

# Developing Performance Measures for Immunization Registries

Kristin N. Saarlax, Kathleen (KC) Edwards, Ellen Wild,  
and Patricia Richmond

*Quantitative performance indicators were developed to monitor immunization registry progress of the 16 All Kids Count (AKC) grantees. Results were reviewed to determine if (1) the indicators measured immunization registry progress, (2) the results could be compared across AKC projects, and (3) other immunization registries could use the indicators. The study found that the AKC performance indicators provide a useful template for registries to measure their progress toward developing fully mature registries. Public health leaders should join with private health sector representatives to build on the immunization registry experience and develop and test performance indicators for integrated information systems in order to develop common goals and monitor changes in a comprehensive way.*

Key words: *immunization, immunization registries, informatics, performance measures*

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## Background

Immunization registries are confidential, population-based, computerized information systems that contain immunization data about children (and adults) in a geographic area.<sup>1</sup> Registries can consolidate vaccination records from multiple providers, identify the immunizations needed at the time of

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**Kristin N. Saarlax, MPH**, is Deputy Director, Center for Innovation in Health Information Systems, Task Force for Child Survival and Development, Decatur, Georgia.

**Kathleen (KC) Edwards, BS**, is an Immunization Program Consultant, National Immunization Program, Centers for Disease Control and Prevention, Atlanta, Georgia.

**Ellen Wild, MPH**, is Director of Programs, Center for Innovation in Health Information Systems, Task Force for Child Survival and Development, Decatur, Georgia.

**Patricia Richmond, BA**, is a Program Associate, All Kids Count, Center for Innovation in Health Information Systems, Task Force for Child Survival and Development, Decatur, Georgia.

service, assess coverage rates, and provide reminder or recall notices when shots are due or overdue.<sup>2-4</sup> According to a 2000 Centers for Disease Control and Prevention (CDC) survey,<sup>5</sup> 26 states, 4 cities, and 2 U.S. territories reported operating population-based registries for their target areas; the remaining states had either operational regional registries (county-wide or citywide) or were still in the planning phase of a statewide system. In recent years, progress has been made toward the Healthy People 2010 goal of having 95 percent of children age 6 years or younger in a population-based immunization registry. CDC<sup>5</sup> estimated that in 2000 21 percent of children were listed in a registry with at least two immunizations recorded. Although registries are not yet fully populated, many states and communities are already using registries to document improvements in coverage rates and identify children at risk for vaccine-preventable diseases. Because immunization registries are considered a key strategy to sustaining the nation's high immunization rates, it is important to have a means to measure their maturity level and progress over time in a valid and reliable way.<sup>2,4,6</sup>

Even though practice- or facility-based immunization registries were under development in the 1980s, it was not until the early 1990s that national leaders promoted population-based registries as important tools for ensuring appropriate immunization of children. The Robert Wood Johnson Foundation (RWJF) first supported the development of population-based immunization registries in 1992 with the initiation of the All Kids Count (AKC) program.<sup>3</sup> As part of this program, two rounds of grants (Phase I, 1992 through 1997, and Phase II, 1998 through 2000), totaling more than \$20 million, were competitively awarded to a total of 26 state and local health departments to develop and implement immunization registries for preschool children in their target areas. These funds supplemented those received from other sources, including federal immunization grants from the CDC. An All Kids Count National Program Office (NPO) was established to monitor the projects; communicate lessons learned; and provide technical assistance, national advocacy, and leadership for the effort.

In Phase II of the program, 16 registry projects (see the box titled "All Kids Count Phase II Grantees") were awarded grants and charged with the goal of becoming fully operational by January 1, 2000 (de-

fining as having 95% of children aged 0 to 2 years in the registry with immunization histories and 90% of providers participating). To measure progress toward this goal, the NPO undertook several monitoring activities, one of which was the development of quantitative performance indicators. While much had been learned about immunization registry development during the first phase of All Kids Count, evaluation efforts had been predominantly descriptive and process oriented. Quantitative indicators were successfully being used in many public health departments to measure progress on programmatic outcomes such as immunization coverage rates. However, most programs had not developed and tested indicators for their information systems, including immunization registries.

