



March 13, 2020

Office of Health Strategy
Via email: HITO@ct.gov.

Dear Allan Hackney,

Health Equity Solutions is grateful for the opportunity to comment on the proposed Guiding Principles contained in the Final Report and Recommendations of the Consent Policy Design Group. We strongly support the state's efforts to create consent policy that informs consumers about how their data will be used and provides accountability through measures to mitigate risks associated with consumer participation. Overall, we support the capabilities of the health information exchange (HIE) and its role in improving the quality of care and patient outcomes through a smooth flow of information between systems. We are committed to ensuring that the consent processes and policies related to the HIE do not contribute to unintended consequences or undue burdens for low-income communities or communities of color in Connecticut.

In order to center health equity in the data consent policy for the statewide Health Information Alliance, we respectfully suggest the following:

- Often, consent documents can be lengthy and challenging to digest. Thoughtful education and outreach will be required as referenced in Recommendation 1, 2, and 3. We support having an opt-out policy but implore you to make the explanation of this option clear, concise, and provide a sufficient window for response. We suggest consumer education materials about health information sharing choices, data use, and the consent process be explicitly required to align with health literacy principles and be inclusive of consumers of multiple backgrounds, reading levels, and language proficiencies.
- Data security is a top concern among the consumers we have spoken to across the state, as emphasized in recommendation 12. We suggest a principle that addresses possible compromises in data security. Given our national history of taking the health information of and engaging in untested health practices on marginalized communities without consent, security may be of particular concern to these groups.
- Recommendation 6 acknowledges the additional burden placed on providers to implement consent yet does not recognize the history of coercive practices targeted towards communities of color in the medical setting. We suggest requiring providers to engage in training that supports integrity in the consent process.
- Recommendation 15 aims to institute a process for addressing consumer complaints. We suggest that this process be both transparent and timely to provide a measure of accountability and to increase the likelihood that any patterns in complaints are detected.

Thank you for taking the time to consider our comments. We look forward to the success of the statewide health information exchange and robust consent policies that center on the needs of consumers.

Sincerely,

A handwritten signature in dark ink, appearing to read "Tekisha Dwan Everette".

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