A National Survey of Immunization Programs Regarding Immunization Information Systems Data Sharing and Use

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Objective: To determine and characterize practices regarding data sharing and usage (particularly for research) in immunization information systems (IISs), as well as barriers to using such data for research. **Design:** We surveyed immunization program managers (IPMs) associated with all 64 Centers for Disease Control and Prevention grantee immunization programs (IPs) between July and September 2012. **Results:** More than 95% of IPMs (61/64) responded. The top 2 barriers reported by IPMs to using IIS data for research were insufficient time and too few employees, irrespective of whether or not the jurisdiction reported using data for research purposes. Those IPMs who agreed with the statement "Research is part of the mission of an immunization program" were more likely to report using data for research ($P = .045$). Among those who responded, the most common kind of IIS research conducted involved determinants of vaccination coverage (n = 24/26; 92%). A greater percentage of IPMs in jurisdictions that reported using IIS data for research reported having data-sharing agreements in place. Those IPs that have used IIS data for research were more likely to report online IIS provider enrollment, integration with insurance company records, and integration with hospital records. Alternatively, IPs that did not report using IIS data for research were more likely to have IISs with modules addressing topics such as adverse event reporting, smallpox, and first-responder vaccination. **Conclusion:** Staff size and time were the 2 most cited barriers to conducting research with IIS data. Therefore, focus should also be placed on providing IPs with the resources needed to conduct such research.

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Immunization information systems (IISs) are "confidential, computerized, population-based systems that collect and consolidate vaccination data from vaccination providers and provide important tools for designing and sustaining effective immunization strategies."[1] Currently, IISs have data on 19.5 million children younger than 6 years (86% of the total population younger than 6 years).[1] Recent legislation implemented in states across the country has encouraged practices that increase IIS use, through methods such as mandated reporting or implied consent.[2] Historically, much immunization research has been conducted through registries that were not population based and

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included only people who sought medical care, increasing potential for selection bias.[3] However, population-based IISs have been used for evaluating associations with coverage and coverage rates (including analysis of the impact of policy changes or public health interventions and adverse events), completion of vaccine series, accuracy of coverage estimates, and completeness of data in the IIS.[4] In addition, one public health benefit of using the IIS is improved accuracy in estimating vaccination coverage when compared with parent or provider estimates alone.[5] Because of the structure and integrity of the data, most IISs have enormous potential for research (as defined in the "Methods" section).

To use IIS data effectively for research, it is important to ensure that as few data are missing as possible. One way to do this is through data sharing and interoperability with other health departments and vaccine providers.[6] In fact, immunization program managers (IPMs) have previously indicated a desire for immunization data to be better integrated with electronic medical records.[7]

Despite these benefits, IISs may be underutilized with regard to research.[4] To our knowledge, barriers to conducting research with data from IISs have not previously been investigated.[4] Therefore, we conducted a survey of the 64 federally funded immunization programs (IPs) regarding data sharing and data use for IISs.

Methods

Survey development

In March 2012, we conducted a focus group with 9 IPMs, based on a convenience sample, and used results to refine the survey. In July 2012, we surveyed IPMs associated with all 64 Centers for Disease Control and Prevention (CDC) grantee IPs.[8]

We developed the survey as a follow-up to our previous IPM surveys and in collaboration with the Association of Immunization Managers (AIM) research subcommittee. The overall purpose of the study was to understand changes to IPs as a result of the 2009 H1N1 vaccination campaign and how to be better prepared for vaccine shortages and other public health emergencies in the future. The final survey contained a total of 39 questions, 17 of which focused on IISs—the focus of this analysis. The full survey is available online at http://web1.sph.emory.edu/PHSR/Emory_PERRC/documents/Emory%20PERRC%202012%20IPM%20Survey.pdf.[9] Respondents were able to complete the survey by mailing or faxing the paper copy of the survey or completing it online.

