SPECIAL EDITION

SnapShots

December 2005

From the American Immunization Registry Association — Immunization Information Systems for a New Era

Healthy People 2010 Countdown

Immunization Information Systems Meeting the Challenge

The **Healthy People 2010** goals are in the forefront of the minds of those committed individuals working in public health. These goals serve as guideposts to making our communities strong and healthy. They provide the vision toward which our activities are focused. The Healthy People 2010 goal for Immunization Information Systems (IIS), also known as immunization registries, is clear: increase to 95% the percentage of children ages 0-6 years who have two or more vaccinations recorded in a registry by 2010. We are now heading into the home stretch of this deadline and AIRA in partnership with Centers for Disease Control and Prevention/National Immunization Program (CDC/NIP) is working to support the IIS community in reaching that objective. By identifying the information needs of IIS stakeholders, AIRA can better target their education and resource efforts toward helping these professionals realize the Healthy People 2010 IIS goal.

AIRA and its partner CDC/NIP/IRSB (Immunization Registry Support Branch) conducted a series of surveys and assessments over the past two years to solicit feedback and information from the IIS community. Information gathered from these surveys and assessments is being used in the development of a comprehensive Education Plan to be implemented over the next two to three years. This Special Edition of *SnapShots* has been published to share with the immunization registry community the results of these surveys and assessments as well as some of the current and planned activities that are based on these results.

The following surveys and assessments are highlighted in this issue. Each was focused to solicit feedback in a specific area.

- *Provider Participation Barriers and Best Practices Survey*
- *IIS Research and Evaluation Agenda Survey*
- *Education and Training Needs Assessment*
- *MIROW (Modeling of Immunization Registry Operations Workgroup) Needs Assessment*
- *PROW Standards of Excellence Utilization Survey*
- *Survey on Data Exchange Between IIS and Health Plans (Managed Care Organizations)*
- *IIS Technical Assistance Survey*

The population targeted to participate in these activities represented many different stakeholders in the immunization and IIS communities including immunization program managers, IIS managers, system vendors, non-profit organizations, public health associations, and providers.

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2004 IMMUNIZATION INFORMATION SYSTEM PROGRESS REPORT

Bobby Rasulnia, Research Fellow
CDC/NIP/Immunization Registry Support Branch

This report summarizes data from the Centers for Disease Control and Prevention (CDC), National Immunization Program (NIP), 2004 Immunization Information System (IIS) Annual Report, a survey of IIS activity among 56 grantees that receive funding under section 317b of the Public Health Service Act. Grantees include the 50 states, 5 cities, and the District of Columbia (DC). The 2004 IIS Annual Report is a self-administered, internet-based questionnaire made available to immunization program managers as part of an annual reporting requirement. Grantees are asked about the number of children aged <6 years participating in the IIS, health-care provider participation in the IIS, and other programmatic and technical functions (e.g., data linkages with other public health programs, data use, vaccine management, software/hardware capability, and reporting functions). All 56 grantees were asked to complete the questionnaire; 51 reported on the number of children aged <6 years participating in an IIS.

The findings suggest that, of approximately 23 million U.S. children aged <6 years, an estimated 48% (11 million) participate in an IIS; the national health objective for 2010 is to increase this proportion to at least 95%. This represents a 4% increase from 2003, or approximately 1 million more children who participate in an IIS. Ten (18%) IIS grantees (Alabama, Arizona, Delaware, Michigan, New Mexico, New York City, North Dakota, Oregon, Philadelphia, and Wisconsin) have achieved the national health objective of >95% of children aged <6 years participating in an IIS. Approximately 76% of public vaccination provider sites and 39% of private vaccination provider sites submitted immunization data to an IIS during the last 6 months of 2004. Private provider participation in an IIS increased by 3% as compared to 2003. Twenty-eight (50%) grantees reported that >95% of public provider vaccination sites submitted immunization data to an IIS; five (9%) reported submission of immunization data by 81%–94% of public provider vaccination sites. Seven (13%) grantees (Arkansas, Connecticut, Mississippi,

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IMMUNIZATION INFORMATION SYSTEMS TECHNICAL ASSISTANCE SURVEY

Gail Williams, Programmatic Team Leader
CDC/NIP/Immunization Registry Support Branch

Section 317(b) funding has been available to state and local immunization programs to develop, maintain and enhance immunization information systems (IIS) to meet the Healthy People 2010 objective: increase to 95% the proportion of children<6 years who participate (i.e., have two or more vaccinations recorded) in fully operational, population based immunization registries.

According to the CY2004 Immunization Registry Annual Report (IRAR), approximately 48% of the U.S. children less than 6 years of age (or approximately 10 million children) had two (2) or more immunizations in 56 grantee state or local IIS. To supplement CDC's ongoing support for grantee IIS activities, the Immunization Registry Support Branch (IRSB) assessed the need for specific technical and programmatic assistance to immunization programs. An assessment was designed to evaluate the types of IIS technical assistance sought by grantees.

Of the 56 grantees, 24 (43%) responded to the assessment. Each respondent was asked to identify their needs in particular areas as well as rank them according to priority. According to the respondents, the highest priorities for assistance were data use and administrative issues. Specifically, respondents identified issues such as guidance on data utilization; data analysis methods; ways IIS data can be used to drive immunization programs; and support in determining how to use IIS data to its fullest potential. Administrative issues identified included: IIS funding; technical and client support personnel; organizational design; legislative support; and alternative funding resources and strategies. The third highest priority for technical assistance was provider relations issues such as strategies to increase private provider recruitment and retention; financial issues in enrolling private providers; and identifying model practices for exchanging data with managed care organizations and other health care providers.

