

Testimony

June 27, 2012

I am Edward J. Murphy, a voting Director of the Central Illinois Health Information Exchange (CIHIE). I was appointed to the CIHIE Board as the designated representative of the Quality Quest for Health of Illinois' Consumer Council. In plain English, that means I'm the Consumer guy, not the Medical guy or the Computer guy.

I've been involved as a volunteer with what is now called CIHIE since Quality Quest first decided to explore the idea of creating an HIE. I started in a workgroup studying alternatives for the fiscal sustainability of an HIE in Central Illinois, a logical endeavor for a retired economist. Since then I have remained actively involved, becoming more interested in and enthused about HIEs generally and CIHIE specifically.

My testimony today is focused primarily on ethical considerations but also on economy, efficiency, and effectiveness regarding privacy, security, and consent management.

I have specific comments on six issues.

1. Opt-in, opt-out, and informed consent

Patients should have a choice about whether their health data should be in an HIE or not.

I do not believe that most consumers are, or want to be, fully informed about data security and privacy issues and protocols for HIEs. I'm not saying they don't want to know anything; I'm just saying they don't want to know everything. They are not stupid or uncaring. They are smart enough to know the details are many and complex. They care enough to want reasonable assurances that someone else understands the details and can be trusted.

An opt-in protocol presupposes that large numbers of patients want to know the multiple highly technical details of how HIEs collect and use and protect their health data. By all means, tell any who ask for the details everything they need to satisfy their perfectly legitimate concerns.

If we trust patients to trust providers to perform medical procedures they rarely understand fully, why shouldn't we trust them to trust us when they decline our offer to discuss (and possibly reject) participation and/or exercise their right to opt-out. We bear the burden of earning the trust of both patients and providers every day. Let's welcome that trust by patients.

I strongly support the opt-out model for the ethical reasons outlined. In addition, I

support the opt-out model because it is more economical, more efficient, and more effective.

2. "Breaking the glass"

I do not support "breaking the glass" for emergency medical treatment. The patient made a decision to opt-out and that decision trumps all other considerations.

3. Patient access to their data in an HIE, including data correction

This is a patient-provider issue, not a patient-HIE issue. The patient needs to talk to the physician (or other designated professional) who can either correct the error if there is one or provide context and plain language explanations that are implicit in HIE data but not likely to be readily identifiable by a typical patient.

4. Using the Notice of Privacy Practices

Notices of Privacy Practices as currently used deal with health information being made available to providers and insurance companies. They already get this data. The HIE assures patients and providers that the data moves through a well protected system and includes data from other sources. Adding HIE to the Notice, including how to opt-out, should readily fit into providers' existing administrative procedures.

As for insurance companies, they don't get HIE data. I have little confidence that they are concerned about my privacy. They are, of course, concerned about protecting my data because they believe my data is their proprietary data to do with as they choose.

5. How long should a consent be valid

A valid consent should be valid indefinitely, unless superseded by a revised valid consent.

6. Secondary uses of HIE health data

I strongly support the use of de-identified multi-year, large population data for epidemiological studies. Data security is a major and obvious concern. The Centers for Disease Control (CDC) has done absolutely first-rate work in this area for decades so they have already established protocols for data and privacy. Similarly, the Bureau of the Census does special surveys to collect and report highly sensitive data. I suggest you consult both CDC and Census before establishing any guidelines.