Survey implementation

We sent a presurvey fax to the 64 IPMs 1 week prior to the survey kit, and the AIM sent an e-mail notifying IPMs of the impending survey and survey purpose and providing the link for the online version of the survey. In addition to the paper copy of the survey, the mailed survey kit contained a Frequently Asked Questions page that served as the informed consent, a cover letter, an addressed, stamped envelope, a pen, and a signed copy of Dr William Foege's book, *House on Fire*, as thank you gift. We e-mailed all participants to verify receipt of the survey kit, update contact information, and answer any questions they had about the survey. Later, we conducted in-person telephone reminders and the AIM sent personal e-mail reminders. The survey period closed on September 20, 2012.

Definition of research

On the survey, the term "research" was defined explicitly as "an activity that involves a research plan and data analysis to answer a research question intended to contribute to generalizable knowledge."[9] This definition is adapted from the CDC and Office for Human Research Protection definitions of research.[10,11] The CDC defines research as an activity that "develop[s] or contribute[s] to generalizable knowledge to improve public health practice."[10] The Office for Human Research Protection defines research as "a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge."[11]

Analysis

For descriptive analyses, we calculated the overall frequencies as well as frequencies stratified on the basis of response to "Have data from your IIS been used for research purposes?" Those IPMs who reported using data for research were referred to as "IIS research users," and those IPMs who reported not using data for research were referred to as "IIS research nonusers." Denominators for each percentage were calculated using the number of people who responded to each question. The question regarding IPM agreement with the statement that conducting research with IIS data is part of the mission of IPs was originally measured on a Likert scale from "strongly agree" to "strongly disagree." To determine whether agreement with this statement was associated with IIS research use, we dichotomized this variable to groups of strongly agree/agree and neither agree nor disagree/disagree/strongly disagree. When asked whether IPMs had developed programs to improve provider group participation, IPMs could

respond "yes," "no," "this group already largely participates in IIS," and "do not know at this time." For each provider group, we calculated the percentage of IPMs who indicated plans to improve provider participation (after excluding those who indicated that the provider category already largely participated).

The IPMs were asked to report on their IIS functionality with regard to online IIS provider enrollment, vaccine ordering, communicating to providers, identifying high-risk recipients, documenting Vaccines for Children eligibility, reporting adverse events, billing for vaccine, antivirals, and/or other administration fees, transferring vaccine to other states or jurisdictions, geographic information systems (mapping), mass vaccination clinic module, smallpox module, first-responder module, integration with insurance company records, and integration with hospital records. Responses included "this was a functionality before H1N1," "occurred during or after H1N1," "this is planned for the future," and "we do not have plans to add this functionality." Answers were dichotomized into IPs that currently possess each functionality (regardless of whether it was instituted before or after H1N1) and those that do not (regardless of whether or not it is planned for the future).

Participants were asked whether their IIS was HL7 compatible (considered to be a standard for ability to exchange health information), and we used the Fisher exact test to evaluate differences in reported compatibility[12] and IPM opinion regarding research among IIS research users and nonusers. We did not test other associations with research status to be parsimonious with regard to multiple testing. All analyses were conducted with SAS v9.3 (The SAS Institute, Cary, North Carolina).

Qualitative analysis

Answers to qualitative questions were reviewed by 2 investigators, and codebooks were created through consensus. Both investigators coded 100% of each question. Questions with lower than 80% agreement were resolved by a third investigator.

Results

Response

More than 95% of IPMs (61/64) responded. Most surveys were completed online (n = 56; 92%). Forty-three percent of IPMs (26/61) answered yes to the question "Has your IIS been used for research purposes?"

Belief that research is part of an IP's mission

Overall, roughly half of IPMs agreed with the statement "Research is part of the mission of an IP" (n = 33; 54%). The IIS research users were more likely to agree with the statement (68% vs 41%; $P = .045$).

