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

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Abstract

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By Eileen Curran

Objective: To determine and characterize practices regarding data sharing and usage (particularly for research purposes) in Immunization Information Systems (IIS), as well as barriers to using such data.

Methods: We surveyed immunization program managers (IPMs) associated with all 64 CDC grantee immunization programs between July and September, 2012.

Results: Over 95% of IPMs responded (61/64). The top two 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. 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=0.045). 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. Immunization programs 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, immunization programs that did not report using IIS data for research were more likely to have IIS with modules addressing topics such as adverse event reporting, smallpox, and first responder vaccination.

Conclusion: Staff size and time were the two most cited barriers to conducting research with IIS data. Therefore, focus should also be placed on providing immunization programs with the resources needed to conduct such research.

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Contents

Chapter I: Background/Literature Review

Introduction:

The Centers for Disease Control and Prevention (CDC) defines immunization information systems (IIS) as "confidential, population-based, computerized databases that record all immunization doses administered by participating providers to persons residing within a given geopolitical area."(1) Development of IIS largely began in the 1980s but was primarily focused in managed care organizations. Starting in 1993 federal funding was provided for the creation of population-based IIS.(2) By 1999, 61 of the 64 state and local immunization programs were using federal funds to implement these systems, and 84% of all children in the United States under the age of 6 had two or more vaccinations documented in an IIS in 2011.(3)

The use of IIS has been suggested as a way to address the fact that children with multiple healthcare providers are less likely to be up to date with their immunizations.(4, 5) In addition to improved vaccination coverage, there are other important outcomes of IIS use, such as cost savings, generating vaccination recall notices, vaccination reminders, and providing official vaccination history forms for use in meeting school entry immunization requirements.(6)

IIS are especially useful because they provide population-based data and thus are less prone to bias introduced by only including people who are able to seek out medical services, though the extent to which this bias is reduced depends on the completeness of provider participation in the IIS.(7) Such reduction of bias makes IIS data a valuable research tool for creating new immunization schedule recommendations, or monitoring the impact of vaccine shortages.(2, 8)

Compiling such comprehensive data opens novel avenues for research including analyzing immunization accessibility, quality, and disparities.(7) Research into these areas with the accuracy that IIS can provide has the potential to increase vaccination coverage and lower the rate of vaccine preventable diseases, especially in vulnerable populations. In fact, South Carolina law states that the use of IIS "will enable research on the causes, distribution, and prevention of vaccine preventable diseases," and New York law states that IIS data may be used "for the purposes of outreach, quality improvement and vaccine accountability, research, epidemiological studies and disease control."(9, 10) In order to maximize the potential of this powerful tool, it important to determine what type of research is being done with data produced by IIS.

In 2010, the Guide to Community Preventive Services conducted a systematic review of papers published using IIS data. Using the 71 published papers and 123 conference abstracts they found, they concluded that IIS are useful for surveillance and investigation of vaccination rates, provider assessment and feedback, providing vaccine reminders and recalls, assisting during outbreaks of vaccine-preventable diseases , facilitating management of vaccines, and identifying missed opportunities, invalid dose administration, and disparities in coverage.(11) This review included conference abstracts, papers that included data from multiple sites (such as Sentinel Site data) and was not restricted to one country. In addition, this review did not examine the use of IIS data specifically for research purposes. Therefore, though findings from this review are important for understanding the utility of IIS, it does not examine the use of individual IIS associated with the 64immunization programs in the United States for research purposes, and it is possible that the full potential of this powerful tool is not being realized. We examined patterns in the use of individual IIS data for research by reviewing all papers published since 1999 that used IIS data.

Methods:

Literature Search:

We identified published IIS research manuscripts using two systems. First, we searched the CDC IIS publication database(11) for papers published from 1999- July 3, 2012. Next, We searched Pubmed during the period April 9, 2012 to July 3, 2012 using the search terms "(immunization OR vaccination) AND ((Information system*) OR registry)" with results limited to papers written in English and published after January 1, 1999. Titles and abstracts were reviewed for possible IIS data usage for research purposes, and the full article was reviewed for those studies that reported research from an IIS. Papers were included if they described using data from an IIS affiliated with an immunization program registry or a "regional registry" that covered the same geographic area as an IIS affiliated with an immunization program registry.(12) For example, a regional registry that covered Philadelphia was assumed to be the Philadelphia citywide IIS, and was included. However, if a "regional registry" was referred to and the study area differed from that of a federal registry, for example a regional registry that covered Boston, MA, the paper was excluded.(13) Papers were also excluded if they were not from the United States, used a managed care organization, hospital or other IIS. In addition, to see how individual immunization program registries were using their data rather than how it was being used as part of a research consortium, we only included studies that covered the area of one IIS, thereby further excluding analyses reported using National Immunization Survey, the Vaccine Safety Datalink, the CDC Sentinel sites, and other studies that used data from multiple IIS. Our focus for this evaluation was on research activities using IIS data, as defined by an activity that "contribute[s] to generalizable knowledge to improve public health practice," the results of which can be used to benefit a population beyond the scope of the study;(14) therefore papers specifically addressing IIS implementation, methodology, or cost issues were excluded. In accordance with this objective, we excluded gray literature, such as information posted on websites or reports, and only included papers published in journals. The reference lists of the IIS papers we had included were then searched for any additional research manuscripts.

