

All Kids Count 1991–2004: Developing Information Systems to Improve Child Health and the Delivery of Immunizations and Preventive Services

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The All Kids Count program began in late 1991 with funding from The Robert Wood Johnson Foundation. The purpose was to improve child health and the delivery of immunizations and preventive services through the development of health information systems. All Kids Count concluded in mid-2004 having worked directly with 38 state and local health agencies through its grant and Connections program. The lessons learned from the 13-year program are applicable to other public health and medical care initiatives. Health information systems projects should: (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, (6) address common problems collaboratively, (7) plan for change, (8) plan boldly but build incrementally, (9) develop a good communications strategy, and (10) use the information (even if not perfect). Opportunities exist for public health agencies to share their experiences from developing immunization registries and integrated child health information systems and to develop collaborative approaches to improving the nation's health information infrastructure.

KEY WORDS: child health, immunizations, information systems, public health informatics, registries

The Robert Wood Johnson Foundation (RWJF) initiated the All Kids Count (AKC) program in 1991, in response to the low immunization rates among preschool

children and the measles outbreaks of the late 1980s. After discussions with the National Immunization Program at the Centers for Disease Control and Prevention (CDC/NIP) and other national stakeholders, RWJF decided to support the development of immunization monitoring and follow-up systems (later referred to as immunization registries or immunization information systems) as a strategy to improve and sustain immunization coverage rates.

In the call for proposals for the AKC program in 1999, the RWJF stated:

The purpose of this initiative, called All Kids Count, is to establish immunization monitoring and follow-up

The authors thank the All Kids Count grantees, extended AKC family, and our partners for their support and encouragement over the past 13 years. Their dedication and willingness to share their experiences and challenges with us and with each other has been the spirit of AKC. The authors also thank the Robert Wood Johnson Foundation and the Task Force for Child Survival and Development for their long-term support of All Kids Count.

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

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systems that—when combined with other local, state and federal immunization efforts—will help increase immunization rates among preschool children and reduce rates of illness, disability, and death from vaccine-preventable diseases.

What began as a seemingly straightforward 5-year demonstration project has resulted in a 13-year, \$30 million investment by RWJF. The AKC program also provides a base of experience for understanding RWJF's current commitment to strengthening the public health information infrastructure. The lessons learned from the All Kids Count experience may help public health practitioners plan and implement future health information systems.

● All Kids Count: The Early Years

In 1991, the RWJF board approved \$9.3 million to be awarded on a competitive basis for immunization registry planning and implementation grants. A National Program Office (NPO) was formed to provide administrative and technical support to the grantees under the guidance of William H. Foege, MD, MPH, and William C. Watson, Jr., former CDC leaders and founders of The Task Force for Child Survival and Development, a small nonprofit organization located in Atlanta. A National Advisory Committee comprising 16 leaders from public health, academic, and health care organizations also was convened to assist the NPO and RWJF with the selection of grantees and to provide guidance over the duration of the program.¹ Expected outcomes of the program were: (1) a documented increase in the rates of immunization among preschool children, (2) a decrease in the incidence of vaccine-preventable diseases, and (3) an opportunity for recipient communities to look beyond immunizations to the broader preventive services needs of their children.

One-year planning grants of up to \$150,000 each were issued in 1992 to 23 state and local health departments. At the time, only a few places in the United States were actively engaged in the development of population-based immunization registries. No definition of registries existed, there was no consensus regarding the functional components of a system or the technology that should be used, and the costs of developing and maintaining them were unknown.² Consequently, planning grantees were given little guidance to develop their immunization monitoring and follow-up systems. At the onset, RWJF had 3 expectations for AKC projects. Grantees must: (1) involve the community in the design and development of the project, (2) build on existing health information systems and be compatible with other registry efforts throughout the community and nation, and (3) keep in mind other public health

applications and the larger goal of ensuring primary care for children.³

In November 1993, 14 of the planning grantees received implementation grants (12 grants of up to \$525,000 total for 4 years and 2 grants with partial funding for 1 year) with 5 other foundations joining in the effort to fund 9 additional projects. RWJF also made a special grant of \$3 million to the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School, making a total of 24 grantees in the AKC initiative (see Appendix 1).

By the end of the 5-year demonstration project, the immunization registry movement had made considerable progress in defining functional standards for registries and identifying technical solutions, but had not achieved its overall goal of fully populated registries that included all vaccines given to children by all providers in the targeted areas. Notable success was reached in achieving a common definition of an immunization registry that could guide development and evaluation of registries. The documentation of essential registry functions was first done in 1996, by the Cecil G. Sheps Center for Health Services Research at the University of North Carolina, Chapel Hill, which had been awarded a grant by RWJF to evaluate the AKC program.^{2,4} In 1997, CDC/NIP, in collaboration with state program managers and AKC, identified 12 functional standards for registries.^{5,6} The 12 standards continue to be used today (see Box 1).