Research being done with data from IISs

Among the 26 IIS research users, 25 reported which groups used IIS data for research; the most commonly reported group was an internal research unit (n = 17; 68%). Also reported were research groups from collaborating organizations (n = 14; 56%), researchers asking for data related to their projects (n = 13; 52%), and finally students needing data for theses or dissertations (n = 8; 32%). Forty-four percent of IIS research users (n = 11/25) responded to a qualitative question regarding which collaborating organizations use IIS data for research. Answers included universities, the CDC, insurance or managed care, and hospitals. Of the 9 IPMs who responded to the qualitative question asking how many full-time employees work in the internal research unit, 5 reported that only 1 employee worked in the unit; other responses included fewer than 1 or more than 1 full-time employee.

For nearly all IIS research users, the research that was conducted involved determinants of vaccination coverage (ie, associations within the population with high- or low-vaccine coverage) (n = 24/26). Nearly one-third of IIS research users (ie, 8/26) reported that data from their IIS have been used to research vaccine effectiveness. One IPM reported that IIS data have been used to address adverse events.

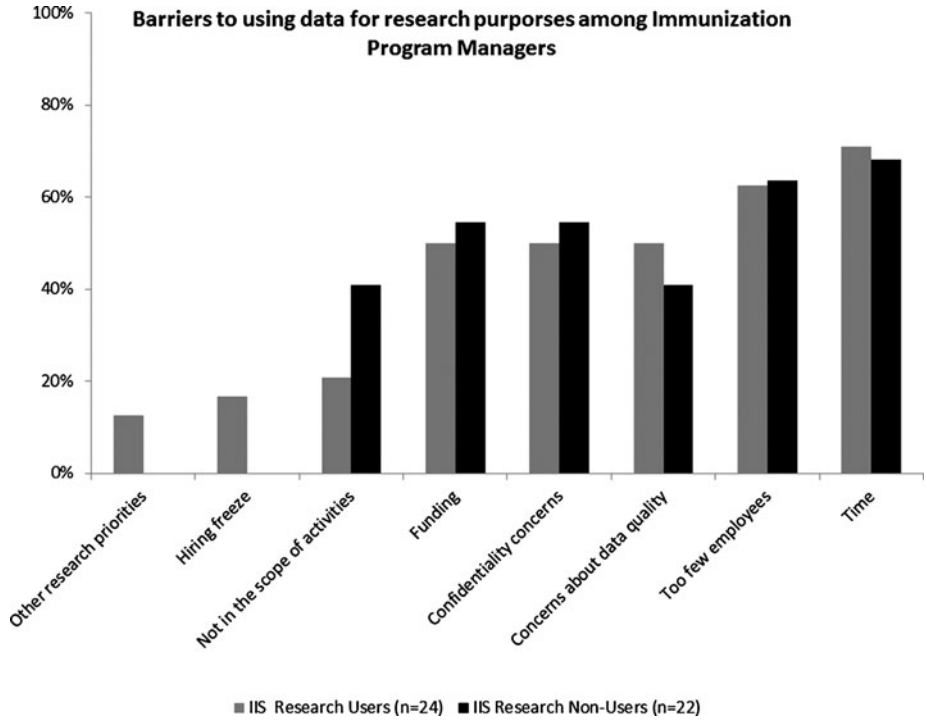
Barriers to using data for research

The 2 most commonly reported barriers to using IIS data for research were time constraints and too few employees, irrespective of research status (Figure). Hiring freezes, other research priorities, and concerns about data quality were reported more often by IIS research users. They also more frequently reported concerns about funding, confidentiality, and scope of activities.

Data entry requirements and provider participation

The IIS research users more frequently reported having plans to improve participation in IIS for each provider type, with the exception of hospitals, community vaccinators, and school-located vaccination clinics (see Supplemental Digital Content Figure 1, available at http://web1.sph.emory.edu/PHSR/Emory_PERRC/Figure2.jpg, which demonstrates plans to improve provider participation among IIS research users and

FIGURE ● Perceived Barriers to Using Data for Research Purposes Among IPMs Who Reported Data Being Used for Research Purposes and Those Who Did Not as Reported in a 2012 Survey of IPMs



Abbreviation: IPM, immunization program manager.

nonusers). Plans to improve pediatrician participation were indicated most often, regardless of research status. Of all provider types, the IIS research users were least likely to indicate plans to improve IIS participation among school-located vaccination clinics and the IIS research nonusers were least likely to indicate plans to improve IIS participation among medical specialists.

