Costs of Immunization Registries Experiences From the All Kids Count II Projects

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Background: Immunization registries are tools to improve and sustain immunization coverage rates for

our nation's preschool children. Developing a means of supporting registries over the long

term requires information on costs to operate registries.

Methods: To determine the annual cost per child to operate immunization registries for the 16 All

> Kids Count (AKC) II projects, some of the most developed registry projects in the United States, we projected a national figure for operating registries and compared the figure with

a variety of potential cost offsets.

Results: When the registries are fully operational, the average cost per child for the 16 AKC II

projects will be \$3.91 (range, \$1.60 to \$6.23; interquartile range, \$2.91 to \$4.81) per year.

Conclusions: Based on the AKC study, maintaining a nationwide network of registries for children aged

0 to 5 will require an estimated \$78.2 million. Cost offsets include not having to manually retrieve records for school entry, child care, change in provider, and Health Plan Employer Data Information Set reports; not having to carry out the National Immunization Survey; and prevention of overimmunization. We estimate these offsets at \$113.8 million annually.

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Medicine

Background

ublic health officials and private providers widely promote immunization registries, automated systems that manage immunization information, as a tool to increase and, more importantly, sustain immunization rates for preschool children. 1-6 Currently, immunization coverage rates for preschool children in the United States are the highest ever recorded.⁷ But with 4 million children born each year, maintaining these rates is a continuous challenge. Several factors threaten this success:

- New vaccines continue to be added to the already complex immunization schedule.
- Families frequently relocate or change medical providers or health insurance.
- Few immunization providers operate reminder or recall systems to ensure that children receive immunizations on time.
- Parents and providers overestimate coverage.^{8,9}

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- Federal funds for supporting immunization activities are declining.
- Disease levels are at an all-time low; therefore, parents and providers are not reminded of the need to vaccinate. 10

When fully operational, an immunization registry will contain complete immunization histories on all children (and adults, if desired) in a given population, provide physicians and health care workers with a list of immunizations needed at the time of a visit, and identify children who are not up to date for one or more immunizations. By consolidating scattered records from multiple providers, registries can automatically provide accurate coverage rates for providers and populations, and can prevent unnecessary (duplicative) immunizations. They can also exchange information with other registries, which will assist parents in obtaining their child's immunization history when they move to a new geographic location. 3,6,10,11

Although many individual public and private provider facilities and health care organizations currently use registries, no statewide population-based registry is yet fully operational (i.e., containing information on all doses of immunizations administered to all children in a defined geographic area by all providers). 3,12 A 1999 Centers for Disease Control and Prevention (CDC)

survey found that all 50 states were at least in the planning stage of an immunization registry and 34 had registries that were partially operational. 13,14

The CDC began supporting the development of electronic information systems to monitor the immunization status of preschool children in 1980. These efforts were directed primarily toward children who received their immunizations in the public sector. The Robert Wood Johnson Foundation (RWJF) initiated the All Kids Count (AKC) program in 1991 to support the development and implementation of population-based immunization registries as a means to help increase immunization rates among preschool children. From 1992 to 1997, RWJF and five other foundations provided grants to 24 demonstration registry projects (AKC I). In 1998, RWJF provided funds to 16 of the nation's most advanced registry projects (AKC II), with the goal of becoming fully operational by January 1, 2000. The 16 sites, selected on a competitive basis, include nine state registries (Arizona, Arkansas, Connecticut, Michigan, Nebraska, Oklahoma, Oregon, Rhode Island, and South Carolina), two single-county registries (San Bernardino and Santa Clara, California), two multicounty registries (Minnesota and Washington), and three large urban city registries (Baltimore, New York City, and Philadelphia). Annual birth cohorts range from 3500 to 130,000, and the 16 registries represent approximately 19% of the nation's birth cohort. Eight of the 16 AKC II sites had been funded under AKC I.