The IIS technical assistance survey results were shared with respective IRSB Grantee Project Consultants. Consultants have been asked to use the information to guide them in identifying resources and support to assist the grantee with their individual needs as well as assisting them in reviewing Section 317(b) grant applications, business plans/strategic plans and interim plans.

PROW STANDARDS OF EXCELLENCE UTILIZATION SURVEY

Anne Cordon, San Diego Regional Immunization Registry Manager
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You may not remember what the letters P-R-O-W stand for, but every immunization program and registry manager should know by now that PROW is a useful tool to evaluate and plan progress toward the Healthy People 2010 immunization goals.

In 2005, eleven more IIS have begun using the PROW standards of excellence. In the 2006 grant guidance for 317 immunization programs, the CDC emphasized the role of data and information technology in conducting immunization activities as another way of pointing programs toward the PROW standards. In addition, the Association of Immunization Managers (AIM) collaborating with the CDC and AIRA began the development of indicators that show how IIS data can be used to help evaluate the performance of an immunization program. The format of the PROW standards has even become a model template for state and regional registries working to develop and organize best practices such as the California SIIS PROW training standards.

By means of conference calls, discussions, presentations, online surveys and other communication methods, the PROW standards of excellence have been marketed to immunization program and registry managers and other public health staff to highlight the role of registry data, as well as application features and functions, to enhance their program activities and accountability.

In early 2005, the PROW Standards of Excellence Utilization Survey was conducted by AIRA in collaboration with AIM to identify IIS projects that were using the PROW standards and IIS projects that were not but were interested in starting the process. This survey was administered online to all immunization program managers and immunization registry managers.

There were seventeen (17) respondents to the survey. Ten respondents indicated that they had already conducted a PROW assessment of their project and have implemented some of the PROW standards. These respondents were then asked to give one or two examples of using the data and functionality of their IIS to enhance their immunization program. These included:

- *Use of the vaccine management inventory function in conjunction with VFC eligibility to complete provider profiles.*
- *CASA exports for AFIX and VFC accountability reports.*
- *Utilizing registry data for an auto-dialer reminder/recall system.*
- *Using registry data to supplement provider reported information on the National Immunization Survey.*
- *Providing registry data to WIC sites.*
- *Providing consumer access to immunization records for school and daycare enrollment.*
- *Expanding participation in the registry to local school districts.*
- *Vaccine management: vaccine usage, inventory, identifying lot numbers due to expire, doses administered, etc.*

The remaining seven (7) respondents indicated an interest in implementing PROW this year. All of these respondents were eager to participate in conference calls sponsored by AIRA to support and mentor these projects as they began their PROW implementation.

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New Mexico, Philadelphia, San Antonio, and South Dakota) reported that >95% of private provider vaccination sites submitted immunization data to an IIS.

The IIS Annual Report analysis also included data on IIS linkages with other public health programs and private entities. Linkages are defined as connecting information between other health information systems and programs. IIS linkages provide health information to immunization programs for decision-making by creating timely, accurate, and complete vaccination coverage histories. A significant number of grantees reported a variety of linkages with the IIS. In 2004, grantee IIS reported sharing data electronically with a Medicaid Management Information System (39%); Special Supplemental Nutrition Program for Women, Infants, and Children (73%); Managed Care Organizations (50%); colleges and universities (32%); correctional facilities (38%); hospitals (54%); and long-term care facilities (9%)

Even though IIS have made progress enrolling children and health-care providers in their systems, such small percentage increases indicate that several grantees must overcome substantial challenges to meet the national health objective. As a result, CDC has developed a plan of action to address those challenges to meet the national health objective. Major components of the plan include, but are not limited to, a multi-year IIS business plan for each grantee and enhanced technical assistance to grantees with unresolved challenges. Implementation of CDC's plan of action is designed to support or enhance a grantee's IIS functionality and use with the goal of developing a national network of IIS, which are: 1) more comprehensive in geographic area participation and coverage levels; 2) interoperable with other public health and clinical information systems; and 3) able to generate data to support all aspects of immunization program operations at national, state, and local levels. For more information on the 2004 IIS progress report and CDC's implementation plan, please visit our website at http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5445a3.htm.

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IIS PROVIDE VALUABLE DATA FOR LOUISIANA RESIDENTS DISPLACED BY HURRICANE KATRINA

Ina Kichen, Research and Development Manager, AIRA

Hurricane Katrina forced the relocation of thousands of children from Louisiana to other states just as the 2005-2006 school year was starting. These children and thousands of adults had to flee their homes without any possessions, least of all written documentation of their immunization status. The Louisiana Immunization Network for Kids Statewide (LINKS) and state and regional immunization information systems (IIS) around the country came to the rescue.

Within hours of Louisiana residents arriving in Texas, the Houston-Harris County Immunization Registry was able to connect to the LINKS system in Louisiana and pull up immunization information for people that ended up in Houston. This was the start of a nationwide mobilization to give access to the immunization records of people from the hurricane stricken areas of Louisiana no matter where they ended up. Every day more state and regional immunization registries around the country began working with the Louisiana system vendor Scientific Technologies Corporation (STC) to establish data sharing with LINKS.

