

Senate Health and Welfare Committee
Testimony on VHIE Opt-In/Opt-Out
April 10, 2019

My name is Julie Wasserman and I have a long-standing career in health policy and human services. I have a Master degree in Public Health and an RN in nursing. I have worked for the State of Vermont for over 20 years but am currently self-employed. I am here today speaking for myself; I am not being paid to testify.

Senator Lyons invited me to speak after I sent all of you an NPR piece based on a Kaiser Health News and Fortune Magazine Investigative Report on Electronic Health Records titled, “*Death by a 1,000 Clicks.*” This national report features a Vermont woman in its opening sentence. A 47-year old Vermonter had head pain and went to her local physician who ordered a head scan using the clinic’s EHR software system. But the order never made it to the lab, and two months later this woman died from an undiagnosed brain aneurysm. This U.S. Government District of Vermont prosecuted the case and landed the largest-ever financial recovery in Vermont’s history - \$155 million.

The article “*Death by 1,000 Clicks*” reveals some of the most onerous problems associated with EHRs.

- Patient harm
- Fraud through “upcoding”. (The EHR was developed as a business model, not as a patient care model. The more “elements” in the record, the more billable services.)
- Lack of interoperability (one EHR does not communicate with the next)
- Secrets (software failures are withheld from the public)
- Physician burnout

Here are four short anecdotes on physician use of EHRs:

- One of my physician friends said this about EHRs – *“The excessive clicking and screen time is physically exhausting and demoralizing. It has a negative effect on human interaction with my patients, my co-workers and other physicians.”*
- A physician colleague who works in a Vermont Hospital Emergency Room said this about the VHIE: *“I have never used it productively. When someone is really sick, it’s what’s in front of me that’s most important (not a medical record). There is a “break the glass” provision in general and also for the VHIE*. So if I need information, I can always get it. The VHIE was a good idea, but in real life it is minimally useful and expensive.”*
- A colleague who is the Medical Director of a local clinic that still utilizes hardcopy charts, uses it as a recruiting tool.

- Another physician who works in one of Vermont's rural clinics that still uses paper charts asks the patient, "Do you want to know how much you weighed when you were born?" Patients are delighted to see their birth weight at the back of the paper chart.

The question before you is whether Vermont should stick with its current "opt-in" provision where patients have to actively agree to have their personal medical information shared in the VHIE, or instead switch to an "opt-out" system where patients are automatically "in" and have to make a formal request to be removed from having their medical information "shared" with other providers without the patient's consent.

The process for deciding whether to have "opt-in" or "opt-out" may be a simple one. But it is an important public issue, one that affects all Vermonters. There are very issues that impact every single Vermonter. For that reason, the decisions on "opt-in" versus "opt-out" should be decided in the Legislative arena, not by the Green Mountain Care Board or VITL. In addition, Act 113 - The All Payer Model, Section 9551, Subsection (13) states that the Green Mountain Care Board and the Agency on Administration "supports coordination of patients' care and care transitions through the use of technology, **with patient consent, such as sharing electronic summary records across providers** and using telemedicine, home telemonitoring, and other enabling technologies" (Emphasis added.) Given this clear Legislative language specifically requiring active "consent" to share electronic medical information across providers, the "opt-out" provision does not conform with the law.

The issue here is "**meaningful informed consent**". This is a basic tenet underlying all health care. Informed consent is a process for getting permission before conducting a healthcare intervention on a person, or *for disclosing personal information*. Informed consent can be said to have been given based upon a clear appreciation and understanding of the facts, implications, and consequences of an action. That will not likely occur with the "opt-out" approach.

The principle concern here is "personal privacy", and "who owns your private medical information". The information should belong to you, and you should have control over it. This is especially true for those with stigmatizing conditions. We would not want to eclipse privacy for the sake of "efficiency".

The DVHA Report supports changing to "opt-out" and they list the organizations involved in their Stakeholder Engagement group:

- VITL
- Vermont Medical Society
- Green Mountain Care Board
- Vermont Association of Hospitals and Health Systems (VAHHS)
- BiState
- Medicaid and Exchange Advisory Board (MEAB)
- ACLU
- Legal Aid

DVHA reports that all but two organizations support changing to opt-out. Interestingly, those two organizations (ACLU, Legal Aid) are the only two representing *consumers*. With regard to protecting one's private medical information, the most important "stakeholders" are Vermonters, the consumers of health care. If you want to know how consumers feel about "opt-out", bring together a group of Vermont's consumer advocates, *not* provider groups. As you know, Vermont has an abundance of consumer advocates.

My understanding is that there have been problems with the implementation of "opt-in". Patients are not asked, the VHIE is not explained, and patients are not educated about the sharing of information. So we haven't yet figured out how to educate and inform patients on the simple act of "opting in". "Opting in" is in the providers' interest and yet we are not yet doing it effectively. How much confidence can we have in informing and educating patients on "opting out" when it is *not* in the provider's interest? In addition, "opting-out" is a far more complicated process.

The Electronic Health Record is here to stay. But given all the problems with it, and given all the problems in implementing the "opt-in" option, and given the importance of meaningful "informed consent", maybe the compromise position is to focus first on successfully implementing the "opt-in" option. Have VITL develop an effective implementation plan and employ it statewide. Find out what works and what doesn't work. Determine the most effective approach to patient education. We will learn a great deal from this and it will inform next steps if "opt-out" is later determined to be a suitable option.

* [VITL Patient Consent form](#): "A Participating Health Care Provider may access the PHI (Protected Health Information) of an individual on the Exchanges without the individual's Consent for use in the treatment of the individual for a Medical Emergency when the Participating Health Care Provider is unable to obtain the individual's Consent due to the individual's Emergency Medical Condition. Participating Health Care Providers accessing PHI for a Medical Emergency must notify the individual or the individual's Legal Representative of such access as soon after such access as is reasonably possible and must obtain Written Consent for further access to PHI of that individual on the Exchange after the Medical Emergency has ended."