

Enduring Legacies: Lessons for the Future

For those looking to the future of IIS and other areas of public health informatics, the history of the IIS community holds many valuable lessons. Taking the time to understand and apply these lessons to future strategies and planning can pay dividends in terms of the outcomes achieved—and the pitfalls avoided. What is clear from the history of IIS is that the key lessons are less about technology and more about the people who compose the community, along with their values and relationships. This spotlight highlights those lessons that potentially offer the most value for the future.

Lessons in IIS leadership: vision, collaboration and standards

Support a learning community to create and share knowledge.

One of the most striking features of IIS history was that, from its beginning, it formed as a scientific community; that is, one focused on testing, building and sharing specialized and collective knowledge in order to advance the field and increase its impact. The early pioneers, both All Kids Count¹ grantees and others, were leading-edge thinkers and implementers who came together as a learning community to confront the surprisingly complex policy, funding, organizational and technical challenges. Participants were willing to learn from each other, not be territorial, learn from both successes and failures, and give freely of whatever time and knowledge they had. This positive synergy led to a highly collaborative period, which was favorable for those registry projects and vendors who would survive the rapid changes in technology.² This attribute of being a scientific learning community is a cornerstone legacy for the IIS community.³

Early lessons from IIS development are as relevant today as they were in 1990s:

- Involve stakeholders from the beginning.
- Recognize the complexity of establishing a population-based information system.
- Define the system requirements to support users' needs.
- Develop according to standards.
- Address common problems collaboratively.
- Plan for change.

- Develop a good communications strategy.
- Use the registry information (even if it's not perfect).⁴

All Kids Count, CDC and the National Vaccine Advisory Committee (NVAC) were the major disseminators of the growing body of knowledge throughout the 1990s. As All Kids Count's funding came to an end, it helped incubate the creation of a national membership association for IIS that could carry on in that role: the American Immunization Registry Association (AIRA). In addition to continuing the tradition of an active learning community, such an organization was needed to expand engagement with private sector organizations interested in IIS and to collaborate with CDC to hold annual IIS national meetings.⁵

Leadership and advocacy are necessary components for success and resiliency.

From the beginning, the IIS community was one that focused on public-private relationship building⁶ with a shared sense of purpose and mission. Public health leaders and local coalitions saw the potential of registries, although not necessarily the extent of the complexities. Nationwide leadership came principally from the CDC, NVAC, the Robert Wood Johnson Foundation's All Kids Count program, and Every Child by Two, while local leadership came from the IIS projects and their often very active advisory groups and/or coalitions. Expert advocacy from the public and private sectors gave early IIS efforts legitimacy and social capital. Most of all, there was a willingness for all stakeholders—public and private—to work together.



Connections

From 2001-2004, All Kids Count created a new community of practice called Connections to bring together 11 public health agencies engaged in building on the IIS experience to create integrated child health information systems. They learned from each other, captured best practices and collaboratively addressed the unique challenges of sharing information among various child health programs within their own jurisdictions. This community of practice built on the lessons from IIS to achieve broader public health goals.¹

During the 1990s, local coalitions, professional associations, health plans and other stakeholders stayed engaged in IIS development because they shared a commitment to raising immunization rates—and in some cases because they were invested in IIS financially. Many IIS programs engaged in a concerted effort to create a shared sense of ownership for the IIS.⁷ Over time, real expertise and cultural knowledge of local community needs faded, both as IIS became increasingly state-based vs. community-based, and also as public-private partnerships, immunization coalitions and IIS advisory committees diminished. There seemed to be a growing sense among immunization stakeholders that the IIS was a governmental responsibility rather than a community resource.⁸ Yet, maintaining such partnerships likely remains an important dimension of ongoing IIS sustainability.

Let a thousand flowers bloom, but develop standards from the start.

Even as the experimentation and trial-and-error approach of the “let a thousand flowers bloom” phase of the first All Kids Count projects were underway, CDC, NVAC and All Kids Count were working toward a shared definition of what constitutes a successful IIS. By 1999, these stakeholders published IIS “key attributes”⁹ core data elements and an HL7 implementation guide, making the IIS community an early adopter of rigorous informatics methods and standards. While innovation was still critical, in no small part because of the ever-evolving technologies,¹⁰ the movement was clearly toward greater standardization in terms of core, defined functionality.¹¹

This era of IIS resulted in crucial lessons learned for the future and for global IIS development:

- Widely adopted standards are critical. Customized IIS functionality may have its benefits, but also its costs to both the program and to IIS and other health information technology vendors. It is difficult and costly to sustain customization over time.
- Collective wisdom is, in the long run, a safer bet than individual vision.
- Idiosyncratic IIS policies are expensive for data submitters, especially those healthcare providers whose market boundaries cross the jurisdictional boundaries of two or

more IIS programs. It costs providers to have to do one thing two or more ways without a compelling reason to do so.¹²

Understand that IIS operates within a complex health information ecosystem.

