

Consent Policy Design Group

Meeting #6






June 18, 2019



Agenda

Agenda Item	Time
Welcome & Introductions	1:00 pm
Public Comment	1:02 pm
Roadmap Review	1:05 pm
Disclosure Notification Policy – Draft Review and Update	1:10 pm
Additional Policies to Support Care Map Use Case	1:25 pm
Policy Recommendation Draft Document	1:55 pm
Wrap-up and Meeting Adjournment	2:00 pm

Consent Policy Design Group – Workplan

Meeting Focus	Meeting Objectives
 Meeting 1 – 4/9/2019 1pm – 2pm Kickoff and orientation	<ul style="list-style-type: none"> • Review and discuss project charter and proposed process for achieving desired outcomes • Orientation on relevant policies and procedures and semantic alignment / shared understanding of key terms
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Meeting 6 – 6/18/2019 1pm – 2pm Use Case B discussion	<ul style="list-style-type: none"> • Discuss the various ways that consent could be collected and possible roles for organizations in the consent process • Establish high-level understanding of technical architecture for electronic consent management solutions • Discuss workflows that could provide individuals with information and the ability to manage preferences
Meeting 7 – 7/9/2019 1pm – 2pm Review draft consent framework recommendations – structure and process	<ul style="list-style-type: none"> • Review and discuss strawman options • Develop draft recommendations for consent policy framework
Meeting 8 – 7/23/2019 1pm – 2pm Vote on draft recommendations	<ul style="list-style-type: none"> • Finalize and approve recommendations • Discuss stakeholder / general population engagement and communication process