Data-sharing agreements

The IPMs were asked what would need to be done to obtain IIS data for research. Compared with research nonusers, a greater percentage of IIS research users reported data-sharing agreements with all institutions asked about: health departments, other agencies, schools, patients, pharmacies, online electronic health records, health maintenance organization/insurance/medical billing, health information exchanges, physician practices, higher education institutions, and "other" (Table). The IIS research users were most likely to have sharing agreements with physician practices (74%) and least likely to share data with patients (18%) (vs 48% and 5% for research nonusers).

Of the IPMs indicating what criteria must be met for data sharing (n = 27/61), the top answers included a signed agreement (n = 11) and registration (n = 10). Other responses included restriction to specific groups of people (n = 5), HL7 compatibility requirements (n = 5), read-only access (n = 2), signed patient consent (n = 2), and restriction based on state law (n = 1).

Of the IPMs who described the top 3 barriers preventing IIS data from being shared with other health departments (42/61; 69%), the predominant themes were information technology (n = 22), followed by data sharing agreements (n = 9) and state law (n = 8).

Functionality and HL7 compatibility

The functionality reported least was billing for vaccine, antivirals, and/or administration fees (n = 5/58). The top 2 reported functionalities in both groups were communication to providers (n = 49/59) and documenting eligibility for the Vaccines for Children program (n = 49/58). The IIS research users were more likely to report online IIS provider enrollment (58% vs 39%), integration with insurance company records (31% vs 10%), and integration with hospital records (50% vs 32%). The IIS research nonusers were more likely to report being able to use their IIS for reporting adverse events (61% vs 46%), smallpox modules (35% vs 23%), and first-responder modules (35% vs 12%).

Both IIS research users and nonusers had a high percentage of reported HL7 compatibility (n = 25/26, 96%,

TABLE ● Data-Sharing Agreement Practices Among Immunization Programs[a]

Data-Sharing Practices	IIS Research Users (n = 23),[b] n (%)	IIS Research Nonusers (n = 21), n (%)
Health departments		
Sharing agreement	15 (65)	10 (47)
Bidirectional sharing permitted	9 (39)	8 (38)
Other agencies		
Sharing agreement	16 (69)	10 (47)
Bidirectional sharing permitted	3 (13)	6 (28)
Schools		
Sharing agreement	14 (60)	9 (42)
Bidirectional sharing permitted	3 (13)	4 (19)
Patients		
Sharing agreement	4 (17)	1 (4)
Bidirectional sharing permitted	1 (4)	0 (0)
Pharmacies		
Sharing agreement	11 (47)	6 (28)
Bidirectional sharing permitted	4 (17)	3 (14)
Online EHRs		
Sharing agreement	16 (69)	6 (28)
Bidirectional sharing permitted	9 (39)	7 (33)
HMO/insurance/medical billing		
Sharing agreement	13 (56)	3 (14)
Bidirectional sharing permitted	9 (39)	1 (4)
Health information exchanges		
Sharing agreement	10 (43)	5 (23)
Bidirectional sharing permitted	5 (21)	5 (23)
Physician practices		
Sharing agreement	17 (73)	10 (47)
Bidirectional sharing permitted	9 (39)	8 (38)
Higher education institutions		
Sharing agreement	12 (52)	2 (9)
Bidirectional sharing permitted	2 (8)	2 (9)
Other		
Sharing agreement	2 (8)	1 (4)
Bidirectional sharing permitted	2 (8)	1 (4)

Abbreviations: EHR, electronic health record; HMO, health maintenance organization; IIS, immunization information system; IPM, immunization program manager.
[a]Data from immunization programs that used data for research and those that did not as reported in a 2012 survey of IPMs.
[b]Not all IPMs responded to every question. n reflects the number of IPMs who respond to each particular question.

and n = 27/31, 87%, respectively). Although the IIS research users were more likely to report such compatibility, this difference was not significant ($P = .236$). With regard to software, IIS research users were more similar, with 63% of their responses being Oracle or the Wisconsin Immunization Registry. The IIS research nonusers appeared to be more varied, with the top 2 reported software categories, Oracle and WebIZ, accounting for only 36% of the total responses for that group.

