



March 20, 2020

Victoria Veltri  
Executive Director  
Office of Health Strategy  
State of Connecticut

Dear Ms. Veltri:

We join our fellow consumer advocates in raising concerns about your Office of Health Strategy's plans to implement a Health Information Exchange (HIE) in Connecticut.

Given that we are in the midst of the COVID-19 pandemic, we recognize this initiative by your office is logically suspended. In light of that, we will look to work with you on this issue when the current health crisis has abated. In preparation for that time, we share our position. The state created a nonprofit to run the HIE with federal grant dollars, paid for by our tax dollars but not subject to public accountability. The HIE's board includes many individuals who appear to have interests in conflict with those whose personal data is at stake. Access to the board meetings is restricted, they are in the evening, in Farmington, without telephone access, and with a limited amount of shared meeting material. Because of this, it has been challenging to follow the process leading to the planned implementation. This should never be the case with a governmental process, certainly not with a process that will have such a widespread impact on our residents and their most personal information.

We anticipate that the impacts of this crisis, as they unfold, will make necessary protections even more acute.

We understand that there are many potential benefits to HIE. We have supported the development of an HIE for our state. An HIE allows the providers treating a patient to share information about care. It is intended to reduce duplicated services and keep us safer. This is already happening, as CT already has four functioning HIEs that were privately funded, raising the question: is this an appropriate role for the government for our tax dollars?

It has been reported that HIE's plans to sell our data to insurers and ACOs to fund the \$10 million annual cost once the current funding runs out. This is unacceptable. You must commit that HIE and its data will never be monetized or available to insurers or Accountable Care Organizations (ACOs). Insurers and ACOs can use the information inappropriately for financial gain to deny needed care and cherry-pick lucrative patients, as has been documented in literature. In addition, 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.

Before any personal medical data, including but not limited to full records or any personal medical data or records, into the system, you must develop consent policies that give consumers control over their data and engage with communities in a robust public education campaign about consumer risks and rights. No data should be entered until each fully informed consumer agrees and gives consent for which providers can see their information.

Sincerely,

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