Once data sharing agreements were signed and IIS staff trained, data sharing was enabled. The functionality that was already built into registries allowed this to happen quickly and easily. Nine registries were able to use HL7 standards to gain direct access to the data in the LINKS system. Another 52 registries had look-up access to LINKS. As of November 14, 2005, over 41,000 patient records have been found in the Louisiana registry.

The impact of having access to accurate immunization information was immense. It meant that schools could get up-to-date immunization records of new students, enabling these children to enter school without delay. It also ensured that children and adults could avoid receiving unnecessary immunizations, saving public health departments thousands of dollars.

The issues surrounding data exchange was a constant theme that surfaced in all the AIRA surveys and assessments. Whether it was providers' concerns about privacy and confidentiality that proved itself a barrier to their participation in immunization registries or the need for education on implementing data exchange standards, data exchange is a hot topic. And the incredible story of how IIS around the country rose to the challenge in the aftermath of Hurricane Katrina speaks to just how important this topic is.

IMPROVING IMMUNIZATION INFORMATION SYSTEMS TOPIC BY TOPIC

Warren Williams, Lead Public Health Analyst
CDC/NIP/Immunization Registry Support Branch

Thomas Moss, Georgia Immunization Registry Manager
Georgia Immunization Program

In April 2005, AIRA's Modeling of Immunization Registry Operations Workgroup (MIROW) Steering Committee conducted an assessment within the immunization registry community to learn which registry functional components were problematic to deploy and could benefit from collective guidance. The overall goal of this effort is to develop (topic-by-topic) an IIS "Best Practice" guidebook for operationalizing registry functionality. Topic chapters will have a mixture of descriptive textual reference materials as well as visual schematics (diagrams) and business rules.

If you were one of the 49 respondents who filled out an assessment conducted by MIROW, we want to say, "Thank you!" More than one hundred individual issues were submitted. These issues were stratified between categories of similar topics. Subsequently, individual topics were examined on the basis of benefit to the registry community, practicality of achieving results, and resources allocation (if other groups were addressing certain topics). Through careful discussions and considerations, the first topic selected to produce a guideline on was the management of the Moved or Gone Elsewhere (MOGE) status and its overlap with reminder/recall and coverage assessment activities.

The charge to the working group was to bring consistency to the use of the MOGE status that providers and registries were using as a basis for various coverage assessment and operational functions (e.g., sending reminder/recall notices). As the workgroup progressed through its charge, it became clear that the issue of the use of the MOGE status was actually part of a much larger discussion of "client status" in general. The MOGE issue and many of these associated components were targeted for analysis. A panel of fifteen subject matter experts met in a face-to-face meeting August 16-18, 2005 in Atlanta, GA, for intense facilitated sessions to derive these guidelines. Since that meeting, the group has been working to refine and finalize the meeting materials into a guideline chapter. The working title of the document is "Management of Moved or Gone Elsewhere (MOGE) and other Patient Immunization Statuses in Immunization Information Systems". The committee has produced a solid document that has already gone through external review and will be made available to IIS projects in 2006.

The next topic to be tackled will be determined from the priority ranking of topic areas identified from the assessment. Some possibilities include: linkage to internal and external systems, deduplication, reminder/recall, forecasting and integrating ACIP schedule changes, and registry rollout. These chapters will be added or revised over time and as resources permit. We look forward to the challenge and to your input as potential subject matter experts.

PROVIDER PARTICIPATION IN IIS: TURNING BARRIERS INTO SOLUTIONS

Sherry Riddick, Immunization Registry Manager
CHILD Profile, Washington State

A key activity for 2004-2005 of the AIRA Provider Participation Committee was to develop a survey to identify IIS projects that had successfully overcome any of the most significant barriers to private provider participation in immunization registries and to document their best practices and successful strategies related to these barriers.

The *Barriers to Provider Participation Survey* process was implemented in two phases. Phase I was an online survey directed to immunization registry staff and immunization program staff to determine the significance of 32 previously identified barriers to provider participation and to identify projects that had successfully overcome these barriers. Phase II followed up with identified projects by asking them to fill out a template designed to document their *best practice strategies*.

Phase I – Online Survey

There were 55 survey respondents from 26 states. The results of the survey showed that while all 32 barriers listed had been encountered, some of them clearly had more impact than others. These were:

1. *Cost and/or time of dual data entry.*
2. *Providers are just too busy to consider one more new procedure.*
3. *Cost and/or time of entering and retrieving data from the registry.*
4. *Perceived difficulty in integrating new procedures into their existing business practice and work flow.*
5. *Cost and/or time of training staff to participate in registry.*
6. *Interfacing with other systems.*
7. *Resistance to change in their office environment.*
8. *Vendors for such systems as EMR and billing systems are sometimes difficult to work with or too expensive to create data downloads.*
9. *Concerns about privacy, confidentiality and HIPAA.*
10. *Coordination required between clinical, administrative and information systems departments.*
11. *Provider does not see any value to their practice of the new information they can get from the registry.*

Phase II – Solicitation of Best Practices

Respondents who indicated they had successfully addressed any of the 11 barriers listed above were sent a template to aid them in documenting their strategies. This resulted in 18 completed templates. Added to these were three documents submitted to AIRA's Provider Participation Committee over the past two years that qualified as a best practice.

