



**Testimony on S.B. 368,
An Act Concerning the Health Information Technology Exchange of Connecticut
Public Health Committee Hearing, March 16, 2012**

My name is Brenda Kelley, and I am the State Director of AARP in Connecticut. AARP's nearly 600,000 members 50+ in CT, care deeply about the quality of their health care and also are concerned about protecting the privacy of their personal health information. Because of this, I was honored to be appointed by the Majority Leader of the House of Representatives as one of two consumer representatives on the Board of Directors of the Health Information Technology Exchange of CT (HITE-CT). I also co-chair the Special Populations' Committee of HITE-CT.

I regret that I am unable to be here today to testify in person on SB 368 due to health issues in my own family that have heightened my desire for improved ways for health care providers to exchange patient information to improve healthcare quality while also giving patients the information they need to be real partners in their own healthcare. So I have a very personal interest in the work of HITE-CT as well.

While well intended, SB 368 could jeopardize the progress that HITE-CT has made thus far, including progress in ensuring that HITE-CT will be designed and implemented to protect patient privacy while also realizing the potential of electronic patient data & health information exchange to improve health care quality, outcome research, prescription drug monitoring, patient safety, informed decision making by patients, to make it easier for doctors and other health professionals to have the information they need in a convenient way, real time way to improve the quality of each patient's care and much more.

Attached to this testimony is a copy of the **Healthcare Consumer Principles and Expectations** that were developed by the Special Populations Committee of HITE-CT and adopted by the HITE-CT Board at their November 21, 2011 meeting. Seven key principles and expectations are included. After each principle, I have highlighted some specific language that relates to provisions in SB 368:

- 1. A healthcare consumer shall be able to access their personally identifiable health information conveniently and affordably;**
- 2. A healthcare consumer shall be notified how their personally identifiable health information may be used and who has access to it;**
 - Healthcare consumers shall receive easily understood information identifying the types of entities with access to their protected health information and all the ways it may be used or shared...
 - Tracking and audit trail systems shall be in place that permits healthcare consumers to request a review of all entities that have

entered, accessed, modified and/or transmitted any of their personally identifiable protected health information.

- As part of this principle, HITE-CT consumers shall be presented with a notice of practices when they visit a healthcare provider in the HITE-CT exchange. Procedures shall be implemented to collect the acknowledgment of these practices from the healthcare consumer or their authorized representative.

3. A healthcare consumer shall have control over whether and how their personally identifiable health information is shared

- A critical privacy protection is that healthcare consumers shall be able to opt-out of having their personally identifiable health information – in whole or in part- shared across the HITE-CT network. This will happen at their health provider's office after they have received the notice of practices referenced above.
- Further, healthcare consumers shall be notified that they have the option to include their "sensitive" protected health information (PHI) in the health information exchange (HIE) by exercising an opt-in to share their sensitive data. If they do not opt in, their sensitive PHI (for HIV, substance abuse, mental health, etc) will be determined according to existing federal & CT laws and will not be shared.

4. Systems for electronic health data exchange shall protect the integrity, security, privacy and confidentiality of a healthcare consumer's information.

5. Health information exchange shall be designed and built to meet the diverse needs of all Connecticut residents, without barriers or diminished function or quality for some.

6. Implementation of the Health Information and Technology Exchange of CT (HITE-CT) shall be accompanied by a significant healthcare consumer education program so that healthcare consumers understand how the network will operate.

- Through the Special Populations Committee, HITE-CT is finalizing consumer educational materials including: a consumer brochure; a consumer section of the HITC-CT web site (under development); a consumer educational video and more. I have shared drafts of some of these materials with the Co-Chairs of the Public Health Committee.
- Through the work of other HITE-CT committees, policies, procedures and the operational details of each of these consumer principles are being finalized.
- The views of many diverse stakeholders, including consumers and consumer advocates, were considered in developing these principles. They have been adopted by the Board of HITE-CT.

7. The governance and administration of electronic health information exchange networks shall be transparent and publicly accountable.

I believe the Healthcare Consumer Principles and Expectations for HITE-CT are very strong. The views of many diverse stakeholders, including consumers and consumer advocates, were considered in developing these principles. They have been adopted by the Board of HITE-CT and are in the process of being implemented through policies, procedures, and operational processes. They are in compliance with the public policy position of AARP regarding health information exchange and the privacy and confidentiality of health information.