Analysis*:*

For each research manuscript, information on publication date, IIS location, study objective, and author affiliation (e.g. university, health department etc.) was extracted. For papers with more than one author affiliation reported, only the affiliation of the corresponding author was included. The number of times each IIS was used was totaled, as was the total number of publications in each year. Categories for qualitative grouping were created based on study objectives to assess patterns in the type of research being conducted through IIS. The manuscripts were grouped into five main categories: coverage associations and estimate evaluations, policy implementation/change, response to short term vaccine supply issues, reminder/recall, and vaccine effectiveness.

IRB:

Since this was a review and used no human subjects, no IRB approval or informed consent was needed.

Results:

We identified 304 and 884 papers from the CDC IIS publication database and PubMed search results, respectively. No additional new manuscripts were found through reference list review. Following removal of duplicates and applying inclusion and exclusion criteria, 44 papers were available for analysis (Figure 1). (15-58) These 44 manuscripts were produced through research at 18 IIS locations. The most number of manuscripts were affiliated with a university (N=16),(15-30) followed by affiliations with a health department (N=9).(19, 31-

38) Other affiliations included the CDC (N=8),(39-46) a hospital (N=8),(15, 28, 47-50) an HMO (N=1),(51) a consulting service (N=1)(52) and an independent research group (N=1). Data from the Michigan IIS (Michigan Care Improvement Registry) were used to generate 9 manuscripts(15, 27-29, 31, 33, 43, 47, 53) the most from any IIS, followed by Philadelphia (8)(22, 24, 30, 40, 42, 45, 46, 49) and New York City (6)(17, 23, 36, 38, 39, 54) (Table 1). Other than these immunization programs, no IIS produced more than three manuscripts. The number of IIS manuscripts published each year followed an increasing trajectory between 1999 and 2011, with the majority of publications data in the year 2008 or later (Figure 2).

The largest group, was coverage associations and estimate evaluations (N = 22 papers), including 11 describing associations with coverage,(15, 17, 22, 29, 30, 35, 43, 52, 54, 55) 2 estimating coverage rates, (32, 55) 2 evaluating completion vaccine series completion,(20, 51) 3 evaluating the accuracy of coverage estimates from parents(21, 22, 36) and 4 describing the completeness of data in the IIS.(40, 41, 45, 53) The Policy implementation/change category included 11 papers, including one that described the coverage of a new vaccine compared to an older vaccine,(33) one that examined recommended ages,(49) two that examined the impact of a policy change,(26, 42) and 7 that evaluated an intervention.(23-25, 34, 36, 37, 46) Two manuscripts described a response to short term vaccine supply issues, including the impact of an outbreak(35) and a shortage.(43) There were six papers in the reminder/recall group, with three papers evaluating the use of an IIS in a vaccine recall (27, 29, 38) and three evaluating the use of IIS in vaccination reminders.(28, 54, 56) Three papers evaluated vaccine effectiveness,(44, 50, 57) all of which focused on the rotavirus vaccine.

Discussion and Conclusion:

We conducted the first assessment, to our knowledge, on the extent of use of publicly funded IIS in the US for research purposes. While IIS have been in place for many immunization programs for over a decade, there have been relatively few research reports utilizing these data. Additionally, the IIS locations conducting these research studies are limited, with more than half of the published research papers coming from three immunization programs. While IIS have served many purposes to aid public health practice (e.g., reminder/recall systems, generation of immunization reports for school entry, and surveillance for immunization coverage), it appears that we are not currently using IIS to their full potential. On the other hand only 2 manuscripts used data collected after 2009,(15, 21) indicating that there is a lag between when data is collected and when research is published. Therefore, it is possible that now that IIS have matured and include more data they are more useful to researchers and manuscripts using current data will be published in the near future.

The largest groups of studies dealt with factors associated with coverage and evaluation of an intervention. Using IIS to answer these questions not only takes advantage of the reduced bias in the population-based data available with IIS, but also helps with one of the main purposes of IIS; increased coverage. Though IIS are useful for researching factors associated with vaccine coverage, they can also be used for other vaccine-related research, such as vaccine effectiveness, or adverse events. Only one study examined recommended ages for vaccination, and all three of the studies examining vaccine effectiveness focused on rotavirus vaccine (though a study published after the time period covered by this review used IIS data to research influenza vaccine effectiveness, showing that these data are being utilized to study multiple vaccine preventable diseases).(58) There were no studies on adverse events. On the other hand, the systematic review conducted by the Guide to Community Preventive Services found more papers and abstracts than included in this review, so it is possible that research into these areas is being conducted, but did not fit our inclusion criteria (e.g. multi-site research or research done with HMO databases).