The documents were evaluated by the committee against a previously established definition of a "best practice." The committee determined that not all of the "best practices" submitted met the set of criteria in the definition and so a second category was added for those strategies that did not meet the bar for being measurable and replicable but were successful in a particular program. These were designated as successful strategies and are defined as "any intervention that led to success in provider recruitment and participation."

The list of barriers was collapsed to six to allow for overlap. Using the revised list of barriers and the added category of "successful strategies," the committee's evaluation of all the submitted documents resulted in the following:

- *Ten (10) submissions were determined to qualify as "best practices."*

INSTITUTE HELPS PUBLIC HEALTH LEVERAGE THE POWER OF INFORMATION SYSTEMS

Terry Hastings, Communications Director
Public Health Informatics Institute

Hurricane Katrina's aftermath has shone a spotlight on the importance of having ready access to critical health information, such as immunization records for children and medication records for adults. This natural disaster also highlighted the need to reduce the time between recognition of a problem and an effective response to save lives and reduce suffering.

While responding to emergencies, public health must continue to pursue its traditional mission and conduct its core activities, such as immunizing children, monitoring newborn screening results, and addressing chronic health problems such as obesity and asthma. Public health is also channeling resources to prepare communities against threats such as pandemic flu and bioterrorism. Addressing these growing public health problems will increasingly rely on innovations and expertise in the field of public health informatics.

The Institute Approach

The Public Health Informatics Institute (the Institute) is dedicated to advancing public health practitioners' ability to strategically apply and manage information systems. The Institute's strategic approach puts the logical before the physical. Customers are engaged in responding to a series of questions to develop a deep, shared understanding among all stakeholders about the health problem to be solved and how information systems can help. *How can information systems infrastructure improve health outcomes? How does the work get done? What are the requirements for the system? How will success be measured?*

The Institute works intensively with health agency staff to understand diverse stakeholder perspectives and information needs, jointly analyze business processes and task flow, and facilitate the development of requirements and logical design specifications – *before* technology decisions are made. The performance of the system is then evaluated to answer the bottom-line question: *Does it make a difference?*

This collaborative approach is the common thread running through all Institute projects as it helps public health agencies address information systems in a wide variety of areas, including child health information systems integration, health information exchange, childhood obesity information, immunization registries, and local public health information systems.

***Connections* Community of Practice**

A good example of collaboration is *Connections,* a community of practice in which the Institute provides technical assistance and facilitates peer-to-peer knowledge sharing and problem solving among its 18 participating public health agencies throughout the country. *Connections* assists its members and other public health agencies with strategies and planning for

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PROVIDER PARTICIPATION IN IIS: Continued

- *Another seven (7) were examples of "successful strategies."*
- *One (1) was determined to be a "lesson learned."*
- *Three (3) were noted as potentially successful but needing more information.*
- *There was at least one best practice for each of the barriers except #7.*

Examples of Best Practices and Successful Strategies

Barrier #1: Cost and/or time of data entry and retrieval

Include assessment of private practice needs in requirements analysis before development of registry and periodically thereafter.

Use focus groups representing target participants to gather crucial information about attitudes and thoughts related to immunization registries.

Barrier #2: Practices are too busy to consider a new procedure and anticipate difficulty integrating registry use into business processes

Cultivate trust and partnership with health care community to understand their needs and concerns, building relationships with professional associations, such as AAP, and recruiting influential practices early.

Develop a communication plan that includes newsletters and other tools that feature providers who have successfully integrated the on-line registry into their workflow.

Barrier #3: Cost and/or time to train staff to participate in registry, including clinic staff turnover

Plan for staff turnover in the practices—be ready to provide training to new staff.

Have CD-ROM or on-line video that educates staff about value of using the registry.

Barrier #4: Issues related to interfacing with EMR, PMS, billing systems, including working with vendors and cost to providers

Work with billing/PMS/EMR vendors on behalf of a group of clinics to negotiate for development of export or interface and to get discounted rates.

Provide registry staff liaison as point person with vendors and providers.

Barrier #5: Concerns about privacy, confidentiality, and HIPAA

Design a parent notification system to inform parents about the registry and their child's inclusion (depending on state law).

Analyze the HIPAA Privacy Rule in relation to the registry's HIPAA status, having explanatory hand-outs available to practices.

