

**THE PROGRAMMATIC REGISTRY OPERATIONS WORKGROUP (PROW)
PROJECT SURVEY**

**PROMOTING PARTNERSHIPS BETWEEN IMMUNIZATION REGISTRIES
AND IMMUNIZATION PROGRAMS**

A Survey Report on Immunization Registry Support of Immunization Programs

Conducted by: **The American Immunization Registry Association (AIRA)
with support from the Centers for Disease Control and
Prevention (CDC).**



EXECUTIVE SUMMARY

I. BACKGROUND

The American Immunization Registry Association (AIRA) was contracted by CDC to coordinate a project to develop programmatic standards for immunization registries to support immunization program core functions.

Key activities include:

- Survey development and administration
- Focus Group.
- Formation of the Programmatic Registry Operations Workgroup (PROW).
- Programmatic Registry Operations standards and best practices recommendations.
- Registry Mentor Resource Group formation.

AIRA is a membership organization founded in July 1999 to advocate for support of immunization registry development and sustainability. Its purpose is to be a resource for standards use and development, training, technical assistance and communication and information sharing. The organization also promotes and supports partnerships and collaborative work and sharing of collective knowledge and successes. Currently there are nearly 100 members representing public health, managed care, community coalitions, computer consultants and software and hardware vendors. It is funded through special project grants and membership dues. CDC, All Kids Count and Wyeth Pharmaceuticals are current funders of AIRA. AIRA has an elected Board of Directors and an Executive Director.

II. SURVEY PURPOSE

The purpose of the *Survey on Immunization Registry Support of Immunization Programs* was to assess current and potential programmatic registry activity and to identify best practice examples. The survey was also designed so that results would serve as one of the tools to inform the work of the PROW.

III. METHODOLOGY

All 73 Immunization Programs from the current CDC list were surveyed. Both Immunization Program Managers and Immunization Registry Managers at each site were asked to respond to the questionnaire. The survey was a web-based tool administered by the AIRA website administrator, WebWorks, Inc. A PDF format of the survey was distributed to the list via broadcast email with instructions on accessing and completing the survey on-line. Distribution of the survey occurred in December 2001. Analysis of responses

occurred in January 2002 and a preliminary findings report was completed for presentation at the CDC Immunization Program Managers Annual Meeting in Atlanta, GA on January 24, 2002. Overall the response rate was high with 70% of all projects surveyed submitting at least one response. *See attached Geographic Distribution of Responses.*

Survey Response Rate

- 70% (n=51) of all programs surveyed submitted at least one response.
- 88% (n=44) of state projects surveyed submitted at least one response.
- 50% (n=6) of city/county/regional projects surveyed submitted at least one response.
- Territories/DC/Puerto Rico/VI (n=1) one response to the survey received.

IV. KEY FINDINGS

- **70%** of Program and Registry Managers combined who responded to the survey rated the *quality and functionality* of registries as ***excellent or good***. Functions falling into this overall category and were rated excellent or good included: **security of database, confidentiality/privacy, ability to print immunization records and timely access to immunization data.**

Breakdown:	Program Managers=58%	Registry Managers=79%
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- **48%** of Program and Registry Managers combined who responded to the survey indicated that their *registry* currently ***helps*** them ***to perform vaccine management functions more effectively***. Vaccine management functions included vaccine inventory management and vaccine ordering (VACMAN).

Breakdown:	Program Managers=41%	Registry Managers=62%
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An additional 20% of all respondents are considering implementing vaccine management functions.

- **41%** of Program and Registry Managers combined who responded to the survey indicated that ***in the area of Provider Quality Assurance their registry currently helps them to perform VFC eligibility and administration functions more effectively.***

Breakdown:	Program Managers=40%	Registry Managers=50%
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An additional 25% of all respondents are considering implementing provider quality assurance functions.

- **29%** of all respondents indicated that their *registry provides support for assuring effectiveness of overall service delivery functions that include school and day care surveys/information, reminder/ recall and WIC and Medicaid access.*

Breakdown:	Program Managers=27%	Registry Managers=36%
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An additional 37% of all respondents are considering implementing these service delivery functions.

- **45%** of Program and Registry Managers combined who responded to the survey indicated that *the registry provides support for surveillance functions that includes adverse events*. **21%** of respondents are *considering implementing surveillance functions*.