The Consent Policy Design Group

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

* Health IT Advisory Council Member

The Support Team

State of Connecticut

Allan Hackney

Health Information Technology Officer
Chair, HIT Advisory Council

CedarBridge Group

Carol Robinson

Michael Matthews, MSPH

Ross Martin, MD, MHA

Chris Robinson

Velatura

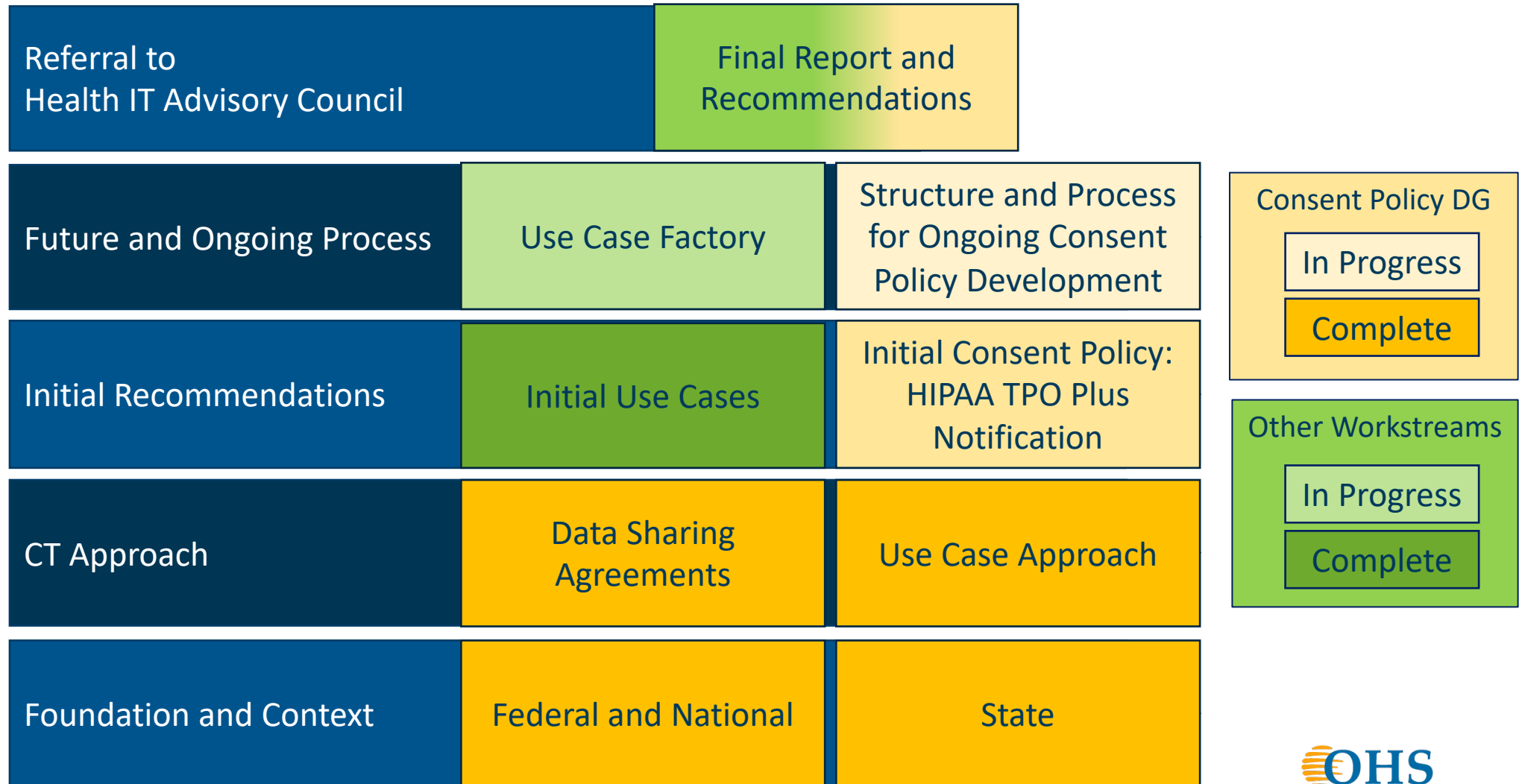
Tim Pletcher, DHA, MS

Lisa Moon, PhD, RN

Public Comment

Roadmap Review

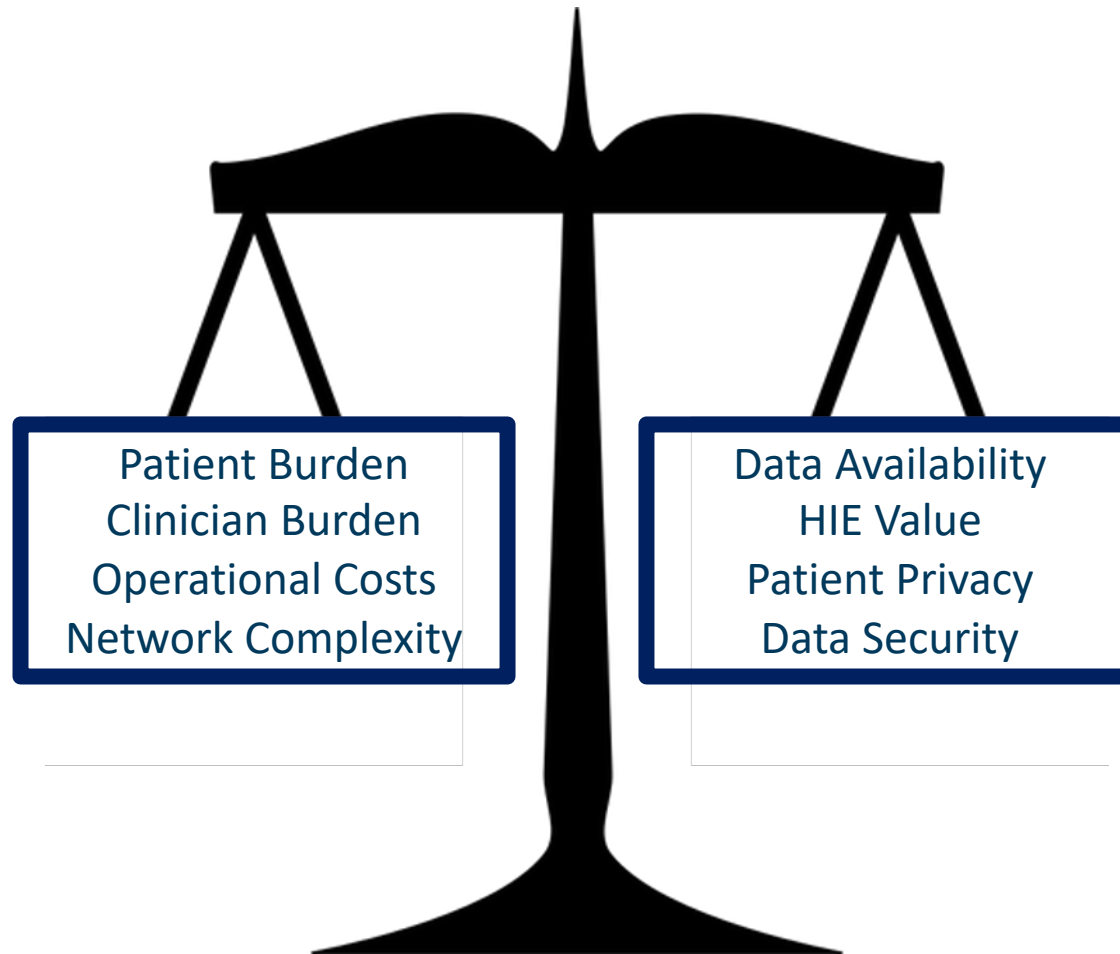
Consent Policy DG Process Review – Where We Are Now



