



CT Health Information Exchange Why we need an opt-in privacy policy

For HITE-CT Board meeting
April 18, 2011
Update April 20, 2011

- Privacy is an extremely sensitive, highly charged issue with the public, particularly privacy of health information.
- Public trust in the health information exchange is critical – to ensuring participation, funding and policymaker support.ⁱⁱⁱ
 - Many consumer and advocacy groups feel strongly about protecting privacy. Their help will be needed to make the HIE successful.
 - Opt-in vs. opt-out is only the first of many policy decisions the HIE will need to make that impact consumers. But many of those policies follow from and/or are complicated by that first decision.
- An opt-in policy is consistent with CT's surrounding states.
 - RI and MA have stricter opt-in policies in that no data can leave its source without patient consent.^{iv}
 - RI policymakers note that states with more stringent privacy policies will be better positioned to work with less stringent states^v
 - Accessing care across borders will be more complicated if CT's policies are inconsistent
 - VT recently shifted from an opt-out to opt-in policy^{vi}
- Legally protected sensitive information (i.e. mental health, HIV, substance abuse) cannot be shared without affirmative patient consent under state and federal law^{vii}
 - This requires labor-intensive, error-prone data segregation by busy providers.
 - The technology for tagging sensitive information is not mature.^{viii}
 - There is ambiguity in what is considered sensitive under law. For example, sometimes a drug or treatment is prescribed for a sensitive condition and sometimes not.
 - Reports find that physicians do not favor edited files, many are concerned about the quality and comprehensiveness of limited data compromising patient care, and have liability concerns if they rely on the record they can see.^{ix}
 - Providers are unlikely to accept liability for ensuring all sensitive information is identified and segregated.
 - Notices of deletions or "flags" to files add to the stigma for patients.

- The vast majority of patients, in CT and other states, choose to participate in opt-in HIEs.

RHIO/Exchange	% of patients asked for consent who signed	Sources
North Adams MA	92%	"Engaging Patients for Health Information Exchange," Health Affairs, March 2009
Newburyport MA	88%	"Engaging Patients for Health Information Exchange," Health Affairs, March 2010
HIXNY	86%	Michael Fitzgerald, HIXNY Health IT Adoption Specialist, personal conversation-April 13, 2011
Hartford Hospital	> 90%	eHealthCT Board Meeting, April 2011
CHC Inc.	Of first 8,000 patients asked, all but 6 consented	Margaret Flinter, CHC Inc., April 2011
Southern Tier NY	91%	Emily Pape, Southern Tier, personal conversation- April 13, 2011
RIQI	95%	Charlie Hewitt, RIQI, personal conversation-April 14, 2011
Western NY Health-e Link	94%	Steve Allen, personal communication, April 19, 2011
Rochester RHIO	97%	Ted Kremer, personal communication, April 20, 2011

- Other states have reported that consumer participation is not a significant challenge, but getting providers to participate has been.^x
- Either policy requires significant patient education.
 - The process of soliciting consent is an educational opportunity to help patients understand how the HIE works, the benefits as well as risks, and could help mitigate negative public opinion and limit liability in the event of a breach or scandal^{xi}
 - The only way to be certain that patients have received a notice of their rights and had an opportunity to exercise them is to require a signature on the notice, with an option on the notice they sign to opt-out or in.
 - Signing a combined HIPAA/HIE consent form that only references a website or phone number does not ensure that it was actually given to the patient.
 - Patients may not be allowed to take the notice home.
 - Expecting patients to remember or write down opt-out instructions, wait through their appointment, go home and then make a call or go online to opt-out is unreasonable.
 - Busy practices are not likely to make a phone line or computer available in the office for patients to opt-out there.

- Audits or secret shopper surveys of patients are unlikely to find that 100% of patients in an opt-out system had an effective opportunity to exercise their rights.
- The HIE consent form can be integrated into a HIPAA form creating no new work for office staff.
 - Most eHealthCT pilot sites have exercised this option successfully.
- Federal guidance has not been issued on privacy policies.
 - It would be difficult and costly to shift from an opt-out to an opt-in policy after implementation.
- If there was ever to be a breach of medical information, public outcry could lead to reactive public policies that would shut down and/or de-fund the HIE.
- Current trends in medicine are to empower patients to take control of health care decisions and take responsibility to keep themselves well.
 - An opt-out policy takes away an important locus of control for patients over their sensitive health care information.
 - An opt-in policy facilitates the provider-patient relationship and creates a foundation of trust that fosters productive health improvements.

Concerns raised in smaller consent meeting:

- Patient participation rates will not be high enough to make the HIE viable with an opt-in policy.
 - This has not been the experience of any opt-in HIE we have surveyed.
 - See consumer participation rate table above.
- It has been suggested that under CT state law, providers are required to identify/flag sensitive information in every chart – paper or electronic – now. The opinion stated that identification and segregation would still be required even in an opt-in system where every patient has consented to share their records, even if the consent form specified that legally protected, sensitive information will be included.
 - We can find no legal rationale for this suggestion and have legal opinions that after a patient signs a comprehensive consent form (that describes types of legally protected sensitive information that will be shared) the provider does not need to flag or segregate sensitive information in records.^{xii}
- Workflow and the continuity of care will be disrupted by having to gain consent.
 - HIE consent can be integrated into the existing HIPAA notice requirement.^{xiii}
 - No disruption has been reported by eHealthCT or any states we contacted.
- Providers who visit the HIE early in development, before most patients have had an opportunity to consent, and find that many records are not available for viewing, will not come back and routinely use the HIE.
 - Other states have solved this problem by collecting consent from patients for a length of time before going live to ensure a well-populated exchange.^{xiv}

ⁱ CT Health Information Exchange: Why We Need an Opt-in Privacy Policy, CT Health Policy Project, April 2011.

ⁱⁱ Consumer Consent for Health Information Exchange, Arizona Health-e Connection, April 2008.

ⁱⁱⁱ TIGER Team recommendations to D Blumenthal, ONC, August 19, 2010.

^{iv} Tripathi, M., et. al., Engaging Patients for Health Information Exchange, Health Affairs 28:435-443, March/April 2009, and D Gifford, Director, RI Dept. of Health, Protecting Consumers' Health Information: RI's experience with confidentiality legislation for RHIOs, for National Governor's Association Center for Best Practices, 9/26/08.

^v D Gifford, 2008.

^{vi} C. Jones, VT Blueprint for Health, personal communication, March 2011.

^{vii} Recommendation for Consent Model, Legal and Policy Subcommittee of CT Health Information Exchange Advisory Committee, 2010.

^{viii} S Cleary, SMC Partners

^{ix} Consumer Consent for Health Information Exchange, Arizona Health-e Connection, April 2008.

^x Charlie Hewitt, RI Quality Institute, 4/14/11.

^{xi} Consumer Consent for Health Information Exchange, Arizona Health-e Connection, April 2008.

^{xii} Greater New Haven Legal Assistance, 4/14/11, Moses Barvas, Robinson & Cole, 4/15/11.

^{xiii} This is the option chosen by most eHealthCT participating provider groups.

^{xiv} Michael Fitzgerald, Health Information Exchange of New York, 4/14/11