Support for developing immunization registries has come from federal, state, and local funding; private foundations; and managed care organizations. CDC estimates that from 1994 to 1998 more than \$135 million in federal funds had been spent on registries. Since 1992, RWJF has awarded more than \$20 million to state and community registries for AKC I and II, and several other foundations and managed care organizations have provided substantial support to develop local city or county registries.

Although immunization registries are increasingly viewed as an essential tool for sustaining immunization rates, the costs of these systems have not been well characterized. 15–17 Cost information is necessary to assess the cost-effectiveness of registries and to determine the resources needed to sustain registries in the future. Consequently, the AKC National Program Office undertook a study to project the annual cost per child of registries when they become fully operational. These estimates were then extrapolated to provide a national figure for operating registries. The national figure was compared with estimates of the cost to manually retrieve records for a variety of purposes, the cost of overimmunization, and the cost to conduct national coverage surveys.

Methods Sample

All 16 AKC II grantees were included. They represent the most advanced registries in the nation. A majority of public providers and a significant proportion of private providers participate in them, and they represent a range of registry models, varying considerably in geographic size and target population.

Survey Instrument

We developed a questionnaire to collect information on (1) development costs before 1997, (2) 1997 annual operating costs, and (3) estimated annual costs for when the registries would become fully operational. We collected information about the date each registry began, the number of years in development, when it became operational, and the date it was expected to be fully operational (i.e., in a maintenance phase). Annual budget figures were provided for major line items: personnel (in-house and contractual), equipment (software and communications), indirect costs (rent, overhead), and in-kind contributions. We held extensive discussions with the project personnel to ensure that the costs of all state, local, and volunteer efforts (including the use of equipment, management personnel, coalitions) were included in cost projections. We included personnel costs to plan, coordinate, and operate the registry, as well as to enter data and recruit providers. In addition, we included personnel costs for private providers to enter data into the registry. We excluded from the study personnel costs to conduct outreach activities and to develop and distribute health education materials. We also excluded providers' costs to purchase equipment (if needed and not provided by the health department) to connect to the registry, because few, if any, providers would buy computers solely for registry use.

We asked the AKC II projects to provide information on the number of sites that report data to the registry, the number of immunization encounters reported to the registry by providers during the preceding 12 months, and the percentage of immunizations administered in the public and private sectors. We also asked whether the registry's scope was broader than immunizations and, if so, what percentage of the registry's costs should be allocated to immunization. To ensure comparability, we used costs to carry out the CDC's proposed 12 "key attributes of a registry" (Table 1). In this study, we did not use costs for registry functions outside the 12 key attributes.

We pilot tested the survey in two states, then modified it and mailed it to all 16 AKC project coordinators in March 1998. Projects were asked to complete and return the survey within 1 month. Subsequently, we used written and telephone contacts as well as site visits to clarify and refine responses. To verify data, we compared costs with budgets published in the AKC II grant proposals and conducted extensive interviews with project personnel.

Costs of Manually Reviewing Records

Data were gathered from five private-sector organizations on the costs to manually review and update immunization records. These organizations included 15 clinics that together

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Table 1. CDC key attributes of an immunization registry

- Accurately and completely consolidate all immunization records from multiple providers.
- Electronically store data on all National Vaccine Advisory Committee–approved core data elements.
- 3. Link electronically with birth data to automatically populate the registry.
- 4. Permit providers to electronically retrieve information on all immunization records at the time of encounter.
- Permit providers to electronically submit information on all immunization encounters on the same day as vaccine administration.
- 6. Ensure accurate and complete immunization records through automated de-duplication and edit checking.
- Protect confidentiality and security of the registry's medical information.
- 8. Recover lost data.
- Exchange immunization records using Health Level 7 standards.
- Automatically determine the immunizations needed at medical encounters, based on recommendations from the Advisory Committee on Immunization Practices.
- 11. Identify individuals late for immunization and produce recall notices.
- 12. Produce authorized immunization records.

provide more than 1.2 million immunizations a year. Fourteen of the clinics were health maintenance organizations, located primarily in the West, and one was a large clinic located in the Midwest. We obtained information on the cost of personnel time to manually retrieve a child's medical chart, review immunization records, provide those data to the nurse or physician for evaluation and appropriate action, record any immunizations in the chart, and return the chart to the file.