#### **All Kids Count Phase II Grantees (February 1998-June 2000)**

##### *State based*

Arizona State Immunization Information System (ASIIS)  
Arkansas Immunization Network for Children (INC)  
Connecticut Immunization Registry and Tracking System (CIRTS)  
Michigan Childhood Immunization Registry (MCIR)  
Nevada's All Kids Count II Project  
Oklahoma State Immunization Information System (OSIIS)  
Oregon Immunization ALERT  
Rhode Island KIDS NET  
South Carolina Statewide Immunization Information System

##### *County/multicounty*

Southwest Minnesota Immunization Information System (20 counties)  
San Bernardino County (California) All Kids Count  
Santa Clara County (California) Immunization Registry Information System (IRIS)  
Washington CHILD Profile (5 counties)

##### *City based*

Baltimore's Immunization Registry Program (BIRP)  
New York Citywide Immunization Registry (CIR)  
Philadelphia KIDS Registry

Source: Data from All Kids Count National Program Office, Decatur, Georgia, 1988.

In developing and testing performance indicators for registries, the NPO sought to answer the following three questions: (1) Which indicators can measure immunization registry progress? (2) Are indicator results comparable across the All Kids Count projects, given the wide range of methods and models of registries being implemented? and (3) Can the indicators used by the All Kids Count projects be used by other immunization registries? This article discusses the indicators used to measure the progress of the 16 All Kids Count grantees as well as the applicability of this experience to the development of performance measures for other public health information systems.

## Methods

### Survey tool development

The All Kids Count NPO convened a meeting in August 1997 to discuss the concept and utility of developing quantitative performance measures for registries. Evaluation experts from the Cecil B. Sheps Center at the University of North Carolina, CDC's National Immunization Program, and registry program managers from All Kids Count Phase I attended. The group reached agreement about the value of developing a set of performance indicators, outlined the areas that might be measured, and produced an initial draft of proposed indicators and definitions for measurement. These indicators were refined by the newly selected Phase II grantees and pilot tested in June 1998. After the pilot test, the indicators were further modified to a final set of eight that was used throughout the duration of the program (see the box titled "All Kids Count II Indicators for Immunization Registries"). The indicators cover four broad areas of immunization registry development: database maturity (i.e., the comprehensiveness and completeness of data in the system), timeliness of data capture, provider participation, and immunization coverage levels.

### Definition of performance indicators

#### **Database maturity**

Two indicators are designed to measure database maturity. One tracks the percentage of children aged 0 to 24 months who have a demographic record in

the database. A demographic record is defined as the child's name, date of birth, and any other identifying information. Demographic information is usually obtained through an electronic link with vital statistics birth data or from the physician at the time of vaccine administration. A second indicator measuring database maturity is the percentage of children in the registry with least one immunization event other than the first hospital-administered dose of hepatitis B vaccine.

By combining these two indicators, a new measure that denotes the number of children in the target area with immunization histories in the registry can be derived. The measure was calculated as follows: Number of children  $\leq$  24 months in the registry with one or more immunization events (from the immunization record measure) divided by number of children  $\leq$  24 months of age in the target area (from the demographic record).

#### **Timeliness of registry data capture**

Two indicators monitor data timeliness: one for birth data and the other for immunization event data. Timeliness of birth data was monitored over a six-month period and measured in three time intervals: percentage of records entered fewer than 43 days from birth; percentage entered between 43 and 90 days from birth; and percentage entered  $>$  90 days from birth. Data on the timeliness of immunization events entered into the registry were collected over a specified two-month period and measured in three time intervals: percentage entered  $\leq$  7 days from date of immunization administration, percentage entered 8 to 30 days from date of immunization administration, and percentage entered  $\geq$  31 days from date of immunization administration.

#### **Provider participation**

Three indicators measure provider participation: (1) percentage of *public* providers submitting immunization data to the registry during a specified six-month time period; (2) percentage of *private* providers enrolled in the registry (defined as having a signed agreement with the provider to participate in the registry); and (3) percentage of *private* providers in the target area submitting immunization data to the registry during a specified six-month time period. Since most registries were just in the early stages of recruiting pediatric practices into the registry in

### All Kids Count II Indicators for Immunization Registries

#### Database maturity

1. 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
2. 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 first hepatitis B administered in hospital  
Denominator: Number of resident children  $\leq$  24 months of age in the registry

