

# Principles and Core Functions of Integrated Child Health Information Systems

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Infants undergo a series of preventive and therapeutic health interventions and activities. Typically, each activity includes collection and submission of data to a dedicated information system. Subsequently, health care providers, families, and health programs must query each information system to determine the child's status in a given area. Efforts are underway to integrate information in these separate information systems. This requires specifying the core functions that integrated information systems must perform.

**KEY WORDS:** child health, immunization registries, information systems, newborn screening

In May 2003, a workgroup was convened to propose a set of core functions of integrated child health information systems (CHIS)—activities an integrated system must be capable of performing. As a starting point, integration of information systems in 4 program areas was considered: newborn dried blood-spot screening, early hearing detection and intervention, immunizations, and vital registration. The result was development of a proposed set of 19 principles, 22 core functions, and 8 desirable functions for integrated CHIS dealing with these 4 areas. This set should provide a base for agreement on core datasets and information transfer standards that will underlie integrated child health information systems. It also provides a base for consideration of possible additional functional needs when further integration with other programs' information systems is undertaken.

Infants undergo a series of preventive and therapeutic health interventions and activities designed to give them the best possible start in life, including screening for inherited and congenital disorders, immunizations, vital registration, etc. Typically, each of these activities includes collection and submission of data about the

infant, the procedure, and the results to a dedicated information system. Subsequently, health care providers, families, and health programs have to query each information system separately to determine the child's status in a given area.

Beginning in 1998, Genetic Services Branch, Division of Services for Children with Special Health Care Needs, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA/MCHB) undertook a series of grant initiatives to facilitate:

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

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- the opportunity to improve service delivery to children and their families that is community-based, culturally competent, and comprehensive
- the enhancement of the ability to coordinate care across multiple programs and providers

There are many different health interventions and programs affecting children and, consequently, the number of information systems that could be integrated is large. As a starting point, 4 programmatic areas were selected: (1) newborn dried blood-spot (NDBS) screening for inherited and congenital disorders, (2) early hearing detection and intervention (EHDI), (3) immunizations, and (4) vital registration. These 4 were selected because they are recommended for all infants/children, they are carried out (or begin) in the newborn period, they are time-sensitive (a delay in carrying them out can lead to adverse outcome), and they are primarily delivered in the private sector but have a strong public sector component (eg, public health agencies, federally qualified health centers). Additionally, they are mandated in most or all states.

Integrating the information systems associated with these programs means that an authorized user (patient/family, provider, program) can determine at a glance the status of a child with respect to these 4 activities as authorized (as well as other activities as other information systems are integrated). The integrated system also permits individual health programs to obtain information readily about the child's status with respect to other programs. Integration of information systems can be accomplished in a variety of ways, including enabling linkages between existing information systems or developing a single comprehensive information system incorporating all program elements. This article focuses on delivery of information in an integrated fashion to the information-user, no matter how this is accomplished technically.

One of the first tasks to achieve integration is to ensure that the integrated system provides access to the information needed to assess the child's status within each participating program area. This requires specifying the core functions that the integrated information system must perform.

The proposed integrated system must support the information and business needs for the NDBS screening program, EHDI program, immunization program, and vital registration. Since no definition of functions for integrated child health information systems has been developed previously, HRSA/MCHB and All Kids Count/Public Health Informatics Institute (AKC/PHII) convened a core workgroup in May 2003 to propose a set of core functions—activities an integrated system must be capable of performing. Participants

(who are the authors of this article) included a range of perspectives, including those of parents, practicing pediatricians, and subject matter/program experts. In addition, staff of AKC/PHII and HRSA/MCHB took part in the deliberations (AKC/PHII staff: Sherry Bolden, Nicole Fehrenbach, Janet Kelly, David Ross, and Kristin Saarlans; HRSA/MCHB staff: Deborah Linzer, Michele Lloyd-Puryear, and Marie Mann).

The goal of the meeting was to develop a framework for integrating newborn screening systems with other related single-purpose child health information systems. The specific objective of the meeting was to gain agreement on the elements of the framework and draft core functions for integrated child health information systems. The current status in the development of practice standards, guidelines, recommendations, and information system core functions for each program area follows.

