Health Care Reform and
Personal Health Information Privacy

Testimony to Senate Judiciary Committee
Hearing on "Health IT: Protecting Americans' Privacy in the Digital Age"
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Thank you for the opportunity to testify on this critical issue. I am currently the Director of the Health Care Reform Commission for the Vermont State Legislature and a member of the board of Vermont Information Technology Leaders (VITL), the state wide health information exchange network (HIEN). My testimony today does not reflect the official positions of the legislature, commission or VITL. (VITL has submitted separate written testimony.) My personal opinions have been shaped by seven years active involvement in health care reform in Vermont and thirty five years of experience in the health care industry where I have been engaged in using information and IT to improve the performance of the health care system. I come before you today not as a privacy expert or IT expert, but rather as one with extensive experience in using information and IT as a means to furthering the end of effective health care reform – making quality health care available to every resident of Vermont.

Health care reform in Vermont has been underway for almost eight years, but was first codified in Act 191 in 2006. Due to a unique combination of conditions including its size, delivery system and collaborative culture, Vermont has become a statewide laboratory for health care reform The reform effort is the most comprehensive state reform initiative in the country, and is built on the 'three legged stool' of

1. **Expanding affordable coverage**: We established the goal of reducing the number of uninsured in the state from 10% in 2005 to 4% in 2010. As of October, 2008, the uninsured rate had declined to 7.6%, even in the face of a troubled economy.
2. **Bending the medical cost curve by improving the prevention and treatment of chronic illnesses:** As of March 2009, 10% of Vermont's residents will participate in 'enhanced pilots' implemented by the Blueprint for Health. These pilots will combine payment reform for all payers, the use of local care teams and information tools and implementation of an integrated prevention program
3. **Using information technology as a catalyst for performance improvement:** Sustainable improvement in coverage and chronic illness care can only be achieved with the support of health information technology. We believe that it is impossible to obtain the desired performance of our health care and prevention system as long as key clinical information is only available to providers and patients through paper charts sitting in filing cabinets.

The primary vehicle for the third component of the health care reform, health information technology, has been VITL. VITL is a new public/private organization which was given the responsibility to plan and implement the statewide health IT strategy. In the last three years it has accomplished the following:

1. Completed a state Health IT plan for both the statewide health information exchange network (HIEN) and the diffusion of Electronic Medical Records (EMR's)
2. Implemented a pilot program in providing medication histories for patients in hospital emergency rooms
3. Provided support for the information tools being used in the Blueprint for Health pilot communities
4. Implemented a pilot program in assisting primary care physicians in selection, contracting, financing and implementation of EMR's
5. Contracted with GE Healthcare to provide the core infrastructure for the statewide health information exchange and begun building the interfaces to hospitals, physicians and other sources. VITL plans to launch an advanced health information exchange pilot in at least one community in 2009.
6. Planned a statewide e prescribing initiative which it hopes to begin by July, 2009

Last May, Vermont became the first state in the country to provide the long term financing to pay for the development of the statewide HIEN and for EMR's for all independent primary care practices in the state. A Health Information Technology Fund was created to raise $32 million over the next seven years through an assessment of 0.2% on all paid claims in the state. The first payment was collected last October and VITL has begun drawing down on this fund.

This transition from creating a plan and implementing relatively small scale pilots to full scale statewide implementation has provided a major impetus for the review of the Personal Health Information privacy and security policies of VITL. The legislature has had a long standing interest in this area, as is indicated by its passing legislation requiring an active patient opt in for consent, passing major limitations and controls of data mining of prescription data, and ensuring that privacy and security standards were included as an explicit component of the state health IT plan. To address its changing needs and respond to concerns, VITL initiated a broad based stakeholder review process to update the health IT plan and revise its operating policies and procedures. Those efforts are in their final stages, but are now on hold pending clarification of the proposed privacy guidelines in the economic stimulus act (American Recovery and Reinvestment Act).

While the health IT financing implemented in Vermont's health IT fund and proposed in ARRA is extremely helpful and goes far toward reducing the financial barrier to widespread implementation of health IT, it is not sufficient by itself. Realizing the benefits of health IT requires broad acceptance by both patients and providers of this new technology which deals with the most sensitive types of data – Personal Health Information. The process that VITL has engaged in represents a delicate balancing act between sometimes conflicting interests of consumer control and needs and provider accountability and responsibilities. Unless consumers are confident that their information is secure and will be used appropriately, they will not participate in electronic health information exchanges. Unless providers believe that the administrative burdens are reasonable and the information is reliable, they will not participate in such exchanges either.