BOX 1 ● Functional standards for immunization registries

1. Electronically store data on all National Vaccine Advisory Committee-approved core data elements.
2. Establish a registry record within 6 weeks of birth for each newborn child born in the catchment area.
3. Enable access to vaccine information from the registry at the time of encounter.
4. Receive and process information within 30 days of vaccine administration.
5. Protect the confidentiality of medical information.
6. Ensure the security of medical information.
7. Exchange vaccination records by using Health Level 7 standards (Health Level Seven Inc, Ann Arbor, Michigan).
8. Automatically determine the vaccination(s) needed when a person is seen for a scheduled vaccination.
9. Automatically identify persons due or late for vaccinations to enable the production of reminder and recall notifications.
10. Automatically produce vaccination coverage reports by providers, age groups, and geographic areas.
11. Produce authorized vaccination records.
12. Promote accuracy and completeness of data.

Source: Reprinted from the Centers for Disease Control and Prevention, *MMWR*, 2004;53(20):431–433.

The most important conclusion from these early years was that states and funding agencies had underestimated the cost and complexity of developing immunization registries. In its final report, the Sheps Center concluded that developing registries proved to be much more difficult and slower than the projects' planners had originally thought.⁷ By the end of 1997, just one project (Chatham County, [Savannah] Georgia) had achieved full implementation status as defined by the researchers (eg, a database containing 90% or more of the target population, 75% participation by targeted public and private providers, all planned functions in operation and reports on data produced). Other projects had made significant progress but, in general, more effort was needed to demonstrate that registries could be developed and used in a way to improve the delivery of immunizations.

At the time, proponents of immunization registries and community health information networks (CHINs) assumed the spread and use of information technology (IT) in ambulatory care settings (eg, use of a computerized patient record) would accelerate quickly and facilitate linking of public health information systems to these larger health information systems. However, we learned that our understanding of the barriers to adoption of IT was incomplete and that a convincing business case was required to increase the health care sectors' participation in health information systems.

● **Striving for Fully Operational Status and a National Policy**

By 1998, immunization registries were in various stages of planning or development in all states as well as many communities and managed care organizations. Thirty-four states and 255 localities had reported to CDC that they were in the process of developing immunization registries.^{5,8} Recognizing the progress that was achieved and the growing momentum of immunization registries, in 1998, RWJF authorized an additional \$11.25 million for the All Kids Count program. The goal of this second (3-year) phase—AKC II—was to help some of the most advanced registries in the country achieve fully operational status by January 1, 2000 and to develop a long-term policy to ensure registries are implemented and sustained nationwide. Sixteen registry projects, representing diverse models and geographic areas, were competitively selected to receive 2-year grants ranging from \$300,000–\$700,000 total (see Appendix 1). Eight of them had been grantees in the first phase of AKC.

Although AKC recognized the importance of having immunization registries achieve functional status on all 12 CDC-defined standards, for the purposes of

the grant, the definition of “fully operational” was limited to six essential measures: (1) 95% of the target children < 2 years of age in the registry, (2) 95% of the children < 2 in the registry with at least one immunization recorded, in addition to the hospital-administered Hepatitis B vaccine, (3) 90% of public and private providers submitting immunization data to the registry within the last 6 months, (4) policies on the protection of confidentiality and security of data, (5) production of reminder and recall notices by the registry, and (6) generation of immunization coverage reports by the registry. Several methods were used to measure progress toward fully operational status. These included biannual quantitative performance indicator surveys (see Box 2),⁹ biannual site visits to each of the 16 grantees, annual profile surveys, annual progress reports, and several ad-hoc surveys. By January 1, 2000, although none of the 16 projects had achieved fully operational status according to the definition, 6 were very close, and all had made considerable progress during the 2 years. Most importantly, states and communities were beginning to use their registry data to measure coverage rates and to identify children in need of services. (Note: information on the current status of immunization registries is available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5320a3.htm>.)

The second goal of AKC II was to work with partner organizations to develop a long-term policy to ensure that immunization registries were implemented nationwide and had sustained funding. In late 1997, public policy set the stage for AKC projects and other state and community registries to take a giant step forward. Then-President Bill Clinton issued a Presidential Directive to Secretary of the Department of Health and Human Services (HHS), Donna Shalala, “to start working with states on an integrated immunization registry system.”⁶ As a result, an Initiative on Immunization Registries was undertaken by the National Vaccine Advisory Committee (NVAC), with support from the National Vaccine Program Office (NVPO) and CDC/NIP. AKC played an active role by partnering with CDC and by communicating with stakeholders regarding registry issues, especially the need for sustained funding.

