



Topics In Public Health Informatics



The fragmented nature of health information is a barrier to effective health care, especially for children because they are the most vulnerable population.

Integration of clinical information systems with public health information systems can improve coordination of care for children. Parents, clinicians, insurers, communities and public health officials all would benefit from the timely and accurate information about the children they serve.

Stakeholders in integrated child health information systems agree that a national coalition, a business and policy case, agreement on standards, and a campaign to increase understanding of the important role of child health information systems are needed for these systems to gain acceptance and widespread adoption.

Integrated Child Health Information Systems

An update on the status and near-term future of information systems that consolidate information about the multiple health care services a child receives.

What are integrated child health information systems?

Integrated child health information systems consolidate information about the multiple health care services a child receives. The goal of integrating child health information systems is to ensure children receive necessary preventive services, screening, and therapeutic follow-up services by providing complete, timely, and accurate information to medical care providers, parents, and public health authorities through a convenient point of access. "Integration" refers to the provision of a range of information to the end user in a simple yet comprehensive format so that he/she can take all recommended actions. In this context, integration does not imply a specific technical model.

Who is calling for integration of child health information systems?

Concern about the fragmented nature of health information has grown in recent years.

In its 2001 report *Information for Health—A strategy for building the National Health Information Infrastructure*, the National Committee on Vital and Health Statistics stated: "The fragmentation of health care delivery today makes it essential to have integrated, effective information systems in order to understand the health care system and how people fare in it. Without this, we lack a composite picture of the preventive and treatment interventions given to individuals and communities."¹

Communication between public health agencies and those who deliver health care is of special concern. The Institute of Medicine concluded in its 2003 report *The Future of the Public's Health in the 21st Century*, "Existing information networks make it difficult, and sometimes impossible, for government public health agencies to exchange information and communicate effectively with the health care delivery system."²

A number of initiatives spearheaded by federal agencies are now underway to address these issues. These include the re-engineering of vital records; the National Health

Because most integrated child health information systems are still under development, little published documentation of their benefits exists. We know, however, that many children “fall through the cracks” because they do not receive the time-specific interventions and follow-up necessary to prevent or reduce adverse health outcomes.

Information Infrastructure (NHII), a comprehensive knowledge-based system that will serve consumers, patients, health care providers and public health professionals; the Consolidated Health Informatics (CHI) initiative, the health care component of President Bush’s eGov initiative that will provide standards for electronic exchange of clinical health information across the federal government; and the Public Health Information Network (PHIN), an initiative of the Centers for Disease Control and Prevention (CDC) that establishes information architecture standards for public health data.

Support for integration of information about children, because they are the most vulnerable population, has received special attention. The Council of Regional Networks for Genetic Services 1997 report recommended that child public health data be integrated to monitor screening activities and to improve health outcomes.³

The Newborn Screening Task Force, convened by the American Academy of Pediatrics at the request of the Health Resources and Services Administration (HRSA), in 1999 recommended integration of newborn dried blood spot screening programs and information systems with other public health programs and coordination with private health providers and other federal and state public service providers.⁴ The Task Force concluded that such integration improves the efficiency and effectiveness of the newborn screening system and maximizes limited resources.

Federal or national initiatives targeted specifically to integration of child health information systems are not yet numerous. Since 1999, the Health Resources and Services Administration has provided plan-

ning and implementation grants to 25 states to integrate newborn dried blood spot screening systems with other child health information systems. In 2000, The Robert Wood Johnson Foundation (RWJF) funded All Kids Count as a National Technical Assistance Center on integration of child health information systems. All Kids Count, which had previously focused on immunization registries, provided support and technical assistance to 11 state and local integration projects over a three-year period to foster their efforts through a peer-to-peer learning network called *Connections*.

What is unique about child health information systems?

