

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

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# Recent press

**The New York Times**

## How Privacy Vanishes Online

By [STEVE LOHR](#)

Published: March 16, 2010

[STLtoday.com](#)

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## Congress considers online privacy rules



## Internet "Do not track" efforts could dash health data collection

## White House backs online 'privacy bill of rights'

Chris Lefkow

March 18, 2011

**THE MIDDLETOWN PRESS**

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## Connecticut one step closer to red light cameras

Published: Saturday, March 19, 2011

# 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