Breakdown:	Program Managers=36%	Registry Managers=55%
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65% of respondents are participating or considering participating in the National Electronic Disease Surveillance Systems (NEDSS) project.

- **36%** of respondents indicated that their *registry supports population assessment functions including identifying geographic or demographic pockets of need*.

Breakdown:	Program Managers=38%	Registry Managers=35%
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An additional 35% of respondents are considering implementing population assessment functions.

- **There was strong agreement** between the Program and Registry Managers who responded to the survey on the question of ranking the most useful areas for registries to support immunization programs. **Most useful areas included: coverage assessments, reminder/recall and provider visits-AFIX**.
- **Program and Registry Managers** responding to the survey **agreed** that **vaccine management, VFC eligibility, disease control and case management functions were moderately useful areas for registries to support immunization programs**.
- **29%** of respondents indicated that their *registry is using, integrating or linking with other child screening, preventive health services* including lead screening, newborn genetic screening, newborn hearing screening and asthma.

Breakdown:	Program Managers=23%	Registry Managers=36%
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An additional 6% of respondents are considering integrating their registries.

- **79%** of all respondents are **collecting or considering collecting adult immunizations and 82% expect to use their registries in future bio-terrorism activities**.

V. CHALLENGES

- **26%** of all Program and Registry Managers who responded **identified** a number of issues that present **challenges** to more effective use of Immunization Registries by Immunization Programs. **Key issues** identified included: *clarity on registry functions; organizational structure and/or communication issues; relationship with Medicaid; funding issues; data quality; private provider participation; technical support and privacy/confidentiality issues.* **32%** of respondents were *neutral* on the issue of these challenges. This has been interpreted as an indication that these respondents feel these challenges are not obstacles to using their registry.

Challenges:	Program Managers=35%	Registry Managers=31%
Neutral:	Program Managers=33%	Registry Managers=30%

- **32%** of respondents felt that using the registry to help them perform vaccine management functions more effectively was a challenge especially in the *areas of ordering vaccines, managing vaccine inventories and documentation of expired doses.*

Breakdown:	Program Managers=41%	Registry Managers=21%
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- **34%** of respondents felt that the area of *Provider Quality Assurance presents a challenge particularly related to VFC eligibility and validating public clinic VFC profiles.*

Breakdown:	Program Managers=37%	Registry Managers=25%
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- **35%** of respondents indicated that use of the registry to support effectiveness of overall service delivery functions was a challenge. *High challenge areas included: school and day care surveys to identify children not up to date, Medicaid and WIC access and identifying medical homes of persons receiving immunizations in public clinics for future immunization referrals.*

Breakdown:	Program Managers=41%	Registry Managers=30%
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- **34%** of respondents *do not use their registry to support surveillance functions.*

Breakdown:	Program Managers=44%	Registry Managers=27%
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- **32%** of the respondents **do not use their registry for support with population assessments especially in the areas of assessment of immunization coverage rates among target children and use of registry data on influenza and pneumococcal coverage levels.**

Breakdown:	Program Managers=44%	Registry Managers=30%
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- **Integrating** registry services with other child health services is an **identified challenge**. **63%** of all respondents **answered no to the question about service linking and/or integration** related to their registry.

Breakdown:	Program Managers=68%	Registry Managers=60%
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- **36%** of all respondents identified **responding to vaccine safety issues** especially in the areas of **VAERS and CISA** participation as a challenge.

Breakdown:	Program Managers=35%	Registry Managers=37%
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VI. BEST PRACTICE HIGHLIGHTS

The survey asked respondents about *current use of the registry in bioterrorism events and current use of the registry that improves, enhances and/or streamlines an immunization program activity*. The following responses highlight current activities in each of these question categories.

CURRENT USE OF REGISTRY IN BIOTERRORISM EVENTS

- **Arizona:** Queried the system for people who may have received anthrax vaccine and prepared the system to add a tracking system for antibiotics (Cipro).
- **Missouri:** Bioterrorism calls are logged into the system.
- **Washington:** We can track the administration of vaccines such as anthrax and smallpox. This is the only aspect already in production that could be implemented if needed.