Information systems for pediatric care must take into account three special considerations to meet this population’s information needs effectively: 1) systems must support management of child health care needs across the continuum of care, taking into account information needs about growth and development; 2) special attention needs to be paid toward connectivity and system integration at the community level since it is essential for pediatric practices to be closely connected to the public health authority, the schools, and, for children with special health care needs, other social and supportive services; 3) consumer health information should extend beyond the child to address the needs of the whole family.⁵ In addition, children are generally seen more frequently by the health care sector than adults, and they are reported to change primary providers often.⁶ The American Academy of Pediatrics has issued a policy statement on the special requirements of pediatric

electronic medical records, which include features that allow for growth monitoring, special terminology and information used by pediatricians, and decision support tools for such functions as prescribing medicine, tracking immunization status and issuing reports for schools and daycare centers.⁷

What are the benefits of integrated child health information systems?

Because most integrated child health information systems are still under development, little published documentation of their benefits exists. We know, however, that many children “fall through the cracks” because they do not receive the time-specific interventions and

follow-up necessary to prevent or reduce adverse health outcomes.

We also know that effective use of single purpose information systems such as immunization registries can lead to more timely delivery of services, reduced missed opportunities and improve care.⁸ Studies suggest that timely information can improve health care services for children.⁹⁻¹¹ Integration of public health information systems with clinical information systems can improve coordination of care for children with multiple preventive and therapeutic health care needs. In addition, parents, clinicians, insurers, and public health agencies would all benefit from timely and accurate information about the children they serve.

(See Table 1. Potential Benefits of Integrated Child Health Information Systems.)

Integration of public health information systems with clinical information systems can improve coordination of care for children with multiple preventive and therapeutic health care needs. In addition, parents, clinicians, insurers and public health agencies would all benefit from timely and accurate information about the children they serve.

For Parents, Providers, Plans, and Purchasers

- Consolidate in one record all preventive health services received (immunizations, newborn dried blood spot and hearing screening results, and lead screening results).
- Provide an accurate official copy of a child’s health history for personal use, day care, school, or camp entry requirements.
- Provide reminders when care is needed.
- Provide recalls when care has been missed.
- Help ensure timely screening and follow-up care for children whose families move or change healthcare providers.
- Prevent unnecessary (duplicative) services.

For Communities

- Help control disease and reduce disability.
- Help identify high-risk populations.
- Help prevent disease outbreaks.
- Provide information on community and state coverage/screening/follow-up rates.

For Public Health Officials

- Provide information to identify pockets of need, target interventions and resources, and evaluate programs.
- Promote reminder and recall of children who need services and screening.
- Facilitate changes in schedules for screening and follow-up.
- Monitor compliance with new recommendations for preventive services.
- Assess changes in health outcomes.
- Inform policy about the quality of care for children.

Table 1: *Potential Benefits of Integrated Child Health Information Systems*

Resources on Integrated Child Health Information Systems

All Kids Count. (2003). *Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Sourcebook for Planning and Development*. Decatur, GA: Public Health Informatics Institute.

All Kids Count. (2003). *Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Tool for Assessment and Planning*. Decatur, GA: Public Health Informatics Institute.

All Kids Count. (2003). *Creating a Road Map: Sharing Knowledge About Integrating Child Health Information Systems (Vol. 1)*. Decatur, GA: Public Health Informatics Institute.

All Kids Count. (2004). *Creating a Road Map: Sharing Knowledge About Integrating Child Health Information Systems (Vol. 2)*. Decatur, GA: Public Health Informatics Institute.

Association of State and Territorial Health Officials. (2003). *Issue Report: Integrating Information Systems to Improve MCH*. Washington, DC: Association of State and Territorial Health Officials.

All Kids Count. (2004). *A Vision for Child Health Information Systems. Proceedings of conference on Developing Child Health Information Systems to Meet Medical Care and Public Health Needs*. December 2-4, 2004. Atlanta, GA. Available from www.allkidscount.org

<http://www.allkidscount.org>

A Supplement to the November 2004 issue of the *Journal of Public Health Management and Practice* will summarize the evolution and current status of integration of child health information systems, as well as providing a preview of the near-term future for these systems.

Who is integrating child health information and what systems are they integrating?

No comprehensive database of child health information integration projects exists. In 2003, All Kids Count conducted a telephone survey of 18 state and local health departments that were known to be integrating two or more child health information systems to learn more about their activities (unpublished data). Information systems most frequently cited as being integrated are newborn dried blood spot screening, newborn hearing screening, immunization registries, and vital registration. These four systems share several common characteristics: they are recommended as essential services for all infants and children; they are carried out or begin in the newborn period; they are time sensitive with possible long-term consequences if the recommended action isn't performed according to the recommended schedule; both private physicians and public health programs share responsibility for their implementation; and they are mandated services in most states.

