IIS Technology Over Time:
Impact and Changing Roles

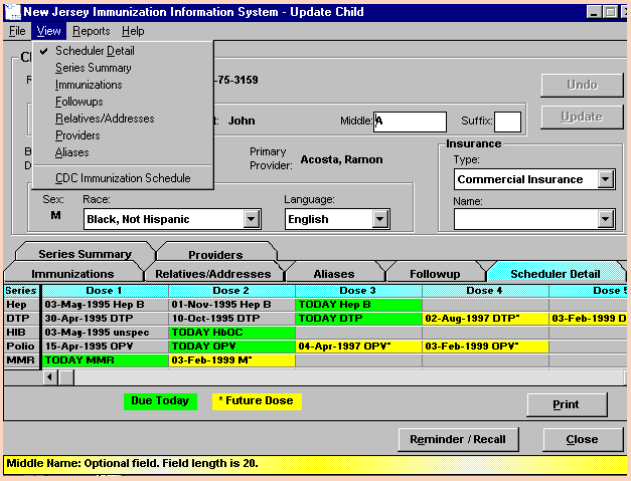
The last two and a half decades of IIS overlapped with a new era of intense and rapid changes in digital technology—what is now termed the rise of the Information Age. This period of time saw the move from mainframes to desktop PCs, to networks, and, ultimately, to the internet, the web, the cloud and mobile technology. While the private sector speedily embraced new developments as they came, healthcare and public health approached these emerging technologies with caution. Over time, IIS have maintained their core mission. But they have also grown and changed as the underlying technologies they require have evolved, and as our culture has imposed new demands and expectations on how IIS—and information generally—are viewed and used. This spotlight highlights the long and pioneering journey of the IIS community, from its scrappy beginnings cobbling together the first IIS in an environment driven by legacy mainframes, to finding its footing in a more digitally connected world.

A glimpse in the rearview mirror: 25 years of IIS technology

After the 1989-1991 measles outbreak, there was brief discussion of a single, national immunization registry. But the political will was not there as both CDC and Congress felt that Americans were not ready for data on kids being held in "a big government database in the sky."[1] As a result, from the early days, jurisdictions individually developed their own IIS[2]—including finding the right technology platform.

One of the first IIS interfaces was a terminal-based system developed by NYSE-West, a Navy contractor working for CDC. It was state-of-the-art for its time, nearly 25 years ago. Flash forward to the present day—for many IIS users, there is no special user interface (UI) at all! They use their local electronic health record (EHR) system to access immunization data on demand when they need it, with no additional login or system to access.[3]

Arguably, the UI historically has been the most conspicuous attribute of an IIS. As long as IIS have existed, the UI was the component most users saw and interacted with, but they have changed dramatically over the past 25 years as the underlying architectures of systems have evolved. Early IIS started as terminal-based systems, but quickly evolved into client-server systems with increasingly rich graphical UIs distributed and running on personal computers, which had been gradually cropping up on IIS users' desktops by the late 1990s.



Client-server user interface for showing an individual's record, New Jersey Comprehensive Immunization Program application, 1994

But as users increasingly came on board, the process of supporting applications distributed on user desktops became increasingly onerous, and updating these applications grew difficult to synchronize and support. Some projects adapted by having users run client/server applications on remote desktops over a network (usually Citrix-based), but slow network speeds and product instability often made this option equally difficult to support reliably.

By 1999, the World Wide Web had demonstrated its utility and was seen as sufficiently secure for private health data,[4] enticing applications to migrate to web technologies. This move in turn made applications much easier to support—assuming the user was accessing them using the correct web browser. "Browser wars" were rampant at the time, leading to some incompatibility issues between certain tools and certain browsers. As web technologies grew richer in features, functions and reliability, increasing numbers of clinical users moved to their EHR systems and found it increasingly difficult and bothersome to access immunization data separately through a special IIS interface or site.