There are many barriers to research, including possible issues with data sharing and confidentiality, as well as staffing limitations due to recent cuts in the public health workforce.(59) In addition, it is possible that immunization program staff have other priorities regarding IIS (such as generating vaccination reports or managing vaccines), and are under time constraints. Though IIS have been shown to be useful in immunization research, such barriers may prevent them from being used in this manner. Our results imply that partnerships with academic institutions may be one way to overcome these barriers and use the data from IIS most effectively. Future research is needed to understand these issues. In response to this need we have conducted a survey of Immunization Program Managers and future direction of work includes analysis of possible barriers to research with IIS research and data sharing and usage.

This study has some limitations. It was assumed that regional registries that covered an area different from a federally funded state or local registry. Since regional registries have been known to combine to form what we now consider state or local registries, it is possible that there were some studies used data from regional registries that later joined to become what are now known as the 64 federally funded state and local registries[58] . However, as we were interested in how those immunization programs in particular were using their IIS data, the resulting bias is likely minimal. Only published studies included in the CDC website and PubMed were reviewed. Therefore, it is possible that gray literature or studies that have been completed but not published were missed. On the other hand, most high quality research is published in peer reviewed databases. Our study shows that IIS are not being used to their full potential with regard to research. Since the largest number of studies were affiliated with a university, it is possible that lack of a relationship with a university could be seen as a barrier to research, and immunization programs that want to use the IIS data for research purposes could be advised to seek such a relationship. There are other possible barriers to the use of IIS data, including concerns regarding confidentiality, data quality, and budget constrictions, but further research is needed in this area. Our study highlights the need for future research, both with IIS data itself, and barriers to such research.

Chapter II: Manuscript

Introduction:

Immunization information systems (IIS) 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”.(60) In 1999, 61 out of 64 immunization programs (IPs) supported by funding from the Centers for Disease Control and Prevention (CDC) had implemented their own IIS,(2) and currently IISs have data on10.2 million children less than six years of age (84 % of the total population less than age 6).(60) Recent legislation implemented in states across the country has encouraged practices that increase IIS use, through methods such as mandated reporting or implied consent.(61) As parents and providers have both been found to over-estimate children’s vaccination, one public health benefit of using IIS is improved accuracy in estimating and anticipating vaccination coverage when compared to parent or provider estimates alone.(62)

Because of the structure and integrity of the data, most IISs have enormous potential for research (as defined in methods section). Historically, much immunization research has been conducted through registries that were not population based, and included only people who sought medical care increasiing potential for selection bias.(7)

To use IIS data effectively for research, it is important to ensure as little data are missing as possible. One way to do this is through data sharing and interoperability with other health departments and vaccine providers.(63) Immunization Program Managers (IPMs) have previously indicated a desire for immunization data to be better integrated with electronic medical records.(64).

To our knowledge, barriers to conducting research with data from IISs have not previously been investigated.(65) Therefore, we conducted a survey of the 64 federally funded IPs regarding data sharing and data use for IIS systems.

Methods:

Survey Development

In March 2012, we conducted a focus group with nine IPMs and used results to refine the survey. In July 2012 we surveyed IPMs associated with all 64 CDC grantee IPs.(66)

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 final survey contained a total of 39 questions, 17 of which focused on IISs – the focus of this analysis.(67) 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 pre-survey fax to the 64 IPMs one week prior to the survey kit, and AIM sent an email 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 (FAQ) 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 an incentive. We emailed 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 AIM sent personal email 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.”(67) This definition is adapted from the CDC and Office for Human Research Protection (OHRP) definitions of research.(14, 68) The CDC defines research as an activity which “develop[s] or contribute[s] to generalizable knowledge to improve public health practice.(14) The OHRP defines research as “a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.” (68)

Analysis

For descriptive analyses, we calculated the overall frequencies as well as frequencies stratified based on response to “have data from your IIS been used for research purposes?” IPs that reported using data for research were referred to as “IIS research users” and IPs that reported not using data for research were referred to as “IIS research non-users.” 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 if 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 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 percent of IPMs that indicated plans to improve provider participation (once those that indicated the provider already largely participated had been excluded).

IPMs were asked to report on their IIS functionality with regards to online IIS provider enrollment, vaccine ordering, communicating to providers, identifying high risk recipients, documenting Vaccines For Children (VFC) 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 responders 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).

We used Fisher’s exact test to evaluate differences between HL7 compatibility (considered to be a standard for ability to exchange health information)(69) and IPM opinion regarding research among IIS research users and non-users. 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, N.C.).