- *NDBS screening*—National standards for Newborn DBS Screening are being developed by the American College of Medical Genetics through a project funded by HRSA/MCHB and will become available in 2004. A number of practice guidelines and recommendations have already been published.<sup>1-5</sup> Statements on core functions of information systems have not been published.
- *EHDI*—No national practice standards have been published for EHDI although the American Academy of Pediatrics has published recommendations for screening.<sup>6-7</sup> Statements on core functions of information systems have not been published.
- *Immunizations*—The National Vaccine Advisory Committee has developed “Standards for Child and Adolescent Immunization” that have been endorsed by a number of national organizations.<sup>8</sup> In addition, a technical working group and the Centers for Disease Control and Prevention have developed minimum functional standards (core functions) for immunization registries.<sup>9</sup>
- *Vital Registration*—The National Center for Health Statistics has issued guidelines on “Specifications for Collecting and Editing the US Standard Certificates of Birth and Death—2003 Revision.”<sup>10</sup> Implementation of the revised standards will improve data quality, ensure uniformity in specifications, and assist in integrating birth and fetal death reporting systems with other information systems.

The process used by participants was to review published practice standards, guidelines, or recommendations for each program area and build on existing descriptions of core functions of information systems. To accomplish the meeting's objective, the core workgroup first reviewed immunization standards and the core functions for immunization

registries, since they were the most established. Participants concluded that the immunization registry core functions could be used as a base to develop the core functions for an integrated information system for the 4 program areas. Participants reviewed the guidelines/recommendations for Newborn DBS Screening and assessed whether an integrated system fulfilling the immunization registry core functions would meet the information needs of this program's activities or whether it would be necessary to modify these functions or define new functions. The same process was used with guidelines/recommendations for EHDI.

The result of this review was expansion and modification of the 12 immunization registry core functions. Participants agreed on a set of basic principles underlying integrated information systems and identified specific core and desirable functions. The principles have implications for the functions. A draft of the principles and functions was circulated back to participants and modified based on feedback. The principles and functions that resulted from this process were then discussed with HRSA/MCHB grantees at a meeting in June 2003. Based on their comments, staff made further revisions and sent the document to a review committee for final review. (Review committee members were: Janice Bach, Don Blanchon, Rachel Block, Owen Devine, Rick Friedman, Nedra Garrett, Maxine Hayes, Celia Kaye, James Lustig, John McLaughlin, Rhoda Nicholas, Patricia Nolan, Mary Shaffran, Michael Skeels, Laura Sternesky, Bradford Therrell, Lee Thielen, Gary Urquhart, Stephanie Ventura, Michael Watson, and Scott Williams.) The final set of 19 principles, 22 core functions, and 8 desirable functions is presented in the following text.

When reviewing the principles and core functions, it must be kept in mind that these refer to the *integrated* information system and the child profile it is intended to create. Individual program information systems may have additional functionality. Additionally, they do not speak to system architecture, data elements, or software, attributes that need to be addressed later. They address *what* the core functions are, not *how* they are to be achieved. However, the delineation of principles and functions serves as an important base for agreement on core datasets and information transfer standards, thereby facilitating the development of integrated child health information systems for these programs. Standardization across programmatic areas of architecture, core datasets, and data transfer standards would be a powerful enabler of integration. The core functions listed here also provide a base for consideration of possible additional functional needs when further integration with other programs' information systems is undertaken.

The 19 principles underlying integrated child health information systems are as follows:

1. The purpose of integrated information systems is to facilitate assessment and prompt provision of appropriate services to ensure an optimal healthy start for all children and improve the health of children.
2. Information systems are designed to make information available to those who have use and need for it—families, patients, providers, and programs.
3. Security and confidentiality are essential and must be an integral part of designing integrated information systems. Systems must be HIPAA compliant.
4. Information must be available in time to take appropriate action.
5. Technologies for integrated information systems should be selected to meet the health needs of the individual and the public.
6. Active participation of stakeholders in the design, development of policies about use, implementation, monitoring, and evaluation of information systems is essential.
7. Integrated information systems must meet minimum information needs of participating programs and facilitate program evaluation.
8. Integrated information systems do not necessarily contain all of the information contained in participating program information systems. Nonetheless, integrated information systems must meet or exceed applicable guidelines, standards, and regulations set forth by the programs. Additionally, integrated systems must adhere to federal and state technology standards to facilitate data access, transmission, processing, and reporting.
9. There must be monitoring and oversight of the use of information in the integrated system, as well as of its operation, maintenance, and financing.
10. Parents/guardians/patients should be notified that information is being entered into the information system. At a minimum, this should be done before sharing/integrating data; ideally, it would be done before data are entered into the system.
11. Information must be used only for intended purposes, as defined in written policies that are updated as needed and/or in written agreements between the primary sources and the information system.
12. The integrated information system should not be used for punitive or discriminatory purposes.
13. The kind and extent of information to which a user has access should be based on roles (eg, patient/family, provider, program).

