

A Framework for Integrated Child Health Information Systems

PRINCIPLES, CORE FUNCTIONS, AND
PERFORMANCE MEASURES



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Introduction

The primary goal of newborn dried blood spot screening programs is to ensure that every child born in the U.S. is screened for certain heritable disorders and that every child who is identified as having a possible disorder receives appropriate care. Critical to achieving this goal is newborn screening programs' ability to coordinate services and information between the public and private health care sectors. Many newborn screening programs use integrated information systems to bring together disparate pieces of information and present the information in a comprehensive, timely manner to medical home providers and public health programs. This concept, termed the Child Health Profile, is an integrated information approach that supports decision-making at the point of health care service delivery as well as supporting public health program needs.¹

The 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) has been funding state health departments to integrate newborn dried blood spot screening systems with other early child health information systems to further the development of the Child Health Profile since 1999. However, each state program has independently defined the purpose and functionality of the systems that create a Child Health Profile. In 2002, HRSA/MCHB funded the Public Health Informatics Institute (the Institute) to develop a framework that would provide guidance in the development of integrated child health information systems to create a Child Health Profile.

Key to the Institute's methodology is the belief that public health practitioners should *first* have a clear understanding of the problem they are trying to solve and how information systems infrastructure can assist in addressing that problem *before* looking at technology. This principle, "putting the logical before the physical," is important in ensuring that information systems are built to meet the needs of the people who use them. The Institute also believes that public health practitioners should develop a process to evaluate the information system's ability to perform effectively. This framework for integrated child health information systems makes explicit the purpose and intent of developing integrated child health information systems, details the functions the system should perform and provides measures to evaluate the systems' effectiveness in providing essential information.

The framework includes principles, core functions, and performance measures for integrating the information systems of four programmatic areas: vital registration, newborn dried blood spot screening, newborn hearing screening, and immunizations. Integration of child health information systems should facilitate the assessment and provision of services to children to improve their health as well as support the participating programs' goals and objectives.

¹ Linzer, D. S., Lloyd-Puryear, M.A., Mann, M., Kogan, M. (2004) Evolution of a Child Health Profile Initiative. *Journal of Public Health Management & Practice*, November(Supplement), S16-S23.

The **Principles** are a set of underlying statements about the fundamental intent and values for integrated child health information systems. As noted in the first principle, the purpose of integrating the information from these child health information systems is ultimately to ensure an optimal healthy start and improve the health of all children. Integrating information systems from the four programs can assist in achieving this goal by providing comprehensive information to the right users, at the right time --- in time for actions to be taken or services delivered. In addition, by reducing duplication and fragmentation, the integrated child health information system can increase the effectiveness and efficiency of services provided by health care and public health professionals, public agencies and the medical home, as well as decrease the cost of collecting patient information for analysis. The principles are the foundation on which core functions and performance measures are built.

Core Functions are the activities the *system* must perform. They are not the procedures or policies to carry out those activities. For instance, the core function “protect against unauthorized access to information and modification of information or loss or corruption of data” (Core Function 1) should be accompanied by procedures to inform providers, families, and policy makers about privacy, security, and consent policies. Integrated child health information projects should also maintain a process for receiving and rapidly responding to stakeholder queries about confidentiality, security, and consent concerns. Policies and procedures like these, along with the core function, help ensure that information is secure and used appropriately, and that families are properly informed.

Performance Measures capture quantitative information to measure how well the integrated information system supports the people who use it. For example, the measures assess the integrated system’s ability to support the goals and objectives of the participating programs. It is important to note that the measures do not assess other features of the information system such as response time and duplication rates. Institute researchers recommend developing additional measures to address system capacity.

Approach

In May 2003, the Institute created a workgroup of public health practitioners, private physicians, and parents to begin the development of the framework (see Appendix). The workgroup decided to focus its efforts on vital records, newborn dried blood spot screening, newborn hearing screening, and immunizations because these services are associated with actions taken in the hospital shortly after a child has been born. Within 48 hours, a newborn typically receives a hearing screening, a dried blood spot screening, and a hepatitis B vaccination. A birth certificate is initiated as well. The workgroup drafted a list of principles and core functions of an integrated child health information system.