Technology trends and IIS

During this same time period, server technology evolved rapidly as well, requiring IIS programs to deploy, and redeploy, their back-end systems, sometimes repeatedly. Early IIS typically ran on either end of the technology spectrum: on large mainframe systems that public health agencies had previously deployed for other functions, or on small desktops or local area network servers. The latter typically ran early versions of Windows Server or Novell Netware, which were nimbler, but far from stable and certainly not scalable. Mid-range servers, usually running Unix as their operating system, soon became available and offered agencies a more affordable, scalable and powerful server choice if they had staff capable of operating it. Soon, a number of hardware vendors offered a range of server platforms (including IBM, DEC and HP, to name a few), but persistence by Intel drove the market to near ubiquitous acceptance of commodity servers based on Intel microprocessors. By the mid-2000s, Linux, an open source version of Unix, became the dominant operating system, which enabled virtualization of server environments (so-called "cloud computing"), which in turn allowed agencies to deploy scalable systems, typically in third-party locations, and pay for as much or as little computing power as they needed.

None of this progress would have been possible without the internet. In the early days, IIS had to rely on dial-up modems, which provided slow communications speeds and required dedicated telephone lines and equipment (on both the user and agency end) to provide connectivity between user desktops in the field and server resources at the agency. Over time, internet service providers (ISPs) began to provide scalable "modem pools" for users to access, but these pools required monthly subscriptions from the ISPs, and they also required that the IIS servers be connected to the internet so users could access them. Some IIS projects offered their own modem pools, but those required users to dial into them specially (and only) to access the IIS and came at increasing cost of infrastructure.

Early registry innovations

```
{
  SetDefaultMode();
  Recommendation = GetEligibleVaccines( Series );
  if ( Recommendation == RECOMMEND )
  {
    CheckOtherSeriesForEligibleVaccines();
    Vaccine = SelectEligibleVaccineForRecommendation();
  }
  if ( Recommendation == UP_TO_DATE )
    Date = SeriesReturnDate;
  return Recommendation;
}
```

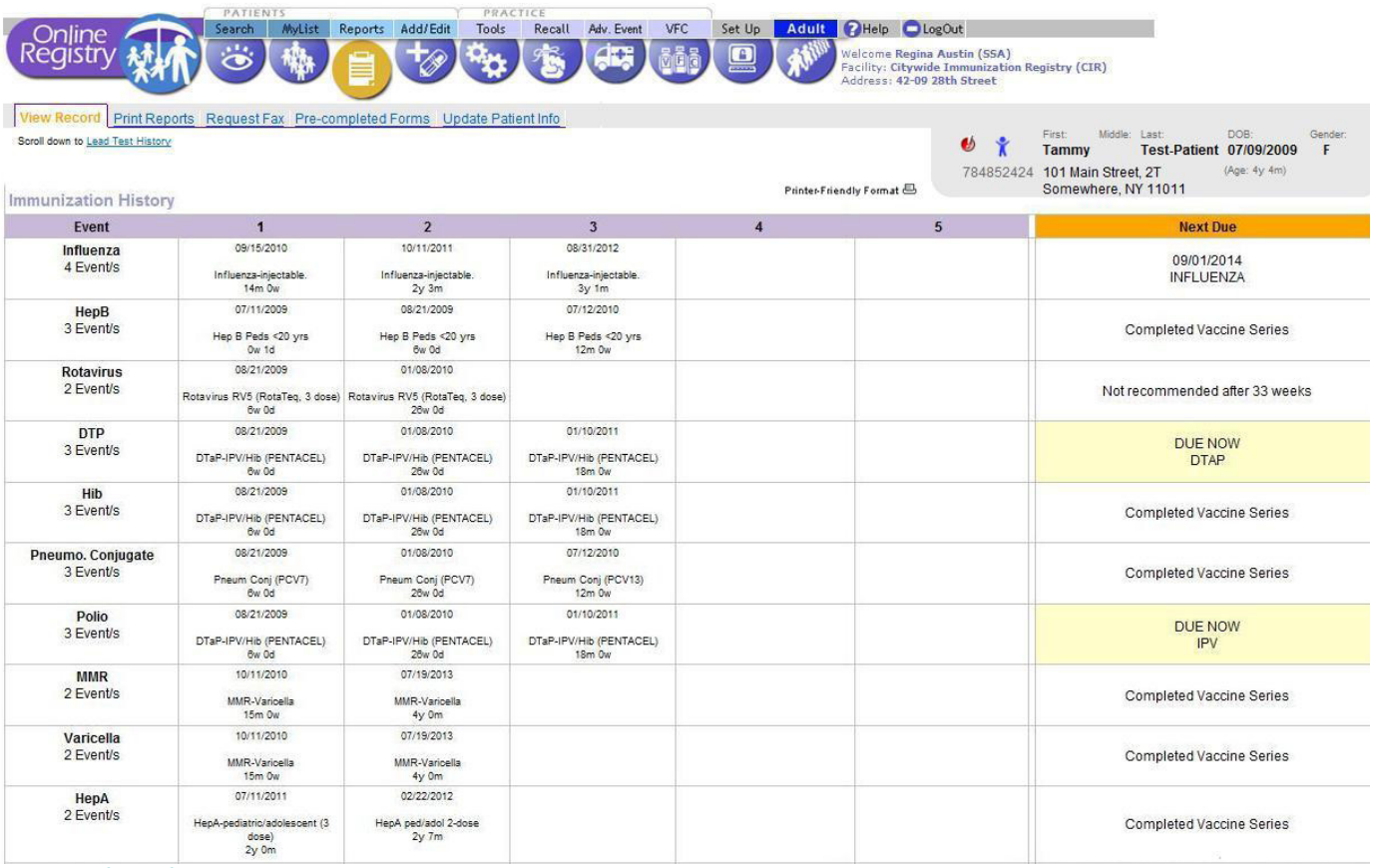
Sample programming from The Automated Immunization Evaluation Process: A Programmer's Guide, CDC, 1996

