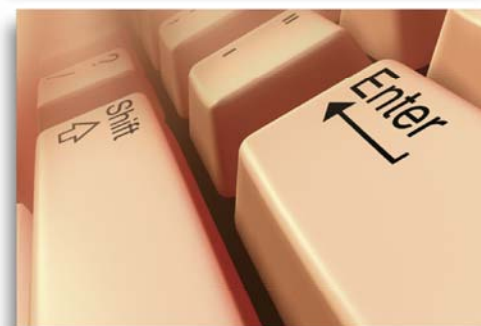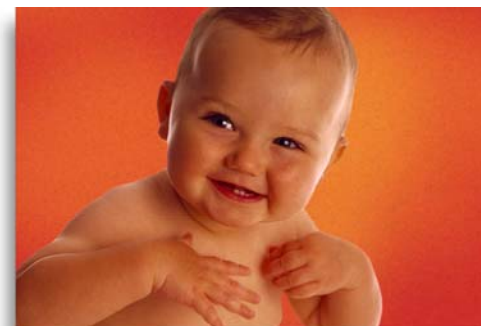# Integrated Information Systems Supporting Child Health in the Context of NHIN

David A. Ross, Sc.D.

Secretary's Advisory Committee

January 13, 2005

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Topics to be covered

- **NHIN, RHIO's, and PHIN – a time of change and transformation for health care and public health**

- **Is there an information problem?**

- **Current activities in integrating health information systems, including pediatric electronic health records**

- **Will health outcomes be improved by integrating child health information systems?**

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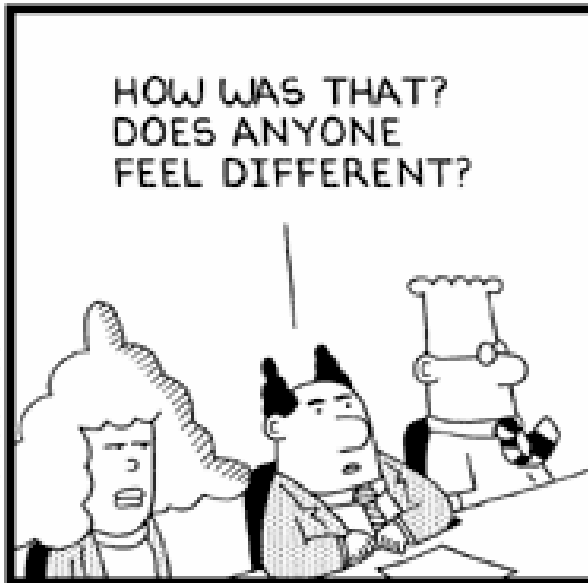
Time of Opportunity

- **Complete information strengthens health and outcomes**

- **Quality movement in health strengthens arguments for EHR's and child profile**

- **Providers and parents have a right to complete information**

- **Public health can and should be able to create a consolidated view of the child**

- **Continued support for integrating systems**

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NHIN

"A National Health Information Network (NHIN) would link disparate health care information systems together to allow patients, physicians, hospitals, public health agencies and other authorized users across the nation to share clinical information in real-time under stringent security, privacy and other protections."

National Health Information Infrastructure

"…NHII is the set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health. The broad goal of the NHIN is to deliver information to individuals—consumers, patients, and professions—when and where they need it so they can use this information to make informed decisions about health and health care."

The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care

Framework for Strategic Action
July 21, 2004

Tommy G. Thompson
Secretary of HHS

David J. Brailer, MD, PhD
National Coordinator for Health Information Technology

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RHIO's

Regional Health Information Organization

- **Holds the data sharing partnership together – declares common purpose**

- **Governs the processes of membership and adherence to mission**

- **Manages stakeholder involvement**

- **Assures conformance with standards and data use agreements**

- **Provides fiduciary role over business model and business practices**

Public Health Information Network (PHIN)

- **A crosscutting and unifying framework to enable consist exchange of response, health, and disease tracking data between public health partners**

- **Information architecture to guide future public health information system developments and to assure that they are in line with NHIN (data coding, vocabulary, message formats, security protocols)**

Is there an information problem?