A group of 22 representatives from state, local, and federal public health agencies and national organizations (e.g., American Academy of Pediatrics, Association of State and

Territorial Health Officials) reviewed the draft list of principles and core functions. The Institute staff incorporated their comments into a document titled “Principles and Core Functions of Integrated Child Health Information Systems,” subsequently published in a supplement to the *Journal of Public Health Management and Practice*.²

Although the draft principles and core functions were a major step in developing integrated child health information systems, the functions needed to be clarified and widely endorsed by public health practitioners in the field. The workgroup felt strongly that the principles and core functions should be feasible and practical, and were eager to know what their colleagues in other public health agencies thought of them.

The Institute conducted a survey of the HRSA/MCHB Special Projects of Regional and National Significance (SPRANS) implementation grantees to determine which principles and core functions they currently incorporate in their integrated systems and how the list could be further refined. SPRANS implementation grantees are states that have received funding from HRSA/MCHB to integrate their newborn dried blood spot screening program with other early child health programs. In March 2004, the Institute reconvened the workgroup to review the results of the survey, the recommended changes to the principles and core functions, and a draft set of performance measures. The Institute then visited six SPRANS implementation grantee states to receive feedback on the principles and core functions and propose revisions to the workgroup to ensure that the final list would be feasible and appropriate. The performance measures were also discussed in the site visits. The Institute then conducted a feasibility study of the performance measures to determine the level of effort needed for public health programs to report on the measures.

In January 2005, the workgroup was convened for a final time to review the results of the site visits and the feasibility study. Based on that analysis, the principles, core functions, and performance measures were refined. The Institute solicited final input from the review committee on the revised Framework and conducted a pilot study on the performance measures. The workgroup then reviewed those comments and the pilot study analysis, and further revised the Framework.

Principles, Core Functions, and Performance Measures

Described below are the principles, core functions, and performance measures for an *integrated* child health information system that would lead to the development of a Child Health Profile. Individual program information systems may have additional functionality. The principles, core functions, and performance measures do not speak to system architecture, data elements, or software, which are subsequent steps in information systems development. The framework addresses *what* the principles, core functions, and performance measures are, not *how* they are to be performed.

² Hinman, A. R., Atkinson, D., Diehn, T. N., Eichwald, J., Heberer, J., Hoyle, T., King, P., Kossack, R. E., Williams, D. C., & Zimmerman, A. (2004). Principles and Core Functions of Integrated Child Health Information Systems. *Journal of Public Health Management & Practice*, November (Supplement), S52-S56.

Principles

| <i>General Purpose</i> | |
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| 1 | The purpose of integrated information systems is to facilitate assessment and prompt provision of appropriate services, support surveillance and other public health purposes, and help ensure an optimal healthy start and improve the health of all children. |
| <i>Security and Confidentiality</i> | |
| 2 | Security and confidentiality are essential and must be an integral part of designing integrated information systems. Systems must be HIPAA compliant. |
| 3 | Parents, guardians, and patients should be notified as soon as feasible that information will be, or has been, entered into the integrated information system. |
| 4 | Parents, guardians, and patients should have the ability to review their information in the integrated system and propose corrections. |
| 5 | 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. Policies must be made available to parents, guardians, and patients. |
| 6 | The integrated information system should not be used for punitive or discriminatory purposes. |
| 7 | The kind and extent of information to which a user has access should be based on roles and on a need to know basis. (e.g., parent, guardians, patient, provider, and programs) |
| <i>Technology Serving Stakeholder Needs</i> | |
| 8 | Information systems are designed to make information available in a timely manner to those who have use and need for it: families, patients, providers, the Medical Home, and programs. |
| 9 | Active participation of stakeholders in the analysis, design, development of policies about use, implementation, monitoring, and evaluation of information systems is essential. |
| 10 | Information must be available in time to take appropriate action. |
| 11 | Technologies for integrated information systems should be selected to support the health and health services needs of the individual and the |

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| | public. |
| 12 | Integrated information systems must at least meet minimum information needs of participating programs and facilitate program evaluation. |
| 13 | Integrated information systems do not necessarily contain all of the information contained in participating program information systems. Nonetheless, they must meet or exceed applicable guidelines, standards and standards implementation guides, 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. |
| 14 | Data entry should be simple. |
| 15 | Duplicate data entry should be eliminated or minimized. |
| 16 | The system must be able to adapt to new business processes and coding schemes. |
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| <i>Quality Assurance and Evaluation</i> | |
| 17 | There must be monitoring and oversight of the use of information in the integrated system, as well as of its operation, maintenance, and financing. |
| 18 | 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. |
| 19 | The system must have a quality assurance process built in from the beginning. |
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| <i>Financing</i> | |
| 20 | Costs and benefits, and to whom they accrue, should be assessed. |

