

Integration of Child Health Information Systems: Current State and Local Health Department Efforts

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Public health departments at the state and local levels are pursuing integration strategies to consolidate child health information systems to improve child health. Eighteen health departments were interviewed in this exploratory research study to gather information to describe their current activities related to integrating child health information systems. Results illustrate the common systems being brought together and the technical process for doing so, financing mechanisms, range of anticipated information-users and their method of access to the integrated system, and common internal and external challenges and strengths that the health departments face. The evidence suggests a trend towards more efficient and thoughtful use of the multiplicity of information systems within public health departments as programs consolidate and share data and expand electronic communication with their external partners in the health care delivery system to improve children's health.

KEY WORDS: child, health department, information systems, public health informatics, systems integration

Public health departments are pursuing projects at state and local levels to integrate child health information systems with the intent of improving delivery of preventive and therapeutic services by consolidating health information and making it available at the point of service to appropriate information-users, such as public health programs, health professionals, and families.

Federal, state, and private funding support health department efforts by linking grants and appropriations to integration. Genetic Services Branch/Maternal and Child Health Bureau/Health Services and Resources Administration (HRSA/MCHB) and Early Hearing Detection and Intervention/Centers for Disease Control and Prevention (CDC/EHDI) have en-

couraged the development and integration of newborn screening information systems with other health information systems through their grant mechanisms.¹⁻³ States such as Alaska and Georgia have encouraged the development of integrated health information systems through the allocation of budgetary resources. From the private sector, All Kids Count has supported integration activities at the state and local level through development of a community of practice, sharing of good practices and lessons learned, and providing small grants for focused projects.

However, little is known about the range or extent of such integration activities. Therefore, All Kids Count conducted an exploratory survey of selected state and local health departments to gather input related to the following question: "What are the current activities

Preparation of this article was assisted by a grant from The Robert Wood Johnson Foundation, Princeton, NJ.

The authors thank the participating state and local health departments: Alaska Department of Health; District of Columbia Department of Health; Georgia Department of Human Resources, Division of Public Health; Hawaii State Department of Health; Illinois Department of Human Services; Indiana State Department of Health; Iowa Department of Public Health; Maine Department of Human Services, Bureau of Health; Massachusetts Department of Health; Michigan Department of Community Health; Missouri Department of Health and Senior Services; New York State Department of Health; New York City Department of Health; Oklahoma State Department of Health; Oregon Department of Human Services Health Services; Rhode Island Department of Health; San Antonio Metro Health District; Santa Clara County Public Health Department; Texas Department of Health; Tennessee Department of Health; Utah Department of Health; Washington State Department of Health; and Wisconsin Department of Health and Family Services, Division of Public Health.

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related to the integration of child health information systems?" Information collection focused on systems being integrated and the technical approach applied, funding sources, anticipated information-users and their method to access the integrated system, and strengths and challenges of integration projects that health departments face.

● Methodology

Integration was defined from the information-user's viewpoint, such that an authorized user can determine at a glance, the status of a child with respect to the programs being integrated irrespective of hardware and software (eg, results of screenings, immunizations administered, services needed).

We identified a sample of 23 public health departments that were self-identified as working on integrating two or more child health information systems. They include:

- Members of All Kids Count Connections, a community of practice of state and local health departments that have active projects integrating child health information systems
- Planning and implementation grantees funded by HRSA/MCHB to integrate newborn dried blood-spot information systems with other child health information systems
- Respondents to the 2000 Immunization Registry Annual Report who reported having an immunization registry exchanging and retrieving information with other health information systems
- Respondents to the American Immunization Registry Association's Programmatic Registry Operations Workgroup survey who reported integrating immunization registries with other public health information systems

The instrument was an open-ended group teleconference questionnaire to gather qualitative data, assessed for face-validity, and pilot tested. Codes and definitions were iteratively refined during data collection and analysis phases.⁴

Twenty-two out of 23 health departments (20 states, 2 cities, and 1 county) participated in 1-hour interviews from April–July 2003. The contact person from each health department was asked to invite two or more stakeholders of the integration project to participate in the group interview. Stakeholders included representatives from several public health areas including immunization, newborn dried blood-spot screening, vital registration, and information technology services.

● Sample for Analysis

The final sample was 18 health departments planning or implementing integrated child health information systems. Twelve of the responding organizations were actively integrating child health information systems and 6 were in the planning stages, with implementation of their projects within 1–3 years. Four of the health departments identified in the sampling frame were not pursuing integration projects and reported that their planning or previous efforts ended because resources were lost or political support for the activity changed. They are not included in the analysis.