By the conclusion of the second phase of AKC, research showed that immunization registries, once fully operational, would save more than they cost.^{10,11} A 1999 NVAC report on community- and state-based immunization registries recommended continued and increased support for registries through the existing federal immunization grant program as well as a special, short-term, grant program to support registries.⁶ In 2000, the Centers for Medicare and Medicaid Services (then the Health Care Financing Administration) agreed to provide Medicaid matching funds to support the development of immunization registries.¹² Also that

BOX 2 ● All Kids Count II Immunization Registry performance measures

1. Database maturity
 - a. Percentage of children 0–24 months of age in the catchment area in the registry
 - numerator: number of resident children \leq 24 months of age in registry
 - denominator: number of resident children \leq 24 months of age in the catchment area
 - b. Percentage of children in the registry with at least one immunization event recorded
 - numerator: number of resident children \leq 24 months in registry with one or more immunization events stored other than the first Hep B administered in hospital
 - denominator: number of resident children \leq 24 months of age in the catchment area
2. Timeliness of records
 - a. Timeliness of birth record entry into the database*
 - numerator: number of births entered into registry by \leq 42 days of date of birth
 - denominator: total births in catchment area for births occurring in a 6-month period
 - b. Median time interval between immunization and entry into the registry database†
 - numerator: number of doses administered that are entered into the registry by \leq 7 days
 - denominator: number of doses entered into registry during the specified time period
3. Provider participation
 - a. Percentage of public providers submitting immunization data to the registry
 - numerator: number of public providers who submit immunization data
 - denominator: number of public provider sites in catchment area
 - b. Percentage of private providers agreeing to provide information to the registry
 - numerator: number of private providers (or provider sites) enrolled
 - denominator: number of private providers (or provider sites) in catchment area
 - c. Percentage of private providers submitting immunization data to the registry
 - numerator: number of private providers (or provider sites) who submit immunization data
 - denominator: number of private providers (or provider sites) sites in catchment area
4. Immunization coverage levels
 - a. Immunization coverage levels for children 24 months of age in the registry
 - numerator: number of resident children at 24 months of age in registry with up-to-date immunizations during the 6-month period prior to the report date
 - denominator: number of resident children 24 months of age in registry with immunization histories during the 6-month period prior to the report date

*Also measures births entered by 43–90 days and \geq 91 days of date of birth.

†Also measures doses entered by 8–30 days and \geq 31 days of administration.

Source: Reprinted from Saarlans KN, Edwards KC, Wild E, Richmond P, Developing performance measures for immunization registries. *Journal of Public Health Management and Practice*, 2003;9(1):47–57.

year, the Institute of Medicine issued a report noting the importance of immunization registries as a tool to identify children in need of immunization services and stated that a commitment must be made to ensure their success.¹³ In addition, a *Healthy People 2010* goal was established of 95% of children 0–6 years of age participating in an immunization registry. By the time of an AKC co-sponsored legislative briefing on immunization registries in May 2000, more than a dozen national organizations, such as the American Academy of Pediatrics (AAP), American Medical Association, American Public Health Association, Association of State and Territorial Health Officers, and the National Association of County and City Health Officials, had issued resolutions or written letters in support of immunization registries.¹⁴

● A Move to Integrate Registries With Other Child Health Information Systems

As the second phase of AKC was closing, several grantees were considering how to use their population-based immunization registries to include additional information on preventive services. AKC was interested in learning if immunization registries could provide the infrastructure to support tracking and sharing of patient-based information within the broader health system. The specific question was whether integrated child health information systems improve and promote the timely delivery of developmental screening and early intervention services, lead screening and treatment, and other services needed by infants and young children, especially children with special health care needs.⁸

Since one of the originally stated outcomes of the All Kids Count program was for “communities to look beyond immunizations to the broader preventive services needs of their children,” we felt it was important to determine if integrated child health information systems could be developed and whether stakeholders would come together to develop a shared vision to support future integration efforts. RWJF responded by supporting a third phase of AKC with a 3-year, \$5 million grant. Unlike the first two phases of AKC, separate grants to state and local health agencies were not part of this phase of the program. However, technical assistance funds were included in the AKC III grant proposal as a means to accelerate learning around key topics. Recommendations from the Newborn Screening Taskforce to integrate newborn dried blood-spot screening systems with other child health information systems¹⁵ led AKC to form a partnership with the Genetic Services Branch of the Division of Services for Children with Special

Healthcare Needs, Maternal Child Health Bureau at HRSA (HRSA/MCHB), which was providing grants to states to plan and implement integrated systems.

Because little was known about integrating immunization registries with other child health information systems, in 2001, we began to bring states and communities together to share their experiences and to begin to document best practices in this new field.¹⁶ The 11 members who formed Connections (Appendix 1) represented a wide range of integration efforts, but all were working to link at least 2 health information systems for the purposes of improving the delivery of services for children. By the spring of 2004, the majority of Connections members had reported making considerable progress, but there were no means to systematically measure their progress due to the lack of standardized definitions and metrics. Principles and core functions for integrated child health information systems were drafted through complementary work in partnership with HRSA/MCHB,¹⁷ and efforts are underway to develop and pilot test performance indicators in 2005.

We conclude the final phase of AKC knowing that integrated child health information systems can be developed despite their complexity. We are confident that such systems can meet both public health and medical care needs if the two sectors can work more closely and ensure families also are involved throughout the process.¹⁸ National efforts to support interoperability of information systems, such as the National Health Information Infrastructure initiative (NHII) and the Public Health Information Network (PHIN), will give leverage to communities that are developing child health information systems. We are, however, still at the early stages of demonstrating the role information systems can play to improve child health outcomes. Likewise, considerable work is still needed to develop a policy case for child health information systems that supports their long-term sustainability.

