2012 AIRA Meeting, Plenary Session Notes from Bill Brand, bbrand@phii.org

In some respects, this meeting could be seen as a 20th anniversary for immunization registries. Both the federal Immunization Action Plan initiative and the largely foundation-driven All Kids Count program had their inception just over 20 years ago.

In the early to mid-90's, in what came to be known later as the All Kids Count I era, the questions that were being asked were, *"Will immunization registries work? How will they work? Can public health design a system intended largely for private medical use that will be accepted by them?"* It was a period of 'let a thousand flowers bloom,' of experimentation, of many uncertainties. Some of you in this room were part of that brave and innovative era. Well, look at you now….

Immunization Information Systems have matured to arguably be the most mature and robust public health information system used in state and local public health. You have gone from over 250 local registries in the late '90's each doing their own thing, to a much more consolidated network of increasingly inter-connected systems, coalescing around more harmonized and standardized ways of capturing and exchanging data. You have jointly taken the world of immunization registries from "*Will they work* (AKC I) to *How will they work best?* (AKC II) to today's *How can we even more closely integrate our information and functions into the workflows and system of clinical care to support and advance their immunization practice?*

The planning committee has asked me to both look back and to look forward during the next few minutes; to see what of the past might be relevant to us as we prepare for the future.

One of my heroes in public health, Dr. Bill Foege, encourages us to study history. This is not so that we will avoid mistakes – he kindly points out that we will make them regardless – but to understand cause and effect: to understand that the decisions we make today will, in fact, shape our future, so they must be made with a clear sense of the future *we want to build*.

So let's begin this journey of looking back, of examining the issues before you today, and the kind of future you might shape for yourselves. I'll use the three important concepts that make up your meeting theme – Connect, Exchange, Advance – to organize this journey.

Connect

When the IAP and All Kids Count initiatives were launched, they were both all about connection. But the connection they were both largely after was connection with people, with communities, with provider practices.

With the IAP, we were asking questions like: how could the world's wealthiest nation experience a measles outbreak that took the lives of so many infants and children? Who were these children? In what neighborhoods did they live, what did we know about their immunization status, their cultural

beliefs and practices, the best way to reach them? 'Action' was the operative word; real connection with these families and communities was paramount.

Immunization registries were a key part of that action agenda. We sought to build a tool that would *connect* parents and their children, immunization providers and public health through the medium of immunization information. Immunization registry were a tool for social justice and vaccine equity, to help ensure every child, regardless of where they lived or their economic status, would have age-appropriate access to vaccines.

I thought it might be instructive to look at the lessons learned from All Kids Count I, published by Kris Saarlas, Alan Hinman and others in 1994. Those lessons are still relevant, although some may take different forms today.

- Involve stakeholders from the beginning.
    - They meant, of course, from the beginning of creating an IIS. But what's clear is that you need to also engage stakeholders at times of major change. Today, that means engaging with the EHR vendor community, HIEs and others.
- Recognize the complexity of establishing a population-based information system.
    - The policy and technical challenges have actually increased since those early days. Perhaps I was the only one to be this naïve, but ten, twelve years ago, I actually thought we might get to the point of being in maintenance mode, with our operations quietly and effectively humming along. It's clear, I at least was not paying sufficient attention to another AKC lesson:
- Plan for change
    - The challenge, of course, is in predicting the direction of that change. We'll get to that shortly.
- Develop the policy/business/value case
    - The same challenge HIEs face today. The growth of IIS and its place in MU point to that value proposition having been made well in most parts of the country.
- Define requirements to support users' needs
    - What is clear, is that user needs are continually evolving. Today, you are focusing on how to interact with EHR systems and on vaccine accountability, which means new requirements. Later, you will hear from Jenne McKibben from Oregon ALERT on the IIS community collaboratively defining requirements for IIS in this rapidly changing environment.
- Address common problems collaboratively.
    - I believe this is more important than ever, and AIRA plays such a critical role here. The days of let a thousand flowers are not only long gone, but any IIS that operates as an island not only threatens its own credibility but, because of the nationwide reach of EHR vendors, that of the entire IIS and even public health communities. So the charge for

you today is to solve problems collaboratively wherever possible but to come to single, consensus-driven solutions wherever possible.

- Plan boldly but implement incrementally
    - Always good advice. The issue today is that the speed of 'incremental' is tied to the speed of change, which is accelerating. Bill Gates has said that we tend to overestimate the amount of change that will occur in two years, and underestimate what will occur in ten. That does seem to be true, and it captures the challenges and risks of planning for the future.
- Use the information (even if not perfect)
    - Nothing improves data quality like use. Unlike most commodities, information increases in value with use.