Core Functions

| <i>Confidentiality and Security</i> | |
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| 1 | Protect against unauthorized access to information, modification of information or loss or corruption of data. |
| <i>Establish and Maintain Client Records</i> | |
| 2 | Promptly establish and maintain a record for every live birth that occurs in the state and for every child who interacts with the system of care that the integrated system serves. |
| 3 | Electronically retrieve and share data on core data elements as specified and agreed on by programs participating in the integrated system. |
| 4 | Protect and maintain information about the child, even if the name or identity of the child should change. |
| <i>Service Functionality</i> | |
| 5 | Promptly record death and legal custodial changes of a child to prevent inappropriate contact with parents or guardians. |
| 6 | Allow authorized users to retrieve and share data in a timely manner from all participating programs, including immunization information, hearing screening information, vital registration, and newborn dried blood spot screening information. |
| 7 | Automatically identify services for individuals that are due/late and provide information to authorized users in a timely manner. |
| 8 | Track the individual from screening through confirmation of diagnosis and record initiation of therapy, as applicable (short-term follow up). |
| 9 | Record whether or not a screening or service was carried out and when. |
| <i>Technical Functionality</i> | |
| 10 | Enable access to the system at the time of a service encounter, for entry and retrieval of information, based on authorized roles. |
| 11 | Have a system-wide process/ability to uniquely identify all children and link their information from participating programs. |
| 12 | Provide summary information from participating programs on a child in an |

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| | integrated presentation to the user. |
| 13 | Have the ability to electronically exchange information using nationally endorsed standards and standards implementation guides. |
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| <i>Reports</i> | |
| 14 | Generate program and service coverage reports (by, e.g., provider, health plan, age group, geographic area) and performance measures. |
| 15 | Support program and service system evaluation. |
| 16 | Produce official records and reports on behalf of programs with appropriate legal authority and need (e.g., official immunization records). |
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Performance Measures

| <i>Establishing records</i> | |
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| PM 1A | Percent of newborns with a record in the integrated child health information system (ICHIS). |
| | <p>N: Number of records entered into the system.</p> <p>D: Total number of live births occurring in jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy).</p> |
| PM 1B | <p>Percent of records of live births occurring in the jurisdiction that were established within</p> <ul style="list-style-type: none"> • 0 – 2 days of birth • 3 – 7 days of birth • 8 – 14 days • 15 – 30 days • > 30 days |
| | <p>N: Number of records in ICHIS entered into the system by ≤ 2 days of birth (3-7 days, 8-14 days, 15-30 days, >30).</p> <p>D: Total number of live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) that has a record established in ICHIS. (Same as the numerator from PM 1A).</p> |
| <i>Integrated record</i> | |
| PM 2A | Percent of records that include data on dried blood spot screening, hearing screening, immunization, and vital registration. |
| | <p>N: Number of records that include data on dried blood spot screening, hearing screening, vital registration, and one or more immunization events.</p> <p>D: Total number of resident live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) that has a record established in ICHIS.</p> |
| PM 2B | Percent of records that include data on the four program elements (dried blood spot screening, hearing screening, immunization, and vital registration) within 90 days of birth. |

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| | <p>N: Number of records that include these data within 90 days of birth.</p> <p>D: Number of records for resident live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) that include data on dried blood spot screening, hearing screening, vital registration, and one or more immunization events. (Same as the numerator from PM 2A).</p> |
| <i>Immunization</i> | |
| PM 3A | Percent of records with immunization information available. |
| | <p>N: Number of records of children who have received an immunization, other than first Hep B administered in the hospital, recorded in ICHIS.</p> <p>D: Total number of resident live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) that has a record established in ICHIS.</p> |
| PM 3B | Percent of records with immunization information available within 30 days of administration for children less than 6 years of age. |
| | <p>N: Number of immunization events recorded in ICHIS within 30 days of the date of administration.</p> <p>D: Total number of immunization events recorded in the integrated system in a specified time interval (mm/dd/yyyy - mm/dd/yyyy) for children less than 6 years of age.</p> |
| <i>Newborn dried blood spot screening</i> | |
| PM 4A | Percent of records with newborn dried blood spot screening information available. |
| | <p>N: Number of records of children with newborn dried blood spot screening information recorded in ICHIS.</p> <p>D: Total number of live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) that has a record established in ICHIS.</p> |
| PM 4B | Percent of records with newborn dried blood spot screening status available within two days of receipt of report from laboratory. (Note: Report on the initial newborn dried blood spot screening results. "Status" refers to either the test result, even if unsatisfactory, or an indication that the test is being conducted.) |