They also were adapted from consumer principles developed by the Consumer Partnership for e-Health, a national, non-partisan group of consumers, patient, and labor organizations dedicated to improving health care quality and achieving a patient-centered health care system through expanded use of information technology and knowledge sharing.¹ Further, the development of their principles was supported by the Markle Foundation's Connecting for Health Collaboration bringing together more than 100 public and private organizations to accelerate information technology to improve health and protect the privacy of personal health information.

In conclusion, while well intended, SB 368 could jeopardize the progress that HITE-CT has made thus far, including progress in protecting patient privacy and achieving a patient-centered healthcare system that AARP members want and, I believe, we all want.

¹Consumer Partnership for e Health members who developed the Health Information Technology Consumer Principles in 2009 are: AARP; AFL-CIO; American Federation of State, County and Municipal Employees; American Federation of Teachers, Bazelon Center for Mental Health Law, Center for Democracy and Education, Center for Medical Consumers, Communications Workers of America, Consumers Union, Department for Professional Employees, AFL-CIO, Childbirth Connection, Health Care for All, International Association of Machinists and Aerospace Workers, International Union, United Auto Workers, March of Dimes, Mental Health America, National Coalition for Cancer Survivorship, National Committee to Preserve Social Security and Medicare, National Consumers League, National Partnership for Women and Families, Service Employees International Union, (SEIU), The Children's Partnership, Title II Community AIDS National Network, United Steelworkers International Union (USW).

Health Information Technology Exchange of Connecticut (HITE-CT) Healthcare Consumer Principles and Expectations

November 21, 2011

The Health Information and Technology Exchange of Connecticut's (HITE-CT) Special Population Committee developed the following document entitled, Healthcare Consumer Principles and Expectations. This document is founded on the consumer principles developed by the Consumer Partnership for e-Health in 2009. The Consumer Partnership for e-Health is a national, non-partisan group of consumer, patient, and labor organizations dedicated to improving health care quality and achieving a patient-centered health care system through expanded use of information technology and knowledge sharing. The development of their principles was supported was by the Markle Foundation and the California Endowment.

The Healthcare Consumer Principles and Expectations were approved at the Special Population Committee meeting on October 6, 2011 and was approved and adopted by the HITE-CT Board of Directors at its meeting on November 21, 2011.

Preamble

The Health Information and Technology Exchange of Connecticut (HITE-CT)¹ shall be designed and implemented to protect patient privacy while also realizing the potential of electronic patient data to support quality measurement, provider and institutional performance assessment, relative effectiveness and outcomes research, prescription drug monitoring, patient safety, public health, informed decision making by patients, addressing health disparities, data security, and other public interest objectives.

The following set of core healthcare consumer principles and expectations will govern the design, implementation and evaluation of health information exchange in Connecticut through the Health Information and Technology Exchange of Connecticut (HITE-CT).

Principles and Expectations

Principle 1: *A healthcare consumer shall be able to access their personally identifiable health information conveniently and affordably.*

Healthcare consumers should have a means of direct, secure access to their electronic health information that does not require physician or institutional mediation.

Healthcare consumers should have access to electronic health records pertaining to themselves (except in cases of danger to the patient or another person).

Healthcare consumers shall have a means to access their patient summary from the participating health care subscribers (PHCS) in accordance with meaningful use guidelines.

¹ HITE-CT is a quasi-public agency of the State of Connecticut charged by statute with "promoting, planning and designing, developing, assisting, acquiring, constructing, maintaining, and equipping, reconstructing and improving healthcare information technology, including the electronic exchange of health information."

Healthcare consumers shall be able to supplement, request correction of, and share their personally identifiable health information without fees or burdensome processes. They shall have the right to request corrections from the participating health care subscribers (PHCS) that registered the health information to the HITE-CT Health Information Exchange (HIE). If the PHCS finds that the information included in the exchange is erroneous, the PHCS shall provide such correction to the HITE-CT HIE.

Principle 2: A healthcare consumer shall be notified how their personally identifiable health information may be used and who has access to it.