● Important Lessons for Health Information Systems Projects

We believe that the lessons learned from the All Kids Count experience in developing immunization registries and integrated child health information systems can be applied to other health information systems projects in both the public health and medical informatics arenas. We offer our “top 10” overarching lessons from the past 13 years (see Box 3).

Involve stakeholders from the beginning

Many grant guidelines (including those for AKC grants) support a planning phase that recommends

BOX 3 ● Lessons for health information systems projects

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.
6. Address common problems collaboratively.
7. Plan for change.
8. Plan boldly, but build incrementally.
9. Develop a good communications strategy.
10. Use the information.

convening multiple stakeholders to seek out their respective needs and concerns. All of the AKC projects were required to form an advisory committee, and many held focus groups with providers and parents as part of their planning efforts. Consequently, most projects were successful in ensuring those needs and concerns were reflected in the resultant information systems. When their concerns are addressed, the majority of health care professionals and parents in these communities are supportive of immunization registries and integrated child health information systems.

Stakeholders, especially those who are the users and beneficiaries of information systems, need to be actively involved throughout the planning and implementation of child health information systems. The importance of a good governance model for managing information technology projects is noted in both health informatics and business textbooks and papers.^{19–21} AKC grantees described the benefits of having a governance body for immunization registries so that stakeholders and partners understood how decisions were to be made and by whom.²² Written charters and by-laws enable each of the members of the governing body to understand their roles and responsibilities in the process. They also formalize their commitment to the project and provide a mechanism for oversight and accountability to the community.²³

The aims of governance are many: to provide vision and leadership; to set direction and priorities; to take into account stakeholder perspectives; to ensure performance; and to exercise stewardship over public resources.²⁴ Good governance can also shape policies that facilitate information technology innovation and resourcefulness. However, even the best governance structure will need to adapt to changes in the organization and community. Public health leaders should be prepared to review the structure and reconstitute the

governance body from time to time to ensure it continues to reflect the priorities of the stakeholders.

Recognize the complexity of establishing a population-based information system

Clinical information systems may be quite complex, integrating information from a variety of sources such as clinical notes, pharmacy, laboratory, and radiology. However, these systems essentially deal with transactions on a population that is quite selective (eg, those admitted to a particular hospital or within a clinical group). Population-based information systems, on the other hand, must ensure that *everyone* who lives in a particular area is included, regardless of whether they make use of clinical or public health services. These systems are unique in that they provide real-time information to serve both public health and medical care needs. Public health requires population-based information to ensure that the community is well protected from disease and disability. This information allows for the identification of high-risk groups and the coordination of services across various sectors. Clinicians need population-based information to ensure that they are delivering the appropriate service to the patient in a timely manner. With a mobile population and frequent changes in health care coverage, population-based information systems are essential to ensuring a healthy community.

Developing a system that is completely populated has been challenging for immunization registries and integrated child health information systems. Having a population-based information system requires knowing the denominator of children. For communities that border multiple states or have a highly mobile population, this has proven to be quite difficult. AKC grantees and Connections members have used several techniques to calculate their population base and to ensure all children are represented in the system. Estimating the denominator for the targeted population requires close monitoring of census information and calculation of the rate of children who have “moved or gone elsewhere” (MOGE). In fast growing urban areas and border cities, this is not an easy task.

Linking with vital records is a critical component of populating an information system; however, electronic birth information at the state level may take several weeks to reach a county- or city-based information system. Several states and communities have also used their Early Intervention or Level 1 screening programs to identify children born in the target area. Newborn dried blood-spot screening and newborn hearing information is also being used to populate some information systems since the results from these services are usually available within the first week of birth.

In addition to capturing births, a population-based system must ensure that all providers of care (in both the private and public health care sectors) are submitting timely information on services provided (eg, immunizations, lead, vision, hearing screening, etc.) to the registry or health information system. To do so, first requires the knowledge of the denominator of providers. This too has proven to be challenging due to frequent mergers and changes within the health plan and clinical arena. Many AKC projects devoted considerable time to working with both local physician and health plan associations to ensure they knew each and every provider of care in their community. Despite the time and complexity of developing a population-based health information system, we believe the long-term benefits are worth the trouble.

Develop the policy/business/value case for the information system

Public health agencies develop information systems for many different reasons. Many of the state immunization registries and integrated child health information systems were initiated as a result of grant money or other funding from a federal agency. Funding limitations and competition with other health department priorities require that information systems sponsors continuously review and refine their “case” for the system if they are to gain support from policy makers. A more systematic and rigorous approach to developing the business or value case for immunization registries and integrated child health information systems is needed.