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| | <p>N: Number of records recorded in ICHIS within two days of receipt of report from laboratory.</p> <p>D: Total number of established records in ICHIS with newborn dried blood spot screening status for live births occurring in the jurisdiction in a specified time interval (mm/dd/yyyy - mm/dd/yyyy). (Same as the numerator from PM 4A).</p> <p>Note: State newborn screening activities are reported annually under the Title V Block Grant Annual Application/Annual Report. The current National Performance Measure (Form 11) does not have the specificity of this proposed measure.</p> |
| <i>Newborn hearing screening</i> | |
| PM 5A | Percent of records with newborn hearing screening results available. |
| | <p>N: Number of records of children with hearing screening results recorded in ICHIS.</p> <p>D: Total number of live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) that has a record established in ICHIS.</p> |
| PM 5B | Percent of records with newborn hearing screening results available within specified time intervals for screening. |
| | <p>N: Number of records with newborn hearing screening results recorded in ICHIS within:</p> <ul style="list-style-type: none"> • 0 – 2 days of birth • 3 – 7 days of birth • 8 – 14 days • 15 – 30 days • > 30 days <p>D: Total number of established records in ICHIS with a hearing screen for children born in the jurisdiction in a specified time interval (mm/dd/yyyy - mm/dd/yyyy) (Same as the numerator from PM 5A).</p> <p>Note: State newborn screening activities are reported annually under the Title V Block Grant Annual Application/Annual Report. The current National Performance Measure (Form 11) does not have the specificity of this proposed measure.</p> |
| <i>Newborn hearing screening follow-up</i> | |
| PM 6 | Percent of children who did not pass initial hearing screening AND who are enrolled in/referred to an early intervention or other appropriate program OR found not to have hearing loss by 6 months of age. |

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| | <p>N: Number of records of children who were found <u>not</u> to have hearing loss OR found to have hearing loss and were enrolled in/referred to an early intervention or other appropriate program within 6 months of age.</p> <p>D: Total number of resident live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) who did not pass their initial hearing screening.</p> |
| <i>Newborn dried blood spot screening follow-up</i> | |
| PM 7A | Percent of children with out-of-range congenital hypothyroidism screening results who have been diagnosed AND are under appropriate management by 21 days of birth. (NOTE: Appropriate management means the child is either in the NICU or has entered into a system of health care.) |
| | <p>N: Number of records of children who have been diagnosed and are under appropriate management by 21days of birth.</p> <p>D: Total number of resident live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) with out-of-range congenital hypothyroidism screening results.</p> |
| PM 7B | Percent of children with hemoglobin screening results suggesting Sickle Cell Anemia, Sickle C Disease or Beta Thalassemia, who have been evaluated and are under appropriate management by 2 months of age. |
| | <p>N: Number of records of children who have been evaluated and are under appropriate management by 2 months of age.</p> <p>D: Total number of resident live births occurring in the jurisdiction during a specified time interval (mm/dd/yyyy - mm/dd/yyyy) with hemoglobin screening results suggesting either Sickle Cell Anemia, Sickle C Disease or Beta Thalassemia.</p> |

Conclusion

The collaborative development of the framework for a Child Health Profile is an important first step toward developing information systems that meet the needs of the people who use them. The framework offers a clear understanding of the purpose of the integrated child health information system, captured in the principles, the functions the system must perform to adequately meet the information needs of the programs it serves, and a set of performance measures to evaluate the effectiveness of the integrated information system in providing the timely flow of critical information to the people who need to act on it. In understanding the intent of the system and the necessary functionality, the framework allows integrated information system developers to think logically before physically, thereby developing information systems that are effective in serving those who make health care services decisions for children.

Appendix

Framework for Integrated Child Health Information Systems Workgroup Participants

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Note: The asterisk indicates which of the three years the member served on the workgroup.
Year 1 = *, Year 2 = **, Year 3 = ***
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