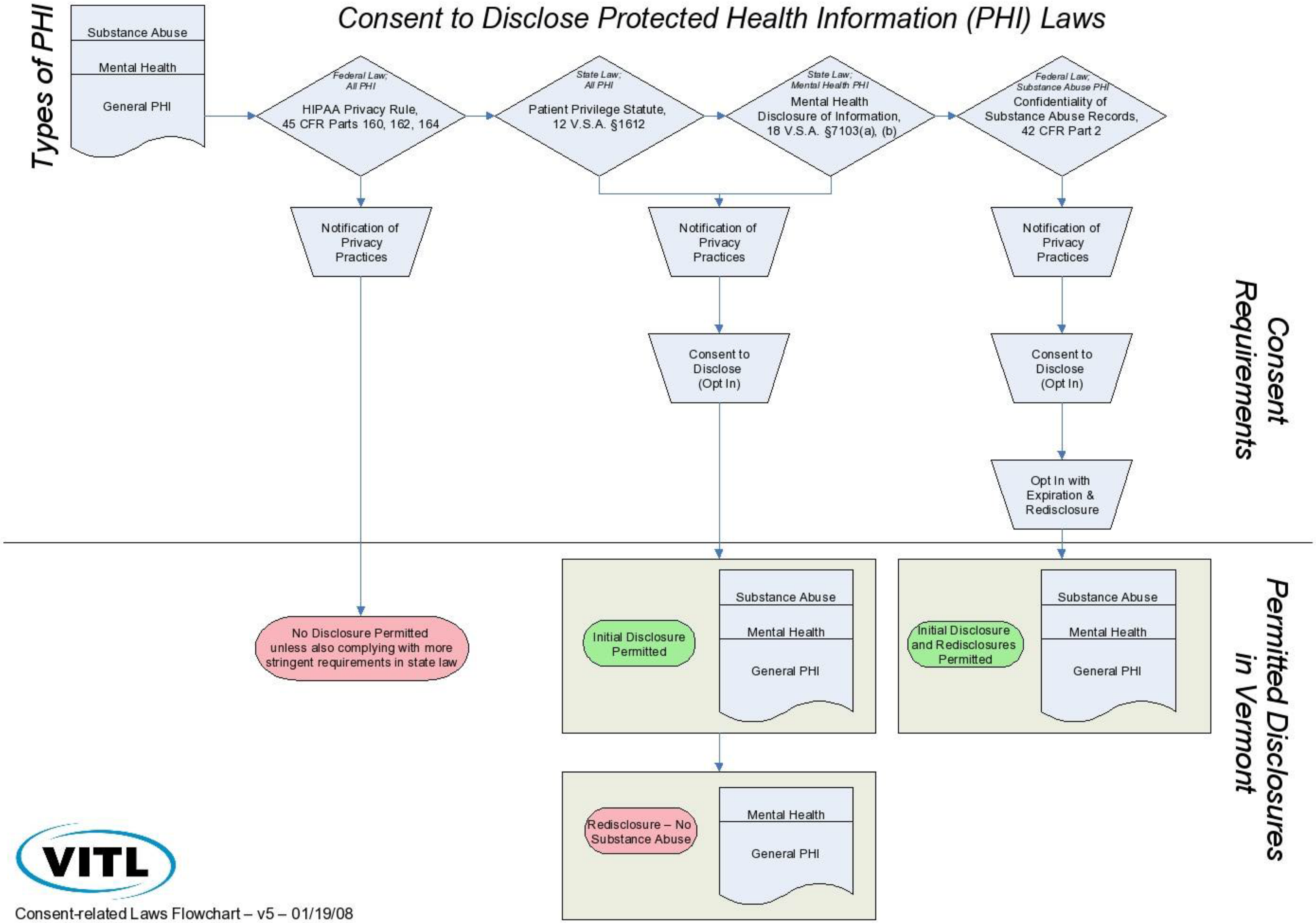
Consent policies provide an excellent case study of this balancing of interests. The attached flowchart shows the state and federal regulations governing consent of PHI in Vermont. Working within this legal framework, VITL had to resolve such questions as

- Given that state law requires that patients opt in to participate in the HIEN, should this initial consent have an expiration date? If not, should patients be periodically reminded of their ability to opt out?
- Should reauthorization to share PHI with other treating providers be required for PHI other than the legally mandated substance abuse PHI?
- What uses, if any, should require a separate consent by the patient?

Moving forward with our health care reform totally depends upon finding an initial balance point between conflicting needs and interests in a way which will encourage broad based participation of patients and providers. I am confident that once the federal privacy guidelines and requirements in the ARRA are finalized, VITL will be able to rapidly complete the revision of its guiding principles and operating policies.

However, this balance point is not static – it will evolve. We fully expect that the implementation of the initial privacy policies in a steadily growing set of pilot health reform initiatives such as the Blueprint enhanced medical home, medication history for ER patients, e prescribing and the proposed pilot community health information exchange will teach us important lessons over the next couple of years. We will have to return to the privacy policies on a regular basis to update them based what we have learned and new technical capabilities. The core security and privacy capabilities have been carefully thought through and provide a sound foundation for beginning this expansion. Experience has demonstrated that the only way to develop a high performing system is to test it through implementation combined with rapid cycle improvement. The Vermont health care reform program has been built on scalable, community level pilot programs which have enabled us to learn rapidly what works and what needs to be improved. We will use this model to evolve our privacy and security policies and capabilities as well.

Given the strong feelings surrounding Personal Health Information and the uncertainties that are inherent in the early stages of the spread of EMR’s and the use of health information exchange, I fully expect that a significant minority of both patients and providers may elect not to participate. A reasonable goal is to devise a program which will satisfy the needs of a large enough percentage (60-80%?) of users to enable robust testing of capabilities, deliver value to the users and drive the next round of privacy and security technology. As capabilities mature and confidence grows, the hope and expectation is that our program will earn the trust of a steadily expanding percentage of both our population and health care delivery system. The successful scaling up of our pilot programs into system wide initiatives and the long term success of our health reform efforts depend on it.



Consent to Disclose Protected Health Information (PHI) Laws

VITL

Consent-related Laws Flowchart – v5 – 01/19/08