● Results

Systems and technical approaches

The results identified current and future program information systems that integrated or planned integration with other health information systems. Future integration activities are those planned for the next 1–3 years. Eleven health departments report integrating 8 or more different public health program databases currently or in the future, while 2 health departments only have 4 systems integrated and no short-term future activities to bring in additional systems.

The number of systems being integrated by individual health departments ranges from 4–10. Commonality exists among the systems being integrated. Eleven of the 18 respondents are consolidating information from newborn dried blood-spot screening, newborn hearing screening, vital registration, immunization registries, and the Women, Infants & Children program (WIC). Those health departments with current or short-term implementation plans of integration for 8 or more systems are also the health departments targeting nonpublic health systems for integration, such as Medicaid, private providers, and private insurers. Notably, 2 of the health departments with 9 systems being consolidated are the only respondents with currently integrated information with Medicaid and private health care delivery system partners.

Respondents were asked about the design of the integrated system, whether it was the development of a single database, middleware solution, or a combination of these approaches. A single database consolidates multiple programs' data into one large database, which requires individual programs to choose to use the new integrated system as their primary database. Middleware solutions are tools that provide real-time, cross-platform connectivity and query databases to enable individual systems to remain distinct. Six of the health departments are using only a middleware approach, while 5 are building a single large database to

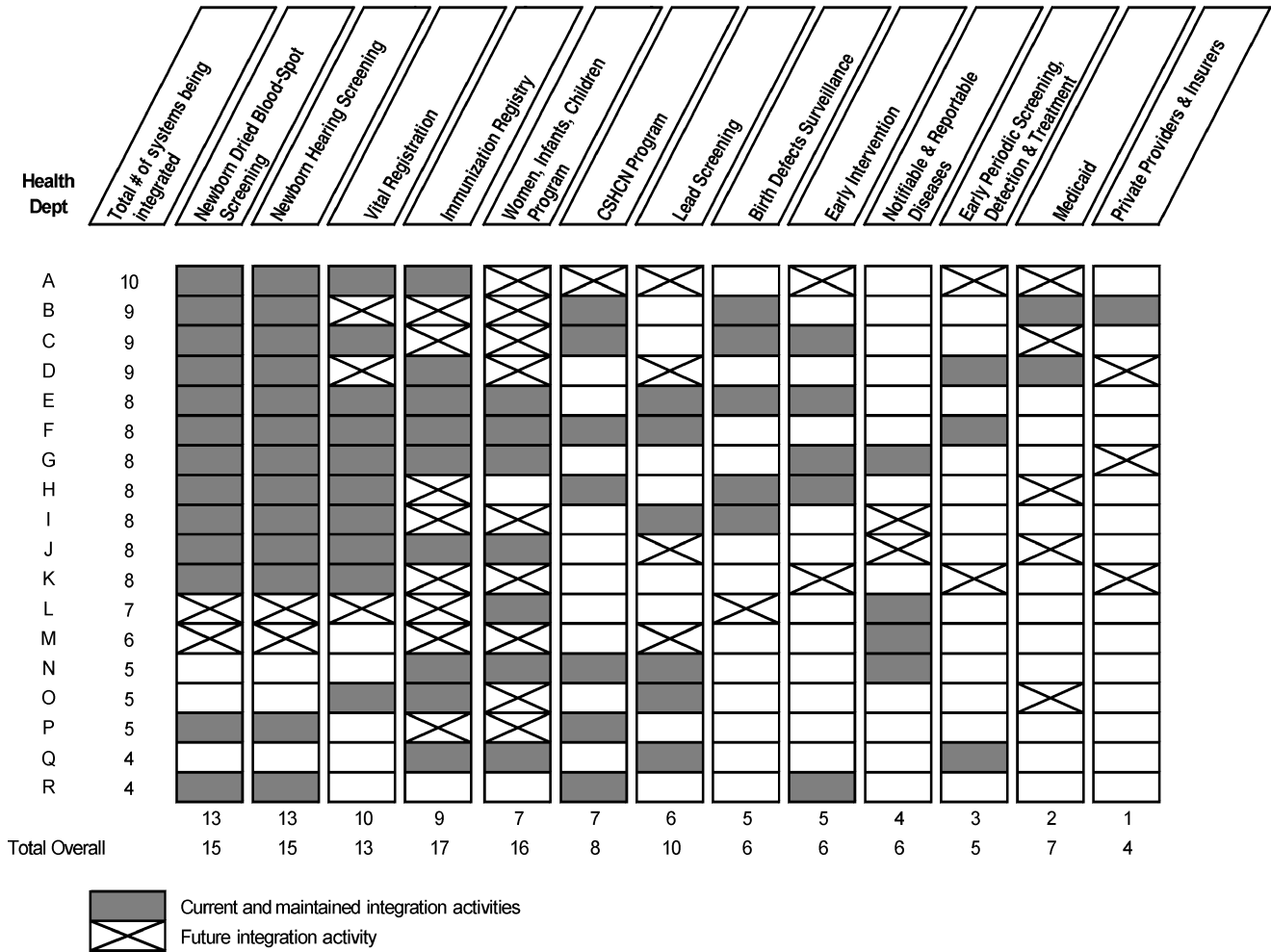


FIGURE 1. Current and future information systems targeted for integration.

consolidate information. Seven health departments are using a combination of these two approaches.

