Funding:
The Pursuit of Sustainability for IIS

In the early 1990s, the growing interest and excitement around the first immunization registries spurred a robust mix of philanthropic, public and even private funding intended to launch these burgeoning projects. However, as the early experimental "launch" years came to a close, many of these short-term funding options dried up, and IIS began to rely more and more exclusively on federal funds—leading to some concern in the IIS community that relying on just one funding strategy may be risky. This spotlight reviews how private and public funding sources for IIS over the past 25 years have evolved in response to community and national needs and priorities, and also considers how IIS can achieve sustainability in the future.

National crisis leads to public-private funding initiatives

The earliest iteration of immunization registry funding in the U.S. came in the wake of a health crisis. The nationwide measles epidemic of 1989-91 shocked the country into the realization that it could not be complacent about childhood immunization.[1] In response, the first Bush administration and Congress quickly moved to authorize new spending to improve vaccine delivery and immunization practice. By 1992, the Department of Health and Human Services (HHS) announced $45 million to assist 87 areas around the country in developing local Immunization Action Plans (IAPs).[2] This funding doubled the money available for immunization programs and for vaccines over the prior fiscal year. As a backbone for a new national strategy, these funds were intended to increase access to immunizations and address the problem of under-immunization of children under two years of age, the most vulnerable in terms of vaccine-preventable diseases. The CDC's goal was to improve immunization levels for these children from about 50 percent to at least 90 percent by the year 2000.

As part of the 1992 HHS initiative, the CDC awarded immunization registry planning grants to its 64 immunization program awardees that received federal funds under Section 317 of the Public Health Service Act. Grantees were required to include registry development as part of their immunization program activities, and funds from Section 317 grants could, at the awardee's discretion, go toward registry development.[3] While there was no specific line item for registries within the Section 317 grants, each immunization program had the option to spend what it considered necessary to promote registry development.[4]

Also during the early 1990s, funding from the private philanthropic sector became available for early registry development, serving as a critical stimulus to innovation. The Robert Wood Johnson Foundation (RWJF), along with several other smaller philanthropies, launched the All Kids Count (AKC) program in 1991. It began with one-year planning grants of up to $150,000 issued to 23 state and local health departments, leading in 1993 to 12 four-year implementation grants of up to $525,000, a phase that came to be known as AKC I. The purpose of AKC I was to use philanthropic funding to learn not only if immunization registries would work, but how they work best and whether they were promising enough to warrant sustained public funding.[5]

In 1998, RWJF authorized an additional $11.5 million to support the most advanced registries in the country as they worked toward full operational status by 2000. For this AKC II phase, 16 projects received two-year grants ranging from $300,000 to $700,000[6], moving beyond the "let a thousand flowers bloom" trial-and-error learning of AKC I to more rigorously defining core registry functions and performance measures. Other foundations also contributed to local initiatives during this time; for example, the Flinn Foundation provided $500,000 for development of the Arizona registry.[7]

Other additional innovative solutions came into play during this phase that expanded IIS funding. For example, Oregon's Medicaid office matched all private, non-federal funds awarded for development of the state IIS. As a result, a $500,000 grant from AKC paired with the promised match from Oregon Medicaid would mean $1 million in funding for the IIS and related immunization program functions. In the early years, private health plans in Oregon contributed about $250,000 annually proportional to their share of the local insurance market, funds which Oregon Medicaid matched. This partnership with state Medicaid gave Oregon's IIS a jumpstart for achieving a fully functional IIS based on CDC guidelines. Not to be outdone, a rural Oregon jurisdiction hosted a "cow-tipping" contest that generated several thousand dollars for local IIS technology solutions.[8]

In 2001, RWJF funded the Connections project through AKC with a three-year $5 million grant to look at the feasibility of integrating data across child health systems, including immunizations and newborn screening.[9] Unlike previous phases of AKC funding, there were no separate grants to local and state health departments during this phase, but instead a shift to supporting a community of practice among those jurisdictions working on integrating data and systems.[10]

The AKC initiative thus continued with rare longevity from 1991 until 2004, providing $30 million to 38 grantee sites and a national program office during those 13 years. The AKC funds also supported a feasibility study on a possible membership-based association for the IIS community, which led to the creation of AIRA in 1999.[11]

Throughout those 13 years, CDC provided significant funds as part of the Bush-era IAP initiative and later the Clinton-era Childhood Immunization Initiative. However, neither Congress nor the CDC created IIS line items, so 317 awardees had discretion in how to allocate for IIS based in part on local priorities and the availability of other funds.[12]