Barrier #6: Provider does not see any value to their practice

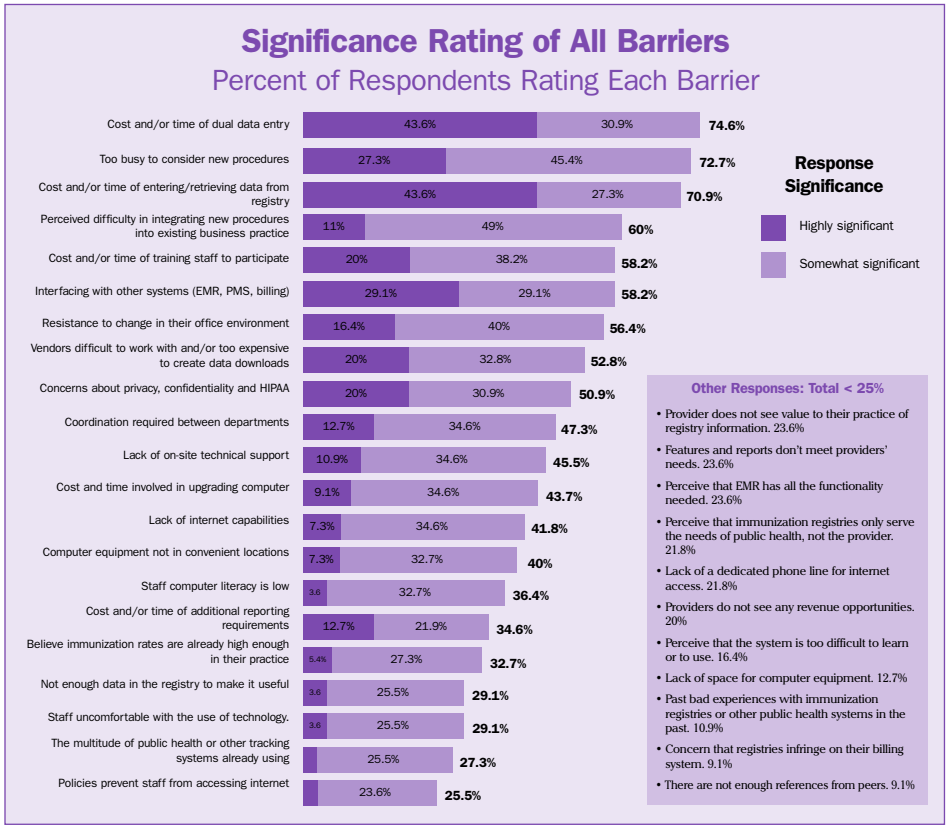
Ensure stakeholder and user involvement in developing the technical requirements as well as the marketing approach and messages

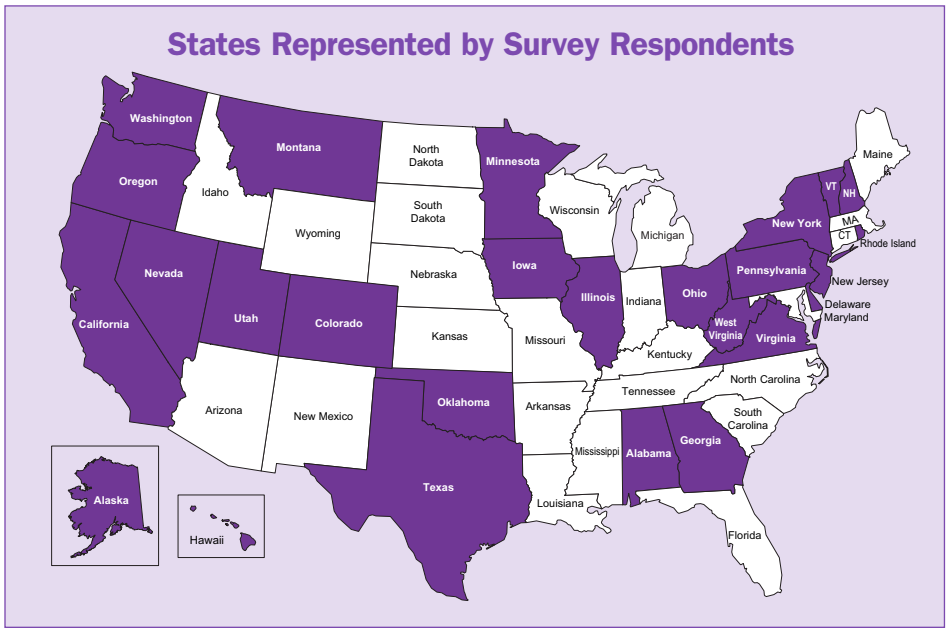
Use focus groups representing target participants to gather crucial information about attitudes and thoughts related to immunization registries.

Conclusions

It was clear to members of the AIRA Provider Participation committee that the extent to which the barriers to provider participation continue to impact coverage rates for IIS will ultimately determine how effective IIS will be in reaching the 2010 Healthy People objective for immunization. Some recommends are: Conduct cost research and evaluation studies, develop plans for IIS interoperability with EMRs, and develop resource tools and guidance documents

PROVIDER PARTICIPATION IN IIS: Continued





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integrating information systems essential to improving the health of children.

Connections also advances the body of knowledge about public health informatics by drawing lessons learned and best practices from agencies that are actively involved in building and integrating health information systems. Through community of practice members' interactions, participants share their experience and avoid "reinventing the wheel" every time they tackle new challenges. *Connections* workgroups also develop useful tools such as the *Unique Records Portfolio,* a guidebook and questionnaire for technical managers and program executives who want to explore the various approaches and planning options for records deduplication. The *Portfolio* will be available in early 2006.

Connections is supported through a cooperative agreement from the Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA/MCHB). The work produced by *Connections* complements other HRSA/MCHB-supported Institute projects, such as the *Framework for Integrated Child Health Information Systems,* which includes principles, core functions, and performance measures, and its companion *Self-Assessment Checklist for Integrated Child Health Information Systems.* The Institute is also working on the business case for integrated child heath information systems.