Some respondents shared their reasons for selecting a single database approach versus a middleware solution or a combination. A respondent using a single database approach identified several deciding factors: (1) the need to reduce the number of the disparate databases, (2) the need for data standardization across public health programs, and (3) the desire to avoid the complexity of using middleware to translate data that resided on numerous different platforms and operating base systems. In contrast, one health department that is using a middleware solution emphasized that the importance of maintaining the individual program databases was critical to the agreement among the participating programs to share their data. Finally, a health department that is using a combination of approaches cited practical reasons: some public health programs had begun a single database strategy prior to the articulation of a health department strategy to integrate its child health information systems, and other child health programs wanted to retain their individual databases that served their programs' needs but also

wanted to share the information, which made a middleware approach a sensible solution.

Respondents were also queried about data warehouse development efforts. A data warehouse provides a historic copy of program data primarily for the purposes of reporting, queries, and analysis. It does not provide real-time connections among multiple databases. Eight of the respondents are building a data warehouse for their health department to support analytic and reporting requirements.

Funding

Nine of the health departments organizationally established the integration project as separate from the categorical programs with its own budget. Other integration efforts were housed within a specific public health program, despite bringing together data from multiple programs. Funding sources included a variety of federal grants, state appropriations, and some private sources. Some health departments had only 2 sources while one health department reported 9 different sources. Ten of the 18 respondents received state

TABLE 1 ● Types of information-users who will have access to the integrated information system by health department, n = 18

Types of information-users	Number of health departments providing access
Medical providers	13
Local health departments	9
Hospitals	7
Schools	6
Families	4
Private health insurance	2

funds. As expected, because of the sample identification process, the most frequent sources of the federal funds were HRSA/MCHB grants for 13 respondents and CDC/EHDI grants for 9 respondents. Six health departments used Medicaid matching funds to support the integrated information systems.

Information-users

Respondents readily identified numerous authorized internal and external partners in the health delivery system who will use or are currently using the data from the integrated system. All respondents anticipated internal use by health department personnel for program needs. Thirteen respondents anticipated active use of the information by medical providers. Eight respondents indicated that medical providers would be both users of information as well as contributors to the data system itself; 3 respondents reported that the data entry will be directly into the integrated system, and the other 5 respondents reported that private medical providers will electronically submit data to individual public health programs. Beyond the health system, 6 respondents will provide authorized, limited access to school nurse teachers (mostly for immunization information), 4 will enable families to have access, and 2 will provide authorized, limited access to private health insurers (usually for HEDIS purposes).

Currently, access to public health program data is provided through multiple mechanisms, including paper-based mailings (10 respondents), Web-interface (8 respondents), dedicated line to a server (7 respondents), and telephone (5 respondents). However, all 18 respondents reported that future authorized access to the integrated public health information systems would use Web-interface.

Strengths and challenges facing the health departments

Finally, when asked to identify the leading strengths of or challenges to the integration projects, respondents

TABLE 2 ● Strengths and challenges facing the health departments, n = 18

	Strengths	Challenges
Organizational commitment/constraints	16	13
External political environment	8	10
Financial resources	8	11
Confidentiality and security	4	9
Information systems issues		
Data sharing agreements	11	9
Technology changes	5	13
Data quality concerns	3	4
Data de-duplication	1	6
Data standards (or lack thereof)	0	3
Existence of a unique identifier	0	2

identified issues categorized as organizational commitment or constraints, external political environment, financial resources, and information systems issues.

Frequently, the respondents identified certain factors as both strengths and challenges. For example, 12 of the 18 respondents cited organizational commitment as both. Leadership support may exist for the integration effort but existing organizational policies may hinder the actual connectivity and need to be changed or amended. Strong organizational commitment to integration by staff or executive management was cited as crucial by 16 respondents. Overall, 13 respondents mentioned organizational constraints, including lack of procedures for integration of multiple programs' databases, categorical programmatic barriers, shifting priorities, and frequency of internal leadership changes at the executive management level.

Looking at the external political environment, strong support from community stakeholders, elected officials, and/or medical providers benefits the integration activities because of the desire to share health information, according to 8 respondents. Ten respondents mentioned challenges (eg, community groups who oppose government-developed information systems, government officials who focused on issues other than public health department efforts to integrate child health information systems, emergence of other priority public health issues such as bioterrorism preparedness, etc.).