#### Timeliness of records and data capture

3. Timeliness of birth record entry into the database\*,†  
Numerator: Number of births entered into registry  $\leq$  42 days of date of birth  
Denominator: Number of births occurring in catchment area during a specified six-month time period
4. Time interval between immunization and entry into the registry database‡,§  
Numerator: Number of doses entered into the registry  $\leq$  7 days  
Denominator: Number of doses entered into registry during a specified six-month time period

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

†During a specified six-month time period

‡Also measures doses entered by 8–30 days and  $\geq$  31 days of administration

§Up-to-date is defined as four DTP, three OPV/IPV, one MMR, three hepatitis B, and three Hib vaccinations

Source: Data from All Kids Count National Program Office, Decatur, Georgia, 1988.

#### Provider participation

5. Percentage of public providers submitting immunization data to the registry†  
Numerator: Number of public providers submitting immunization data  
Denominator: Number of public providers in catchment area
6. Percentage of private providers enrolled in the registry  
Numerator: Number of private providers (or provider sites) enrolled  
Denominator: Number of private providers (or provider sites) in catchment area
7. Percentage of private providers submitting immunization data to the registry†  
Numerator: Number of private providers (or provider sites) submitting immunization data  
Denominator: Number of private providers (or provider sites) sites in catchment area

#### Immunization coverage levels

8. 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§  
Denominator: Number of resident children 24 months of age in registry with immunization histories

1998, two measures of private provider participation were thought to be needed to document incremental progress and identify problem areas.

#### Immunization coverage levels

Immunization coverage was measured by the percentage of children in the registry who were up-to-date on their immunizations at 24 months of age (defined as having four diphtheria-tetanus-pertussis [DTP], three oral/inactivated polio virus [OPV/IPV],

one measles-mumps-rubella [MMR], three hepatitis B, and three *haemophilus influenzae* type B [Hib] vaccinations) during a specified six-month period.

#### Data collection and analysis

The All Kids Count NPO pilot tested the indicators in June 1998 and conducted four surveys between January 1999 and June 2000. All 16 projects participated in each of the surveys; however, a few were initially unable to report on all eight indica-

***The All Kids Count NPO pilot tested the indicators in June 1998 and conducted four surveys between January 1999 and June 2000.***

tors until they redesigned their software. By the last survey in 2000, all projects reported on all indicators. Information was collected on the numerator and denominator data for each indicator, the data source, and collection method. Staff validated data through telephone calls and site visits. Definitions and data sources were documented to ensure consistency throughout the survey period. For each survey, a report summarizing the results was disseminated to all 16 projects on completion of data cleaning and analysis.

## **Results**

### **Database maturity**

Survey results indicate that by June 2000, 11 of the 16 projects had demographic records in their registry for at least 90 percent of their 0- to 2-year-old target population. Six of the 11 reported levels of 100 percent or more, but they estimated that 3 percent to 5 percent of their records were duplicates. Given the lack of sophistication of deduplication software and algorithms for registries during the study period, all projects reported problems with duplicate records, but most were only able to estimate the magnitude of the problem.

During the study period, ten projects reported an increase in the percentage of children with immunization records in the registry, five reported a decrease, and one was unable to report on this indicator. Increases in the indicator reflected greater numbers of providers submitting immunization data to the registry. Reasons reported for decreases included the lack of an accurate process for calculating the denominator of children in the target area, changes in the methods used for consolidating records, and delays in data downloads from large provider organizations.

By June 2000, 6 of the 16 projects reported 75 percent or more of their target population in the registry with immunization events. Figure 1 shows the results of this combined measure of database maturity.

### **Timeliness of registry data capture**

As expected, projects that had electronic interfaces to vital record databases and routinely downloaded birth data directly into the immunization registry were most likely to report entering the majority of births within 42 days. Although the number of projects capturing at least 50 percent of births within 42 days only rose from seven to eight during the two-year study, seven others demonstrated improvements in timeliness (Figure 2). Three projects reported that it took more than 90 days to enter 50 percent of births into the registry. Two projects were initially unable to report on this indicator because linkages to birth data had not yet been established.

At the time of the last survey in June 2000, six projects reported more than 50 percent of the doses administered were entered within seven days, and seven projects reported that it took more than 30 days to enter 50 percent of the doses administered (Figure 3). All reported great variability in this indicator during the two-year study period as a result of various electronic and manual methods used to submit data (e.g., on-line, batch, paper, barcodes) and the difficulty of capturing this information with their current systems.