The IIS is regarded as the first large-scale public health information system to be designed and built primarily with clinical care in mind. The original and primary goal of the IIS was to improve immunization practice and by extension coverage levels. From the beginning, successful IIS were those that would integrate with the workflow and needs of those who gave and recorded the shots. This attention to the detail paid off even though most public health staff had limited knowledge of clinical workflows, at least initially.⁹

The need for operational IIS within a broader health information ecosystem often comes into stark relief during times of health crises, emergencies and outbreaks. For example, during the anthrax bioterrorism events of 2001, some IIS tracked anthrax prophylaxis.¹³ In another example, during the 2009 H1N1 pandemic, many IIS met the crucial demand for rapid turnaround of data to inform outbreak interventions. In turn, this service provided by IIS provided an opportunity to solidify partnerships with pharmacists.¹⁴ During Hurricane Katrina in 2005, the Louisiana IIS remained online following the hurricane, making immunization histories available for health care providers caring for displaced persons within Louisiana and in all 50 states throughout the country.¹⁵ After the 2015 Flint Michigan water crisis, the Michigan Care Improvement Registry (MICR) began to capture blood lead testing results so that they could be available to providers as well as to researchers for longitudinal studies.¹⁶

Understanding how IIS integrate within this broader public health ecosystem has been critical. Based upon a literature search that identified 240 sources describing or evaluating IIS, the Community Preventive Services Task Force in 2015 concluded that there was “strong evidence of effectiveness [in IIS] increasing vaccination rates.”¹⁷

Be willing to reassess how to accomplish goals.

Through the 1990s, especially when registries operated more closely to the community than the state level, it was hard for IIS programs to see that they were more similar than different in their functions and processes.¹⁸ In New York state, there was an assumption that each of the four regional registries should operate separately based on unique business requirements. However, an independent assessment compared the regional registries and found that, in fact, there were no regional differences in business requirements. New York state then moved to a single, web-based application.¹⁹ In 2013, AIRA, realizing that common problems should result in common solutions, launched the Joint Development and Implementation Initiative “to broaden and formalize the planning, coordination, and implementation of collaboratively developed products.”²⁰

Lessons in IIS sustainability: operational and financial

Diversify funding sources where possible.

Across the first 25 years of IIS history, IIS transitioned steadily from receiving a mix of federal, state, local and private funding to relying more and more on federal funding alone. Although Section 317 funding has remained available over time, that funding has had to stretch further and further as new vaccines were introduced, other immunization program demands arose, and maintenance and support costs for IIS climbed with ever increasing functionality and complexity. Increases in federal funds, when they occurred, were often offset by losses in state/local or private funds. VFC operational funding supports IIS activities, but not to as great an extent as initially envisioned by NVAC.²¹

The most successful IIS programs, measured by size of the staff, innovation and leadership within the community, both in the past and today, tend to be those that could leverage Medicaid, state-local general funds, health plan or other funding sources.^{22,23}

Balance support for innovation with “raising all boats.”

Over time, the IIS community has faced the persistent challenge of simultaneously ensuring that all IIS programs were moving toward shared goals and standards, while also supporting the most mature programs to innovate, to use their data to highlight the value of IIS, and to implement new functionalities. While maintaining Section 317 funding to all awardees, CDC also periodically made available sentinel site, interoperability and other focused funding, which for a variety of reasons tended to go to the most mature IIS programs. An unintended consequence was increasing the gap between the “have” and “have-not” programs.²⁴ An intentional goal of the 2013 IIS Strategic Plan was to address such disparities when possible.²⁵

Focus on immunization information as the primary asset; technology is a means to that end.

Technology often becomes the focus of planning, operations and financing, so it’s hard to remember that it is still primarily a means to an end. IIS ultimately are about use of immunization information; the technology behind IIS is about how that information is managed in order to enable its effective use in decision making.²⁶ In turn, increased demand for immunization information by clinical and public health programs, health care organizations and other stakeholders has helped to drive innovation in technology.²⁷

Some experts claim that the IIS community is at a tipping point in its use of immunization information. They argue there is a need to unleash this intelligence in the market and to bring all this data to life – to create value in the form of dynamic, real-time information that will result in action. IIS continue to serve multiple purposes, but the community cannot afford to make access to its information cumbersome to its stakeholders.²⁸

Leverage the IIS role as an exemplar of public health informatics.