Longitudinal analysis

In a previous IPM survey (2010) we asked “during the H1N1 vaccination campaign, was data entry into your state’s Immunization Information System mandatory for providers?”(70) We compared to the question from our current survey: “during or after the H1N1 vaccination campaign, did your state or territory change the law/statute that requires providers to entry data or submit data for direct entry into IIS.” Answers were dichotomized into IPMs who reported requiring data entry and those that did not, and compared with the results from 2010 to determine if more IPs are requiring data entry into IIS, and how many of those who reported mandatory data entry in 2010 also reported this in 2012.

Qualitative analysis

Answers to qualitative questions were reviewed by two 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 responded (61/64). The majority of surveys were completed online (n=56, 92%). Forty-three percent (26/61) reported using IIS for research.

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=17/25, 68%). Also reported were research groups from collaborating organizations (n=14/25, 56%), researchers asking for data related to their projects (n=13/25, 52%) and finally students needing data for theses or dissertations (n=8/25, 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 nine IPMs who responded to the qualitative question asking how many full time employees work in the internal research unit, five reported that only one employee worked in the unit.

For nearly all IIS research users, the research that was conducted involved determinants of vaccination coverage (i.e. associations within the population with high or low vaccine coverage) (n=24/26). Nearly one third (i.e. 8/26) of IIS research users reported 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 two most commonly reported barriers to using IIS data for research were time constraints and too few employees, irrespective of research status (Figure 3). Hiring freezes, other research priorities and concerns about data quality were reported more often by IIS research users. IIS research non-users more frequently reported concerns about funding, confidentiality and scope of activities.

IIS research users were more likely to agree with the statement “research is part of the mission of an immunization program,” (68% vs 41%, p = 0.045).

Data entry requirements and provider participation

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 (Figure 4). Plans to improve pediatrician participation were indicated most often, regardless of research status. IIS research users were least likely to indicate plans to improve IIS participation among school located vaccination clinics. Alternatively, IIS research non-users were least likely to indicate plans to improve IIS participation among medical specialists.

Data sharing agreements

IIS research users were more likely to require submitting to an institutional review board (IRB), submitting to a data use oversight committee specific to IIS, completing technical requirements to obtain data and obtaining publication review or clearance, for both internal and external research (Figure 5). IIS research non-users were more likely to require submitting to a data use oversight committee not specific to IIS, obtaining formal data sharing agreements or fulfilling other requirements. No IPMs reported charging a data use fee for internal research. For external research, IIS research non-users were more likely to require submitting to a data use oversight committee not specific to IIS, and fulfilling other requirements.

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, HMO/insurance/medical billing, health information exchanges, physician practices, higher education institutions, and "other" (Table 2). IIS research users were most likely to have sharing agreements with physician practices (74% and 48%, respectively, for users and non-users) and least likely to share data with patients (18% and 5%, respectively).

Of the IPMs who described the top three barriers preventing IIS data from being shared with other health departments (42/61,69%) the predominant theme was with information technology (IT) (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 two reported functionalities in both groups were communication to providers (n=49/59), and documenting eligibility for the Vaccines for Children program (n=49/58). 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%). Alternatively, IIS research non-users 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 responders modules (35% vs 12%).

In 2010 and in 2012, the same number of IPMs who reported that data entry into IIS was mandatory remained the same, although the percentage was slightly lower (n=26/52 , 50% vs n=26/57, 46%). A total of 39 IPMs reported mandatory data entry in at least one of the years. Of these, one third (n = 13) reported mandatory data entry in each 2010 and 2012, and one third reported mandatory data entry in both 2010 and 2012.

IIS research users and non-users both had a high percentage of reported HL7 compatibility (n=25/26, 96% and n=27/31, 87% , respectively). Though IIS research users were more likely to report such compatibility, this difference was not significant (p=0.236)

IIS research users were more similar in the software they reported using, with 63% of their responses being Oracle or the Wisconsin Immunization Registry (WIR). Alternatively, IIS research non-users appeared to be more varied, with the top two reported software categories, Oracle and WebIZ accounting for only 36% of the total responses for that group.

Discussion:

IIS research non-users were more likely to report IIS functionality that allowed adverse event reporting, smallpox modules, and first responders modules.

Alternatively, IIS research users were more likely to allow for online provider enrollment and to integrate with hospital and insurance records. This may indicate a focus on functionalities that promote IIS data completeness, rather than emergency preparedness , which is important for conducting research as more complete data may be less subject to bias.

The focus on data completeness among IIS research users was also supported by the fact that a greater percentage of IIS research users reported data sharing agreements with every institution we asked about. In addition, IIS research users were more likely to report concerns with data quality as a barrier to conducting research, whereas IIS research non-users were more concerned that using data in this manner was not in the scope of their activities.

The top two reported barriers to conducting research were too few employees, and time constraints. Recent budget cuts and layoffs have reduced many health departments' overall capacity and may disproportionately affect their ability to function outside of their perceived mission.(71) It is possible that IPMs who believe 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 the their mission. Most of the research conducted using IIS data was on determinants of coverage.