14. Responsibility for the accuracy of the information entered resides with the primary source of that information; accuracy of reports is a shared responsibility of the primary source, programs, and the manager of the integrated system.
15. Data entry should be simple and duplicate data entry should be eliminated or minimized.
16. The system must have a quality assurance process built in from the beginning.
17. Costs and benefits and to whom they accrue should be assessed.
18. Costs of development and operation should be shared by users/beneficiaries.
19. The system must be able to adapt to new procedures or coding schemes.

The 22 core functions of integrated child health information systems are as follows:

1. Protect confidentiality of information.
2. Ensure security of information.
3. Electronically store (and retrieve) data on core data elements as specified and agreed upon by programs participating in the integrated system.
4. Establish a record for each newborn within 2 weeks (ideally 24 hours) of birth and in no case later than one month (ideally no later than 24–72 hours).
5. Capture information about death within 2 weeks (ideally 5 days) of the event.
6. Establish a unique identifier for or a process to individually identify all children that all participating programs can use to cross-link information.
7. Add a record beyond the birth timeframe—when a new child moves into the state or when a delayed birth certificate is registered in vital records—so the system can establish a service record for that child.
8. Enable access to the system at the time of an encounter for entry and retrieval of information, based on authorized role.
9. Verify the identity of those providing or retrieving information.
10. Maintain an audit trail of entry or alteration of information in the system. (Ideally, maintain an audit trail of all accesses to the system.)
11. Retrieve and process immunization information and hearing screening information within 1 month of service provision and newborn DBS screening information within 24–48 hours from date reported by the lab.
12. Electronically exchange information using nationally endorsed standards.
13. Automatically identify individuals who are due/late for services (or in need of follow-up) to enable flag alerts or generation of reminder/recall notifications.
14. Automatically determine the services needed, in compliance with current recommendations, when the system is accessed (eg, when an individual presents for a scheduled appointment).
15. Generate service coverage reports (by, eg, provider, health plan, age group, geographic area) and performance measures.
16. Produce official records and reports on behalf of programs with appropriate legal authority and need (eg, official immunization records).
17. Provide a comprehensive quality assurance process to assure accuracy and completeness of information.
18. Enable the evaluation of services included in the system and support overall program evaluation.
19. Record whether a screening/service was carried out and when.
20. Provide a record of those who have refused or opted out of screening or services for appropriately defined program needs.
21. Allow authorized users to access results of screening tests (positive and negative) and immunization status. (Note: This mechanism does not substitute for direct (telephonic) notification of abnormal results to the provider. Significant abnormal results should be communicated immediately to the provider and not be delayed by the information system.) Users include the provider of record (medical home), families, and others with authorization. (Ideally, prompt the public health program, provider, and any authorized user of the need for follow-up screening, additional testing, referral, or services. Also ideally, prompt the recommended action [based on result] that adheres to current guidelines, standards, or recommendations.)
22. Track the individual from screening through confirmation of diagnosis and initiation of therapy, if applicable (short-term follow-up).

The 8 desirable functions of integrated child health information systems are as follows:

1. Establish a record within 2 weeks (ideally 7 days) of the first visit to any program or provider for one of the services included in the information system when a new child moves into the state.
2. Identify those who have moved or gone elsewhere within 90 days (ideally 30 days).
3. Track long-term follow-up care into adulthood.
4. Record whether children are linked to a medical home and identify current provider of record.
5. Generate a printed report or transmit electronically core information about a child from one system to another when the child moves to another state or another provider.

6. Record additional information as it becomes relevant to the health of the child and the programs participating in the integrated system.
7. Provide information on a real-time basis to all authorized users as soon as it is entered into the integrated system.
8. Permit users to access and generate aggregate data reports online and generate selected reports with identifiable information depending on user role.

## ● Conclusion

A proposed set of principles, and core and desirable functions for integrated child health information systems has been developed. This set should provide a base for agreement on core datasets and information transfer standards that will underlie integrated child health information systems. It also provides a base for consideration of possible additional functional needs when further integration with other programs' information systems is undertaken. There will be further refinements of these principles and functions as further experience is gained.

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