In the early 1990s, practitioners documented vaccinations entirely on paper; shots were recorded on index cards or in running clinical notes. Few immunization providers even used a single flowchart that showed all shots in one place. The only source of information that came close to displaying the immunization schedule in one place was the immunization card maintained by parents. It's easy today to underestimate how tremendously revolutionary and helpful it was when registries displayed a consolidated shot history in a single, compact view, such as in the image on page 1.

A second and even more impactful innovation came in the form of vaccine validation and forecasting. Because shots were frequently given in health departments through much of the 1990s, records were scattered to a greater degree than they are today. Rather than simply "eyeballing" the chart or the parent's card, immunization providers now had a consolidated and authoritative resource to know what, if anything, could be given today and still count. In other words, registries transformed data into information and knowledge that could improve practice.

By the turn of the millennium, internet access became so compelling, and technology improved sufficiently in terms of speed, stability and security, that not only did users find better and cheaper ways to connect, but most agencies realized that their IIS simply had to be internet-accessible if they were to keep up with demand for access in a period of increasingly uncertain budgets. Fortunately, this uptake came at a time when more and more agencies were becoming internet-enabled anyway, many through the funding made available post-9/11 by the Health Alert Network initiative.

With an increase in access came growing concerns about information privacy and security. While HIPAA made provisions for public health authorities that gave them latitude to use their own discretion when making decisions about information use and exchange, agencies were becoming increasingly aware of the negative impact that inappropriate disclosure might bring on their projects. An entire chapter of the 1997 Community Immunization Registry Manual was devoted to confidentiality.[5] Not all risks,



