

A Public Comment submitted to CT Office of Health Strategy (OHS)

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March 15, 2020

Re: Public comment on Draft Consent Design Guiding Principles

I would like to thank you for this opportunity to provide a public comment on the Office of Health Strategy's (OHS) proposed Draft Guiding Principles in the *Final Report and Recommendations*² put together by the Consent Design Workgroup. I am in the healthcare policy and information technology (HIT) sector for economic development in Connecticut. I work with small startup businesses, major corporations, hospitals, non-profits, and academic institutions (UConn & Yale Universities). I am part of the State Innovation Model (SIM) program in the Practice Transformation Task Force (PTTF) group. I am also a Connecticut Health Foundation Healthcare Leadership Fellow.

I seek further elaboration of certain points below in the management of the State Health Information Exchange (HIE) as stated in the *Final Report and Recommendations*.

New Rulings from US Dept of Health & Human Services (HHS)

On March 9, 2020 HHS released transformative rulings that further empowers the patient consumer over their healthcare records³. This “will give patients unprecedented safe, secure access to their health data. Interoperability has been pursued by multiple administrations and numerous laws, and today, these rules finally deliver on giving patients true access to their healthcare data to make informed healthcare decisions and better manage their care.” How will the Guiding Principles address this recent ruling? What will be the default setting for patient participation – ‘opt-in’ or ‘opt-out’? This applies to ‘Recommendation 1, 8, 9, and 16’ of the Guiding Principles.

The new HHS Interoperability and Patient Access final rule (CMS-9115-F)⁴ has several other items that will need to be considered: Patient Access API, Provider Directory API, Payer-to-Payer Data Exchange, Dual Eligibility Data Exchanges, Public Reporting and Information Blocking, Digital Contact Information, and ADT (Admission, Discharge, and Transfer Events) Notifications. How will the Guiding Principles address these items? This applies to ‘Recommendations 4, 5, 11, 12, and 13’ of the Guiding Principles.

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² Consent Design Group Final Report and Recommendations - CT Office of Health Strategy

https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/Reports/OHS_Consent-Design-Group_Final-Report_2020.pdf

³ HHS Finalizes Historic Rules to Provide Patients More Control of Their Health Data - CMS March 9, 2020

<https://www.hhs.gov/about/news/2020/03/09/hhs-finalizes-historic-rules-to-provide-patients-more-control-of-their-health-data.html>

⁴ Interoperability and Patient Access Fact Sheet - CMS March 9, 2020

<https://www.cms.gov/newsroom/fact-sheets/interoperability-and-patient-access-fact-sheet>

Privacy and Health Equity

While the new HHS Interoperability and Patient Access final rule (CMS-9115-F) provides the patient consumer the benefit of organizing their healthcare and related data – the matter of privacy⁵ of the data is unclear. How will the Guiding Principles address the privacy concerns? This applies to ‘Recommendations 5, 11, 12, and 13’ of the Guiding Principles.

Utilization and Monetization

As the patient consumer data will be managed by various vendors and institutions – it gives them the opportunity of utilization and monetization of patient consumer data⁶. How will the Guiding Principles address the concern of utilization and monetization of the patient consumer data? Can the patient consumer completely opt-out of the utilization and monetization of their data? This applies to ‘Recommendations 5, 7, 8, 10, 11, 12, 13, 18, and 19’ of the Guiding Principles.

Thank you,

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⁵ Sharing Your Digital Health Data: New Rules Ease Access - Wall St Journal. March 9, 2020
Consumers might be able to organize all their health visit and insurer data on their smartphones, but will face privacy questions

<https://www.wsj.com/articles/sharingyourhealthdatanewdigitalrules-11583702453>

⁶ Acquisition, Analysis, and Sharing of Data in 2015 and Beyond: A Survey of the Landscape
- Journal of American Heart Association Nov 5, 2015

<https://www.ahajournals.org/doi/10.1161/JAHA.115.002810>