### **Provider participation**

Among the 16 All Kids Count projects, 11 reported having at least 90 percent of their public providers and 7 reported 80 percent or more of their private providers submitting immunization data to the registry as of June 2000 (Figure 4). One project had no public providers administering immunizations. Data on the percentage of private providers enrolled are not reported since results were found to be unreliable because of varying procedures used among projects to identify a provider as "enrolled."

### **Immunization coverage levels**

The percentage of children 24 months of age who were up-to-date on their immunizations was reported as below 80 percent by all but one project. These results do not reflect immunization coverage levels reported by other validated studies. At the

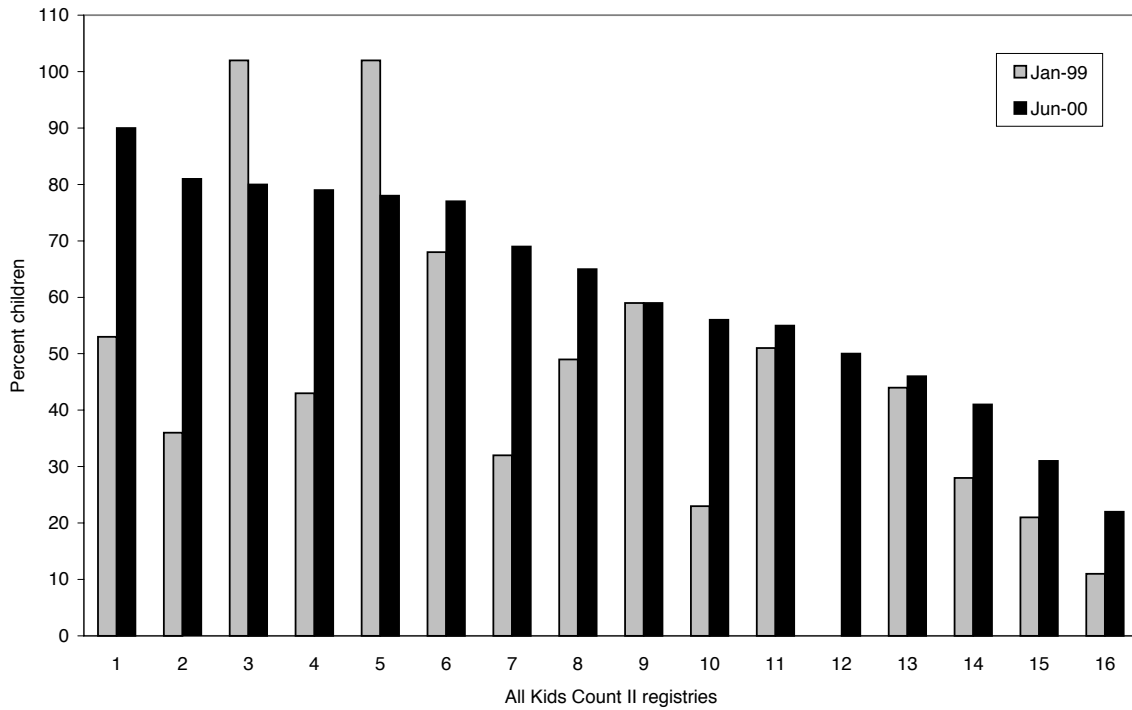


Figure 1. Percent of children 0–24 months with at least one immunization event in the registry