Event	1	2	3	4	5	Next Due
Influenza 4 Event/s	09/15/2010 Influenza-injectable. 14m 0w	10/11/2011 Influenza-injectable. 2y 3m	08/31/2012 Influenza-injectable. 3y 1m			09/01/2014 INFLUENZA
HepB 3 Event/s	07/11/2009 Hep B Peds <20 yrs 0w 1d	08/21/2009 Hep B Peds <20 yrs 6w 0d	07/12/2010 Hep B Peds <20 yrs 12m 0w			Completed Vaccine Series
Rotavirus 2 Event/s	08/21/2009 Rotavirus RV5 (RotaTeq, 3 dose) 6w 0d	01/08/2010 Rotavirus RV5 (RotaTeq, 3 dose) 26w 0d				Not recommended after 33 weeks
DTP 3 Event/s	08/21/2009 DTaP-IPV/Hib (PENTACEL) 6w 0d	01/08/2010 DTaP-IPV/Hib (PENTACEL) 26w 0d	01/10/2011 DTaP-IPV/Hib (PENTACEL) 18m 0w			DUE NOW DTAP
Hib 3 Event/s	08/21/2009 DTaP-IPV/Hib (PENTACEL) 6w 0d	01/08/2010 DTaP-IPV/Hib (PENTACEL) 26w 0d	01/10/2011 DTaP-IPV/Hib (PENTACEL) 18m 0w			Completed Vaccine Series
Pneumo. Conjugate 3 Event/s	08/21/2009 Pneum Conj (PCV7) 6w 0d	01/08/2010 Pneum Conj (PCV7) 26w 0d	07/12/2010 Pneum Conj (PCV13) 12m 0w			Completed Vaccine Series
Polio 3 Event/s	08/21/2009 DTaP-IPV/Hib (PENTACEL) 6w 0d	01/08/2010 DTaP-IPV/Hib (PENTACEL) 26w 0d	01/10/2011 DTaP-IPV/Hib (PENTACEL) 18m 0w			DUE NOW IPV
MMR 2 Event/s	10/11/2010 MMR-Varicella 15m 0w	07/19/2013 MMR-Varicella 4y 0m				Completed Vaccine Series
Varicella 2 Event/s	10/11/2010 MMR-Varicella 15m 0w	07/19/2013 MMR-Varicella 4y 0m				Completed Vaccine Series
HepA 2 Event/s	07/11/2011 HepA-pediatric/adolescent (3 dose) 2y 0m	02/22/2012 HepA ped/adol 2-dose 2y 7m				Completed Vaccine Series

User interface of a present-day web-based IIS showing an individual record, New York Citywide Immunization Registry

though, were related to data exposure. More and more, targeted online attacks seemed to be aimed at disrupting operation rather than stealing data. The IIS community continues to struggle with the tradeoff between security and ease of access to systems and data; some information security efforts may be effective, but may also seem intrusive and disruptive to immunization program goals and IIS activities. This tension will likely continue for some time and even intensify as the internet continues to be a haven for bad actors with nefarious intent.

Evolution of IIS software

From the start, immunization programs had a choice between acquiring commercial IIS software or developing the IIS in-house. During the early 1990s, in the infancy of IIS, projects were forging new ground whether they were developed commercially or in-house. A number of software vendors began modifying existing products or developing products from scratch to try to meet the new need—the All Kids Count project funded many of these activities.[2] In 1996, the CDC assembled a list of 17 IIS vendors.[6] Some companies succeeded while some were less successful, and over time, the commercial market consolidated until today, when only two major commercial IIS products remain. One major withdrawal from the market in 1999, HumanSoft and its Acclaim, Adios and QS products, caused considerable consternation for many programs, leaving agencies scrambling for replacement products; two states, however, were able to keep the source code alive and evolving.

As for developing products in-house, the results have been somewhat mixed. Some early in-house projects moved later to embrace commercial solutions as their internally developed products became unsustainable, either technically or financially. Other programs had contractors walk away from their custom-developed software and were left to either find a new contractor or have in-house application development staff take over. As of 2017, 18 IIS projects still used internally developed applications, and some of these applications are among the shining stars of the IIS world because of their leading-edge innovation. Nevertheless, the trend continues to move away from in-house development of one-off IIS applications.