Data Analysis

We assumed that the following variables would remain relatively constant over the next several years: the number of live births, the number of immunization visits from birth to school entry, and the percentage of immunizations administered in the public and private sectors.

We used operating costs for 1997 to estimate costs when fully operational (maintenance costs). Costs of fully operational registries were projected in 1998 dollars. All projects provided estimates of the costs to operate the registries after they become fully operational (i.e., containing, at a minimum, immunization histories, in addition to the first hepatitis B immunization administered in the hospital) on at least 95% of children younger than 25 months of age for the defined geographic area. However, because registries provide benefits through school entry, projected annual costs per child were calculated for each project based on 95% of children aged <5 being active in registries.

Results

Fully Operational/Maintenance Costs

Estimated annual costs per child once the registry becomes fully operational ranged from \$1.60 to \$6.23, with a mean of \$3.91 (median cost \$3.93). For purposes of further calculation, we used the mean and the interquartile range (range including the middle 50% of values, \$2.91 to \$4.81) (Figure 1).

We found no statistically significant correlation between the annual cost per child and the percentage of immunizations administered in the private sector. We also analyzed costs per child for each project by annual birth cohort and rural vs urban environment, but found no significant relationships.

Costs for Manually Retrieving Records

The costs per encounter for manually retrieving and reviewing a child's immunization record at the five private organizations were \$6.00, \$14.00, \$16.50, \$17.00, and \$19.00 (average \$14.50).

Discussion

Although none of the projects in the survey included all providers and all children in their systems, we believe that they were sufficiently developed to accurately estimate their annual operating budgets. The average cost of \$3.91 per child per year is based on standard functionality of a registry, with the majority of the 12

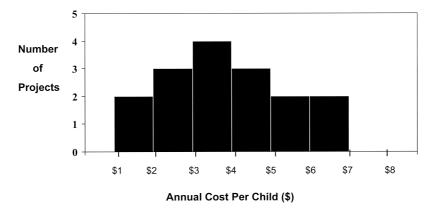


Figure 1. Frequency distribution of annual cost per child (16 AKC II Projects)

Table 2. Annual costs and cost offsets for a nationwide network of immunization registries

	Costs (\$ millions)	Cost offsets (\$ millions)
Registry operations	\$78.2	
Manual record pull for school/day care entry		\$ 58.0
Manual record pull for change in provider		\$ 16.2
Duplicative immunizations		\$ 26.5
Record pulls for HEDIS reports		\$ 2.0
National Immunization Survey		\$ 11.1
Totals	\$78.2	\$113.8

HEDIS, Health Plan Employer Data Information Set

key attributes operational. At the time of this study, about 80% of these attributes were functional. Preliminary analysis of data from a separate study of three immunization registries carried out by the CDC, using comparable methodology, indicates a range from \$3.38 to \$5.03 per child per year. ¹⁰

To get a national estimate for the cost of a nation-wide network of fully operational immunization registries, we multiplied the average cost per child per year (\$3.91) by the annual national birth cohort (4 million) and by the number of years a child's record would reside in a registry before school entry (5 years). This results in an expected national cost of \$78.2 million per year to maintain immunization registries. Using the interquartile range, the projected costs would be \$58.2 to \$96.2 million per year.

Estimated Cost Offsets From Registries

We compared the estimated fully operational costs of immunization registries with some costs that would be offset by having a registry (Table 2). Because most children receive services in addition to immunizations when they visit a provider, we did not include the cost of record review during regular well-child visits. However, we assumed that each child would require a special record review at least once in the first 5 years of life for entry into school, child care, or camp. Consequently, we multiplied the average cost per record review from the five private organizations (\$14.50) by the annual national birth cohort (4 million), yielding a total of \$58 million per year.