What are funding sources for integration of child health information systems?

Projects to integrate child health information systems are supported by multiple federal, state, and local funding sources. Federal funding sources include the Centers for Disease Control and Prevention (CDC); Genetic Services Branch/Health Resources and Services Administration (GSB/HRSA); Centers for Medicare and Medicaid Services (CMS); and the Agency for Healthcare Research and Quality (AHRQ). State appropriations also

contribute to integration projects. Private funding sources have included All Kids Count (RWJF) and managed care organizations.

What's necessary for integrated child health information systems to succeed?

All Kids Count's experience with supporting and promoting the development of immunization registries suggests several key activities must take place to ensure future success for child health information systems.

- A shared vision and plan of action that is supported by a broad spectrum of stakeholders at federal, state, and local public health levels, from the pediatric practice community, and by the health plans, community organizations, schools, and families.
- Agreement on core functions that will result in a common definition for integrated child health information systems by those developing and funding such systems.
- Incorporation of child health and public health data into the standards process to improve interoperability, and therefore, data usefulness.
- Definition and testing of performance indicators to measure progress and outcomes in a systematic way across health agencies.
- Documentation and dissemination of best practices (or at least "pretty good practices") to prevent "recreating the wheel" and to optimize use of scarce resources such as time and money.
- Studies that provide data on costs, cost savings, and changes in outcomes so that supporters of integrated systems will be able to demonstrate a return on their investment.
- Education of stakeholders in public and private sectors at

federal, state and community levels to increase the support for improving child health outcomes through the development and integration of information systems.

What current or planned activities address these needs?

Representatives of 55 organizations and government agencies met at an invitational conference in Atlanta in December 2003 to recommend next steps for development of child health information systems that meet medical care and public health needs. The diverse group of stakeholders, convened by All Kids Count/Public Health Informatics Institute and 17 co-sponsors (*see Meeting Co-sponsors*), identified actions that should be taken immediately and in the next three to five years to integrate the information about the health care that a child receives, from birth forward, in a simple yet comprehensive format. The goal is to enable the end user (parents, families, health professionals, insurers and policymakers) to take all appropriate actions.

Meeting participants forged recommendations reflecting the input of stakeholders in the areas of governance, economic issues, information infrastructure, and data use. The groups reached consensus on these needs:

- To develop a national coalition of stakeholders to promote integration of separate child health information systems within the context of ongoing national initiatives such as NHII and PHIN.
- To develop the business and policy cases for integrated child health information systems.
- To develop agreement on standards for collecting and transferring information.

- To get the word out about the importance of integrating separate child health information systems to improve health and health services.

A follow-up meeting with stakeholders is planned for mid-2004 to develop a more detailed and prioritized action plan, including developing a governance structure for the initiative.

A number of initiatives underway or planned by GSB/HRSA will add to the knowledge and support for integrated child health information systems. GSB has contracted with All Kids Count to facilitate the definition of core functions for integrated systems and performance indicators to measure progress at the state level.

Documentation of best practices and tools to assist states in achieving them was initiated by All Kids Count in 2002. (*See Resources.*) Recognizing that continued support for peer-to-peer learning among the 18 health departments and their communities that have current integration efforts underway is essential to accelerate progress, GSB/HRSA also will be supporting a learning community among its systems integration grantees.

Conclusions

Although understanding of the challenges and benefits of integrated child health information systems has increased, the near-term and long-term future of these systems is dependent on a coordinated, sustained effort that ensures they meet the collective needs of key stakeholders—families, medical care, public health, and business communities. The potential for broad-based changes in approaches to health care delivery for children can be realized through better information, but its achievement will take collective commitment to a shared vision.

Meeting Co-sponsors

The following organizations co-sponsored the December 2003 meeting on Child Health Information Systems to Meet Medical Care and Public Health Needs.