CURRENT USES OF THE REGISTRY THAT IMPROVES, ENHANCES AND/OR STREAMLINES AN IMMUNIZATION PROGRAM ACTIVITY

- **Alabama:** Used to create benchmark reports for VFC providers.
- **Arizona:** Use of GIS mapping to identify high rate/low immunization coverage level areas and use of this information to provide education and technical support to providers in these locations.
- **California:** CASA report for providers leads to improvement in coverage.
- **Connecticut:** Currently working with NIP on Prevnar vaccine efficacy study. Plan to use registry to do a study looking at breakthrough varicella cases. Currently monitor pneumococcal conjugate vaccine usage for VFC eligible population.
- **Delaware:** Registry is currently used to assist in identifying WIC children who need shots and reminder/recall letters.
- **Illinois:** Through public data that is input via EDI, quarterly coverage level reports are generated for the WIC-Immunization initiative mandated by DHS/WIC program.

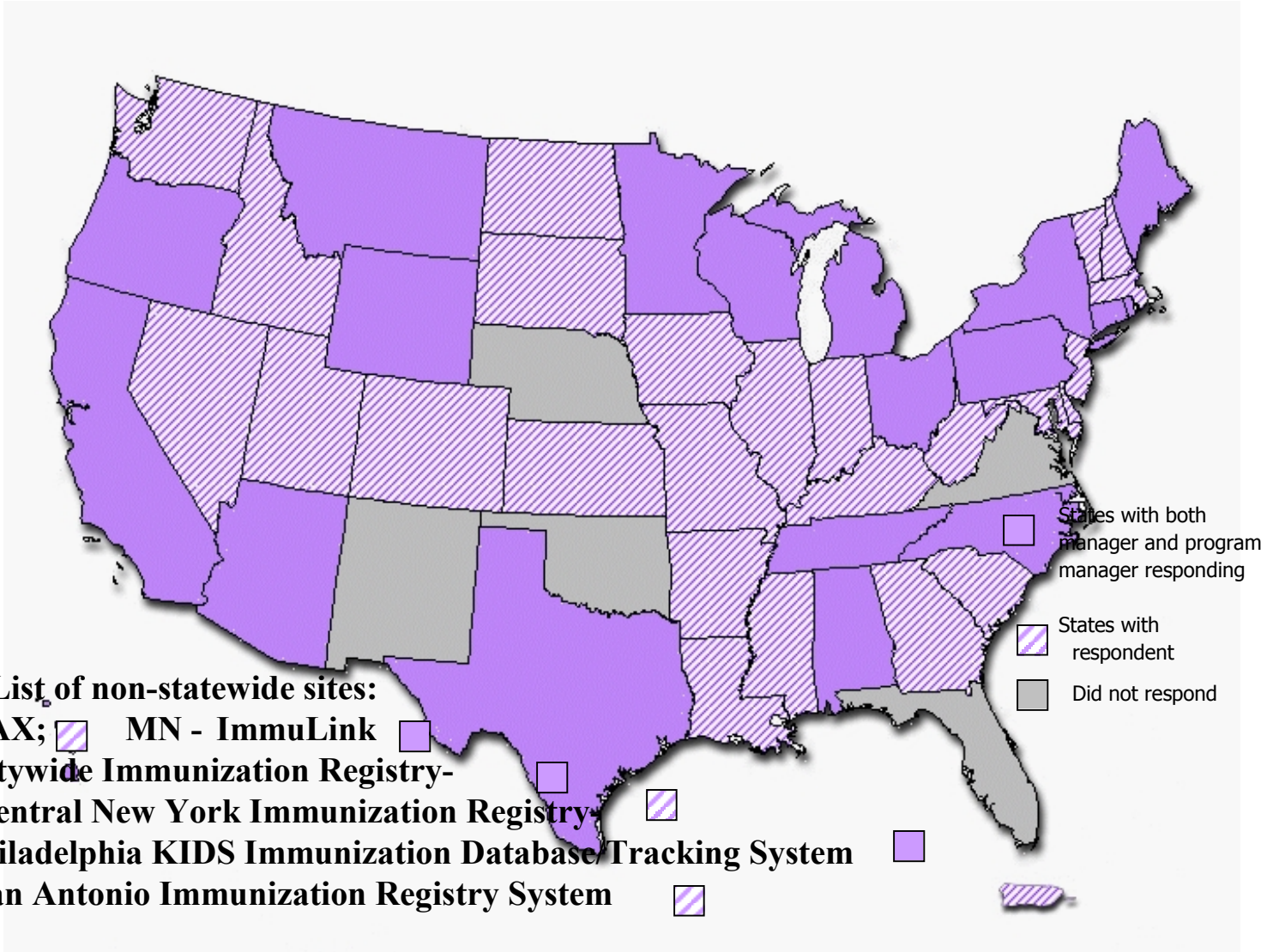
- **Maine**: Reporting of patient VFC information for practices. Monitoring of vaccine balances and redirection of inventory affected by vaccine shortages.
- **Michigan**: Michigan is a sentinel site participant. We monitor population base immunization levels for health jurisdictions, county and statewide coverage using registry data. We also use the registry to help identify pockets of need, patterns in vaccine usage and uptake of new vaccines.
- **Minnesota**: We do quality checks on all data before it is added to the registry and do a 200 chart review to confirm accuracy and completeness before any provider joins our registry. They must pass the audit with 90% accuracy and 80% completeness. Most pass the first time but there are generally improvements needed such as: using vaccine only for ages licensed, updating charting and billing for OPV/IPV, PCV7, charting correctly for DT and TD, etc. Every time a new vaccine comes out we help clinics update their charting and billing practices. The registry supports the immunization program functions including provider feedback/quality improvement, assessment, vaccine management, VFC operations and case management.
- **Montana**: Provider coverage assessment and vaccine inventory management are supported by the registry. We are also beginning to use the registry to assess the immunization rates of public providers prior to clinic evaluations/visits.
- **North Carolina**: Accountability for local health departments. Data from the NCIR is used to provide CASA-ready files to local Health Departments on a regular basis for use in tracking. Annual compliance assessments of LHDs are done using NCIR data replacing manual chart audits.
- **New Hampshire**: More accurate accounting of vaccine usage and vaccine waste. Reduces administration of invalid doses.
- **New Jersey**: Perinatal Hepatitis B case management.
- **Nevada**: Enhances and improves the efficiency of reminder/recall, doses administered reporting and vaccine algorithms that determine needed vaccines.
- **New York City**: Communication with childhood immunization providers for broadcast faxing and access to an informational web site. Communication with parents through distribution of printed materials promoting both immunization and use of the registry to obtain child records. The registry is also used to assist the assessments team in identifying the patients of private physicians to assist with the chart pulls. Assessment teams encourage physicians to use the registry and also check to see if they are reporting to the registry. They inform the registry provider relations staff of their findings for follow up. The registry is also used to monitor pneumococcal vaccine uptake.

