

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

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By [STEVE LOHR](#)

Published: March 16, 2010

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Public trust is critical

Ultimately, to be successful in the use of health information exchange to improve health and health care, we need to earn the trust of both consumers and physicians.

From August 2010 TIGER Team recommendations to ONC

Public trust is critical

- Without that, patients will not participate
- It will not be useful to providers
- Policymakers will not support
- Uses for data collected will be suspect
- Funders will not support
- Invites vigorous oversight
- Discourages collaboration

eHealthCT process -- Committee

- AARP
- CT Health Policy Project
- Hispanic Health Council
- CT Legal Services
- Many providers – hospital and practice based
- Substance abuse treatment provider
- Mental health clinic
- CT AIDS Coalition
- 1199
- CT Center for a New Economy
- Office of State Comptroller
- State Health Care Advocate
- New Haven Legal Assistance
- Universal Health Care Foundation

Public process

- 2 forums at Capitol, attended by at least 100 people over the two forums
 - Televised on CTN
 - AARP volunteers flyers
 - Blogs, listservs, flyers at community meetings
- Conference calls
- Media outreach
- Online comment
- Dedicated webpage
- Webinars
- Survey stakeholders

Reasons for opt-in

Consistent with surrounding states

NY, RI, MA all use opt-in policies

accessing care across borders more complicated

VT recently shifted from opt-out to opt-in

Under current state law exchanging info on “Sensitive conditions” requires affirmative consent

Providers would have to delete

Error-prone

And accept the liability for that function

Incomplete records compromise quality

Notices of deletions add to stigma

Reasons for opt-in

MA study found that 88 to 92% of patients elect to participate in their opt-in system

Either opt-in or opt-out requires a substantive public education campaign

Can be integrated into HIPPA notice
no more work for front office staff

If there is ever a breach of medical information, public outcry could lead to reactive policies to restrict or even shut down HIE

Builds on patient self-management, empowerment in PCMHs

Need to trust consumers if you expect them to trust you

Federal recommendations

From August 2010 TIGER Team recommendations to ONC

- **We must consider patient needs and reasonable expectations. Patients should not be surprised about or harmed by collections, uses, or disclosures of their data.**

From ONC Framework document December 2009

- **Individuals should be provided a reasonable opportunity and capability to make informed decisions about the collection, use, and disclosure of their individually identifiable health information.**

To be conservative, in case federal regulations are more restrictive, we should implement an opt-in

Switching from an opt-out to an opt-in later could be very difficult