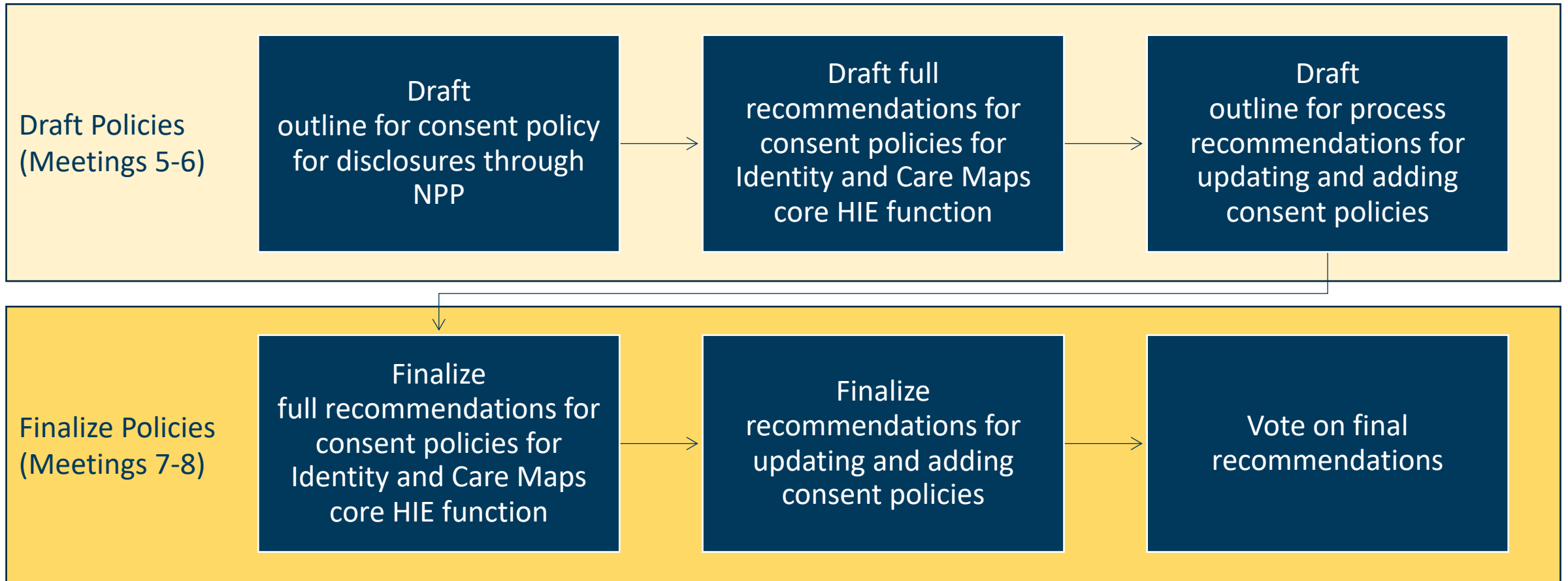
What is out-of-scope for this Design Group?