- **Ohio**: We have used the registry to assess what features/functions health care providers use. This enables us to make changes to improve the flow and function of the registry.
- **Oregon**: Registry is used to monitor the impact of changes in the vaccine schedule.
- **Philadelphia**: Reported on Rotavirus Vaccine given in Philadelphia so that providers could follow up with their patients. KIDS can report on Prevnar and Varicella uptake, and with varicella we have reported on coverage rates within specific geographic areas of Philadelphia.
- **Rhode Island**: Registry is used to identify inappropriate vaccine use and to monitor the use of new vaccines or schedule changes. It is also used to monitor doses administered and identifying vaccinated children in outbreak areas.
- **Tennessee**: The SIIS is involved in PCV7 use studies and studying schedule reductions. Target children at high risk of non-completion of immunization series.
- **Texas**: Registry is used to monitor the impact of vaccine issues with usage (e.g. HepB vaccine at birth and preservative used in vaccine; MMR press regarding autism). SAIRS is currently sharing data with CDC and Texas Department of Health for individual/series vaccine tracking and accountability. SAIRS is available for all public clinics and all VFC providers in addition to other 3rd party immunization partners/providers.

VII. SUMMARY

- The status of immunization registries based on all respondents to the survey indicates that 66% are population-based registries, 10 % are non-population based and 24% are in the development phase. 24% of the programs surveyed have submitted, and/or have approved Medicaid APDs, and 23% are planning on submitting an APD. Of the programs surveyed, 62.5% of the registries are under direct management of the immunization program, 25% are somewhat a part of the immunization program and 12.5% are not organizationally aligned with the immunization program.
- Immunization Programs currently use registries to support core functions and there is interest in expanding this use.
- There appears to be strong agreement between Immunization Program Managers and Immunization Registry Managers regarding the most useful areas for registries to support immunization programs.
- Registries are improving immunization program effectiveness through assessing coverage levels, and increasing vaccine accountability and management.
- There is high interest in using registries in future bioterrorism related activities.

Geographic Distribution of Responses



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