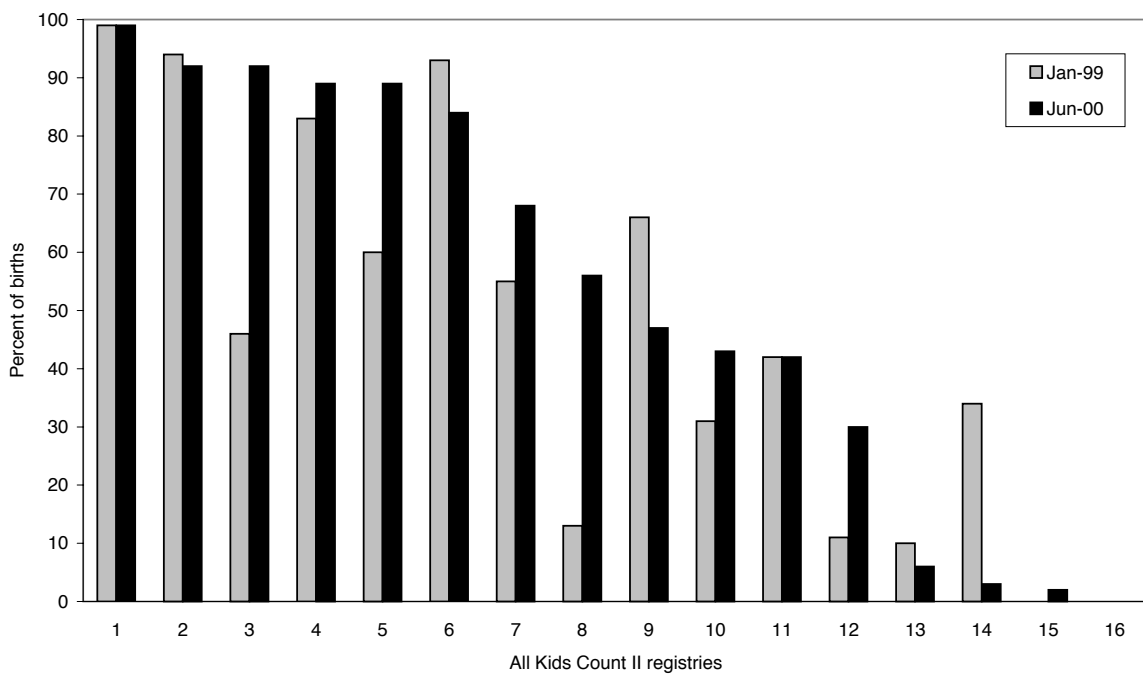
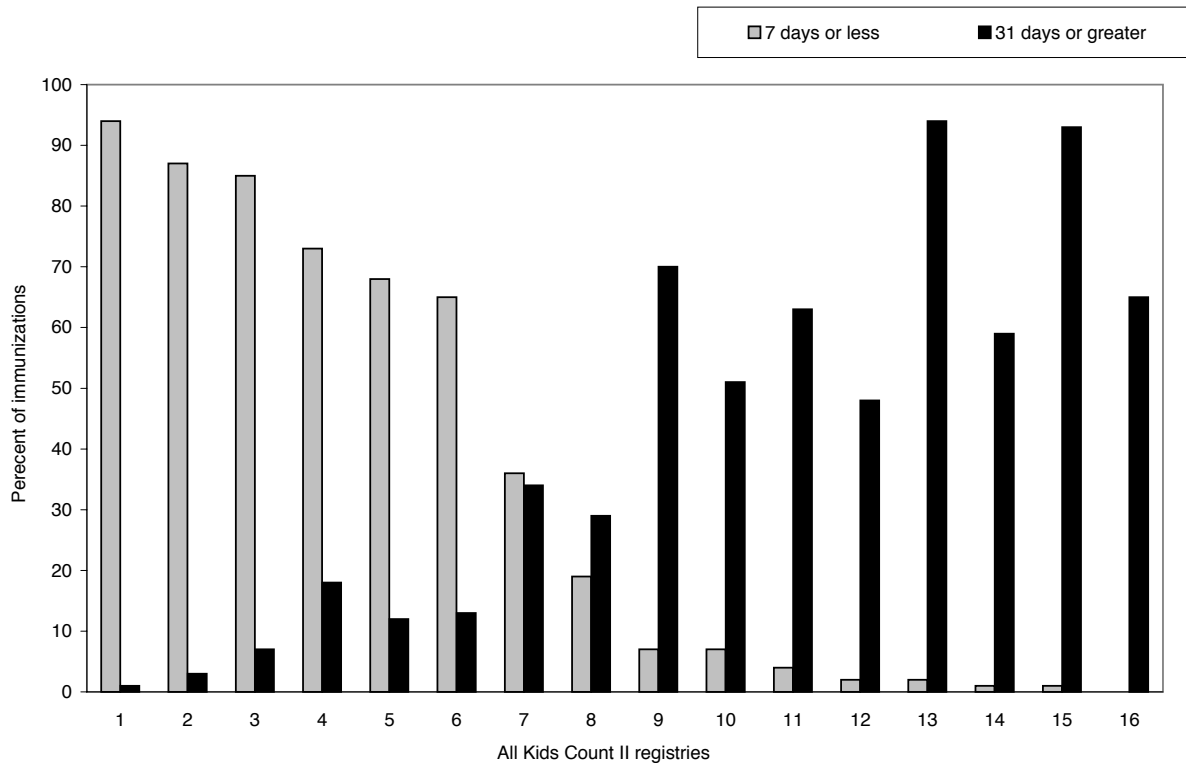