- **Our work assumes that:**
 - **Security will be managed appropriately.** This includes: user access; data security in motion and at rest; HIE vendor management; User and vendor auditing; application of breach notification policies, etc.
 - **Use Cases have been prioritized through the Use Case Factory process.** Our job is to recommend consent policies for each use case.
 - **Data is accessible only to those who have a reason to access and their use is monitored and audited.**
 - **The work we are doing is the beginning of an ongoing process for addressing consent policy issues.**
 - **The HIE Entity will create detailed implementation methodologies and workflow processes to support the final consent policies.** We don't have to "micromanage" their operations, but provide high-level policy recommendations.

Consent Design Balancing Act



Process Between Now and Meeting 8 (July 25, 2019)



Today's task: Draft outline for consent policy for disclosures through NPP that apply to the Identity and Care Map core function use case.

In between meetings: Staff works on synthesizing comments and refining language as draft consent policy.

Disclosure Notification Policy Draft Review and Update

Discussion of Additional Policies to Support Care Map Use Case

Disclosure Notification Policy (FIRST DRAFT)

- Name: Disclosure Notification
- Purpose:
 - To inform patients and their representatives of the existence of the HIE Entity and notify them of the Participating Organization's involvement with the HIE.
 - To give the patient basic information on the nature and purpose of health information exchange and how to seek out additional information on the consent process for participation in the HIE – either through active or passive consent mechanisms.
- Applies to: All approved HIE Use Cases (currently, Patient and Provider Identity and Care Maps)

Disclosure Notification Policy (DRAFT)

- **The HIE Entity will provide content and materials to all HIE participants to support their required patient disclosure notification activities.** The capabilities of participating organizations will vary widely – from multi-facility health systems to large multi-specialty practices to small solo physician practices. The HIE Entity will create and maintain content and materials in multiple forms to accommodate the various types of participating organizations and at a reading level suitable for a general patient population. These materials will include:
 - Sample language for inclusion of the participating organization’s [Notice of Privacy Practices](#).
 - Templates for supplements to Notice of Privacy Practices that can include the participating organization’s name and other identifying information such as location and logo.
 - Non-English language support and translation services as needed to accommodate patients and their representatives for whom English is not a primary language.

Disclosure Notification Policy (DRAFT)

- **The HIE Entity will maintain a website and a customer service capability to address patient and caregiver questions about the details of the services offered and the rights and responsibilities of patients.** The website should be regularly updated with changes to policies and services and should be sufficiently detailed and transparent to give patients and their advocates a full understanding of the role of the HIE Entity; the services it provides; the governance and legal duties of the organization; links to relevant laws and regulations that apply to the HIE Entity; and the actions a patient can take related to the exchange of their information (e.g., requesting an accounting of HIE activities for their information, opting in or out of certain services, submitting requests for correction of inaccurate information, who to contact for additional information, etc.). Examples or templates of the legal agreements signed by participating organizations should be made available as well as links to approved use cases and other non-sensitive policy documents governing the HIE Entity.