This is likely because having a discernible goal (e.g. targeted intervention) (2) may be the most obvious short-term benefit, and may be more likely to be perceived as part of an IP's mission.

IIS research non-users were more likely to report functionalities not related to data completeness such as smallpox modules and first responders' modules (which can be used to make entering and tracking data easier in a public health emergency).(72) IIS have also been found to be useful after hurricanes, floods, and torndoes, as well as in other public health emergencies, such as outbreaks or shortages, when they can be used to monitor vaccine administration (73, 74) In fact, AIM recommends IIS technology enhancements such as HL7 compatibility and data sharing as a way to prepare for future pandemics.(75)

Strengths and Limitations

Actual data usage may differ from reported data usage. Also, although we explicitly defined research to mean as "an activity that involves a research plan and data analysis to answer a research question intended to contribute to generalizable knowledge."(67) it is possible that some IPMs considered certain activities to be programmatic, and did not consider such investigations as "research." Our 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 IIS. IIS research users are more likely to focus on data sharing and completeness for IIS data. Alternately, IIS research non-users appear to focus more on other functionalities, such as using their IIS for emergency preparedness. Emergency preparedness and immunization research are both individually important to public health, and there can also be overlapping benefits (e.g. surveillance). Therefore, efforts to maximize the potential of IIS should take these differences into account, and emphasize functionalities important to emergency preparedness among IIS research users and completeness of IIS data among non-research programs. In addition, focus should also be placed on providing immunization programs with the resources needed to both conduct such research and use IIS for other purposes. Ideally IIS could be used for both immunization tracking, research as well as emergency preparedness and response enhancement.(74)

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Figures and Tables:

Figure 1. Research papers published between 1999 and July 3, 2012 utilizing data from immunization information systems, identified through a review of a CDC database [54] and PubMed, with searches conducted between February 13, 2012 and July 3, 2012.

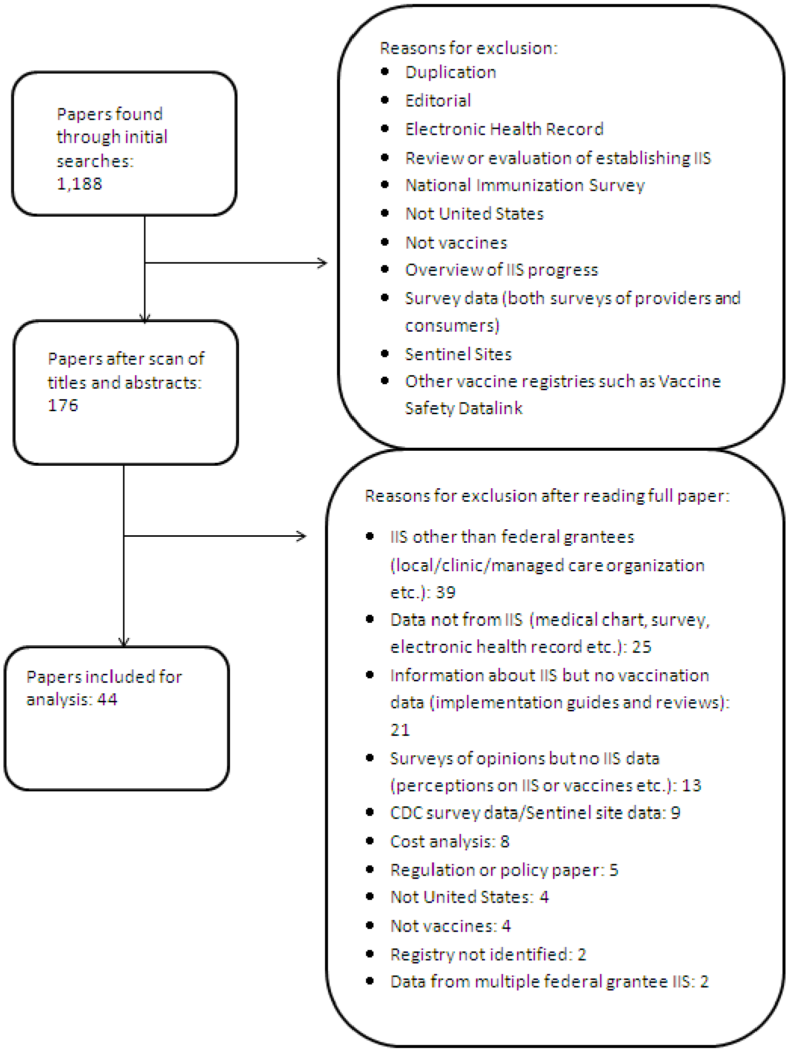

Figure 2. Number of published research papers using data from an immunization information system, by year of publication, 1999-2011 [a].