- **Look at experience with newborn dried blood spot screening and newborn hearing screening**

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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??

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Newborns screened for hypothyroidism – 1999 - 1

No. screened	4,024,850
No. NOT NORMAL	52,217
No. NOT NORMAL lost to f-u	1,371
No. confirmed	
1º hypothyroidism	1,550

Newborns screened for hypothyroidism – 1999 - 2

52,217 NOT NORMAL–1,371 lost to f-u=

50,846 NOT NORMAL with f-u ->

1,550 1° hypothyroidism =

50,846/1,550 = 1 case/32.8 f-u

1,371 NOT NORMAL lost to f-u/32.8 =

42 missed cases??

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Days from birth to initiation of Rx - 1° hypothyroidism

Days	No.
0 - 7	218
8 – 14	455
15 – 21	143
>21	225
Unknown	492

Barriers to gaining access to newborn screening results

- **Infants born in hospital where physician does not have privileges**
- **New transfers to the practice**
- **Infants born in other states**
- **Personnel time to track results**
- **Parents notified before Primary Care Pediatrician**
- **Name change**
- **Absence of direct communication system linking state newborn screening program to Primary Care Pediatrician**

Average time for notification of initial screen-positive result

Days	%
1 - 3	12.5
4 - 7	33.1
8 – 10	16.2
11 – 14	14.5
15 – 21	9.4
> 22	4.4
Not	4.5
?	5.4

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Average time for notification of screen-negative result

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

Source: Desposito *et al*, Peds 2001;108:e22

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Greensboro NC Newborn Hearing Screening, 1998-1999

- **175 / 5010 (3.5%) of non-ICU newborns had abnormal screens**

- **157 / 175 (89.7%) of abnormal screens had follow-up (18 did not)**

- **9 confirmed hearing loss**

- **Ratio of positives to confirmed hearing loss = 17**

- **?did any of 18 not f-u have hearing loss?**

Source: Pediatrics 2000;106:e7

Can information systems improve health and health care?

- **Look at experience with immunization registries**

Demonstrated usefulness of immunization registries

- **Sending reminder/recall notices to children**

- **Generating official immunization records**

- **Assessing immunization levels (HEDIS)**

- **Reducing missed opportunities**

- **Preventing unnecessary immunization**

- **Recall for re-vaccination**

- **Vaccine inventory management**

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**
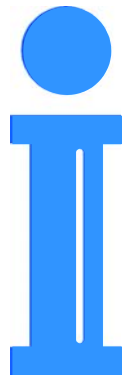
Why do we need integrated CHIS?

- **Many children do not receive all preventive or therapeutic services in a timely manner**
- **Several studies have found low immunization coverage rates to be correlated with insufficient screening for lead and anemia**
- **Multiple PH programs focus on the same target population w/o coordination of services & outreach**
- **There is a need for population-based information that can better identify at-risk children and target programs and services to their needs**

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Goal of integrated CHIS

- **To provide all appropriate information to patients/families, providers, and programs**

- **Complete, accurate & timely information $\Rightarrow$ improved service delivery and health outcomes for children**

- **Integration - providing a range of information to the end user in a simple, comprehensive format so he/she can readily take all indicated actions**

- **Integration relates to the end user, not to the background machinery**

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Targeted programs/systems for integration

1st tier

– **Immunizations (immunization registries)**

– **Newborn dried blood spot (NDBS) screening**

– **Early hearing detection and intervention (EHDI)**

– **Vital registration**

2nd tier

– **WIC**

– **Lead screening**

– **Medicaid/EPSDT**

– **Birth defects surveillance**

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Why these?