Cost studies conducted by AKC,¹⁰ CDC,⁶ the Sheps Center,²⁵ and other researchers^{26,27} were important information for policy makers as they looked for long-term funding solutions for immunization registries. Additional studies will be needed for integrated child health information systems, although these costs are more difficult to gather due to the variety of programs involved. As with many public health and preventive health initiatives, the savings from the system often accrue to a different sector than the one that bore the costs. Clearly identifying the costs and benefits of child health information systems from the perspectives of all stakeholders (ie, parents, providers, health plans, and public health agencies) will help each sector understand how its contributions affect the overall outcome. As registries and integrated information systems mature, the ability to document and measure benefits improves. Evaluation efforts should include measuring the cost-benefit and cost-effectiveness of integrated information systems. This information will be essential to policy makers if we expect their continued investment in child health information systems.

Developing immunization registries and integrated child health information systems requires coordinating funding from multiple program sources, which can be challenging but offers unique opportunities to leverage scarce resources. States will need to develop a comprehensive funding strategy for developing information systems that includes multiple funding sources. For several immunization registries (ie, Wisconsin, Michigan, North Carolina, Ohio, New Mexico, and California), the approval of Medicaid match funding from CMS is instrumental to ensure adequate and long-term support. Other states, such as Oregon, have successful financial partnerships with health plans that pay for immunization data required for HEDIS reports.

It will be important for federal agencies that fund categorical programs to specifically support the integration of their systems with other child health information systems. HRSA's SPRANS (Special Projects of Regional and National Significance) grants are a good example but should not be the only opportunity available to states. We need a long-term funding strategy that endorses coordinated financial support from multiple federal agencies and private sources and provides incentives to those who can demonstrate improved outcomes.¹⁸

Define the requirements of the system to support users' needs

Effective information systems are those that help the user "do the job" faster, easier, or more effectively. Immunization registries can eliminate time-consuming record pulls, chart audits for physicians, and labor-intensive coverage surveys for health departments and insurers, saving both time and money. In addition, registries provide more complete and accurate information on children's immunization status. Integrated information systems, which have the capacity to consolidate information from a variety of sources, enable even more efficiency and accuracy in the delivery of health services.

Despite general agreement on the purpose of these systems, the ability to design one that meets the multiple needs of public health, medical care, and families is challenging. AKC grantees and Connections members have learned that it takes considerable coordination between IT and program staff to design requirements for the system. All agree that providers' and parents' needs should be considered, but bringing them to the table as equal partners in the planning stage requires significant effort. Likewise, in an integration project, multiple sectors outside of public health (eg, Medicaid, environment, education, social services) must work together to design a system that meets the collective needs.

Such an effort requires strong leadership from the top executive and department levels and skillful facilitation of discussions. Reaching consensus requires stakeholder groups to agree to work together and to support the project. Successful developers provide multiple opportunities for physicians and other users to provide input throughout the information system life cycle.

When AKC began in the early 1990s, there was little understanding of the barriers to adoption of health information technology. Subsequently, many studies have been published on the subject.^{28–30} Most frequently noted barriers are lack of time, cost of purchasing and using an information system, concerns about privacy and confidentiality of data, and lack of knowledge and training. Today, with less than 13% of physicians using an electronic health record, it is clear that the barriers to adopting information technology are significant.³¹ In AKC, we found that projects that adopted the motto "if we build it, they will come" were more likely to fail. Successful registry projects were those that surveyed their users' needs and tried to build the information system in a way that could integrate into the daily workflow of the physician. Several states, such as Arkansas, Mississippi, and Oregon, have reported more than 75% of private providers actively using the immunization registry,³² demonstrating that the barriers to use can be overcome if the users perceive a benefit and the information system supports the delivery of services.

Future public health information systems that expect to link with providers' systems will need to be developed in ways that take into account physician behavior and work practices. Not only is there a substantial learning curve to use information technology, but the usefulness of an information system often is not seen until a large quantity of patient information has been entered. This can be a time-consuming task that may disrupt the provider office's daily routine and be perceived as a cost to participation that is too high to afford. More emphasis needs to be placed on designing information systems that support the work processes of physicians and on developing tools and techniques to help them overcome both perceived and real barriers to using information systems. Federal agencies, such as CDC and HRSA, can play a key role in supporting states and organizations to conduct operations research to identify successful ways to reduce barriers to participation in information systems.

Develop information systems according to current standards

A key function of a registry or integrated child health information system is the ability to link with health

information systems in the private sector to exchange records. Today, despite the recognition of the importance of using Health Level 7 (HL7; Health Level 7 Inc., Ann Arbor, Michigan) and other data coding and communication standards, few registries are yet able to use them as intended. Barriers to implementation include outdated information technology, failure to participate actively in standards implementation processes, variations in coding definitions among the participating health care organizations, and a misbelief that a given registry's situation is so unique that standards do not apply.

The immunization registry community has established a superlative example of a standards implementation process through CDC's development of minimum functional standards and NVAC-approved core dataset; endorsement of the HL7 messaging standard and development of an HL7 implementation guide; and the creation of CIRSET (Committee on Immunization Registry Standards and Electronic Transactions) for those involved in the implementation of the HL7 immunization messaging standard.

