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Comments regarding VHIE Consent Policy

Delivered to the House Committee on Health Care

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Thank you for the opportunity to comment on potential changes to the Vermont Health Information Exchange's (VHIE's) Consent Policy – specifically the shift from an “opt-in” approach to an “opt-out” consent architecture.

I am the Executive Director for the Vermont Council on Developmental Disabilities (“the Council”). The Council is composed of 60% individuals with developmental disabilities or their family caregivers. Developmental disabilities are significant, lifelong conditions that impact 18.4% of the population, or nearly 1 in 5 Americans. Councils exist in every state and territory with the federal mandate that we advocate for policies that advance the independence, productivity, self-determination, and community inclusion of people with developmental disabilities.

The Council is concerned that a shift to an opt out consent policy would degrade patient privacy rights. For the population we represent, which generally has a low level of health literacy, shifting the burden from provider to consumer would compromise the ability of people with developmental disabilities to make an informed decision about their personal health information. In addition, the Council believes that the Legislature has a responsibility to put this decision in statute, rather than leave the Green Mountain Care Board to treat this important issue as a matter for administrative rule or regulatory guidance.

The Legislature has a duty to determine how Vermonters' information will be managed

A shift to an opt-out policy would set a significant precedent for individual privacy in the evolving world of electronic data. It is an important public issue, one that affects all Vermonters. For that reason, the decision on “opt-in” versus “opt-out” should be decided in the Legislative arena, not by the Green Mountain Care Board or by VITL. The legislative process has the advantage of ensuring that members of the public have the highest degree of decision-making authority afforded in our democratic system. Given the value that our society places on privacy, legislative action is the appropriate course in this matter.

In addition, legislative action is necessary to revise existing statutory language. 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). In other words, there is existing legislative language that requires active “consent” to share electronic medical information across providers. Only the legislature has the authority to revise this language.

It is misleading to claim that opt-out better reflects Vermonters’ intent.

Opting in to the VHIE is not the same thing as signaling support for an opt-out approach. The State, however, has repeatedly made this logical mistake: The fact that most individuals, *when asked*, agree to opt-in does not give the State blanket permission to change the consent policy. One of the key advantages of an opt-in system is the fact that it affords greater patient engagement. It is supposed to spark a conversation, to create an opportunity to educate patients about the need for coordinated services. Absent this education, it is not at all clear that the average Vermonter would want their health information automatically placed in an accessible database.

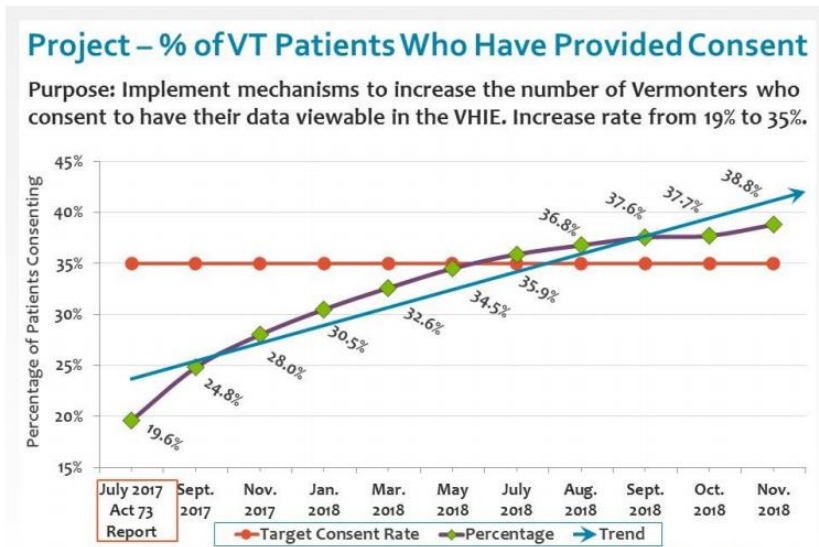
In either scenario, the Legislature must act to protect Vermonters’ right to informed consent.

At stake is Vermonters’ fundamental right to make an informed decision about their personal health information. Indicators to date suggest that VITL and providers using VITL have not fully risen to this responsibility – Admittedly, a challenge, especially when one considers the difficulty of balancing a legal requirement with the needs of non-English speakers, individuals with low literacy, and people with a wide range of cognitive styles.

That said, provider reluctance to engage consumers in an opt-in scenario indicates that they would be an unreliable point of contact for consumer engagement in an opt-out scenario. Simply put, if providers are burdened by asking patients to opt-in, which is in the provider’s interest, how likely will they be to inform consumers that they have the right to opt-out, which is not in the provider’s interest? The Legislature should not agree to a change in policy without first reviewing a compelling plan to ensure that consumers understand their options. Such a plan will likely still impose some level of burden on the provider. If addressed responsibly, the duty to explain someone’s right to opt out should take about as much time as it might to encourage them to opt-in.

It should be noted that the processes currently in place for consumers to navigate decisions about their health information are already confusing and unduly burdensome to the individual patient. For example, if I change my mind and want to revoke consent, I must ask a participating provider for a revocation form. If I wish to exercise my right to an audit of access to Patient Health Information, I must not only find the correct form, but have it signed by a participating health care provider or a public notary. The same is true if I wish to see a copy of my own Protected Health Information.

Vermont appears to be making solid progress with an opt-in approach.



In its November 2017 report, *Evaluation of Vermont Health Information Activities*, HealthTech Solutions found that in 2017 only 20% of Vermont patients were solicited to provide consent, with 19% opting in.¹ More recently, on January 1, 2019, VITL delivered a progress report to this body and to the legislature that indicated a significant increase in the statewide “ask rate.” In fact, VITL exceeded its target with 38.8% of

Vermonters’ opting in. The trend has been solidly in the direction of greater patient engagement and consent². How has VITL achieved this significant improvement? Could Vermont simply do more of what has begun to work? VITL’s leadership has claimed that this positive trend will soon “plateau,” but they have not put forward evidence to explain this claim. Moreover, since the trendline relies heavily on VITL’s support, their claim may prove a self-fulfilling prediction.

What is being described as “provider burden” is a concern, but one that is outweighed by the need to protect the patient’s right to determine an acceptable level of privacy. Soliciting patient consent is part of delivering fully integrated care, an opportunity to engage individual Vermonters in our State’s new approach to healthcare. The Legislature should consider how best to use this opportunity to build patient trust and widespread support for the healthcare system that it is working so diligently to create.

¹ *Evaluation of Vermont Health Information Activities*, final report (November 10, 2017), page 42. Found 1/9/19 at: <https://legislature.vermont.gov/assets/Legislative-Reports/VT-Evaluation-of-HIT-Activities-FinalReport-Secretary-Signature.pdf>

² VITL Progress Report (January 1, 2019). Found 1/9/19 at: <https://legislature.vermont.gov/assets/Legislative-Reports/DVHA-VITL-HITWorkPlan-ProgressUpdate5-1.1.19-Final.pdf>