Figure 2. Percent of births entered into the registry within 42 days of birth



**Figure 1.** Percent of children 0–24 months with at least one immunization event in the registry

time of the survey, none of the registries had fully populated databases with complete immunization records on every child.

## Discussion

### Can indicators be used to measure progress of an immunization registry?

To answer this question, the following features of the indicators were considered: (1) reliability and consistency of methods used to measure the indicator; (2) accuracy of indicator denominator over time; and (3) sensitivity of indicators to detect changes and measure progress. Relative to reliability and consistency of methods used to measure indicators, formal testing of the reliability of the indicator survey instrument was not done due to the small sample size and the need for flexibility in design. Therefore, reliability of data was determined by examining the methods and data sources used by projects to report

results. Despite stating standardized definitions and measures for indicators on the survey instrument, methods to collect data varied considerably across projects due to the diversity of registry system design. For example, to capture birth data in the registry, projects reported using direct electronic linkages to vital statistics systems, manual entry, and data transfers via diskette. To improve reliability, projects reported refining their registry software to better capture information and training staff on indicator methodology and data collection. Projects also were asked to use consistent definitions and report any changes in the methods used to the NPO.

Regarding accuracy of denominators, to be maximally useful immunization registries should be population based. To be considered a population-based system, the registry must be able to capture all births and have a method for including those children who have moved into the area and excluding those who have moved out. An accurate denominator of the targeted population is a challenge for a registry,

especially in areas where there is high mobility and where many births occur out of the defined jurisdiction. For the All Kids Count indicators, projects had to state the definition used to determine “moved or gone elsewhere” (MOGE) and the source of the data for their denominators.

Obtaining accurate denominator data on private providers also was difficult for most projects. Multiple sources of information (e.g., telephone book, American Academy of Pediatrics [AAP] chapter membership lists, Vaccines for Children roster) were reviewed to calculate the number of private providers; this number had to be updated constantly. There also was variation among projects as some chose to count the number of individual providers and others chose to count the number of provider sites as the denominator. As long as a project maintained consistency in reporting from survey to survey, these variations were allowed.

Relative to sensitivity and ability of indicators to measure change, indicators must be sensitive to

changes to measure progress in an accurate and useful way. Four of the eight indicators demonstrated this sufficiently: percentage of children in the registry; percentage of children in the registry with at least one non-hospital-administered immunization, percentage of public providers submitting data to the registry, and percentage of private providers submitting data. However, as previously noted, several projects initially reported difficulties in establishing accurate denominators, which are required if these four indicators are to track change over time.

Indicators addressing timeliness of birth record and immunization data entry into the registry were not valid measures of progress because they both can be influenced by external factors, such as system linkages and data downloads with vital records and large managed care organizations or provider groups. During the study, data from these indicators were difficult to interpret when trying to measure progress over a length of time. However, the indicators address important aspects of registry functionality and