Successful exchange of information between public health and clinical information systems will require public health agencies to support standards-based systems as an essential investment in their infrastructure. With the evolution of the Public Health Information Network (PHIN) architecture, which includes a comprehensive approach to standards and standardized processes, public health agencies will begin adapting existing (legacy) systems, such as registries, to conform to current standards.

Public health practitioners can assist the growth and evolution of standards-based systems by participating actively in forums like the Public Health Data Standards Consortium (PHDSC). Practitioners should also maintain an active voice in PHIN's development to ensure that its architecture supports programmatic goals, objectives, and desired health outcomes.

Address common problems collaboratively

Throughout AKC's history of convening grantees, we observed a natural tendency for each of the state and local communities to initially focus on the unique nature of its needs. Over time, however, it became clear to AKC and grantees that, despite some local variations, the problems and challenges of developing an immunization registry were very similar ("diversity within commonality"). By focusing on what immunization registries, and subsequently, integrated information systems, had in common, we were able to identify examples of "best (or pretty good) practices" that could be applied universally. In addition, because few guide-

lines existed for immunization registries in the early and mid-1990s and few exist today for integrated child health information systems, we encouraged "parallel research," whereby different approaches were tried simultaneously, the results compared, and the best approaches adopted (and adapted as necessary). Our challenge today is to be more systematic about evaluating the approaches being used and to ensure rapid dissemination of information so others can implement effective approaches quickly and easily.

A key factor in successful collaborative efforts is camaraderie and trust among a group's members that problems (and failures) can be shared without negative consequences. AKC deliberately refrained from being judgmental, establishing an atmosphere that was noncompetitive. We observed that in the nonthreatening setting of AKC conferences and workshops, AKC grantees and Connections members were willing to talk honestly with each other about problems they were encountering and openly share their strategies for solving them. We believe that our neutral status as a nonprofit organization funded primarily by private funds made it easier for us to play this convener role effectively. Other public health information project initiatives could benefit from approaches such as those we used with our Connections community of practice to facilitate peer-to-peer learning and problem solving.¹⁶

Collaborative models have also successfully been used in the planning and design stage of developing an information system. AKC and NIP/CDC used a collaborative approach to work with states to develop the core immunization registry functions and performance indicators. AKC and HRSA also used a collaborative approach with implementation grantees and stakeholders to define the principles and core functions of an integrated child health information system.¹⁷ Recently, the Association of Public Health Laboratories (APHL) and the Public Health Informatics Institute partnered with 16 states to collaboratively define the business processes and functional requirements for a public health laboratory information systems.³³ The Institute observed that as projects worked together, they discovered that they had more in common with one another than they initially believed, and it is logical that this is true across all domains of public health (eg, laboratory information systems, child health information systems, environmental registries, etc.). If we work together to identify common requirements of an information system, we could have greater "purchasing power" with vendors. A collaborative approach to development should also produce significant savings to state and local health agencies since they can pool their human and financial resources rather than

developing their requirements (and information systems) independently.

Plan for change

The tenure of the All Kids Count program has spanned significant changes in health care financing and organization, advancements in information technology and science, and 3 different presidential administrations. When AKC planning grants were first awarded in 1992, we had no experience on which to base predictions about how fast (or slow) the idea of immunization registries would take hold or what barriers to expect. The shift from fee-for-service to capitated payments for preventive services, along with financial incentives for private providers to administer vaccines through the Vaccines for Children and State Children’s Health Insurance Programs, significantly changed immunization delivery during this last decade. More recently, the changes in Medicaid reimbursement, the focus on bioterrorism and public health preparedness, and the fiscal crisis of states have influenced public health programs’ ability to develop and implement child health information systems.

We have observed a few key principles that have helped information systems persevere through uncertain times:

- Foster external support for the project from important stakeholders such as the local AAP chapter, health plans, and parents and consumers so “demand” for the system is noticed by the leaders of the public health department.
- Foster broad internal support for the project, especially at the executive level. Do not make the registry or integrated information system a “pet” project of just one person.
- Develop a change management plan and recognize that the long-term goal of the information system is to improve the program but that its implementation can result in changes that can be threatening to some. A good communication plan is also needed to describe how everyone is affected by change and to identify support available to stakeholders who experience the greatest impact.
- Continually re-evaluate the environment by staying abreast of technical advances, political priorities, and overall changes in the health care system.
- Periodically revise strategic and operational plans based on the new information—and communicate these changes to key stakeholders.
- Develop risk mitigation strategies that articulate how these risks may impact the program and how best to avoid or overcome them.

- Diversify funding sources to help minimize sudden changes in a particular funding stream.