IIS arguably represents the most mature and advanced example of public health informatics in the United States.²⁹ IIS was the first large-scale, outwardly-facing manifestation of public health informatics, and among the first to adopt health care industry standards. The early identification of functional standards and especially the adoption of rigorous business modeling techniques through MIROW highlight how advanced the IIS community remains in terms of informatics methods. In many respects, the IIS community was a pioneer, paving the road to a more widespread understanding and acceptance of informatics as a critical and core discipline in public health, and blazing a trail for other public health areas to follow as they begin their own data stewardship journeys.³⁰



Citations and notes

1. For more on All Kids Count, the 13-year Robert Wood Johnson Foundation grant program that did much to support IIS development, see *Origin Story: Creating a Culture of Collaboration*, another spotlight in this series.
2. Dave Ross, interview 6/01/2017; Robb Linkins, interview 04/28/2017; Kim Salisbury Keith, interview 6/2/2017; Mike Popovich, interview 6/8/2017; Mary Beth Kurilo, interview 4/27/2017; Therese Hoyle, interview 04/21/2017; Robb Linkins, interview 04/28/2017
3. Cindy Sutliff, interview 6/2/2017; Bill Brand, interview 04/25/2017; Dave Ross, interview 6/1/2017
4. Kristin Saarlans et al., "All Kids Count 1991-2004: Developing Information Systems to Improve Child Health and the Delivery of Immunizations and Preventive Services," *Journal of Public Health Management & Practice* 10 (November 2004): S3-15.
5. Kris Saarlans, interview, 4/20/2017
6. Therese Hoyle, interview 04/21/2017; Alan Hinman, interview 4/26/2017; Dave Ross, interview 6/1/2017; Sue Salkowitz, 2016 interview for PHII; Warren Williams, interview 4/25/2017
7. Bill Brand, interview 04/25/2017; Kevin Dombkowski, interview 4/19/2017; Kim Salisbury Keith, interview 6/2/2017; Kris Saarlans, interview 4/20/2017; Sue Salkowitz, personal communication 6/23/2017
8. Bill Brand, interview 04/25/2017; Kris Saarlans, interview 4/20/2017; Sue Salkowitz, personal communication 6/23/2017
9. For more information, see *Origin Story: A Culture of Collaboration*, another spotlight in this series.
10. For more information, see *IIS Technology Over Time: Impact and Changing Roles*, another spotlight in this series.
11. Warren Williams, interview 4/25/2017; Dave Ross, interview 6/01/2017; Kim Salisbury Keith, interview 6/2/2017; Mary Beth Kurilo, interview 4/27/2017
12. Bill Brand, interview 04/25/2017; Dave Ross, interview 6/01/2017; Mary Beth Kurilo, interview 4/27/2017; Warren Williams, interview 4/25/2017
13. Sue Salkowitz, personal communication, 6/23/2017
14. Kim Salisbury Keith, interview 6/2/2017; Mike Popovich, interview 6/8/2017
15. Mike Popovich, interview 6/8/2017; Mike Flynn, interview 4/18/17
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17. Holly Groom et al., "Immunization Information Systems to Increase Vaccination Rates: A Community Guide Systematic Review," *Journal of Public Health Management and Practice: JPHMP* 21, no. 3 (June 2015): 227-48; Community Guide, <http://www.thecommunityguide.org/vaccines/RRimminfosystems.html>
18. Dave Ross, interview 6/1/2017
19. Mike Flynn, interview 4/18/17
20. <http://www.immregistries.org/joint-development-implementation>
21. NVAC, <https://www.hhs.gov/sites/default/files/nvpo/nvac/reports/nvacisreport20070911.pdf>
22. Therese Hoyle, interview 04/21/2017; Mary Beth Kurilo, interview 04/27/2018
23. For more information on the impact of funding shifts on IIS operations, see *Funding: The Pursuit of Sustainability for IIS*, another spotlight in this series.
24. Mike Popovich, interview 6/8/2017; Bill Brand, interview 04/25/2017
25. Bill Brand, interview 04/25/2017
26. Bill Brand, interview 04/25/2017; Warren Williams, interview 4/25/2017
27. Laura J. Pabst and Warren Williams, "Immunization Information Systems," *Journal of Public Health Management and Practice* 21, no. 3 (2015): 225-26.
28. Mike Popovich, interview 6/8/2017; Kim Salisbury Keith, interview 6/2/2017
29. Mike Popovich, interview 6/8/2017; Noam Arzt, interview 4/20/17
30. Noam Arzt, interview 4/20/17; Bill Brand, interview 04/25/2017; Martin LaVenture, interview 04/28/2017

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