

**Vermont AIDS Services Organizations (AIDS Project of Southern Vermont,
HIV/HCV Resource Center, Vermont CARES, Vermont People with AIDS Coalition)
Planned Parenthood of Northern New England
Vermont Network Against Domestic and Sexual Violence**

**House Health Care Committee/Senate Health and Welfare Committee
Vermont Health Information Exchange Proposal - May 1, 2019**

If Vermont moves from an opt-in to an opt-out system for the Vermont Health Information Exchange, it is imperative to ensure that every patient is informed about their right to opt out. Patients have the right to determine who can know what about some of their most sensitive information. While we recognize that there are many benefits to health care information sharing, the main focus must be on preserving privacy and confidentiality.

Proponents stated in their testimony that opt out would support patient privacy and autonomy at least as well as the current model, In order for that to happen, *every patient* must be informed of the policy change and their right to opt out of information sharing.

We are concerned that, given the citing of administrative burden as a reason for not wanting an opt-in system, it will be considered too burdensome for health care practitioners to inform every patient of their right to opt out. We have heard that less than 40% of patients were asked if they wanted to opt in. We must ensure that 100% of patients know that they can opt out – and how they can opt out if they so choose. They need to know what information will be shared, with whom the information will be shared, in what manner the information will be shared, and for what purpose the information will be shared.

As such, we propose that the Legislature enact language this session that addresses the following, in the event Vermont moves from an opt-in to opt-out system for the Vermont Health Information Exchange

- Written materials must be developed for health care practitioners to provide to every patient at least once per year, that clearly explains
 - the process for opting out.
 - what health care information will be shared
 - with whom their health care information will be shared;
 - how their health care information will be shared;
 - for what purpose their health care information will be shared. And
 - how they can switch from opt in to opt out in the future.

- There should be a report back to the Legislature in 2020 regarding
 - the informative written materials
 - how the materials are being disseminated so that all patients are informed of the opt out policy
 - how many patients have opted out

Thank you for considering this proposal.