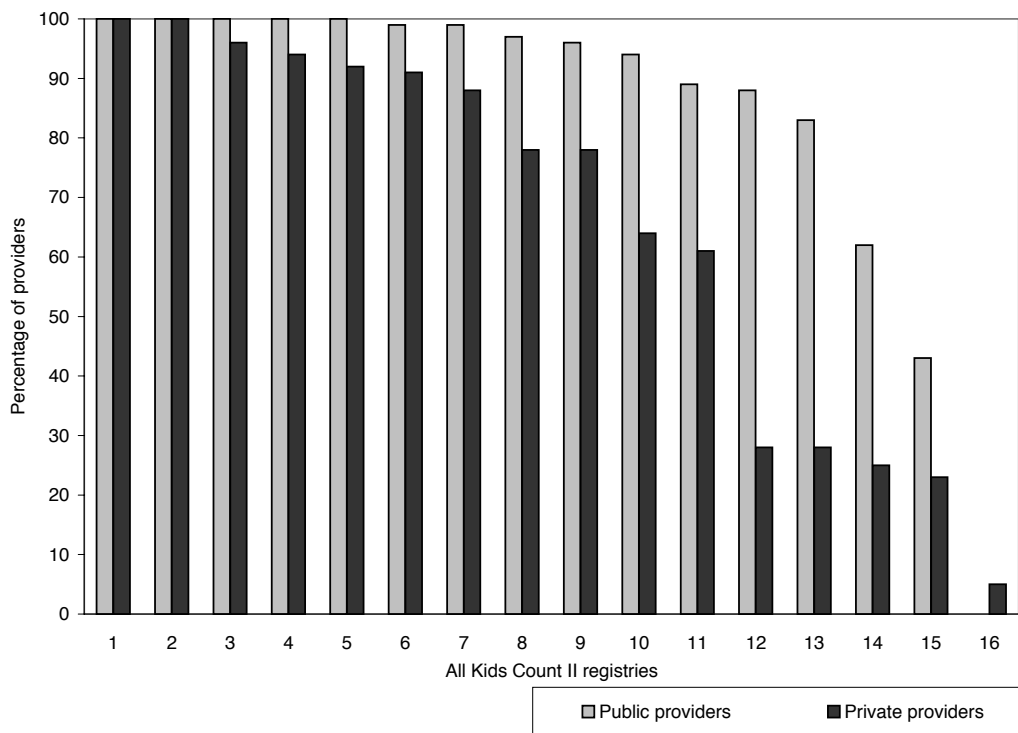


Figure 1. Percent of children 0–24 months with at least one immunization event in the registry



can highlight operational problems that should be monitored by program managers.

As stated previously, the indicator that measures immunization coverage status did not reflect the true immunization levels in the population at the time of the study because of incomplete records in the registry. Nonetheless, several projects reported using registry data to measure improvements in coverage levels of specific populations or geographic areas requested for Health Plan Employer Data and Information Set (HEDIS) and Medicaid studies.<sup>7-9</sup>

**Are indicator results comparable across the All Kids Count projects, given the wide range of methods and models of registries being implemented?**

Although the primary purpose of the indicators was to measure individual project progress toward the goal of fully operational status, ability to assess whether results could be compared across projects also was important. The 16 All Kids Count projects varied significantly in geographic size, annual birth cohort (3,897 to 133,649), health care environment, technical sophistication, and political structures. One project had no public providers of immunization, whereas others had as many as 75 percent of immunizations administered in the public sector. The number of private sector providers also ranged from only 52 in southwest Minnesota to more than 2,200 in the state of Michigan.

Despite these variations among projects, results were comparable for the two indicators that measured the percentage of children in the registry and the percentage of children with immunization events. Because projects tracked standardized data units (births and immunizations events), differences in population characteristics and data collection methods did not influence results. When the definition of the unit of measure varied across projects (e.g., provider sites versus individual physicians) or when data sources were unreliable, the indicators could be used to monitor individual project progress but not to compare maturity levels across projects.

**Can the indicators used by the All Kids Count projects be used by other immunization registries?**

Although the 16 All Kids Count projects represent a small number of the nation's state and local regis-

***Most state and local health departments should be capable of measuring immunization registry progress using the All Kids Count indicators.***

tries, their diversity in size, geographic and ethnic characteristics, health care status, and technical models is representative of other registries in the United States. Together they have an annual birth cohort of more than 773,000, or 19 percent of the annual 4 million U.S. births. We expect that most state and local health departments should be capable of measuring immunization registry progress using these indicators and will encounter similar problems (e.g., accuracy of denominator information, duplicate records, delays in data linkages and downloads) as those reported by the All Kids Count projects during the survey period.

**Limitations of the Study Design**

The purpose of this study was to develop an evaluation tool to monitor the progress of the All Kids Count grantees. Therefore the results are biased by the small and self-selected sample size and self-reported methodology. Also, at the time of the survey, there was no established gold standard for data accuracy or registry functionality, so efforts to validate results were limited to phone calls and site visits. In addition, it was often difficult to maintain reliable results over the two-year survey period due to changes in project staff responsible for completing the survey and registry software.