[a] Note that only January-July was included for 2012, so the three publications from 2012 are not included in this figure

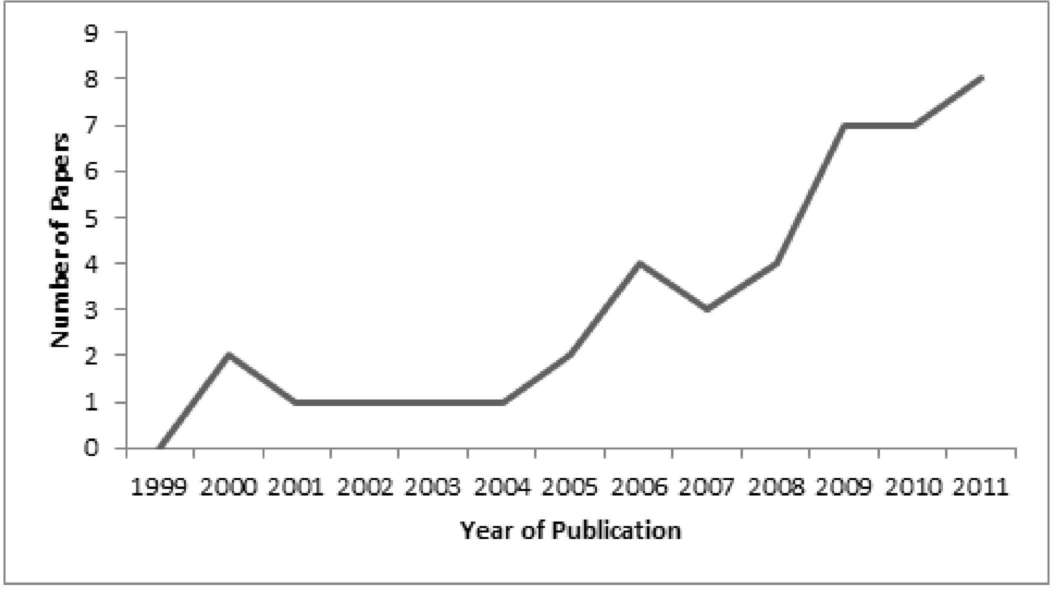

Figure 3. Perceived barriers to using data for research purposes among Immunization Program Managers (IPMs) that reported data being used for research purposes and those that did not as reported in a 2012 survey of PMs.

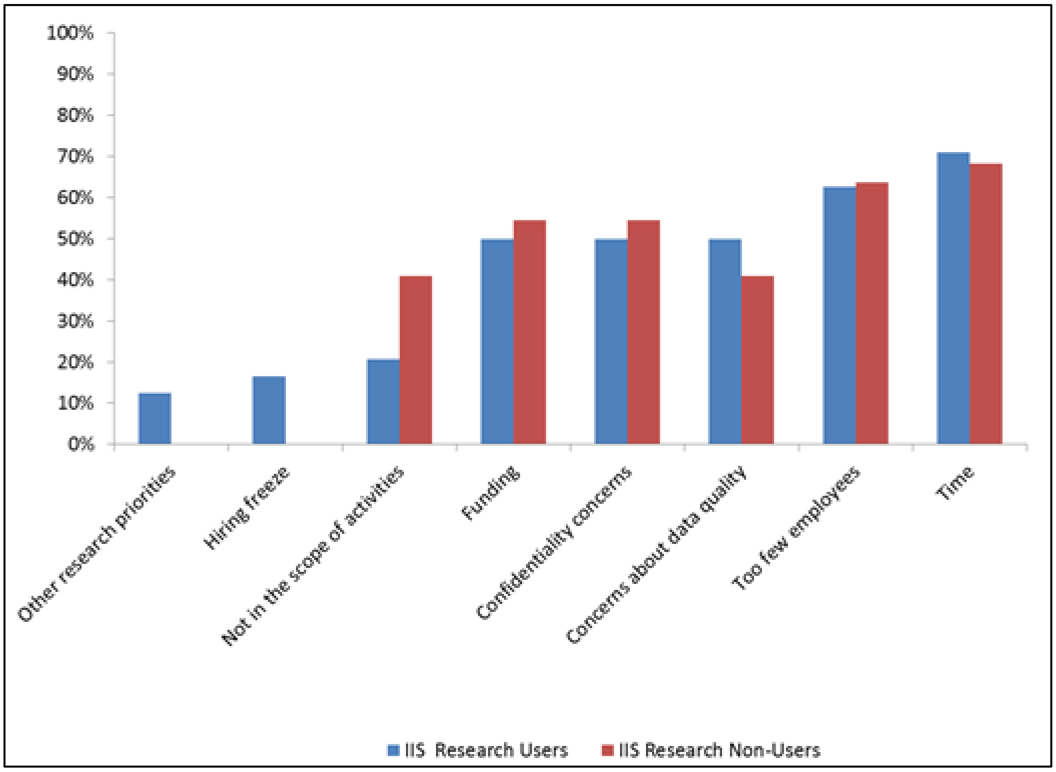

Figure 4. Plans to improve provider participation among immunization programs that have used data for research and those that have not as reported a 2012 survey of Immunization Program Managers.