Studies show that 22% of children see two immunization providers in the first 2 years of life and an additional 3% see three or more providers. The record review required to obtain information on these children would add an annual cost of \$16.2 million. This cost offset may be greater if children must provide proof of immunization more than once before school entry or if they change providers between age 2 and school entry.

Other important offsets are likely because registries

can prevent unnecessary (duplicative) immunization of children. Data from the 1997 National Immunization Survey (NIS) indicate that 21% of 19- to 35-month-old children had received at least one dose of vaccine they did not need, at a national cost of \$26.5 million per year. ¹⁹

The CDC conducts the NIS every year to measure state and major metropolitan area immunization coverage levels at an annual cost of \$13.5 million.²⁰ Fully operational registries should be able to accurately and efficiently provide coverage data on populations and identify high-risk areas, obviating the need for the NIS. However, a need for significant central-level analysis of summary data, estimated at 25% of current expenditures, would continue.

Provider-specific coverage information will help physicians improve their individual practices by quickly identifying which children are underimmunized and also by providing the data required for Health Plan Employer Data Information Set (HEDIS) reports. According to a 1999 report by the American Medical Association, 94% of physicians are associated with one or more managed care organizations²¹; and according to the National Council for Quality Assurance, approximately 500 plans (400 commercial and 100 Medicaid) currently submit HEDIS results. To conduct the HEDIS reports, each plan must review 411 children's records. In 1998, approximately 67% of records required a manual chart pull (Thompson JW, written communication, March 1999). Using these figures and the estimated \$14.50 per review, we estimate that \$2 million was spent in 1998 to provide the required HEDIS information.

When added together, these cost offsets total \$113.8 million/year, substantially more than the annual estimated cost of \$78.2 million for immunization registries. A further major cost offset (not yet fully quantified) would occur because school personnel would not have to manually retrieve immunization records on all children entering school—the registry could provide summary lists of up-to-date children with an indication on each immunization certificate that the child is (or is not) up to date. One state (Minnesota) has estimated this annual cost at \$5 million (Glen Koops, written communication, 1999). Data are currently being collected in other states to better quantify the national expenditure. Additional offsets could come from prevention of vaccine spoilage through better vaccine inventory management and through streamlining records for other diseases. Data about these cost offsets have yet to be gathered.

Because reminder/recall functionality is a key feature of a registry, children at risk can be brought back into medical care more rapidly than previous methods allowed. Currently, only 35% of pediatricians and 23% of family practitioners offer reminder services. ¹⁰ Registries can also strengthen the concept of a "medical"

home" by facilitating accurate assessment of a child's immunization history followed by immunization or referral back to the designated primary care provider.²²

Finally, although we considered immunization registries in isolation in this study, it is quite likely that in 10 to 20 years, they will merely be components of comprehensive patient information systems, and costs attributable to immunization registry functions will be substantially lower.

Long-term Funding Strategies

As current federal immunization grant funds decline, it will be difficult for most projects to ensure that their registries will become fully operational in the next 5 years. The National Vaccine Advisory Committee has recommended a 5-year grant program to assist projects to reach operational status and to establish long-term funding mechanisms. The National Vaccine Advisory Committee also recommended that the National Vaccine Program Office consider options for funding registries in the long run, including continuing federal appropriations, inclusion of registry costs in reimbursement mechanisms, or a vaccine surcharge. To date, neither the grant program nor the long-term mechanism for funding registries has been established.

The continuing need to follow and immunize the four million children born each year makes it clear that immunization registries are essential to maintain the successes we have achieved in childhood immunizations. This study indicates that fully operational registries would cost substantially less than is currently spent on functions the registries could provide (estimated \$35.6 million less per year). Our nation's children need and deserve the benefits of immunization registries.

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