**Conclusions**

The eight indicators used in this study do not represent all aspects of a successful immunization registry. It is not sufficient for a registry to be fully populated with complete provider participation; it also must demonstrate its utility to public and private health care providers, identify high-risk children, keep data confidential, and ensure high data

quality. Expanding the All Kids Count indicators to include other performance measures will be necessary as registries mature during the coming years. In response to the 1999 National Vaccine Advisory Committee report<sup>1</sup> on immunization registries, CDC convened a technical working group to develop criteria to measure the progress made toward achieving the Healthy People 2010 objective of 95 percent of children under 6 years of age in a population-based immunization registry.<sup>5</sup> Several of these criteria built on the early AKC indicator experiences and will soon provide clear guidance to immunization registry managers on how to measure the 12 CDC-approved functional standards.

Progress of immunization registries should be monitored and measured at the local, state, and national level for many reasons. Immunization managers are being asked by policymakers and funding agencies to be accountable for their funds and demonstrate results in a timely way. CDC<sup>1</sup> estimates that from 1994 through 1999 more than \$178 million in federal funds were spent on developing and implementing registries, in addition to the millions provided by state, local, and private sources. CDC and All Kids Count studies estimate the national cost to maintain a record for all children younger than age 6 years in immunization registries is approximately \$100 million to \$125 million a year.<sup>1,10</sup> Research conducted by All Kids Count also showed that immunization registries can save costs by eliminating or reducing processes such as manual record pulls; over-immunization; and national, state, and school assessment surveys.<sup>10–12</sup> However, to fully realize these cost savings, a registry must be fairly mature, with the majority of the children in the database with up-to-date and complete immunization histories and almost all providers submitting and accessing immunization data in the system. By tracking progress through quantitative indicators, immunization registry managers can assure key policymakers and the populations they serve that they are providing a valuable service to the community.

Immunization registries have been an important part of the larger movement toward developing and improving the public health information infrastructure. A report published by the President's Information Technology Advisory Committee<sup>13</sup> on transforming health care through information technology discusses the lack of information available to

providers and policymakers about the efficiency of their technology investments and impact on health outcomes. CDC's<sup>14</sup> 2001 public health infrastructure report also identified problems with the current public health information system and recommended improvements in health departments' ability to electronically access and distribute up-to-date health information and measure population-based health outcomes. Moreover, in the last decade there have been increased federal efforts to improve performance measurement and accountability. The Healthy People 2010 objectives specify measurable objectives for public health data and information systems (including immunization registries), and there is a federal plan to implement national performance standards for all state public health agencies. These performance standards address the essential services for public health and include indicators such as the ability of the state to collect health data, monitor trends, and track progress toward national goals. However, additional efforts are needed to develop and pilot test indicators and performance measures for specific public health information systems.

The indicators used by All Kids Count have shown that quantitative performance measures can monitor the maturity and progress of public health information system development, but there are significant challenges to formulating generic indicators that are comparable across multiple systems. The All Kids Count study also identified several lessons learned that can be applied broadly to systems-based performance measure development. First, the impact of data quality on performance measurement sensitivity and accuracy should be considered when designing an indicator. Whenever possible, indicators should be developed to measure data quality to ensure progress is made in this area. Second, external influences such as system-dependent automated or manual processes must be taken into consideration and accounted for when developing a performance measure. Last, the use of consistent, reliable indicator data sources and collection methods must be established and maintained. This requires evaluation and monitoring beyond compiling and assessing indicator results. It requires active participation in, or at least awareness of, data collection activities to ensure the integrity of indicator results.

In many states and communities, immunization registries are linking to broader public health in-

formation systems. Several states have plans to link their immunization registries with lead poisoning and prevention systems, newborn metabolic and hearing screening systems, and Women, Infants, and Children program and Medicaid systems. These efforts will require ongoing feedback to funding agencies on progress and achievements. Federal, state, and local public health leaders need to join together with private health sector representatives to build on the immunization registry experience and develop and test performance indicators for integrated information systems. By doing so we can develop common goals with reasonable milestones for the development of public health information technology and monitor changes in a comprehensive way. Public health information systems have the potential to document how well the nation's health is being protected and the extent to which critical services are being provided to our children and our communities.

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