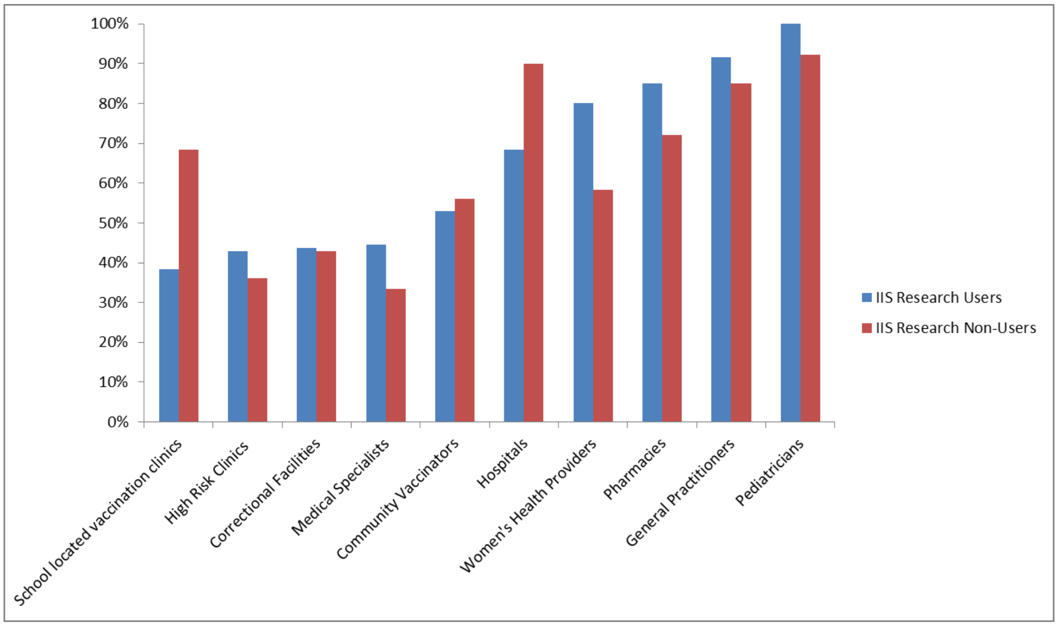

Figure 5. Steps required to obtain access to data from IIS for internal and external research purposes among immunization programs that have used data for research and those that have not as reported in a 2012 Immunization Program Manager survey.