Top 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

Progress in initiatives - 1

- **eGov Consolidated Health Informatics project adopts govt-wide interoperability standards**
  - HL7 messaging standards
  - LOINC – lab test identifiers
  - SNOMED – lab result content
  - EPA substance registry system
- **Govt license for SNOMED**
- **Proposed HL7 standard for EHR**
- **Medicare Modernization Act includes e-prescribing**

Progress in initiatives - 2

- **Appointment of David Brailer as National Health Information Technology Coordinator**

- **ARHQ grants**

- **NHII => LHII => RHIO**

- **Congress does <u>not</u> appropriate $50 million for support of ONCHIT in 2005**

HRSA/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**
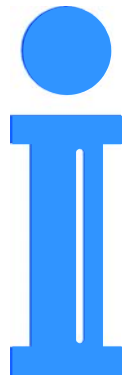
Integration of Newborn Screening and Genetic Service Systems with Other MCH Systems

A Sourcebook for Planning
and Development

Prepared by
All Kids Count
Public Health Informatics Institute
2002

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Lessons Learned

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

Source: Sourcebook

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Principles and core functions of integrated child health information systems

- **Developed by workgroup 2003**

- **19 principles**
- **22 core functions**
- **8 desirable functions**

- **Currently undergoing revision based on further stakeholder discussion**

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Performance measures for integrated child health information systems

- **Developed by workgroup March 2004**
- **Revised based on stakeholder discussions and site visits**
- **Final revision in January 2005**
- **To be pilot tested in early 2005**
- **Further revisions as needed**

Other PHII activities

- *Connections* Communities of Practice
  - began as a technical assistance activity support All Kids Count III project areas
  - Expanded in partnership with HRSA/MCHB to support HRSA/SPRANS grantees
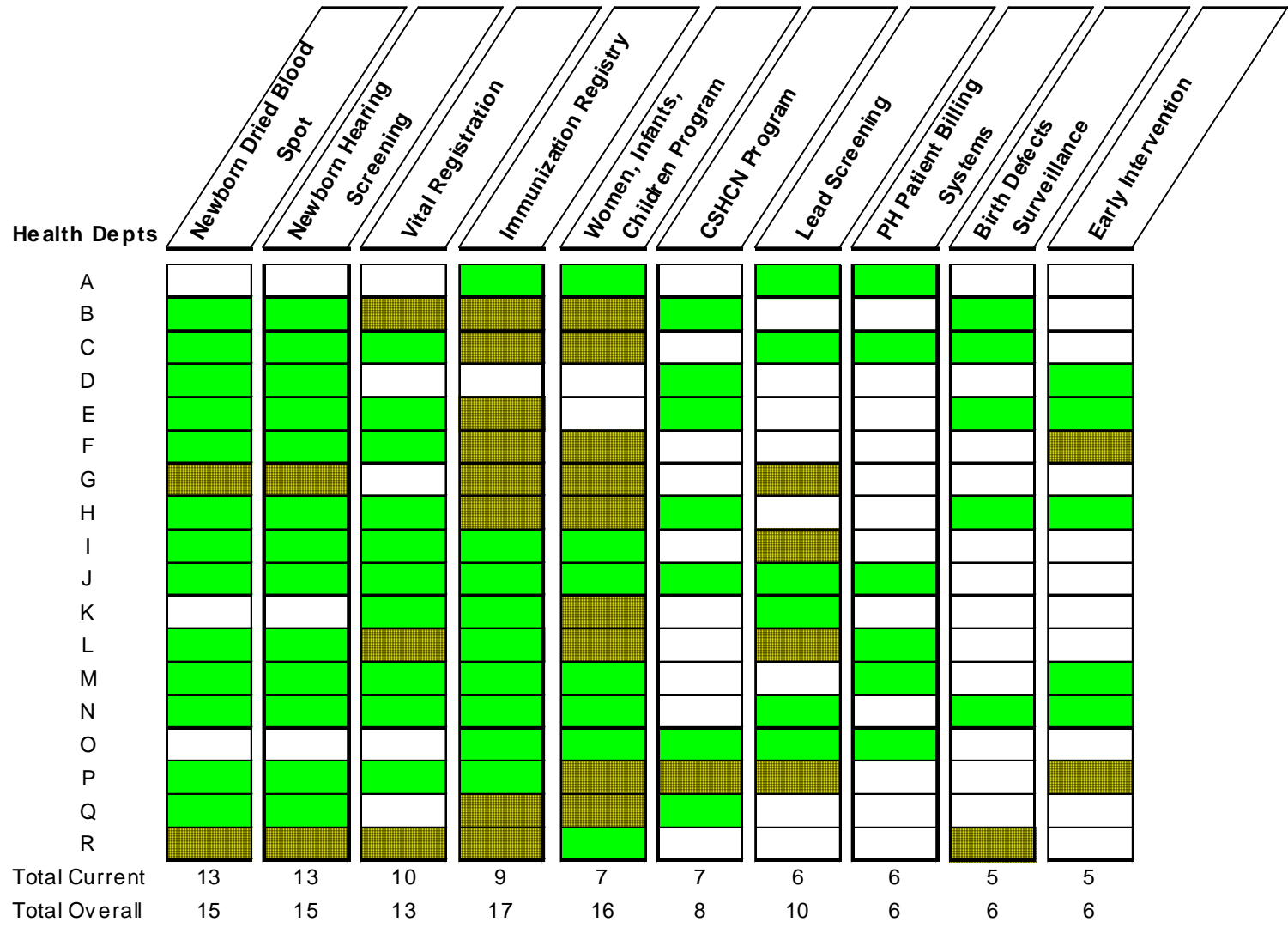- Developing the business case for integrating health information systems