Healthcare consumers shall receive easily understood information identifying the types of entities with access to their protected health information (PHI) and all the ways it may be used or shared. The explanation shall include any sharing for purposes other than the immediate care of the individual, and shall explicitly identify intentions for data use such as public health protection, quality improvement, prevention of medical errors, medical research or commercial purposes.

Access to protected health information (PHI) must be limited to authorized individuals or entities.

Tracking and audit trail systems shall be in place that permits healthcare consumers to request a review of all entities that have entered, accessed, modified and/or transmitted any of their personally identifiable protected health information (PHI).

Consumers shall be presented with a notice of practices. Procedures shall be implemented to collect the acknowledgement of these practices from the healthcare consumer or their authorized representative.

Principle 3: A healthcare consumer shall have control over whether and how their personally identifiable health information is shared.

Healthcare consumers shall be able to opt-out of having their personally identifiable health information – in whole or in part – shared across an electronic health information network.

Healthcare consumers' personally identifiable protected health information (PHI) will not be made available for commercial purposes.

Healthcare consumers shall be able to designate someone else, such as a family member, caregiver or legal guardian, to have access to and exercise control over how records are shared, and also shall be able to rescind this designation in accordance with federal and Connecticut state law.

Healthcare consumers shall be notified that they have the option to include their "sensitive" protected health information (PHI) in the health information exchange (HIE) by executing an opt-in to share their sensitive data. Disclosure of sensitive PHI (for HIV, substance abuse, mental health, etc.) will be determined according to existing federal and Connecticut state laws governing such disclosure.

Principle 4: *Systems for electronic health data exchange shall protect the integrity, security, privacy and confidentiality of a healthcare consumers' information.*

Personally identifiable health information shall be protected by reasonable safeguards against such risks as loss or unauthorized access, destruction, use, modification, or disclosure of data. These safeguards will be developed at the front end and will follow the information as it is accessed or transferred.

Healthcare consumers shall be notified in a timely manner if their personally identifiable health information is subject to a security breach or privacy violation.

In the case of a suspected breach, the healthcare consumer that is the data subject of such a breach may request an investigation by filing a report or complaint with HITE-CT's privacy and security officer.

In the case of a security breach, there shall be a process by which healthcare consumers receive information about the available remedies that exist under existing law to get relief.

Meaningful legal and financial remedies should exist to address any security breaches or privacy violations.

Federal and Connecticut laws that restrict the use and disclosure of personally identifiable and sensitive protected health information shall apply to all entities engaged in health information exchange through HITE-CT.

Principle 5: *Health information exchange shall be designed and built to meet the diverse needs of all Connecticut residents, without barriers or diminished function or quality for some.*

HITE-CT will be designed to accommodate the differing needs of younger people and older people; of people from diverse cultures and communities; of people who use diverse languages; of people with diverse abilities and disabilities; of people across the range of income levels; and of people across the range of literacy in reading, health care, and electronic technology.

Principle 6: *Implementation of the Health Information and Technology Exchange of CT (HITE-CT) shall be accompanied by a significant healthcare consumer education program so that healthcare consumers understand how the network will operate.*

Healthcare consumer education will include: what information will and will not be available on the network; the value of the network; its privacy and security protections; how to participate in it; and the rights, benefits and remedies afforded to healthcare consumers.

The educational efforts shall include outreach to Connecticut healthcare consumers and will be designed to accommodate the differing learning needs of younger people and older people; of people from diverse cultures and communities; of people who use diverse languages; of people with diverse abilities and disabilities; of people across the range of income levels; and of people across the range of literacy in reading, health care, and electronic technology.

Principle 7: The governance and administration of electronic health information exchange networks shall be transparent, and publicly accountable.

The Health Information Technology Exchange of Connecticut (HITE-CT) is a quasi-public agency of the State of Connecticut charged by statute with promoting, planning and designing, developing, assisting, acquiring, constructing, maintaining and equipping, reconstructing and improving healthcare information technology, including the electronic exchange of health information. The work of HITE-CT shall be transparent and is publically accountable.

Consumer representatives are appointed members of the HITC-CT Board and consumers shall be an integral part of the design, implementation, and evaluation of health information exchange in Connecticut.