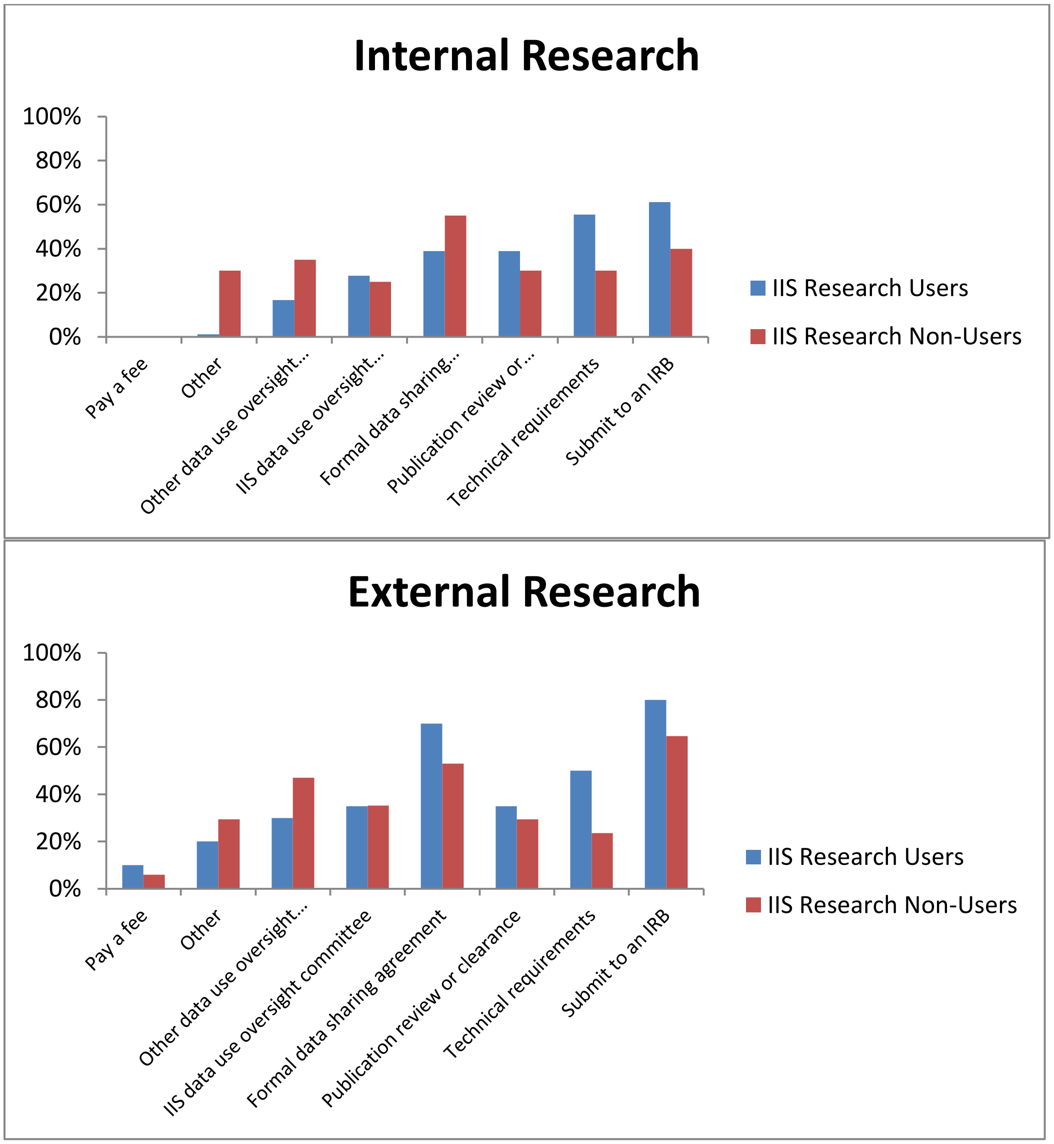

Table 1. Number of papers published using IIS data from individual Immunization Programs and the number of minimum functional standards met by those Immunization Programs as of 2009.

Immunization Program	Number of Papers
Michigan	9
Philadelphia	8
New York City	6
Arizona	3
North Carolina	2
Oregon	2
Houston	2
Connecticut	2
Wisconsin	1
District of Columbia	1
Minnesota	1
Utah	1
Washington State	1
San Antonio	1
Chicago	1
Colorado	1
Delaware	1
North Dakota	1

Table 2. Data sharing agreement practices among immunization programs that have used IIS data for research and those that have not, as reported in a 2012 survey of Immunization Program Managers.

Data sharing practices	**IIS research users N(%) N=23**	**IIS research non-users N(%) N=21**
Health Departments		
Sharing agreement	15 (65.22)	10 (47.62)
Bidirectional sharing permitted	9 (39.13)	8 (38.10)
Other Agencies		
Sharing agreement	16 (69.57)	10 (47.62)
Bidirectional sharing permitted	3 (13.04)	6 (28.57)
Schools		
Sharing agreement	14 (60.87)	9 (42.86)
Bidirectional sharing permitted	3 (13.04)	4 (19.05)
Patients		
Sharing agreement	4 (17.39)	1 (4.76)
Bidirectional sharing permitted	1 (4.35)	0 (0.00)
Pharmacies		
Sharing agreement	11 (47.83)	6 (28.57)
Bidirectional sharing permitted	4 (17.39)	3 (14.29)
Online EHRs		
Sharing agreement	16 (69.57)	6 (28.57)
Bidirectional sharing permitted	9 (39.13)	7 (33.33)
HMO/Insurance/Medical Billing		
Sharing agreement	13 (56.52)	3 (14.29)
Bidirectional sharing permitted	9 (39.13)	1 (4.76)
Health information exchanges		
Sharing agreement	10 (43.48)	5 (23.81)
Bidirectional sharing permitted	5 (21.74)	5 (23.81)
Physician Practices		
Sharing agreement	17 (73.91)	10 (47.62)
Bidirectional sharing permitted	9 (39.13)	8 (38.10)
Higher Education Institutions		
Sharing agreement	12 (52.17)	2 (9.52)
Bidirectional sharing permitted	2 (8.70)	2 (9.52)
Other		
Sharing agreement	2 (8.70)	1 (4.76)
Bidirectional sharing permitted	2 (8.70)	1 (4.76)

Chapter III: Summary, Public Health Implications, Possible Future Directions

Our study shows that IIS may be underutilized in public health research. We highlight potential causes of IIS underutilization and identify common characteristics among programs that successfully use IIS for research purposes. Our findings could lead to increased use of IIS, both for immunization research, and emergency preparedness. Our results highlight the importance of data sharing, and promote partnerships between immunization programs and universities and other research organizations. This could lead to greater collaboration and increased use of IIS data, and thus more representative immunization research. Finally, our results may encourage immunization programs to be more well-rounded in their approach to IIS functionality. Immunization programs may not focus on just emergency preparedness or immunization research, but work to strengthen both. These efforts would all help to maximize the potential of this powerful tool.