● Discussion

Despite various benefits to using IIS data for research, they seem to be underutilized in this area.[4] In fact, in this study, only about half of IPMs reported having used IIS data for research. Prior to this study, barriers to using IIS data for research and associations between IPs and the use of IIS data for research had not been investigated.[4]

The IIS research users were more likely to allow for online provider enrollment and integrate with hospital and insurance records. Alternatively, the IIS research nonusers were more likely to report IIS functionality that allowed adverse event reporting, smallpox modules, and first-responder modules. This may indicate a focus on functionalities that promote IIS data completeness among research users, rather than emergency preparedness, and data completeness is important for conducting research because more complete data may be less subject to bias. The IIS research users reported a greater percentage of data-sharing agreements with every institution we asked about, which also shows a focus on data completeness. In addition, the IIS research users were more likely to report concerns with data quality as a barrier to conducting research whereas the IIS research nonusers were more likely to report that using data in this manner was not in the scope of their activities.

The top 2 reported barriers to conducting research for both IIS research users and nonusers were too few employees and time constraints. Recent budget cuts and layoffs have reduced the overall capacity of many health departments and may disproportionately affect their ability to function outside of their perceived mission.[13] It is possible that IPMs who believe that research is a part of their mission are more likely to focus the time and resources they have on data sharing and data completeness. For example, most of the research being done appears to be conducted by internal research units, which may relate to the view that research is part of their mission.

Most of the research conducted using IIS data was on determinants of coverage. This is likely because having a discernible goal (eg, targeted intervention)[14] may be the most obvious short-term benefit and may be more likely to be perceived as part of an IP's mission. This is supported by previous findings that IIS research often involves associations with coverage and estimating coverage rates.[4]

The IIS research nonusers were more likely to report functionalities not related to data completeness such as

smallpox modules and first-responder modules (which can be used to make entering and tracking data easier in a public health emergency).[15] IISs have also been found to be useful after hurricanes, floods, and tornadoes, as well as in other public health emergencies such as outbreaks or shortages, when they can be used to monitor vaccine administration.[16,17] However, there is an overlap between the use of IIS for emergency preparedness and data completeness. In fact, the AIM recommends IIS technology enhancements such as HL7 compatibility and data sharing as ways to prepare for future pandemics.[18]

Strengths and Limitations

Actual data usage may differ from reported data usage. Also, although we explicitly defined research to mean "an activity that involves a research plan and data analysis to answer a research question intended to contribute to generalizable knowledge,"[9] it is possible that some IPMs considered certain activities to be programmatic and did not consider such investigations as "research." Also, certain differences, such as how long the IIS has been in place and in-depth information regarding the software and funding, were not analyzed. In addition, since this survey included only IPMs and not IIS managers, it is possible that IPMs did not have an in-depth understanding of IISs. However, IPMs may have a better view of the big picture of IPs and their use of IISs. The very high response rate for this survey limits some sources of bias and provides a representative set of results.

Conclusion

Immunization programs differ in how they use their IISs. Although emergency preparedness and immunization research are both individually important to public health, there can also be overlapping benefits (eg, surveillance). Therefore, efforts to maximize the potential of IISs should take these differences into account and emphasize functionalities that can support both emergency preparedness and completeness of IIS data. In addition, focus should be placed on providing IPs with the resources needed to conduct such research and use IIS data for other purposes. Ideally, IIS could be used for immunization tracking and research, as well as emergency preparedness and response enhancement.[17]

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