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Key Lessons

1. **Involve stakeholders from the beginning**

2. **Recognize the complexity of establishing a population-based information system**

3. **Develop the policy/business/value case for information systems**

4. **Define the requirements of the system to support users' needs**

5. **Develop information systems according to current standards**

Key Lessons

6. **Address common problems collaboratively – "diversity within commonality"**

7. **Plan for change**

8. **Plan boldly but build incrementally**

9. **Develop a good communications strategy**

10. **Use the information – "The best is the enemy of the good"**

Health Depts

Columns: Newborn Dried Blood Spot | Newborn Hearing Screening | Vital Registration | Immunization Registry | Women, Infants, Children Program | CSHCN Program | Lead Screening | PH Patient Billing Systems | Birth Defects Surveillance | Early Intervention

Rows: A, B, C, D, E, F, G, H, I, J, K, L, M, N, O, P, Q, R

	Newborn Dried Blood Spot	Newborn Hearing Screening	Vital Registration	Immunization Registry	Women, Infants, Children Program	CSHCN Program	Lead Screening	PH Patient Billing Systems	Birth Defects Surveillance	Early Intervention
Total Current	13	13	10	9	7	7	6	6	5	5
Total Overall	15	15	13	17	16	8	10	6	6	6

Legend:
- Current and Maintained Integration Activities
- Future Integration Activity

Supplement to the Journal of Public Health Management and Practice on the Future of Child Health Systems and summary of the All Kids Count Experience

AAFP one voice vision statement

"Every primary care provider will use information technology that includes electronic health records with the ability to access and communicate needed clinical information to achieve high quality, safe and affordable health care." (2001)

Source: www.aafp.org/x6774.xml

AAFP goal

"...to have at least half of its members using EHRs by 2006."

Source: www.centerforhit.org/x162.xml

AAP meeting recommendation

"adoption of electronic health records by a majority of AAP members in the next 5-10 years is at the highest priority"

September 19, 2004

So, what does all this mean to for the future?

- **There is a lot of information system activity going on**

- **Most of it is focused on clinical systems**

- **Some of it is focused on public health systems**

- **A little of it is focused on integrating the two**

- **Almost all of it is geared to programmatic functions rather than research functions**

So, what does all this mean to the future?

- **There is a great opportunity to assure that program systems support research endeavors**
- **This will not happen unless researchers are part of the process (AT THE TABLE)**
- **There will always be need for some specific information systems for research**
- **The vast majority of resources are being, and will be, directed to the program systems**
- **Epidemiologists should assure they can get the most/best information from program systems**

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Will health outcomes be improved?

- **Evidence indicates that health outcomes can be improved by timely provision of accurate information in individual program areas**

- **Too early to demonstrate impact of integration but it is rational to anticipate that providing more information to more users will lead to better outcomes**

Why integrate?

- **Current rate of loss to follow-up of abnormal hearing screens is unacceptably high (40-50%)**

- **Children receive immunizations at birth, 2, 4, 6, and 12-18 months, providing multiple opportunities to act IF the information is available**

- **New EHDI guidelines promote integration of systems**

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www.allkidscount.org