Those lessons learned certainly still fit as we think about the work you are doing with providers, hospitals and others in implementing Meaningful Use.

I realize that, for many of you, MU may feel like the bane of your life right now. But HITECH and MU are part of larger trends that were occurring anyway. What HITECH brought was an acceleration and, more importantly, an increased focus and standardization in those trends. When you or your successors look back on the period of MU, I believe you will realize it was a painful but necessary and ultimately beneficial phase. By helping to create more standardized and less proprietary EHR systems, and by including public health reporting as required functionality, HITECH is corralling the EHR marketplace in ways that should make it easier for you to work with over time.

Another aspect of HITECH, and in many places a particularly thorny one, is working with the nascent Health Information Exchanges, which brings us to your theme of Exchange.

Exchange

Perhaps the least clear aspect of the current e-health transformation is how to best address the challenge of Health Information Exchange. There is a great deal of angst in many corners of public health around working with HIEs right now. There are certainly some success stories but they are often with HIEs that were well-established before HITECH.

Whether you are hopeful, despairing or fearful about working with HIEs, I believe three things can be agreed to:

- As a nation, we simply *have to solve* the issue of secure HIE if we are to meet our goals of continuous, quality, safe and affordable care. We simply have no choice about finding a way—or ways—of getting the right information to the right person at the right to support making the right decision.
- Having said that, it anything but clear if today's models of HIE will be the ones that will survive, or if new models will emerge. There are so many unanswered questions about HIEs right now. To what extent will they be pure pass-throughs, and to what extent value-add entities that

transform messages, support public health reporting, support assessment and research, etc.? What business models will prove the most sustainable? What architectures the most useful and affordable? What will be the role of EHR-to-EHR exchange be in the larger exchange picture? While it's not clear what the answers to these questions will be—and it's unlikely to be a single answer—we do know that, one way or another, we have to solve the challenge of health information exchange.

- A third premise is that public health has to be part of that solution, both as a partner in the inter-connected information ecosystem that exists, but also because of its mission of promoting and protecting the population's health and so needing health reform and e-health to succeed.

When you think of it, IISs are very much like HIEs, or at least the more robust HIEs: Both gather data from disparate sources, standardize and aggregate it, then make it available to others to support improved practice and assessment. If immunization registries had, back in the 90s, had no 317 funds available after the All Kids Count funding ended, and they were told they had to sustain themselves financially based on legislative appropriations, user transaction fees or subscriptions or other means, they would have been in the same boat that HIEs are in today. The financial, policy and technical challenges HIEs face are non-trivial—they are much like the challenges you faced over the past 20 years—and they deserve whatever support you can give them. They are very much kindred spirits in terms of their purpose and the challenges they face.

The HIE marketplace is very unstable right now. That may mean an HIE in your jurisdiction may not be the most reliable or collaborative partner. I suspect more are in a panic mode than we might suspect. I urge you to not give up on them but to help solve the problem of what HIE should look like in our country.

Advance

Let's move on the theme of Advance, your third and perhaps most important theme. What lies ahead for the IIS community? In what directions might you advance?

While it's always a risk to look into the future, it's usually good to begin with being clear about the assumptions you hold about what trends will be most influential. Many of these may be outside your control, but that's all the more reason to be clear about them.

For what it's worth, here are my assumptions about the future:

- To begin with the bad news, and a safe prediction, the financial picture for government, and so public health and IIS, will stay gloomy for quite a while. Even a recovered economy will not restore HD budgets or return the workforce to former levels any time soon. But I do believe that 317 funds will be held harmless more than many other program areas, although Congress and CDC are likely to prioritize issues like VFC accountability and preparedness for flu over other aspects of the program.