Understanding early funding needs

During the early to mid-1990s, the costs of building and running an immunization registry were still unknown, in part because no one had arrived at a shared understanding or definition of what a registry was. What was known by the end of AKC I was that developing registries was proving to be slower, more challenging and more costly than most had imagined.[13]

Cost studies conducted by AKC, CDC and other researchers explored both development and operational costs, as well as possible long-term funding solutions. Slifkin et al. examined the costs of developing several AKC-funded registries. The total cost to plan and implement a registry at that time ranged from $2.4 million to almost $7 million over the first five years.[14] These costs reflected the fact that the AKC registries studied were among the first community-based information systems to be developed, with higher costs due in part to experimentation.[15] Cost studies

Early legislation around vaccine records

The Clinton White House wanted to create a national system for vaccine purchases and tracking, and to use it to trace vaccines, dose by dose and child by child. But the vaccine proposal "…died in the early days of health care reform and then the health reform itself failed." When Congress did enact vaccine legislation, it contained no provision for tracking vaccines. Instead, health plans and Medicaid managed care plans would be responsible for immunization rates for the populations they served. Even though the plans for this national system failed, officials still wanted to use immunization registries as a means of accountability for protecting children from preventable diseases.

-Robbins and Freeman, "Commentary on Immunization Registries," *Public Health Reports*, 1998

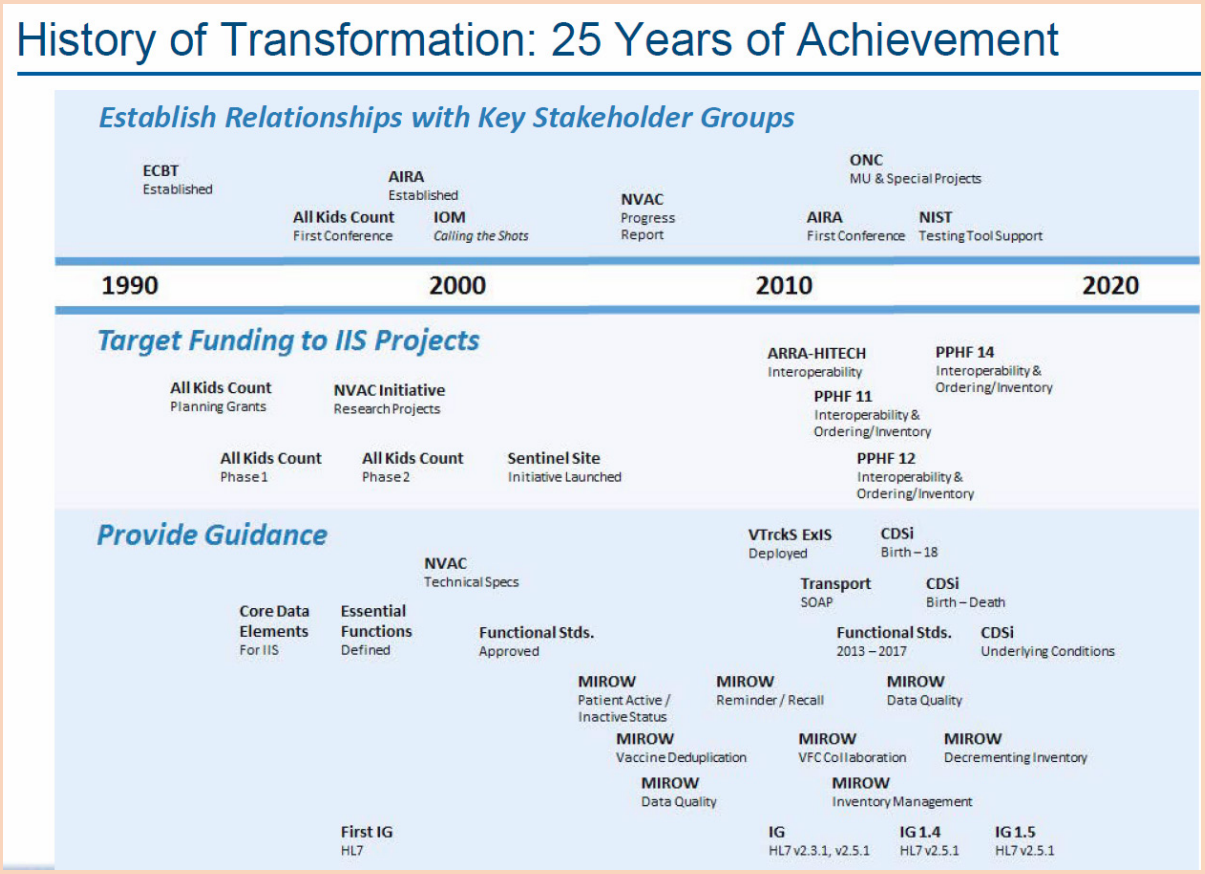
by Rask et al. also concluded that considerable resources would be required to establish and maintain immunization registries.[16] Most of the cost was related to the very labor-intensive provider recruitment and support approaches in use at the time, as well as the cost of supporting a variety of inefficient data capture methods, including paper forms, mailed floppy discs and dial-up modems.[17] For example, in two years, the Michigan IIS spent over $600,000 just on dial-up modems.[18]