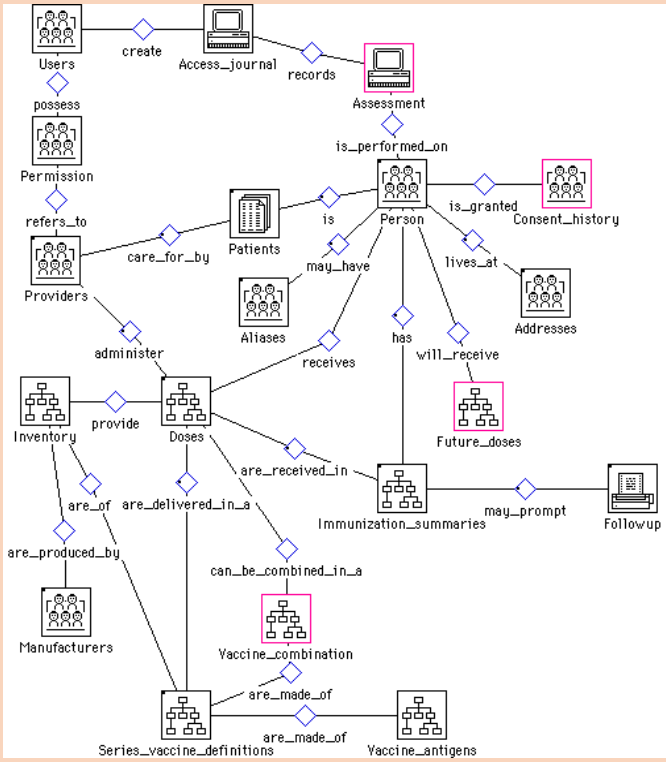
One internally developed IIS deserves special mention. The Wisconsin Immunization Registry (WIR) was originally developed by a contractor for the state of Wisconsin, relying heavily on Medicaid matching funds. Beginning in 1999, other projects noticed its rich functionality and asked Wisconsin for permission to deploy it in their jurisdictions. Under a license agreement, Wisconsin has, to date, shared the WIR software code with 19 jurisdictions, which in 2017 formed an active user group. While the availability of WIR has helped some jurisdictions immensely in terms of lower acquisition cost and a speedier acquisition process, there have been some limitations. Most notably, the software itself has not been managed over time in a coordinated way, leading to variations of the software being deployed that inhibit some collaboration and software sharing, preventing cost efficiencies that might otherwise have been possible.

As open-source software became more popular, IIS began to move in this direction as well. The WIR software is shared among jurisdictions, but is not strictly speaking open-source, since it is not released under an open-source license. Other products—more notably modules or components of larger IIS systems—have been developed and released as open-source products available to any project to use and even modify. Several open-source immunization evaluation and forecasting products have been released in recent years, as well as other tools for data quality assurance, HL7 message parsing and patient matching.[7] Completely open-source IIS are a possible outcome of this trend as yet another choice for jurisdictions concerned about increasing cost or limits in functionality.

IIS as technology and policy innovators

IIS were often the first systems in an agency to have "outside" access—i.e., users external to the agency. This meant that many agencies were forging new ground in terms of technology development as well as policy development. One relatively recent example of innovation, technology and policy coming together is the collaborative development of logic specifications, test cases and guidance for evaluating and forecasting vaccines due for individuals. Led by CDC and engaging experts from across the country, this Clinical Decision Support for Immunizations (CDSi) initiative seeks to ensure that all IIS can consistently meet and test to the recommendations of the Advisory Committee on Immunization Practices. This approach focuses on the ability of IIS to achieve an expected outcome rather than on dictating a methodology for achieving the outcome.[8]

For many agencies, IIS projects were initially allowed to pursue their objectives with little interference. This independence often left IIS programs having to bear the sole responsibility for selecting and maintaining appropriate technologies and security, since IT support in agencies tended to be much more decentralized years ago than is true today. Over time, as resources became more constrained and the threats to information security were perceived to be more serious, agencies increasingly began to exert more influence and control over IIS policy, technology and direction. In some cases, these changes had nothing to do with the IIS at all—larger forces in the agencies or even the jurisdiction were working to consolidate control and investment in information technology as IT became recognized as both a strategic resource and a potential source of uncontrolled spending. The net result was often a slowdown in IIS technical advancement, though balanced by a more rigorous and less idiosyncratic approach to and methodology for IT management.



An early data model for IIS, circa 1995

Evolving data submission, exchange and standards

An IIS rises and falls on the quality and completeness of its data, and providing easy, effective, timely and user-friendly ways of capturing data has remained an ongoing challenge. Early IIS often used a combination of various techniques, including:

- Direct data entry by clinical users into an online application.
- Submission of paper forms to a service bureau for professional data entry into the IIS.
- Submission of paper forms (sometimes by fax) with special bar coding to make completion of the forms going to the IIS easier and faster.
- Absorption of extract files from practice management systems or early EHRs to avoid manual data entry altogether.

