

Consent Policy Design Group

Guiding Principles

Accepted as of October 15, 2019

Guiding Principles

Recommendation 1:

Consent policies should require patients be provided clear and unambiguous information about health information sharing choices under applicable State and Federal law.

Other Considerations:

- 1) Patients must be allowed to opt-out of the HIE. 2) If not, it must be clearly stated which data the patient may not opt-out of nor give additional consent for, beyond accepting treatment: 3) their identifiers for matches to providers and any data sent to them and for any data sent to OHS: 4) public health, tumor registry, discharge summaries, quality measures, CDAS, etc..5) Citing HIPAA as allowing the sharing of identified data without consent does not remove Connecticut's nor the provider's Hippocratic obligation to obtain it.

Recommendation 2:

Consent policies should require Connecticut's Office of Health Strategy to develop an educational resource tool kit on health information sharing, leveraging and adapting content from recognized third-party resources.¹ Educational content should be reviewed and approved by the Health IT Advisory Council, and should not only include information for patients, parents and guardians, but also for providers, pharmacies, labs, health plans, state and local government agencies, and employers. The information should be translated for non-English speakers and should conform to the Web Content Accessibility Guidelines² developed by the Web Accessibility Initiative (WAI), part of the World Wide Web Consortium (W3C).³

Other Considerations:

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Recommendation 3:

Information and educational resources on consent policies should be distributed broadly throughout Connecticut and be made widely available and easily accessible through a variety of sources including the Health Information Alliance, all health and human services agencies and departments in the state of Connecticut, and organizations participating in HIE services in Connecticut. The distribution process will be supported by HIA's partners, including the Office of Health Strategy (OHS).

Other Considerations:

¹ Adapted, with permission, from the CARIN Alliance Trust Framework and Code of Conduct (<https://www.carinalliance.com/our-work/trust-framework-and-code-of-conduct/>)

² <https://www.w3.org/WAI/standards-guidelines/wcag/>

³ <https://www.w3.org/WAI/>

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Recommendation 4:

A review of consent policy considerations should be conducted by appropriate subject matter experts for each HIE use case before an HIE use case is put into production, with a use case-specific consent policy developed if indicated from the review.

Other Considerations:

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Recommendation 5:

Notification of a healthcare organization's participation in electronic health information exchange(s) should be included in the Notices of Privacy Practices (NPP).

Other Considerations:

- Health care organizations should also provide patients with the location of where they can find more information on which HIEs providers participate in.

Recommendation 6: *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.*

Other Considerations:

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Recommendation 7: To be discussed further

Other Considerations:

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Recommendation 8: To be discussed further

Other Considerations:

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Recommendation 9:

Consent policies should explain clearly and completely when a patient revokes consent, including what happens with patient data and their previously expressed consent.

Other Considerations:

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Recommendation 10:

Consistent with federal and state law, including but not limited to HIPAA, consent policies should require third-party vendors and contractors be contractually bound by Business Associate Agreements (BAAs) to publish privacy policies of any organization facilitating electronic health information exchange in Connecticut, and prohibit use or disclosure of patient information (including de-identified,

anonymized or pseudonymized data) for any undisclosed purposes without express consent from the patient.

Other Considerations:

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Recommendation 11:

Consistent with federal and state law, including but not limited to HIPAA, consent policies should require safeguards be followed consistent with the responsible stewardship associated with protection of a patient's health information against risks such as loss or unauthorized access, use, alteration, destruction, unauthorized annotation, or disclosure.

Other Considerations:

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Recommendation 12:

Consent policies shall address sensitive and specially protected data in alignment with federal and state statutes, as may change from time to time.

Other Considerations:

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Recommendation 13: To be discussed further

Other Considerations:

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Recommendation 14:

Consent policies should be reviewed periodically to ensure it is aligned with these principles and complies with any changes in best practices or federal or state law.

Other Considerations:

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Recommendation 15:

Consent policies should provide a clear procedure for addressing complaints by individuals regarding the use of their data.

Other Considerations:

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Recommendation 16: To be discussed further

Other Considerations:

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Recommendation 17: To be discussed further

Other Considerations:

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Recommendation 18:

Consent policies should require a consent decision is not used for discriminatory purposes or as condition for receiving medical treatment.

Other Considerations:

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Recommendation 19: To be discussed further

Other Considerations:

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