InformationLinks

Beginning in January, the Institute will provide technical assistance to the 21 grantees of *InformationLinks,* a new Robert Wood Johnson Foundation program. The grants support the participation of state and local public health agencies in health information exchanges. The program is designed as a one-time, short-term stimulus to catalyze and facilitate greater participation by public health agencies in health information exchanges.

The Institute will facilitate a community of practice to connect grantees with their peers and provide opportunities for them to learn from one another's experiences and share their knowledge. Institute staff will also provide support around issues that are likely to emerge, such as engaging health care agencies' executive sponsorship, navigating the organizational and legal issues of health information exchanges, and understanding and articulating the value of bringing public health into the health information exchange.

For more information, including a complete list of grantees, visit: www.phii.org/RWJFgrant.html.

The Public Health Informatics Institute envisions a future in which public health increasingly shares information that improves the health of the communities they serve. For more information on the Institute and its programs, visit www.phii.org.

PROMOTING IMMUNIZATION INFORMATION SYSTEM DATA USE AND DATA QUALITY: THE CDC/NIP IMMUNIZATION INFORMATION SYSTEM SENTINEL SITE PROJECT

Diana L. Bartlett, Health Scientist
CDC/NIP/Immunization Registry Support Branch

The Centers for Disease Control and Prevention's National Immunization Program (NIP) coordinates an immunization information system sentinel site project that promotes the population-based analysis of immunization information system (IIS) data for assessment, surveillance, and immunization program evaluation. To increase IIS data reliability and data use for immunization program activities, sentinel sites have received supplemental immunization grant funds to maintain high data quality and to dedicate staff to analyze IIS data on a routine basis for state programmatic decisions, as well as NIP queries.

Every quarter, participants in this project, Arizona, the District of Columbia, Michigan, Minnesota, Montana and Oregon, report their vaccination coverage levels for routine childhood vaccinations for children of 7, 13, 19, 24, and 19-35 months of age who reside in their sentinel site study area. IIS-based estimates for childhood vaccination series are compared with the most recently released estimates of the National Immunization Survey (NIS). The latest data collected from these sites for vaccinations administered as of August 15, 2005, revealed that two of the six sites produced vaccination coverage levels for the 4:3:1:3:3[1] and 4:3:1:3:3:1[2] vaccination series that were either within the estimated confidence intervals of the NIS or within 3 percentage points of the NIS lower confidence interval estimate. Other sites were 10-15 percentage points below the NIS lower confidence interval estimate. Although sentinel sites have data quality protocols in place and >90% of public and private provider participation in their study areas, the issues of completeness and timeliness of data still influence the IIS-based estimates. Site estimates also may not directly correlate to NIS estimates because the areas targeted by the sentinel site may not directly correlate with NIS geographic areas. This may

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AIRA EDUCATION SURVEY

Cheryl Stephens, Executive Director
Community Health Information Collaborative
Cindy Sutliff, Executive Director
American Immunization Registry Association

The AIRA Education Survey was developed in the fall of 2004 and administered in February 2005. The purpose of the survey was to identify the education and training needs of the AIRA membership with a focus on IZ registry managers and staff. It was distributed to 160 people and included IZ program and registry managers, AIRA vendor members and partner organization members. Sixty-two individuals responded to the questionnaire representing a 39% response rate. Of the 62 respondents, 54 identified themselves as public health agency staff, two (2) as vendors and six (6) as other: non-profit hospital, public health contractor, private non-profit and/or consultant to public health. On average, respondents said they spent approximately 72% of their time on registry related activities. The following summarizes key survey findings.

Education/Training Topics

The education/training content identified as most needed by survey respondents is in the areas of data quality, funding, integration and data use, defined as:

- ***Data quality:*** *Ensuring complete and accurate data both coming into and residing within the registry, with a minimum of duplicate records or incorrectly merged records.*
- ***Funding:*** *Ensuring stable resources for operating your registry.*
- ***Data use:*** *Relying on data from the registry for coverage and other types of assessment, as well as to meet other immunization program purposes.*
- ***Integration:*** *Merging or linking registry data to other public health information systems with information on the same individuals.*

Within each of these areas, specific issues surfaced as high priority areas. They included:

- ***Data quality:*** *accuracy, deduplication, completeness*
- ***Funding:*** *sustainability*
- ***Data use:*** *assessment reports, WIC, AFIX and vaccine inventory management*
- ***Integration:*** *data exchange (EMRs, health plans, WIC, schools), HL7, PHIN*

Other topic areas that emerged as important to respondents of this survey include: provider relations-recruiting, training and supporting providers; technical capacity-hardware, software and infrastructure components of a registry and privacy & confidentiality as it relates to protecting the data in a registry from unauthorized disclosure and uses.

Preferred Education/Training Methods

Based on the results obtained by the survey, the most preferred education/training methods are web-based interactive forums (61% of respondents rated this as most preferred) and face-to-face workshops (50%). Conferences were identified as the third most preferred method (48%) and in-house training fourth with 46% ranking it as most preferred.

Education/Training Content Development

The education, training and material needs identified through the survey process should be developed by subject matter experts within CDC/NIP, AIRA, ECBT, and other partner organizations. Programs should be diverse and include both web-based interactive events as well as face-to-face events such as workshops, summits, think tanks and conferences. Materials should be in multiple formats such as web-based, print, and electronic media. Efforts should be made to identify IIS programs that have successfully addressed some of these education challenges and are willing to share their strategies.

