



February 26, 2014

Tamim Ahmed, PhD
AccessHealth Analytics
Via email

Dear Mr. Ahmed:

I am writing to urge you to adopt an opt-out participation consent policy for consumers in Connecticut's developing APCD.

The Connecticut Health Policy Project has a fifteen-year history of advocating for access to affordable, quality healthcare for every resident of our state. Supporting that mission, we have been strong supporters of building an APCD for Connecticut. Comprehensive information across payment sources, shared with consumers, with robust analysis is critical to ensuring efficient use of scarce resources, improving the quality of care in Connecticut, and costs are controlled. A successful APCD is central to meeting those goals.

Strong public support is vital to the sustainable funding and political will necessary for a successful APCD in our state. Protecting people's privacy and the security of data will be critical to that success. The public must have the strongest trust in the system eventually adopted in Connecticut for it to be widely accepted and effective. If public trust in the integrity of the system is eroded, the system will be useless. Even the perception of inadequate privacy protections and policies would undermine and significantly damage the system's effectiveness.

Central to creating a trusting relationship with the public is fully informed consent to participate. Trust can only be mutual. To earn the public's trust, the APCD must trust people enough to allow them to make an informed decision to participate. The first time the public hears that their most personal and sensitive information is in a database cannot be in a breach notification.

There is no basis for concerns that implementing an opt-out policy will result in inadequate levels of participation in Connecticut's APCD. The experience of state health information exchanges that include an affirmative opt-in requirement, far more than we are suggesting here, is that between 86% and 98% of patients agree to share their information on the exchange and sign the opt-in consent form. Rhode Island is now implementing an opt-out policy for their APCD. There is no indication that we need to deny people's most basic rights to achieve the goals of the APCD.

I urge AccessHealth Analytics to incorporate an opt-out privacy policy ensuring the integrity, public support and long term sustainability of Connecticut's APCD. Thank you for your attention to this critical matter. I am happy to discuss this issue at any time.

Sincerely,

A handwritten signature in cursive script that reads "Ellen M. Andrews". The signature is written in black ink and is positioned below the word "Sincerely,".

Ellen Andrews, PhD
Executive Director

cc: APCD Advisory Council
Kevin Counihan