No. NOT NORMAL</td>
<td>3,494</td>
</tr>
<tr>
<td>No. NOT NORMAL lost to f-u</td>
<td>154</td>
</tr>
<tr>
<td>No. Classical PKU or clinically significant variant</td>
<td>302</td>
</tr>
</tbody>
</table>
Newborns screened for hyperphenylalaninemia – 1999-2

3,494 NOT NORMAL – 154 lost to f-u =
3,340 NOT NORMAL with f-u ->
302 classical PKU or sig. Variant

3,340/302 = 11 f-u/case

154 NOT NORMAL lost to f-u/11 =
14 missed cases??
Average time for notification of screen-negative result – Desposito et al

<table>
<thead>
<tr>
<th>Days</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 7</td>
<td>4</td>
</tr>
<tr>
<td>8 – 14</td>
<td>19</td>
</tr>
<tr>
<td>15 - 21</td>
<td>22</td>
</tr>
<tr>
<td>22 – 28</td>
<td>13</td>
</tr>
<tr>
<td>&gt;28</td>
<td>16</td>
</tr>
<tr>
<td>Not</td>
<td>26</td>
</tr>
</tbody>
</table>
GSB/MCHB Grants since 1998

Purpose to facilitate:

• the development of integrated child health information systems to include newborn screening systems

• the opportunity to improve service delivery to children and their families that is community-based, culturally competent, comprehensive

• the enhancement of the ability to coordinate care across multiple programs and providers
Child Health Profiles - 1

• Goal – to provide up-to-date information about children’s health status to families, health care providers, and public health programs, thereby facilitating appropriate care

• Authorized users can determine at a glance child’s status with respect to all components

• Individual programs can assess information about child’s status with respect to other programs
Child Health Profiles - 2

Start with 4 programmatic areas:

- Newborn dried blood spot (NDBS) screening
- Early hearing detection and intervention (EHDI)
- Immunizations
- Vital registration
Child Health Profiles - 3

4 areas chosen share characteristics:
• Recommended for all infants/children
• Carried out/begin in newborn period
• Time-sensitive
• Primarily delivered in private sector but have strong public sector component
• Mandated in most/all states
Integration of Newborn Screening and Genetic Service Systems with Other MCH Systems

A Sourcebook for Planning and Development

Prepared by
All Kids Count
Public Health Informatics Institute
2002
Key Elements for Success

• Leadership
• Project governance
• Project management
• Stakeholder involvement
• Organization and technical strategy
• Technical support and coordination
• Financial support and management
• Policy support
• Evaluation
Lessons Learned

- Data are for sharing
- Listen up
- Change is hard
- Let public health program needs drive technology
- Stay the course

Source: Sourcebook
Core Workgroup Meeting
May 8-9, 2003

• Goal – Develop a draft Model of Practice (Framework) for integrating newborn screening systems with other related early child health information systems that includes a comprehensive set of core functions, activities and services

• Objective – To gain agreement on the format of the Model of Practice and draft core functions
Points to keep in mind

• Principles/functions refer to integrated systems – individual program systems may have additional functionality

• Do not speak to
  – System architecture
  – Data elements
  – Software

• Address what the functions are, not how they are to be achieved
Principles and Core Functions of Integrated Child Health Information Systems
Principles underlying integrated child health information systems

- Purpose – 1
- Security & confidentiality – 5
- Technology serving stakeholder needs – 8
- Quality assurance & evaluation – 3
- Financing – 2

- Total – 19
Core Functions of Integrated Child Health Information Systems

- Confidentiality & security – 5
- Establishing & maintaining client records – 4
- Service functionality – 6
- Technical functionality – 4
- Reports – 3

- Total – 22
Desirable functions of integrated child health information systems

- Establishing & maintaining client records – 3
- Service functionality – 2
- Technical functionality – 1
- Reports – 2

- Total – 8
AKC Integration Survey

- 23 HD identified as integrating CHIS
  - AKC Connections members
  - GSB/HRSA grantees
  - 2000 Immunization Registry Annual Report responses
  - AIRA Programmatic Registry Operations Workgroup responses
- Telephone interviews April-July 2003
- 18 reported current/future integration activities
<table>
<thead>
<tr>
<th>Health Depts</th>
<th>Newborn Died Blood</th>
<th>Newborn Hearing Screening</th>
<th>Vital Registration</th>
<th>Immunization Registry</th>
<th>Women, Infants, Children Program</th>
<th>CSHCN Program</th>
<th>Lead Screening</th>
<th>PH Patient Billing Systems</th>
<th>Birth Defects Surveillance</th>
<th>Early Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>H</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>J</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>L</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>O</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total Current</strong></td>
<td>13</td>
<td>13</td>
<td>10</td>
<td>9</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total Overall</strong></td>
<td>15</td>
<td>15</td>
<td>13</td>
<td>17</td>
<td>16</td>
<td>8</td>
<td>10</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

- **Current and Maintained Integration Activities**
- **Future Integration Activity**

*Public Health INFORMATICS Institute*
Developing Child Health Information Systems to Meet Medical Care and Public Health Needs

December 3-4, 2003
Atlanta GA
Conference vision

Improving children’s health and health services through timely provision of accurate and comprehensive information
Conference recommendations

• A series of action steps in four areas
  – Governance
  – Information infrastructure
  – Economic issues
  – Use of information

• Meeting summary and recommendations posted at
  www.allkidscountr.org
Common threads in recommendations

- Development of national coalition of stakeholders to promote integration of separate CHIS within the context of ongoing initiatives such as NHII and PHIN
- Need to develop business and policy cases for integrated CHIS
- Need to develop agreement on standards for collecting and transferring information
- Need to get the word out about importance of integrating separate CHIS to improve health and health services
Public Health Laboratories Take the Next Step: A Collaborative Approach to Laboratory Information Management Systems Design

April 21, 2004

Anita Renahan-White, MPH
Rationale for the requirements project

• Fall 2001
  – Public Health Laboratories (PHLs) overwhelmed
  – Inadequate LIMS
  – Inability to electronically exchange information

• APHL’s Strategic Plan (2002-2005)
  – Goal III: Improve the capability to capture, process, and communicate laboratory information and develop consensus on the essential elements of effective LIMS.
Background

• Partnered with APHL and PHLs October 2002 through June 2003 to define requirements
• Participated in successful collaboration of 16 PHLs (15 state PHLs and one county PHL)
• Collaborative initiative showed common set of LIMS requirements is feasible
• Recognize current implementations need more than the high level system requirements
• Recognize the value of a common LIMS design as a key component of achieving interoperability
Developing Requirements

The essential step in developing or acquiring a LIMS

- Enables PHLs to develop or acquire a system that meets users’ needs
- Enables PHL enterprise view of all lab functions, information needs, and interdependencies of information across business functions
- Enables PHLs to match system requirements to commercial vendors’ software products
The End Result

Comprehensive requirements

• A roadmap for helping PHLs move in the direction of the overall vision expressed by the document (contact APHL)

• A tool for assessing LIMS products measured against the complete set of requirements and individual laboratory needs (see APHL Members Only site)

• A basis for public health labs to issue comprehensive RFP’s for commercial LIMS solutions
Contact information

ahinman@taskforce.org

www.allkidscount.org