

Integrating Child Health Information Systems

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All Kids Count

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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

No. screened	4,024,850
No. NOT NORMAL	3,494
No. NOT NORMAL lost to f-u	154
No. Classical PKU or clinically significant variant	302

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

<u>Days</u>	<u>%</u>
1 - 7	4
8 – 14	19
15 - 21	22
22 – 28	13
>28	16
Not	26

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

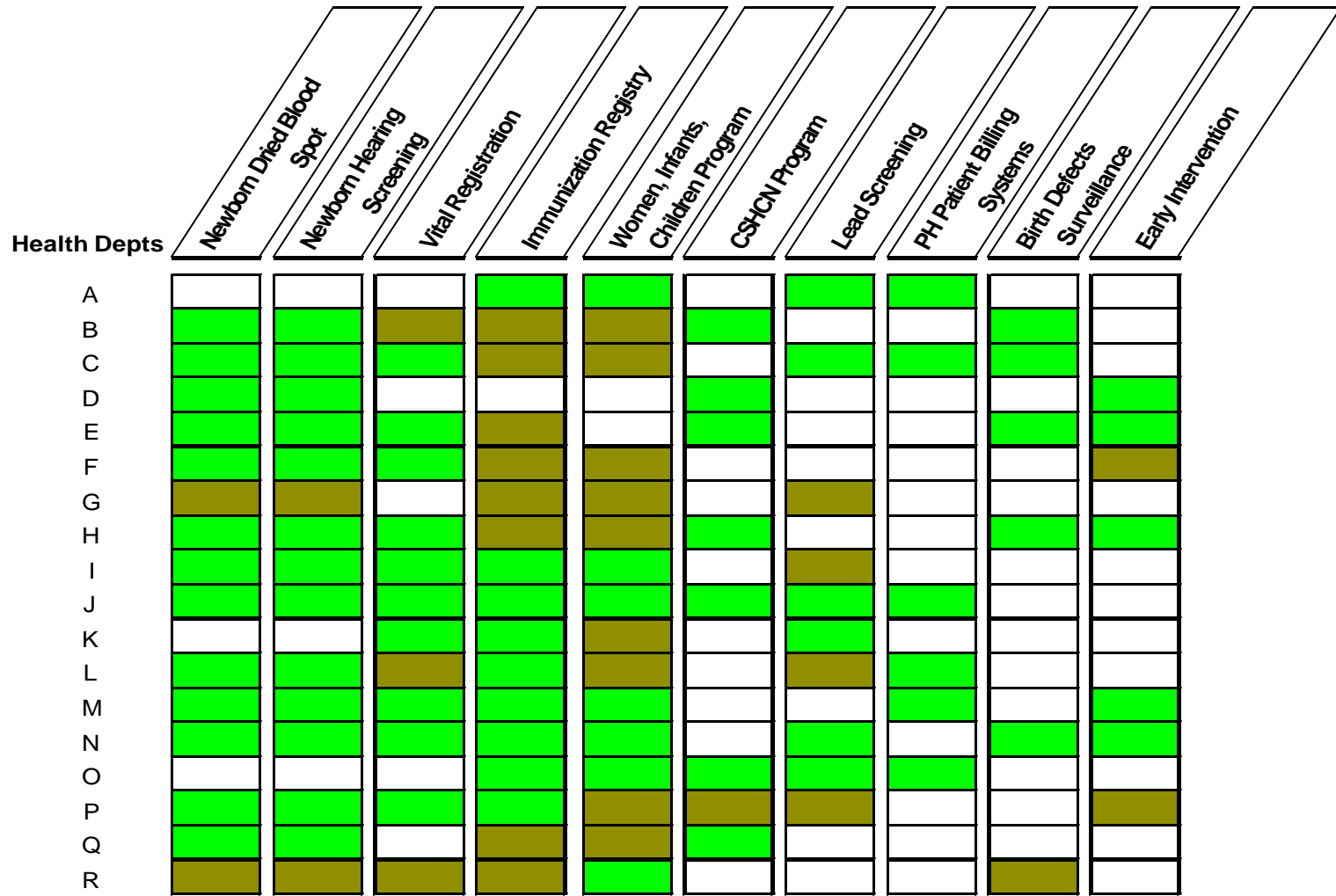
Desirable functions of integrated child health information systems

- **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**



Total Current
Total Overall

13	13	10	9	7	7	6	6	5	5
15	15	13	17	16	8	10	6	6	6

 Current and Maintained Integration Activities
 Future Integration Activity

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

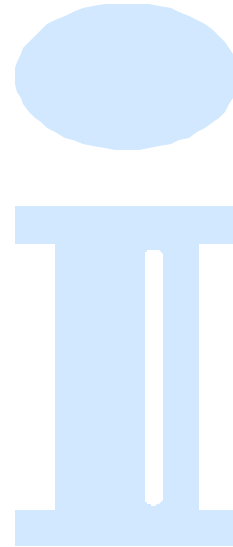
Conference recommendations

- **A series of action steps in four areas**
 - **Governance**
 - **Information infrastructure**
 - **Economic issues**
 - **Use of information**
- **Meeting summary and recommendations posted at**
www.allkidscount.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



Public Health **INFORMATICS** *I n s t i t u t e*

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

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www.allkidscount.org