A pivotal AKC cost study published in 2000 showed that, although a nationwide network of immunization registries would cost $125 million annually, it would be offset by annual savings of $280 million.[19] Cost offsets included not having to manually retrieve records for school entry, child care, provider and Health Plan Employer Data Information Set (HEDIS) reports; not having to carry out the National Immunization Survey (still not achieved by 2017); and prevention of over-immunization.[20] However, savings achieved by registries often benefited different programs in the public sector than those that bore the costs.[21]

Shifts in funding over time

By the year 2000, 42% of registry funds were federal, 32% came from state dollars, and another 26% were from other sources, such as foundations.[22] Most national and local foundation funding was dwindling by this time. A 2001 NVAC Progress Report indicated that financial sustainability for immunization registries had not been achieved.[23] Based on the proportion of registry costs that were provided from 317, NVAC estimated that approximately $50 million/year was spent on registries. Compared to the $125 million/year needed to maintain registries calculated by the AKC cost study, there was an apparent shortfall of approximately $75 million/year.[24]

NVAC's recommendations for long-term immunization registry funding included federal funds, vaccine surcharges, and incorporating funding into health care financing systems such as



PPHF and 317 funding

This figure highlights targeted funding streams for IIS projects since 1990, including All Kids Count, the IIS Sentinel Site program, ARRA-HITECH and PPHF. These funding streams were in addition to ongoing sources such as Section 317 and Medicaid funding. Source: Warren Williams, April 12, 2017, AIRA Conference, Chicago

Medicaid.[25] Other funding mechanisms included Vaccines for Children operational funds as a stable base of financing, health plans, additional funds from state and local government, and renewed funding from foundations. In 2000, the Institute of Medicine (now The National Academy of Medicine) reinforced NVAC's recommendations and called for a commitment to be made to ensure the success of registries.[26] Also in 2000, the Centers for Medicare and Medicaid Services (then HCFA – Health Care Financing Administration) agreed to provide Medicaid matching funds to support development of immunization registries, although the complexities and requirements involved inhibited widespread adoption.

The proportion of 317 funding allocated by awardees for immunization registries has always varied greatly, in part based on what other funding was available locally.[27] A 2000 study concluded that Section 317 funding, while playing a vital role in supporting immunization infrastructure, had also been unstable and unpredictable.[28] According to a report from Freeman and DeFriese published in 2003, Section 317 funding available for registries was at a peak in 1995, but declined thereafter.[29] A 2013 National Vaccine Advisory Committee (NVAC) report noted that appropriations for the Section 317 Program had not kept pace with the increasing demand to update the nation's immunization infrastructure at the local, state and federal levels.[30]

One additional source of funding from CDC was the Immunization Information System (IIS) Sentinel Site program, launched in 2001. The sentinel sites were a small group of high functioning IIS with good participation rates and the ability to analyze data. This program promoted timely analyses of population-based IIS data to identify trends in vaccine use, among other issues. From a volunteer pilot project conducted during 2001-2003, the IIS sentinel program has grown to become a reliable source of funding for participating sites. Since the pilot project, CDC has provided about $1.5 million annually to six to eight sentinel sites to advance the use, strengths and benefits of IIS data.[31]

Additional funds for public health emergency response emerged after 9/11. Many IIS programs leveraged this new funding for smallpox, Countermeasure and Response Administration, and Strategic National Stockpile inventory tracking. While providing needed support for IIS staff, these expanded functionalities also distracted from the core IIS mission to increase immunization coverage rates.[32,33]