Over time, use of paper forms has all but fallen by the wayside as online applications have improved, but even online data entry into IIS applications has been significantly by-passed by data transfers to IIS from clinical EHRs. The CMS EHR Incentive Programs ("Meaningful Use," now known as the Promoting Interoperability [PI] Programs) have spurred the deployment of EHR systems and provided incentives for electronic interoperability with IIS. For most IIS projects today, the proportion of data received via direct data entry or any other means is far overshadowed by the proportion of data received via electronic interface.

Though the CMS PI programs have provided the policy driver for the shift to electronic interoperability, the use of health data standards has created the enabling technology. The IIS community has been an active participant in the Health Level Seven International standards development organization almost since its inception and has continued to develop and promulgate standards-based approaches to data interoperability, including standards formats (HL7 version 2 messages) as well as data transport (a standardized SOAP Web Service Definition Language [WSDL]). Exchange of immunization-related data has been at the forefront of nearly every nationwide health data exchange initiative, including the American Health Information Community (AHIC), the Health Information Technology Standards Panel (HITSP), CMS EHR incentive programs' Meaningful Use (MU) and subsequent variations (e.g., MACRA/MIPS). The public health community continues to look to IIS to forge new ground with both clinicians and public health professionals, leading the way and showing agencies what can be done with data.[9]

IIS support for immunization programs

As IIS data became more complete and timely, immunization programs found new ways to use them to support their initiatives. In the early days, amassing immunization data seemed like almost an end in and of itself, given that it involved so many challenges with limited telecommunications capabilities, limited source data in electronic form, and in many cases limited interest. A catch-22 also persisted: programs were hesitant to use IIS data they believed to be incomplete, but IIS projects had difficulty encouraging data collection when their own programs would not use the systems. The CDC Sentinel Project was (and is) one initiative that recruited and funded a limited number of IIS to provide data to the CDC and to help use that data to identify pockets of need and evaluate how well IIS data can support program needs.[10]

In the early days, some IIS projects were not even located within the public health agency in the same division as the immunization program, or they were not managed jointly. Over time, IIS projects have become more tightly integrated with immunization programs and more directly support program needs, including Vaccine for Children (VFC) program accountability, the Assessment, Feedback, Incentives and eXchange (AFIX) clinical quality improvement program, vaccine recall response, and vaccine ordering and distribution.[11]

Using IIS in times of crisis

Over the years, IIS have been selectively leveraged in response to specific public health crises. Hurricane Katrina caused a huge dislocation of Louisiana's population. IIS were able to alleviate this health information difficulty by supplying flexible access to providers in other states that temporarily, and in some cases permanently, received people who had fled Louisiana.

The fear of bioterrorism in the post-9/11 era led to some agencies leveraging IIS to support CDC Strategic National Stockpile readiness, which required the ability to track the availability and administration of vaccines and in some cases other medications to a large portion of a local population in the event of a serious threat. During this same time, the CDC began a program of rapid smallpox vaccination that was limited to first responders, but could have expanded to the population at large, and some IIS were modified to support this initiative.

IIS as public health informatics pioneers

Throughout its first 25 years, the IIS community was on the forefront of the emerging discipline of public health informatics. IIS arguably represent the most mature exemplar of public health informatics in the United States, given the functional complexity of the systems and the data being exchanged and managed.[12] "Everything you need to know about public health informatics can be learned from the history of IIS development," as one observer noted.[13]

Some jurisdictions recognized IIS as potential participants in a more integrated approach to public health data and systems as agencies began to acknowledge the redundancy and limitations in "stovepipe" systems—i.e., systems that need be interoperable with other systems to be truly useful, but instead function in isolation. For Michigan, having an integrated child health information system—the Michigan Care Improvement Registry—provided additional value to healthcare providers through transparent,

The aftermath of Hurricane Katrina in New Orleans

The widespread damage to New Orleans and other areas affected by Hurricane Katrina resulted in widespread relocation of residents from affected areas, prompting IIS to step up in an emergency response role to fill the health information gap.

