



**Guiding Principles of the Final Report and Recommendations,  
Consent Policy Design Group  
Public Comment**

**March 15, 2020**

Universal Health Care Foundation of Connecticut appreciates the opportunity to comment on the proposed Guiding Principles contained in the Final Report and Recommendations of the Consent Policy Design Group of the Health IT Advisory Council.

Universal Health Care Foundation envisions a health system that is accountable and responsive to the people it serves; that supports our health, takes excellent care of all of us when we are sick, at a cost that doesn't threaten our financial security. A well-functioning health information exchange (HIE), could be a crucial tool to bring us closer to this vision. But it must appropriately balance the need for health information data sharing to improve care with the need for privacy protections and truly informed consent.

We are glad to see an overall emphasis on several key themes, including:

- Policy decisions will need to be revisited regularly, given that both consent and data privacy are fields that are evolving rapidly
- Well-designed, understandable consent forms and accompanying educational materials will be necessary to ensure that patients comprehend the consent decisions they are making with regard to the HIE
- Consent policy will vary, depending on the nature and sensitivity of the data in question

HIEs rely on trust between patients and providers. Marginalized communities, particularly people of color, have endured a history of privacy breaches and testing without consent, leading to a higher bar to build and maintain that trust. The principles should explicitly acknowledge this challenge. And they should state the need for cultural competence, sensitivity and humility in the development of both consent policies, educational materials and provider training.

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Finally, recommendation 19 lays out a process for developing consent policy going forward. It rightly emphasizes transparency and stakeholder input, but it also relies heavily on the Health IT Advisory Council. The Foundation would like to see improved representation of consumers on the council.

While industry and patient interests may often be aligned, that is not always the case. It is crucial that patient protections remain top-of-mind as policy is developed. Note that recommendation 6 states, “Consent policies should result in the lowest possible burden on providers responsible for their implementation and maintenance, without compromising the need for sufficient patient understanding and ability to exercise meaningful consent.” To maintain this balance, it is important for consumers to be well-represented on the Advisory Council. This representation should also reflect the racial and ethnic background of Connecticut residents.

*Universal Health Care Foundation of Connecticut's mission is to serve as a catalyst that engages residents and communities in shaping a democratic health system that provides universal access to quality, affordable, equitable health care and promotes health in Connecticut. We believe that health care is a fundamental right and that our work is part of a broader movement for social and economic justice.*