Because complex information systems development takes 10 years or more, public health agencies should expect significant changes in technology, funding, and political priorities. Opportunities to reflect on the environment and the consequences of change to the project need to be built into annual project reviews and discussed with peers at conferences and meetings. Although change can be hard, it can be managed effectively with leadership who are aware of the magnitude of the change and committed to long-term success.²³

Plan boldly but build incrementally

Just as it is important to have a “grand” view of the end product (eg, a national health information infrastructure), it is important to build the system incrementally. This allows demonstration of completed products and each success increases the likelihood of a subsequent success. It also permits adaptation to the inevitable changes in environment and technology. Several of the AKC Connections members reported having developed strategic plans for integrating child health information systems within their agencies with clearly identified timelines for when and how each of the impacted programs will be integrated. For example, developers of the Utah CHARM (child health advanced records management) system suggest that the incremental approach offers several advantages: (1) the ability to demonstrate the viability of the approach to stakeholders through multiple prototypes with opportunities for feedback, (2) the ability for participating programs to be added at their own pace into the integration effort, (3) the assurance of the availability of funding to implement successfully, (4) the assessment of technology appropriateness with users of the system, and (5) assurance of political support at each step in the process.³⁴

Investments in health information systems must be viewed as strategic investments to achieve long-term objectives, rather than just short-term purchases. The development of a health information system almost always costs more and takes longer than originally planned. Although AKC never thought the \$500,000 grants to immunization registry grantees would be sufficient to completely develop their systems, the real cost was unknown. With so few models in existence, states and communities had difficulty producing realistic plans and budgets. As a result, registries and integrated child health information systems have struggled to find sustainable sources of funding and to convince policy makers that an investment is beneficial. With

systematic planning, however, incremental milestones and successes can be documented and therefore lessen the potential risk for large-scale failure.

Develop a good communication strategy

A good communication strategy begins with listening to the various stakeholders and understanding their concerns and needs before shaping informational messages. Immunization registries and integrated child health information systems have presented communication challenges to public health managers. Although most parents and providers support the notion of improving immunization coverage through better information, they often become confused or anxious when they hear about an information system being developed by a government agency that will “track” their children’s health information wherever they are. To alleviate the potential for misunderstanding, the immunization registry community has had to develop clear communication messages regarding the purpose of immunization registries and other child health information systems. For example, when talking about the goal for immunization registries, AKC used terms such as “nationwide network of registries” rather than “national system” to reflect the fact that registries are community- or state-based and should only share information with other systems when necessary.

Parents have been mainly concerned about who would have access to their children’s health information and how and with whom it would be shared. In response, CDC and AKC partnered in the mid-1990s to develop recommendations on privacy and confidentiality of data, as part of the manual on community- and state-based immunization registries.²² This chapter was revised in the late 1990s and approved by NVAC in 2000.⁶ The guidelines stress the need to communicate with parents about the existence of an immunization registry and how they can “opt out” of having data shared. With the implementation of federal HIPAA guidelines, it’s even more important to ensure that the intent and use of the information system is clearly communicated and understood by both parents and their providers.

Our experience with AKC grantees supports the fact that most people look to their peers or other trusted sources to hear about the benefits of a new product. As expected, pediatricians will listen more closely to a statement from their local AAP chapter that the registry is worth their time and effort. Likewise, parents may be more receptive to what a known parent organization is saying than the same message being communicated by the health department. We have been fortunate to have advocates (and AKC advisory committee members), such as Rosalynn Carter and Betty Bumpers (from

Every Child by Two), to speak on behalf of immunization registries to state and congressional leaders. Their support has helped pave the way for states to develop promotional campaigns with the governors and their spouses.

A good communication strategy ensures a message is repeated many, many times. It requires a commitment of resources to ensure that key groups such as AAP, American Association of Family Practitioners (AAFP), health plans, and parent organizations have continuous, up-to-date information about the purpose and progress of registries and integrated child health information systems. Public health managers must work hard to find and educate spokespersons that can successfully communicate messages to their constituents. We have observed the success of the Leapfrog Group, e-health Initiative, and Connecting for Health in attracting business leaders to promote the use of electronic health records. We hope that public health can join these efforts as equal partners to ensure that we have a common voice for future child health information systems.

Use the information

The best is the enemy of the good.

—Voltaire, 1764

When developing an immunization registry or integrated child health information system, there is a natural tendency to want to ensure all data in the system are complete and accurate before using the system to support clinical and programmatic decisions. An information system that inaccurately reports a child’s immunization status risks exposing a child to disease and jeopardizes the trust of the physician using the system. Parents also will question the utility of the information system if it sends reminders for services already completed or, even worse, sends a reminder for a deceased child. Public health agencies have taken the responsibility of ensuring completeness and accuracy of both demographic and clinical service information very seriously. Much effort has been dedicated to developing algorithms and techniques to uniquely identify children and records. In general, health departments take a conservative approach to setting sensitivity and specificity targets and, therefore, spend significant man hours reviewing and consolidating records.

The downside to public health’s quest for perfect data is the risk that the data will not be released for use. Physicians participating in immunization registries often submit immunization information to the registry but receive little feedback about their patients. By routinely providing physicians with lists of patients who have been identified by the information system as needing immunizations (or other preventive services),

providers can verify this information against the chart records and subsequently update and correct information that is inaccurate. Establishing a systematic cycle of quality improvement and feedback of data in the information system is essential to improving its usefulness.