More recent funding opportunities

Other funding opportunities emerged over the next decade. One of the most significant was the Prevention and Public Health Fund (PPHF) authorized under the Affordable Care Act of 2010, aimed at expanding and sustaining national investment in prevention and public health programs.[34] By 2015, the PPHF supplied more than 50

percent of the Section 317 immunization program funding.[35] The CDC has also awarded these funds to immunization programs to establish interfaces between IIS and VTrckS, CDC's national vaccine ordering and inventory management system.[36] In 2015, CDC made available approximately $10 million in 317 funding to be dispersed equally among all immunization program awardees ($156,000 per awardee) for the express purpose of assuring EHR-IIS interoperability and to facilitate the onboarding of EHR-IIS data for CMS Meaningful Use.[37] As with any public source of funding, PPHF was subject to changing political tides, and ended in 2017 as parts of the ACA were repealed.

Funding at the end of the first 25 years

Over time, IIS funding has shifted from a mix of public-private sources to a greater reliance—for some IIS programs, a total reliance—on federal funds. This change, perhaps not coincidentally, mirrors the reduction in coalitions, IIS advisory committees and other forms of broad professional and community engagement in and support for IIS as a shared resource and utility.[38] As IIS focused more over time on supporting an increasing array of immunization program priorities (e.g., VFC ordering, vaccine management, surveillance, assessment and AFIX), Section 317 and VFC operations funding became the primary sources for sustaining operations. While this funding has been a critical resource for IIS, an overreliance on one funding stream creates an inherent risk—making this lack of diversity in private-public funding a potential growing threat to IIS sustainability.

In 2016, the CDC Immunization Information System Support Branch announced four strategic priorities for IIS (see "Strategic Priorities" figure on page 4), one of which is financial and operational sustainability, in part through diversifying funding. All four of the priorities call for effectively leveraging partnerships.[39] Learning from IIS history can help programs do this well—particularly when reflecting on how engaging community partners through a variety of mechanisms contributed in the past to both legislative and direct financial support. Other approaches to sustainability will likely come from innovation, such as in developing new models of centralized services that avoid duplication of effort and leverage existing IIS investments.

Impact and value of IIS funding

Given the significant and diverse funding that has supported the evolution and operations of IIS, what can be said about the value delivered in return? In 2015, Groom et al. published an extensive review of IIS capabilities specifically related to improving vaccinations. Of 240 studies, 110 studies demonstrated improved vaccination coverage and/or reduced missed vaccination opportunities, invalid dose administration and disparities in vaccination rates. Half of the studies included in this review came from IIS within the U.S. Sentinel Site program. As a result of these findings and other findings, the Community Preventive Services Task Force published in 2014 its recommendation for use of IIS to increase vaccination rates, citing the "strong evidence of effectiveness" in IIS "through their capabilities to (1) create or support effective interventions such as client reminder and recall systems, provider assessment and feedback, and provider reminders; (2) generate and evaluate public health responses to outbreaks of vaccine-preventable disease; (3) facilitate vaccine management and accountability; (4) determine client vaccination status for decisions made by clinicians, health departments, and schools; and (5) aid surveillance and investigations on vaccination rates, missed vaccination opportunities, invalid dose administration, and disparities in vaccination coverage."[40]

Strategic priorities

Source: Warren Williams, April 12, 2017, AIRA Conference, Chicago

Sustainability into the future

What did those interviewed for this commemorative history project say about sustaining IIS into the future? Some noted the critical need to create and sustain value by delivering meaningful information to stakeholders on demand. Consolidated, complete and accurate immunization information is the raison d'être of IIS, a commodity no other organization or technology can yet provide. But that information must be put to effective use to build and maintain interest, credibility and value, particularly in an era focused on population health analytics.[41]

Others noted the importance of public-private partnerships, highlighting how the IIS community can enlist partners who will make investments in mobile apps, artificial intelligence, voice recognition, etc., potentially leapfrogging older technologies using private capital.[42]

Public health is an integral part of a much larger health and health information ecosystem. Both the public-private nature of vaccine delivery and the investments made in IIS have made IIS an exemplar of public-private information exchange and use. Maintaining this status will require continued investments in sustaining and growing a skilled workforce, reducing the resource disparities across IIS programs, diversifying funding and modernizing systems. The payoff will be a nationwide network of IIS that can provide timely clinical decision support, tracking of increasingly expensive vaccines, and the comprehensive analytics required for monitoring immunization coverage, disease trends and treatment outcomes.[43]

Citations and notes

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