

IPHI Testimony to the Illinois Health Information Exchange Authority (ILHIE) Data Security and Privacy Committee (DSPC)

Peter Eckart, Director of Health and Information Technology, Illinois Public Health Institute, July 17, 2012

The Authority has charged the ILHIE Data Security and Privacy Committee with developing recommendations for possible privacy, security and consent management policies for the ILHIE. The Illinois Public Health Institute is pleased to be able to provide testimony on this important issue facing the ILHIE and involving all of Illinois' residents. IPHI works through partnerships to promote prevention and improve public health systems that maximize health and quality of life for the people of Illinois.

IPHI's role in health information exchange, EMR adoption, and privacy and security

From 2007-2009, IPHI staffed Illinois' participation in the national Health Information Security and Privacy Collaborative (IL-HISPC), an early federal initiative to address privacy and security in the (then) upcoming world of inter-connected electronic medical records.

In 2009, IPHI started working with Illinois' Office of Health Information Technology, when it was still with IDHFS. We monitored and supported the regional planning processes for the sixteen medical trading areas that eventually led to the creation of Illinois' regional HIEs.

In 2010, IPHI helped to form the statewide Illinois Health Information Technology Regional Extension Center (IL-HITREC) that provides services and support to healthcare providers installing or upgrading medical record systems. IPHI created and staffed the online training platform to support that initiative.

Finally, for the last fifteen months, IPHI has worked with the Illinois Department of Human Services on the Illinois Health and Human Services Framework, an initiative that seeks to integrate the client and provider information systems of seven state agencies, including DHS, HFS, DCFS, IDES, DCEO, IDPH, and Aging. On behalf of the Framework, IPHI hosted 25 Listening Tour conversations with service recipients and community providers, in order to introduce the idea of the Framework to these important stakeholders and to gather their feedback about the impact of state agency systems in their lives.

IPHI CEO Elissa Bassler serves on the HIE Authority Advisory Committee and this Privacy and Security Sub-committee. I serve on two OHIT working groups – on public health and consumer education – and formerly served on the OHIT Privacy and Security Working Group that preceded this committee's work.

Over the course of our involvement in public efforts leading to the development of the ILHIE, IPHI has developed expertise and opinions on many of the questions before these panels. Today, we're focusing our remarks on the topic of options and permitted uses for patient data.

IPHI strongly favors the opt-out model of patient consent

IPHI strongly favors the opt-out model of patient consent: all patients should be given the option to opt out of electronic medical record and health information exchange systems. To be clear, we are saying that the Illinois HIE and its affiliated regional exchanges should make patient data available through the ILHIE and among the regional exchanges as its default policy. We believe that this creates concomitant obligations on the part of the state/exchange operators to secure patient data as strongly as possible, and to restrict access to this data to only those who need it for valid medical or operational reasons.

Health information at the heart of assessment, advocacy and assurance

The Opt-Out approach is important to the efficient and effective operation of the HIE. It is also critical to ensuring the highest quality of patient care; without access to medical records, physicians and other health professionals are less able to make appropriate diagnoses and treatment decisions.

However, IPHI believes there is another critical public good that is at stake in this decision. Improving health at the population level – across groups of people rather than the individual level – is the mission of public health. Examples include: clean, potable water reduces disease among everyone who drinks it; improving the nutritional quality of school lunches helps all students be healthier. Public health is reliant on aggregated, not individual, data for understanding what health problems are affecting which groups of people and where. Data helps public health plan population-level interventions, evaluate the efficacy of public health programs, and advocate for policies that improve the public's health.

The success of health care reform is dependent on people being healthier/less sick overall. On the clinical side, that is why there is such focus on primary care and preventive services. It is also why there is a significant focus in the ACA in strengthening population health outcomes. IPHI sees the Illinois HIE as a new and powerful mechanism that will improve our understanding of the health of Illinois residents and sub-groups within the population. Simply put, more and better data can lead to better outcomes, and comprehensive data leads to the best outcomes. Opt-out consent is likely to lead to the highest percentage of residents participating in the Exchange, which will give us the most detailed descriptions of the health of our communities. That is why we support it.

Let me make clear that for the purposes I describe, we do not need access to individual patient data. Public health works with population level data, which means that we count up the occurrences of a particular health indicator across a group or the whole population, and then analyze the data to understand trends, emerging health issues, and disparately affected groups, whether defined as a geographic community, a racial or ethnic group, or age group. Then we plan and implement interventions that can reduce the burden of disease in the group or population. Comprehensive aggregated data is the key to better policies and healthier people.

Obesity as an example

The current public attention to obesity gives us a good way to understand how comprehensive data supports good policy making and program design. In the last few years, we have come to understand obesity as an epidemic that is sweeping the country. Perhaps you are familiar with the famous set of slides from the CDC that show a map of the percentage of obese Americans state by state over the last 25 years. In 1985, eight states reported the highest level of obesity, with 10-14% of residents significantly overweight. Over time, the maps add colors to represent 15%, then 20%, then 25%. By 2010, 13 states have an obese population equal to or greater than 30%, and no state is below 20%. As percentages of overweight and obesity increase each year, the map gets darker and darker, showing simply and clearly how pervasive a problem this has become for the entire country. That's the power of comprehensive health data.

Now, imagine that we have that same kind of data in Illinois, but available at a much finer level of detail. Most EMRs will contain height and weight measurements (along with age and gender), which gives us an indicator of being overweight or obese: body mass index (BMI). When that BMI data is available in an individual's medical record, that provider can quickly evaluate that individual patients' danger for overweight and obesity.

When that BMI data is available within the HIE, it can be added to BMI data for patients across the community and across the state, and reported back by community, age, race, ethnicity, health status, and a host of other factors. When combined with other analyses – such as available parks and recreation, crime statistics, access to health foods, educational attainment, employment data, and other community characteristics– we can pinpoint the places and populations where obesity is most prevalent, and also start to understand the reasons why it is better in one place or worse in another. With comprehensive aggregated data, we can design programs that target the highest risk communities, and also have the means to evaluate the effectiveness of those interventions.

In conclusion

Public health has long been a leader in generating, collecting and disseminating information about the health of communities. Public health deals in whole populations, and this population-level data is hard to come by. The opt-out policy of consent health information exchange will result in as comprehensive a set of data as possible. We have the opportunity to aggregate the data about the residents of Illinois, and help them to be healthier overall – a public goal that will help save lives and conserve resources.

Thank you.