All Kids Count/Public Health Informatics Institute

American Immunization Registry Association (AIRA),
Alliance of Community Health Plans (AHCP)

Association for Health Center Affiliated Health Plans (AHCAHP)

Agency for Healthcare Research and Quality (AHRQ)

American Academy of Pediatrics (AAP)

Association of Maternal and Child Health Programs (AMCHP)

Association of State and Territorial Health Officials (ASTHO)

Centers for Disease Control and Prevention (CDC)

Commonwealth Fund
Family Voices

Health Resources and Services Administration (HRSA)

March of Dimes

National Association of County and City Health Officials (NACCHO)

National Association of School Nurses (NASN)

National Health Information Infrastructure (NHII)

National Initiative for Children's Healthcare Quality (NICHQ)

U.S. Department of Agriculture Food and Nutrition Service (USDA/FNS)

Note: *The conclusions and recommendations of the conference are those of conference participants and do not represent the official views of the sponsors. The conclusions and recommendations have not been officially endorsed by any of the sponsoring agencies/organizations.*

Notes

¹ National Committee on Vital Health Statistics. *Information for Health: A Strategy for Building the National Health Information Infrastructure. Report and Recommendations from the National Committee on Vital and Health Statistics.* Washington, D.C. November 15 2001.

² Institute of Medicine. *The Future of the Public's Health in the 21st Century.* Washington, DC: National Academy Press; 2003.

³ Council of Regional Networks for Genetic Services (CORN). *Guidelines for Clinical Genetic Services for the Public's Health.* Atlanta, GA: CORN; April 1997.

⁴ Newborn Screening Task Force. *Serving the Family from Birth to the Medical Home: A Report for the Newborn Screening Task Force Convened in Washington DC, May 10-11, 1999.* *Pediatrics.* August 2000;106(2):389-427.

⁵ Shiffman RN, Spooner SA, Kwiatkowski K, Brennan PF. Information Technology for Children's Health and Health Care. *Journal of the American Medical Informatics Association.* 2001;8:546-551.

⁶ Rodewald L, Peak R, Ezzati-Rice T, Zell E, Thompson K. Who are the immunization providers for U.S. children: findings from the 1994 National Health Interview Survey (NHIS) Provider Record Check (PRC). *Ambulatory Child Health.* 1997;3(1):168.

⁷ American Academy of Pediatrics. Special Requirements for Electronic Medical Record Systems in Pediatrics. *Pediatrics.* August 2001;108(2):513-515.

⁸ National Vaccine Advisory Committee. *Development of community- and state-based immunization registries: Report of the National Vaccine Advisory Committee (NVAC).* Atlanta: Centers for Disease Control and Prevention; January 12 1999.

⁹ Adams WG, Mann AM, Baucher H. Use of an Electronic Medical Record Improves the Quality of Urban Pediatric Primary Care. *Pediatrics.* March 2003;111(3):626-632.

¹⁰ Bordley CW, Margolis PA, Stuart J, Lannon C, Keyes L. Improving Preventive Service Delivery Through Office Systems. *Pediatrics.* September 2001;108(3).

¹¹ Rodewald L, Szilagyi P, Humiston S, Barth R, Kraus RM, Raubertas R. A Randomized Study of Tracking with Outreach and Provider Prompting to Improve Immunization Coverage and Primary Care. *Pediatrics.* January 1999(103):31-38.

Topics in Public Health Informatics Staff

Authors: Kristin Saarlus,
Terry Marie Hastings

Editor: Terry Marie Hastings

About Public Health Informatics Institute

The Public Health Informatics Institute is dedicated to advancing public health practitioners' ability to strategically apply and manage information systems.

The Institute assists federal, state, and local public health agencies and other public health stakeholders that are grappling with information systems challenges.

Our services provide clarity about the information systems problems to be solved and identify the solutions to those problems.

The Public Health Informatics Institute is a component of The Task Force for Child Survival and Development.

For more information visit www.phii.org, call toll-free (866) 815.9704, or e-mail info@phii.org.

© 2004 Public Health Informatics Institute
For additional copies or to be added to our mailing list, please contact us at: info@phii.org



750 Commerce Drive
Suite 400
Decatur, GA 30030

Address Service Requested