Concerns about transmission of electronic health information and confidentiality and security needs were associated with the Health Insurance Portability and Accountability Act (HIPAA). Eleven health departments cited the current budget crises affecting states and inadequacy of funding for integration activities. Eight respondents recognized that without the current funding to support the integration efforts, the projects would not be making progress. Therefore, current funding levels were strengths and enabled the health

departments to implement their integration activities. However, the budget crises were anticipated to reduce available funding in the future and potentially threaten the sustainability of the integration activities.

Technical changes have advanced the integration efforts for 5 respondents by enabling new mechanisms for linkages. Strong data sharing policies within the health departments (11 respondents) and data quality improvement efforts (3 respondents) were reported as supporting the integration efforts and advancing the use of and support for the integrated system. On the other hand, technical challenges were numerous and reported by all 18 respondents. Thirteen respondents identified rapid technological advances and changes in technology practice (ie, the emergence of new technology standards and complex security protocols as viruses and threats to privacy become increasingly sophisticated). Data issues included ownership of the data being integrated from various sources (9 respondents), de-duplication of data elements and individual electronic records (6 respondents), and quality concerns (4 respondents).

● Discussion

The commonality among the 18 responding state and local health departments' integration activities, funding sources, and intended information-users suggests that, even though strategies were designed independently, public health programs have consistent needs that information systems can support. While the drivers (eg, funding, political will, current information system trends across sectors) for the integration strategies may differ, the similarity is noteworthy.

The frequency with which immunization registries, WIC, newborn dried blood-spot and hearing screening systems, and vital registration systems are integrated suggests a logical starting point for the integration of child health information systems. Four of the 5 public health programs 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 health component. The WIC program is initiated at birth for qualifying parents and has an immunization requirement. Additionally, the services assessed and ensured by the 5 programs are mandated in most or all states.

Health departments with several systems currently integrated are also those with the innovative outreach to entities beyond the walls of the individual organizations and those that link information-users with information providers (eg, public and private insurers and health care professionals). These activities among health departments that are presumably more advanced in their integration strategies signal the need to bridge the information gap among public health, health practitioners, and public and private payers.

Likewise, the level of integration varies by the respondents. This difference may reflect how long the various respondents have been pursuing integration strategies and are able to successfully secure funding and other resources. However, different areas within a health department may agree that integration is a worthwhile strategy while others may disagree or may be unsure. Circumstances may exist wherein the integration of disparate information may not be a sensible mechanism for addressing programmatic needs. Or the ongoing maintenance of a complex information infrastructure may be too risky to invest limited resources during a time of considerable concern about state budget situations and uncertainty of federal grant support. The value case for integration has not been firmly established and is an area for future research.

The range of information-users highlights public health's intimate connection with the larger health delivery system. Public health agencies work in partnership with the private health sector to ensure the provision of preventive and therapeutic services, for which the public health sector is accountable. The integration of child health information systems supports the information needs of public and private sector health care professionals who are seeking to provide timely, appropriate care to children.

The diversity of funding by some of the respondents implies that innovative health departments use a variety of sources to sustain their integration activities and are moving beyond the constraints of traditional categorical funding streams to build systems that support the enterprise of public health. Such creative use of funds was urged by a joint inter-agency agreement letter from HRSA and CDC.⁵ Although the sample numbers are too small to conduct statistical analyses to make inferences, trends can be noted. Among the health departments with numerous funding sources, they have been diligently pursuing integration activities and have formally articulated

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integration as part of the strategic direction of their respective agencies.

The survey results are exploratory and limited in their scope and conclusions. The method of identifying state and local health departments pursuing integration activities is narrow; however, the response rate (22/23) is excellent. The open-ended questions constrain the analysis to quantification of themes and common responses. The exploratory survey design provides a broad overview of activities; it does not enable an in-depth exploration of any one facet of integrating child health information systems. The qualitative and exploratory interview design had multiple benefits. The open-ended, conversational style engaged the respondents, enabling them to share stories. It also allowed them to discuss, as a group, key integration activities from multiple perspectives and increase the depth of the interview data.

Finally, the 18 respondents working on integrating child health information systems provided insights into the types of systems being brought together with different technical solutions, the challenging issues each faces, and the desire to provide access to a range of information-users. The respondents to this survey believe that child health can be improved through the timely provision of clinical and therapeutic information. The results indicated that steady progress is being made toward the realization of this goal. Further

research in this area should explore the benefits of integrated systems in terms of internal benefit to the health department, effects of electronic communication with external health care partners, and outcomes evaluation of the impact of integrated information systems on child health.

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