Education/Training Delivery Development

Some ideas on the delivery of education and training, based on the survey results include the following:

- ***Interactive web-based forums**: Education and training content can be developed and provided through a series of web-based forums. Content can then be made available on the CDC/NIP, AIRA and/or other partner organization web sites, or in CD-ROM format. These programs can be developed and delivered through partnerships and collaborations with other organizations.*
- ***Face-to-face workshops:** Workshops could be held regionally across the nation to maximize participation, reduce travel costs for participants and delivery of educational content. Subject matter experts would provide input as to content and method of instruction.*
- ***Conferences:** Conferences provide a perfect opportunity for transfer of knowledge and experience between IIS programs, dissemination of general interest information and networking. Conferences can also provide opportunities for problem solving and solutions development, action planning, and development of ongoing communities of practice centered around specific learning topics and areas of interest. Other options to conferences might include summits and think tanks.*

Funding

Funds for the development and delivery of the learning activities described can be obtained from a variety of sources: foundations, government partners, corporations, and other non-profit organizations.

Next Step Recommendations

Develop an education and training implementation plan that will include the following key components:

- *Development of strategies for the planning, and development of workshops that can be conducted at conferences and/or regionally.*
- *Development of strategies for the planning and development of web-based forums.*
- *Development of strategies to identify the most appropriate lead organizations for education and training content planning and delivery.*
- *Development of a plan to evaluate all education and training content, methods, and delivery effectiveness.*
- *Establishment of a timeline for implementation.*

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lead to different demographics of the study population. For example, participants specifically chose specific geographic areas of their state/district that contained a population of children with complete vaccination histories and high levels of vaccine provider participation. Populations of children in these projects ranged from 10,500-450,000. Some project participants, such as the District of Columbia, have chosen urban areas with dense populations primarily living below the poverty level, while others have chosen sparsely populated rural areas.

Project participants likewise report quarterly data quality measures such as the number of vaccinations received and processed within 30 days of vaccine administration. Sentinel sites aim to have 90% of vaccine data processed within this duration. For vaccines administered as of August 15, 2005, project participants on average processed 73.2% of vaccines within 30 days. One state reported over 50% of its vaccines processed within 30 days, four states reported over 70% processed, and one state reported that 91% of its vaccines were processed within the 30-day window.

The sentinel sites have used their data in a variety of programmatically useful ways. Within the past 12 months, sentinel sites collaborated with NIP to evaluate pediatric influenza vaccination coverage and vaccination administration practices for the 2003-2004 and 2004-2005 flu seasons. Michigan provided data to evaluate pneumococcal conjugate vaccine practices during the 2004 vaccine shortage and to measure the uptake of the Pediarix vaccine in clinic practice. Sites have also used their data to measure the uptake of MCV4 and Tdap, measure the effectiveness of recall effects for the administration of subpotent pertussis vaccine, and evaluate the Hepatitis A vaccination coverage levels of their American Indian/American Native population. Upcoming data queries will include evaluating the extent of extraimmunization in their study areas.

[1] •4 doses of diphtheria, tetanus toxoids and any acellular pertussis vaccine; •3 doses of poliovirus vaccine; •1 dose of any measles-containing vaccine; •3 doses of Haemophilus influenzae type b (Hib) vaccine; •3 doses of hepatitis B vaccine (4:3:1:3:3)

[2] 4:3:1:3:3 plus •1 dose of varicella vaccine

SURVEY ON DATA EXCHANGE BETWEEN IIS AND MCOs

Ina Kichen, Research and Development Manager, AIRA

In 2003 AIRA and Every Child By Two (ECBT), as a first step in their efforts to promote data exchange between IIS and Managed Care Organizations (MCOs), commonly referred to as Health Plans, developed and administered a survey to determine which IIS (registries) were exchanging data with Health Plans and which were not. AIRA and ECBT were interested in identifying the challenges and barriers that registries encountered in their efforts at this data exchange, and the benefits realized by those registries that were already exchanging data with health plans.

This survey was distributed electronically to all immunization registry managers across the country. AIRA received thirty-eight (38) completed surveys. Of these, fifteen (15) responded that they were involved in data exchange with health plans and twenty-three (23) responded that they were not.

The challenges encountered by registries that were not exchanging data with health plans at that time broke down into two basic categories: technical issues and legal/policy issues.

Nine registries stated that they were just not technically capable of exchanging data with health plans although most said that they were working toward developing that capability.

Eight registries mentioned legal and policy issues as the main reason they were not exchanging data. HIPAA issues and state laws were barriers to this exchange even if the registry was technically capable.

Six registries mentioned other factors as the main reason for their lack of data exchange. These included: there are no health plans in their state; data exchange with health plans is a secondary priority after adding private providers; and a lack of resources.