Photo credit: Infrogmation

behind-the-scenes interoperability.[14] Being population-based means IIS can serve as a platform for other child health data, such as developmental screening and integration with schools.[15]

Interventions themselves were often equally siloed, leading to limited and at times wasteful outreach by multiple agency staff to the same individuals. In the area of maternal and early childhood health—the basis of most IIS projects at least initially—the need for integrated data across programs was even more acute. All Kids Count's Connections program (2001-2004) was funded by the Robert Wood Johnson Foundation to encourage, study and evaluate these emerging integrated systems. For participating IIS, this often meant a new (and needed) source of funding, albeit a temporary one, and exposure to new and interesting ideas from other jurisdictions. As noted in another spotlight in this series, Enduring Legacies: Lessons for the Future, the early identification of functional standards and especially the adoption of rigorous business modeling techniques reflected how advanced the IIS community was in terms of informatics methods.

IIS and consumer access

The near-ubiquity of the internet and the rapid expansion of reliable and fast cellular service have spurred a sea change in social attitudes toward information availability: mobile technologies and anytime/anywhere access to data in the U.S. and around the world are now considered a given. This cultural shift, however, has been very slow to infiltrate IIS. Some early pilot projects attempted to develop mobile clients for clinicians to use to enter and access immunization data at the point of care, but device compatibility was a difficult challenge, and standards were not yet fully developed. Mobile access, as driven by consumer needs, has had slow adoption for IIS. While a number of projects have provided a consumer portal for access to IIS data by parents and other citizens – especially during school, child care and camp enrollment seasons – many jurisdictions have felt limited by restricted data access policies and have also struggled with uncertainty that a mobile system can accurately identify users and prevent inappropriate access.

The road ahead: a glimpse toward the future

So what might the IIS of the future look like, reflecting back on how far it has come over its first 25 years? A likely scenario is that IIS front-end applications will continue to diminish in use at the point of service in deference to increasingly-functional EHRs (or their successors). Data query from IIS to clinical systems will continue to increase and improve, making bi-directional interoperability between IIS and clinical systems routine and effective. While adoption of consumer access has been slow for IIS, emerging and enabling authentication and mobile computing tools will eventually sweep IIS data into the consumer mainstream. Vaccine supply chain support will continue to improve as vaccine accountability becomes even more important in a time of shrinking funding and increased scrutiny. And though integrated public health systems have had strong but limited success, interoperability between programs and systems within public health agencies will bring new ways to look at data and serve the public good.

Citations and notes

1. Alan Hinman, interview 4/26/2017; Kris Saarlas, interview 4/20/2017; Sue Salkowitz interview, 4/7/17; Dave Ross, interview 6/1/2017
2. For more information, see *Origin Story: Creating a Culture of Collaboration*, another spotlight in this series.
3. Kevin Dombkowski, interview 4/19/2017; Noam Arzt, interview 4/20/17; Therese Hoyle, interview 4/21/2017; Bill Brand, interview 04/25/2017
4. The internet was proposed for intra- and inter-state immunization data transmission as early as 1994 in the *Preliminary Technical Plan for the State Immunization Information System (SIIS)*, a study by NISE West for the CDC National Immunization Program, available in the AIRA Repository.
5. See *Community Immunization Registry Manual - Chapter II: Confidentiality* in the AIRA repository.
6. See *Registry Software Vendors* 1996 in the AIRA repository.
7. See the AIRA Repository for more information on open source products: http://repository.immregistries.org/resources/filtered/by/open-source.
8. https://www.cdc.gov/vaccines/programs/iis/cdsi.html
9. For more information, see *Balancing Community and Autonomy: The Evolution of IIS Standards*, another spotlight in this series.
10. For more information on the sentinel site program, see https://www.cdc.gov/vaccines/programs/iis/activities/sentinel-sites.html.
11. See the *PROW Standards of Excellence* in the AIRA Repository.
12. Katie Reed, interview 6/9/2017; Bill Brand, interview 04/25/2017
13. Personal communication with Sue Salkowitz, 3/18/17
14. Therese Hoyle, interview 4/21/2017
15. Kim Salisbury Keith, interview 6/2/2017

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