- The e-health trajectory will continue, only in part driven by HITECH. EHRs will continue to evolve, slowly, and perhaps occasionally dramatically, being driven by customer needs. EHR systems were initially designed as transactional databases, largely to improve revenue capture. Today, they are being asked to transform into patient-centric, longitudinal, smart and highly functional systems to support clinical and patient decision making. So I think we will eventually EHRs being re-architected to meet these new expectations. That may also result in a big shakeout of the industry perhaps as early as the MU stage 3 requirements.
- We will witness the growth of increasingly sophisticated patient registries being developed within health care settings. These registries will be powerful analytic tools to support quality measurement and research in identifying the most cost-effective ways to improve outcomes and safety.
    - As an aside, the growth of these robust registries may mean you can go back to using immunization registries, since the term *registries* will convey the analytic utility of your systems much better than 'information system.'
- Health reform will continue to evolve as well, focused initially and largely on payment reform. I am optimistic that the US will eventually have a more equitable health system, although we will grope our way there in fits and starts. I believe we will continue to work toward a reformed and transformed health care delivery and national health insurance policy sufficiently that we will no long have health status indicators below those of many developing nations, despite spending one out of five dollars on health care.
    - There is a lot of focus now on management and accountability for the VFC vaccines. But our larger public health purpose should be to make the VFC program and all such other safety net programs unnecessary. That will require our nation to agree that access to health care and preventive services is a right of all who live in this country. We are not there yet, but I am hopefully we will get there eventually, if for no other reason than we can afford no other way.
- HIEs will instantiate in various forms but grow slowly across the country, likely more at the regional than statewide level initially. Because HIE moves at the speed of trust, regional or provider-to-provider exchanges will be the easiest to launch and sustain.
- In public health, we will see a greater emphasis on population health services, community health assessment, data analytics, an expanded reliance on data from non-health sources. LHDs will move away from providing clinical services. And agencies will increasingly be a secondary user of data that was collected by others for their own purposes, and reported to public health as a secondary use case. That, of course, includes immunizations.
    - This means that public health will have to learn much more about how and why information is collected for clinical or others purposes. This will be critical background information to have in ensuring ongoing data quality.
- On the larger front, we will see growing use of cloud-based computing by government entities. The federal government, not normally associated with innovation, is making increased use of the cloud, including for public health surveillance work, and that will extend to states.

Certainly many other trends that will likely have an impact on IIS but let's move on to the decisions I believe you can make today that will help keep IIS effective and credible in an e-health world.

1. The most critical decision for the IIS community to make and act on is to rapidly accelerate your efforts to harmonize and standardize your approaches to working with your data sources and their EHR vendors. You have made a lot of important progress on this with the 2.5.1 IG, but much work remains to be done. AIRA must pay a big role here in being a natural convener, facilitator and disseminator of collaboratively developed and agreed-to approaches. I see this as job #1 for the IIS community and for AIRA, in large part because of its urgency.

2. Another such area is cloud-based computing.There is always a risk in IT to lunge after the newest tool. But I do think that the cloud, coupled with open source solutions and shared services, are substantial and promising enough approaches to have staying power. They have been developed well in private industry, and I believe they must be explored by public health.

   Given the challenges of working with increasingly unresponsive central IT shops, is moving to the cloud a viable and even preferable model? I can see shared governance of IIS in the cloud where participating IISs have their own vault for their data, but sharing key IIS components such as the vaccine validation and forecasting module, report generating and other shared services

   The IIS community, as the most mature technologically within the ph family, could be in the forefront of such exploration. It may help to realize that the cloud is where the internet was 12-15 years ago: proving it is secure and accessible enough for health data.

3. Claim the vaccine forecasting/decision support space as your own. EHR vendors should not be duplicating what could be made available from public health. Given the complexity of translating ACIP recommendations into computable rules, this should eventually be a joint, national effort to which all users, IIS and EHRs alike, point.

4. Lastly, engage with the Public Health System and Services Research community to research new approaches to reminder-recall (mobile technologies, e-mails, etc.), optimal ways to display vaccine forecasting in EHR systems, overlaying immunization coverage with other data to better understand remaining pockets of need. Engaging the applied research community can help to identify emerging promising practices in a rapidly changing world.

So, in what directions can the IIS community advance?

- Make an all-out commitment to standardizing your approaches to working with EHR and other system vendors. You are now players in a much bigger, higher stakes game, and neither you nor public health can afford to have you play alone or by old rules.
- Move aggressively to be *the* experts in vaccine forecasting. Claim that space but ensure you are delivering measurable quality.

- Explore directions that are being paved by private industry and that help position you for the new, more affordable technologies and approaches. This may include cloud-based computing, open source solutions and shared services.
- Don't lose sight of the social justice dimension of your work. It's an important part of your legacy and of public health as a whole.

Remember the lessons from All Kids Count I: Plan for change, plan boldly but implement incrementally, continue to refine and push the value proposition for IIS, and, more important, stay engaged with the growing number and variety of stakeholders.

You are the most visible and leading edge of public health in an e-health world. In the 90's, people like Susan Abernathy and others predicted the need for greater use of standards, well before others saw that future. Those decisions helped to move IIS into that leading edge position.

Today, your challenge is to peer into the future, to anticipate trends, and to jointly make decisions that will move you into an era of effective integration and collaboration that we could not have imagined in the 90's.

The vision and the leadership to do that are in this room today. I have every confidence that you will succeed in charting a course that will greatly increase the value of IIS to a growing number of others, that you develop new and innovative solutions to increase your effectiveness in improving immunization practice, and find new way to be an instrument of social justice and vaccine equity.

Thank you.