Health IT Advisory Council

November 21, 2019

OHS
CONNECTICUT
Office *of* Health Strategy

Agenda

Agenda Item	Time
Welcome and Call to Order	1:00 pm
Public Comment	1:05 pm
Review and Approval of Minutes – October 17, 2019	1:10 pm
Review and Discuss the Consent Design Group Guiding Principles	1:15 pm
Council action: Accept, Reject or Modify Consent DG Recommendations	2:10 pm
Review and Discussion of Proposed Milestones for HIE Deployment	2:15 pm
Announcements and General Discussion	2:30 pm
Wrap up and Meeting Adjournment	2:40 pm

Welcome and Call to Order

Public Comment

(2 minutes per commenter)

Review and Approval of:

October 17, 2019 Meeting Minutes

OHS CONNECTICUT Office of Health Strategy

Consent Design Group
Final Report & Recommendations

Michael Matthews, CedarBridge Group

Consent Design Group Members

- Stacy Beck, RN, BSN* – Anthem / Clinical Quality Program Director
- Pat Checko, DrPH* – Consumer Advocate
- Carrie Gray, MSIA – UConn / HIPAA Security Officer
- Susan Israel, MD – Patient Privacy Advocate / Psychiatrist
- Rob Rioux, MA* – CHCACT / Network Director
- Rachel Rudnik, JD – UConn / AVP, Chief Privacy Officer
- Nic Scibelli, MSW* – Wheeler Clinic / CIO

* Health IT Advisory Council Member

Consent Design Group Role

- The Health IT Advisory Council charged the Consent Design Group with the responsibility for recommending an initial approach to patient consent and an ongoing structure and process for evolving the consent model over time.
  - With the HIA technical architecture and legal framework still evolving during this period, the Design Group was lacking enough specificity on the initial use cases to achieve the original objective.
- The modified objective was to create Guiding Principles to support consent policy development, rather than creating consent policy language.
- Focusing on Guiding Principles was deemed to be more aligned with the current state of use case implementation.
- Furthermore, the principles would not only support initial use cases, but apply to the consideration of future use cases as well.

Consent Policy Design Group Workplan & Timeline

Meeting Goal and Focus
Meeting #1 (April 9, 1pm-2pm) : Kick-off and Orientation
Meeting #2 (April 23, 1pm-2pm): Current Consent Policies
Meeting #3 (May 7, 1pm-2pm): Use Case Approach to Sharing Data
Meeting #4 (May 21, 1pm-2pm): Use Case Approach to Sharing Data (Part 2)
Meeting #5 (June 4, 1pm-2pm): Roadmap to Final Consent Recommendations and Patient Provider Identity Care Map Function
Meeting #6 (June 18, 1pm-2pm): Disclosure Notification Policy Draft Review
Meeting #7 (July 9, 1pm-2pm): Disclosure Notification Policy Draft Review and Update
Meeting #8 (July 23, 1pm-2pm): HIE Governance and Likely Initial Use Cases
Meeting #9 (September 17, 1pm-2:30pm): HIE Governance and Likely Initial Use Cases (Part 2) & Guiding Principles Introduction
Meeting #10 (September 24, 1pm-2:30pm): Review Guiding Principles
Meeting #11 (October 15, 1pm-2:30pm): Review Guiding Principles
Meeting #12 (October 29, 1pm-2:30pm): Finalize Guiding Principles
Meeting #13 (November 12, 10am-11:00am): Review and Finalize Final Report & Recommendations

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Consent Design Group Guiding Principles

Recommendation 1*

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

** Additional Considerations provided for this Recommendation.*

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. 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 Guidelines developed by the Web Accessibility Initiative (WAI), part of the World Wide Web Consortium (W3C).

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).

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Consent Design Group Guiding Principles

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.

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).

** Additional Considerations provided for this Recommendation.*

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.

Recommendation 7

Clearly written information about consent policy changes should be provided to patients, parents and guardians, state and local health and human service agencies, and all licensed healthcare entities in a timely manner when policies or practices have changed, adhering to the principles of broad dissemination and accessibility of information described above.

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Consent Design Group Guiding Principles

Recommendation 8*

Mechanisms, including paper based and digital tools, for expressing consent policy preferences should be user-friendly and easily accessible.

** Additional Considerations provided for this Recommendation.*

Recommendation 9

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

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.

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.

Consent Design Group Guiding Principles

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.*
Recommendation 13 *Consent policies should be aligned with certain national interoperability initiatives, including the Common Agreement (CA) under development as part of Trusted Exchange Framework and Common Agreement (TEFCA), to support the ability to exchange data with entities outside the state.*
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.*
Recommendation 15 *Consent policies should provide a clear procedure for addressing complaints by individuals regarding the use of their data.*

Consent Design Group Guiding Principles

Recommendation 16

Consent policies should require that patients have ample opportunity to review educational material before making a consent decision.