Disclosure Notification Policy (DRAFT)

- **The HIE Entity will publish a continuously updated list of all Participating Organizations and the Use Cases in which they are participating.** This list should include the types of data that are provided by participating organizations and the dates on which these data were made available through the HIE Entity.
- **The HIE Entity will create and maintain a method for patients to sign up to receive regular updates on HIE policies, use cases, and participants.** Patients should be able to learn when their providers expand or change their relationship with the HIE. This could be through an annual or quarterly report directed at consumers or through a customized report specifically for registered and identity-validated patients. The HIE Entity should provide patients with access to reports on overall activity and evolution of exchange in the State of Connecticut and its relationship with regional and national networks.

Disclosure Notification Policy (DRAFT)

- ***Responsibilities of the Participating Organization – Questions for Discussion***
- *Should the Participating Organizations be required to display information about their participation in the HIE in a patient-accessible location (waiting area, website, etc.)?*
 - ***Proposed language: Participating Organizations will display information about their participation in the HIE Entity in patient-accessible locations. Information display can include displaying HIE Entity-provided posters and fliers in patient waiting areas; including information about participation in the HIE Entity on the Participating Organization’s website; etc.***

Disclosure Notification Policy (DRAFT)

- *Should Participating Organizations be required to update their Notice of Privacy Practices (NPPs) and make this available to all incoming patients? Should Participating Organizations be required to distribute updates to NPPs to all active patients on a recurring basis (e.g., annually)? Should Participating Organizations be prohibited from submitting patient information to the HIE until that patient has received notification of their participation in the HIE? Should Participating Organizations be required to provide the patient with an updated account of the Use Cases in which they are participating?*
 - *Proposed language: **Participating Organizations will include information about their participation in the HIE Entity as part of their Notice of Privacy Practices and seek acknowledgement of receipt of this information in compliance with [HIPAA regulations](#).** The information provided should include details under which use cases the Participating Organization is sending or receiving data from the HIE Entity. Participating Organizations should update their Notice of Privacy Practices in a timely fashion whenever they sign on to new use cases. Participating Organizations should make clear to patients whether failure to acknowledge the notification of disclosures to the HIE Entity will limit the sharing of information with the HIE Entity (i.e., can the patient restrict the sharing of their information with the HIE Entity by the Participating Organization).*

Please share comments with the group!

When providing comments:

- CedarBridge will share an outline of the policy recommendations to members and staff between meetings.
- To make a comment, reply to all and change the subject. Begin all subject headers with [Consent Policy] and the section reference (e.g., [Consent Policy] Responsibilities of HIE Entity).
- Please create a separate email for each section of the policy and include that section header in your subject line.
- If someone has already commented on a section, please add your comments about that section as a response to the initial email. Create a separate email if you want to comment on a different section.
- If you want to make a general comment, please create an appropriate subject header.

Disclosure Notification Policy (example)

- Responsibilities of Patients and Caregivers – Questions for discussion
 - Are there any specific expectations for patients and caregivers (e.g., acknowledging receipt of notice of privacy practices related to HIE)?







Additional Policies to Support Patient and Provider Identity and Care Map Use Case

Discussing the Need for Additional Policy Recommendations

- *Are the current proposed policy recommendations regarding notification disclosure sufficient to cover the Patient and Provider Identity and Care Map use case?*
 - *Is there a need for the CPDG to develop a patient opt-out policy to support this use case? If so, should it apply to all Participating Organizations or only to certain ones?*
 - *Is there a need for the CPDG to develop a patient opt-in policy to support this use case? If so, should it apply to all Participating Organizations or only to certain ones?*
- *What mechanisms for opt-out should be made available to patients? Should it be sufficiently granular to apply to a specific Participating Organization? If so, should it also include a global opt-out for all HIE activities to which an opt-out policy could apply?*
- *Should the Participating Organizations be involved in the opt-out process beyond informing the patient of their options through the Disclosure Notification Policy process?*
- *What are the responsibilities of the HIE Entity?*
- *What are the responsibilities of the Participating Organization?*
- *What are the responsibilities of the Patient?*

Policy Recommendation Draft Document

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