

March 17, 2020

Victoria Veltri
Executive Director
Office of Health Strategy
State of Connecticut

Dear Ms. Veltri:

We are writing as advocates with concerns about your Office of Health Strategy's plans to implement a Health Information Exchange (HIE) in Connecticut. We urge you, before entering any personal medical data, including but not limited to full records or any personal medical data or records, into the system, to develop consent policies that give consumers control over their data and to engage with communities in a robust public education campaign about consumer risks and rights. Nothing should enter the system until each fully informed consumer agrees and gives consent for which providers/business associates can see their information. **We especially urge you to commit that data in the HIE will never be sold/monetized or available to insurers or Accountable Care Organizations (ACOs), large unregulated health systems.**

We understand that functional HIEs have potential benefits. Several of us have supported and worked on building an HIE for our state. An HIE allows the providers treating a patient to share information about care. It could reduce duplicated services and could keep us safer. But getting an HIE in Connecticut been mired in years of failed attempts, turf wars, bad decisions, and millions of wasted tax dollars.

There is rising concern about privacy and the use of data. Medical records are especially sensitive. For example, a recent study found that algorithms meant to direct care management services to people who most need them discriminated against people of color. Getting privacy and security wrong risks discrimination, loss of employment, and embarrassment. Fear will keep some people from getting care for mental health, substance abuse, HIV, or other critical needs and conditions.

Once federal funds run out, the HIE's plans to sell our data to insurers and ACOs to fund the \$10 million annual cost are unacceptable. Insurers and ACOs can use the information for financial gain by denying us needed care and cherry-picking lucrative patients, as has been documented in the literature.

The process to develop this HIE has been hidden. The state set up a nonprofit to run the HIE with millions of tax dollars but without public accountability. The HIE's board includes insurers and unregulated ACOs and meets evenings in a conference room in Farmington. There is no telephone access to the meetings and slides are not posted online. The decision on a consent policy defining consumer rights to control their information has been delayed until after consumer records are in the system. State law requires all Connecticut hospitals and doctors to put their records in the HIE, making consumers choose between protecting their information

and getting healthcare. The state has historically been very deceptive when informing people about risks and their rights. For example, Medicaid members were misled about the risks under PCMH Plus, a new Medicaid payment model with ACO incentives to lower healthcare costs and deny care.

The HIE may not even be necessary. Over 70% of Connecticut hospitals and 57% of doctors are already sharing information between health systems. Connecticut already has at least four functioning HIEs built without tax dollars including CT Health Link, created by the state medical society, that do not sell data to insurers or ACOs.

Trust in both healthcare and government is at historic lows. Despite this, HIE proponents are rushing to get our medical records into the system before a federal grant opportunity ends. They are delaying decisions about who gets the information and how it's paid for until it's too late. If Connecticut needs another HIE, the state should pay for it directly rather than selling consumer data to insurers and ACOs that could use it to deny Connecticut consumers vital healthcare.

Sincerely,

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