All of the registries that were already exchanging data with health plans noted benefits to both the registry and the MCO. Benefits to the registry included:

- *Helped establish and maintain good relationships with the health plans.*
- *Improvement of data quality.*
- *Increased enrollment of Medicaid children in registry.*
- *Overall increase in immunizations recorded in registry.*
- *Ability to upload data in batches is time and labor saving for providers.*
- *Increased visibility of registry with private providers.*
- *Health plans help fund the registry.*

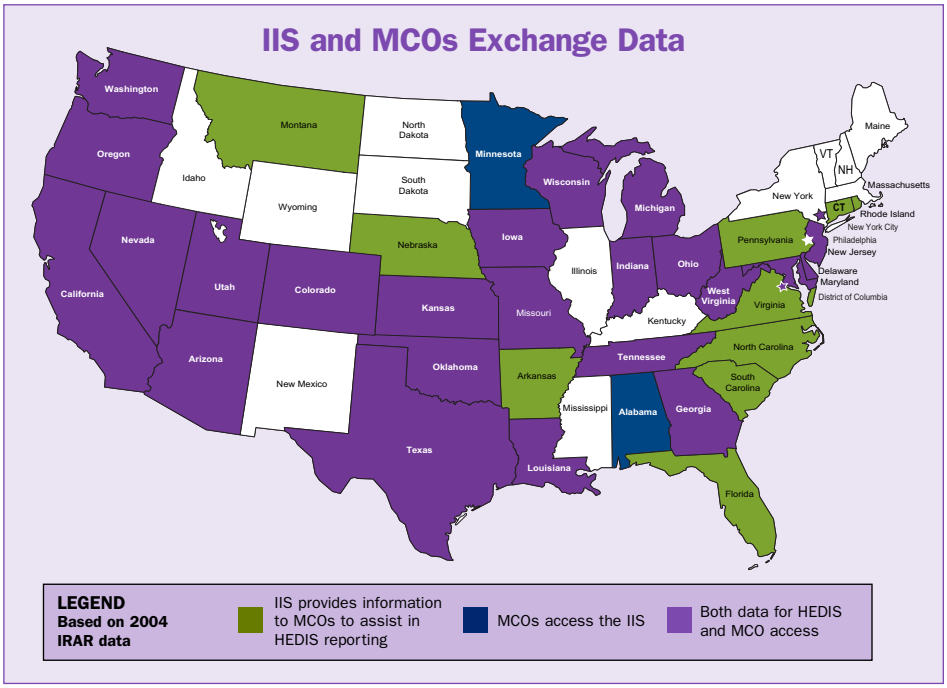
The two most mentioned benefits to health plans were:

- *Registry data helped significantly increase health plans' HEDIS rates.*
- *Data exchange saved the health plans time and money from pulling records and charts.*

Registries also noted challenges in their data exchange with health plans. These included:

- *Technical problems with the data, mostly noted when first establishing data exchange.*
- *Deduplication issues.*
- *Lack of resources to resolve data quality problems.*
- *Developing an information sharing agreement.*

NOTE: The 2004 IRAR (Immunization Registry Annual Report) showed that out of the 61 projects that reported, 30 noted that MCOs access their registry, including six out of the 15 registries that responded to the MCO survey in 2003 stating that they did not exchange data with MCOs. The 2004 IRAR data also showed that 37 projects reported that they supply data to health plans for HEDIS reporting.



IIS RESEARCH AND EVALUATION AGENDA

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Katie Reed, Vice President
Partners In Health Systems

In the summer of 2005, the American Immunization Registry Association (AIRA) and the Centers for Disease Control and Prevention (CDC) partnered with other key stakeholder organizations and individuals to identify and prioritize an Immunization Information System (IIS) research and evaluation agenda. The goal was to utilize the Delphi methodology to develop agenda items determined by IIS subject matter experts. A workgroup was created to ensure stakeholder community representation and development of appropriate survey questions.

Individuals with diverse expertise from national, state, and local organizations were surveyed on their views of the most important IIS research topics and their prioritization. AIRA's web site was used to distribute and collect survey data from participants. After compiling the data, the research and evaluation agenda workgroup determined that a journal article would be the best way to distribute the final research and evaluation agenda. A manuscript should be submitted for publication within the next six months.

Next Steps

AIRA now is in the process of strategically evaluating the results from each of these surveys and assessments, and working collectively with IRSB is developing an integrated Education Plan for implementation. Many clear themes emerged through this process that indicates the need for continued development of appropriate tools for sharing information with the IIS community.

More and more, registries are moving into a stage where the emphasis is not only on data collection but also increasingly on the importance of data use. This brings with it the need to focus resources on such areas as the role of integration and interoperability for IIS. Another critical issue that remains prominent, even as the IIS community continues to evolve, is the role the private provider plays in its overall success. The need to stay current with the topics of the provider's environment as they continue to participate and support IIS development is critical.

As immunization information systems mature, the complexity of issues the IIS community faces increases, and the IIS community itself becomes more sophisticated. AIRA looks forward to helping facilitate these discussions by providing education and information sharing tools that ensure the IIS community stands in front of the move for Public Health Information Technology advancement and that leads us to the achievement of the HP 2010 objective and beyond!

DISCLAIMER

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AIRA AMERICAN IMMUNIZATION REGISTRY ASSOCIATION

IMMUNIZATION INFORMATION SYSTEMS FOR A NEW ERA

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Arizona State Department of Health Services, Immunization Program
California Department of Health Services, Immunization Branch
CHILD Profile Immunization Registry (WA)
Colorado Immunization Information System
EDS – (Wisconsin Immunization Registry)
Hawaii Department of Health, Immunization Branch
Idaho Immunization Program
Illinois Department of Public Health
ImmuLink Immunization Registry, Hennepin County (MN)
Indiana State Department of Health
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