Equally important, showing the potential of the information system (even with imperfect data) helps all stakeholders support additional efforts to improve its quality. Over time, demonstrating how the quality and quantity of information in the system has improved will assist public health agencies to justify its continuation. Several states have used immunization registries to identify pockets of need,³⁵ show the impact of a vaccine shortage or change in schedule,^{35,36} save providers time, and increase coverage rates through the consolidation of records.^{6,36} Information systems can be powerful tools for public health policy makers and practitioners and can allow for more targeted use of education and outreach strategies. We recommend an increased emphasis on developing metrics to monitor and evaluate the application of registries and integrated information systems as a means to improve the quality of primary care for children.

● Conclusions

We believe the All Kids Count program achieved its goals of developing information systems that can help improve immunization rates and other preventive services for preschool children. We have moved beyond proof of concept with immunization registries and integrated child health information systems to address issues of how to implement and use them effectively. The grantees, Connections members, and other AKC partners are to be commended for their dedication to these goals and their perseverance in developing a sustainable information infrastructure for children's health care. The lessons learned over the past 13 years should be applied to future public health and medical informatics initiatives. Information systems projects can be successful and their development accelerated if we make the effort to learn from the past and from others.

We believe the All Kids Count program achieved its goals of developing information systems that can help improve immunization rates and other preventive services for preschool children. We have moved beyond proof of concept with immunization registries and integrated child health information systems to address issues of how to implement and use them effectively.

Although the AKC program has ended, it leaves its legacy with the Public Health Informatics Institute. The Institute, also largely supported by RWJF, has as its mission to advance public health practitioner's ability to strategically apply and manage information systems. The AKC experience demonstrates the benefits of using a collaborative approach to information systems development.

We see the efforts to integrate child health information systems as a core part of our future work. Challenges to address in the coming years include:

- forming a collaborative governance model with broad stakeholder representation to support future decisions regarding child health information systems
- developing a business or value case for integrated child health information systems that ensures their long-term support and sustainability
- using integrated child health information systems to improve the delivery and quality of preventive services for children and documenting improved health outcomes
- ensuring that public health, medical care, and families work together so that future child health information systems meet our collective needs

The recent efforts by the business community and federal agencies to improve the nation's health information infrastructure have opened doors for public health to share their experiences from developing immunization registries and integrated child health information systems so that the lessons learned do not have to be repeated by others. We know that while technology can be a barrier, still more difficult to overcome is the challenge of working effectively with all sectors of health care. The potential for broad-based changes in approaches to health care delivery for children can be realized through better information, but it will take our collective action and commitment to a shared vision.

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● Appendix 1

All Kids Count Grantees and Connections Members, 1992–2004

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|--|---|
| Arizona Department of Health Services ^{†,‡} | New York City Department of Health ^{‡,§} |
| Arkansas Department of Health [‡] | North Carolina Department of Environment, Health, and Natural Resources [†] |
| Baltimore, Maryland City Health Department ^{†,‡} | Oklahoma State Department of Health [‡] |
| Cal-Optima, California [§] | Oregon Health Division ^{‡,§} |
| Chatham Co, Georgia Health Department* | Philadelphia, Pennsylvania Department of Public Health ^{*,‡} |
| Cleveland, Ohio Department of Public Health* | Rhode Island Department of Health ^{*,‡,§} |
| County of Orange Health Care Agency, California [†] | Richmond City, Virginia Health Department* |
| Detroit, Michigan Health Department [†] | San Bernardino County, California Health Department ^{*,‡} |
| Hartford, Connecticut Health Department [‡] | San Diego County, California Department of Health Services [†] |
| Iowa Department of Public Health [§] | San Luis Obispo County, California Public Health Department [†] |
| Kansas Integrated Public Health Information System [§] | Santa Barbara County, California Health Department [†] |
| Los Angeles, California Child Health and Immunization Network [†] | Santa Clara Valley, California Department of Public Health ^{‡,§} |
| Maine Bureau of Health [§] | Santa Cruz, CA Health Department [†] |
| Medical and Health Research Associates of New York City, Inc.* | South Carolina Department of Health and Environmental Control [‡] |
| Metropolitan Health Department of Nashville and Davidson County, Tennessee* | Snohomish, Washington Health District ^{*,‡} |
| Michigan Department of Community Health ^{‡,§} | UMDNJ-Robert Wood Johnson Medical School, New Jersey* |
| Minnesota Department of Health [‡] | Utah Department of Health [§] |
| Mississippi State Department of Health* | |
| Missouri Department of Health and Senior Services [§] | |
| Monterey County, California Health Department [†] | |
| Nevada State Health Division ^{*,‡} | |

* All Kids Count/Robert Wood Johnson Foundation (RWJF) grantee, 1992–1998.

† From 1992–1993, funded by RWJF; from 1993–1998, funded by The Annie E. Casey Foundation, The Flinn Foundation, the California Wellness Foundation, The Skillman Foundation, or The David and Lucile Packard Foundation.

‡ All Kids Count grantee, 1998–2000.

§ All Kids Count Connections member, 2001–2004.