Recommendation 17

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

Consent Design Group Guiding Principles

Recommendation 18*

Transparency and stakeholder input are foundational to the development of meaningful consent policies. While the HIA, Inc. Board has responsibility for overall governance of its health information exchange services, consent policy development should be led by the Office of Health Strategy (OHS), and advised by the Health IT Advisory Council. The process proposed is as follows:

a. *The Health IT Advisory Council should draft, review and approve consent policies for the health information exchange that are conformant with these Guiding Principles and State and Federal law;*
b. *The Health IT Advisory Council may choose to convene ad hoc or standing work groups to support consent policy development;*
c. *Once consent policies have been endorsed by the Health IT Advisory Council, OHS should review the recommendations and determine any necessary statutory or regulatory actions that may be required*;*

    ** Additional Considerations provided for this Recommendation.*

d. *HIA, Inc. will be responsible for the implementation and maintenance of consent policies adopted by the State through OHS policy, statute or regulation;*
e. *Should HIA, Inc. have concerns about any consent policies received from OHS, it may request a meeting with OHS to resolve those concerns; such resolution may require a review of proposed changes by the Health IT Advisory Council;*
f. *All meetings of the Health IT Advisory Council are open to the public and the public is provided an opportunity to make comments at each meeting, including comments related to consent policies;*
g. *All board meetings of the HIA, Inc. are open to the public; and*
h. *Draft consent policies should be made available for a 30-day public comment period prior to approval by the Health IT Advisory Council and the Health IT Advisory Council should review and consider recommendations or comments from the public to determine whether revisions to policies should be made.*

Additional Considerations

- In reference to Guiding Principle 1 (re: providing patients clear information on health sharing choices):
  - *Patients must be allowed to opt-out of the HIE completely. If not, it must be clearly stated which of their data will be included in the HIE without their express consent, because this can be allowed by the HIPAA business associate agreements. Such data may include their identifiers for matching to providers and identified medical information shared between providers and with OHS for public health, tumor registry, discharge summaries, quality measures, CDAS, etc.*

- In reference to Guiding Principle 5 (re: HIE participation provide in NPPs):
  - *Health care organizations should also provide patients with the location of where they can find more information on which HIEs providers participate in.*

- In reference to Guiding Principle 8 (re: user-friendly tools for expressing consent preferences):
  - *Regardless of what consent methodology is in place (e.g., opt-in or opt-out), the mechanisms for expressing consent preferences should also provide clear information regarding the impact and consequences of the consumer's choice.*

- In reference to Guiding Principle 18c (re: OHS review for statutory and regulatory requirements):
  - *Consent policies should be decided in the public domain and accepted by the Regulations Review Committee. In preparation for drafting the consent policies for the LRRC, OHS/HIT Advisory Council should hold hearings on the proposed consent policies to be held at the Legislative Office Building with notice in the Legislative Bulletin, along with a well-publicized, written input process for each consent policy and the public posting of all comments. Additionally, bi-annual hearings should be held to review the consent policies and their efficacies. This is needed to ensure that the public has some control over who sees their medical information. Otherwise, OHS may be able to put data into the HIE without patient consent, as allowed by HIPAA for treatment, payment and health care operations.*

Next Steps

- Approval of Guiding Principles by Health IT Advisory Council
- Review of Final Information Blocking Rule
- Assessment of Impact on Final Information Blocking Rule on Consent Policy in CT
- As defined by Guiding Principle 18, development, review and approval of consent policy for initial use case(s)
- Implementation of interim mechanism for patients to use to express information sharing preferences
- Development and implementation of comprehensive consent management solution through IAPD funding

Review and Discussion of Proposed Milestones for HIE Deployment

Allan Hackney

Key Early Milestones to Operations

Objective	Target
Seed money contract – OHS/HIA	Nov 2019
Full FFY20 contract – OHS/HIA	Jan 2020
HIA basic business functions active	Jan 2020
Participating organizations sign trust agreement	Dec 2019+
Pilot participating organizations exchange data in beta test	Feb 2020
General onboarding begins	Mar 2020

Announcements and General Discussion

Allan Hackney, Council Members

Wrap up and Next Steps

Upcoming Health IT Advisory Council Meeting

Thursday, December 19, 2019
1:00-3:00 pm

Please note *room* change:
1A, Legislative Office Building
300 Capitol Avenue
Hartford, CT 06106

Contact Information

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Health IT Advisory Council Website:

https://portal.ct.gov/OHS/HIT-Work-Groups/Health-IT-Advisory-Council

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