

# Consent Policy Design Group

## Meeting Minutes

MEETING DATE	MEETING TIME	Location
July 9, 2019	1:00PM – 2:30PM	<b>Join Zoom Meeting:</b> <a href="https://zoom.us/j/269726549">https://zoom.us/j/269726549</a> <b>Dial:</b> +1 646 876 9923 US <b>Meeting ID:</b> 269 726 549

DESIGN GROUP MEMBERS					
Stacy Beck, RN, BSN		Susan Israel, MD	x	Nic Scibelli, MSW	x
Pat Checko, DrPH	x	Rob Rioux, MA		Steve Bonafonte	
Carrie Grey, MSIA		Rachel Rudnick, JD	x	Lauri Johnson	
Damien Fontanella					
SUPPORTING LEADERSHIP					
Allan Hackney, OHS		Chris Robinson, CedarBridge		Tim Pletcher, Velatura	
Carol Robinson, CedarBridge	x	Ross Martin, CedarBridge	x	Lisa Moon, Velatura	
Michael Matthews, CedarBridge	x	Sheetal Shah, CedarBridge	x	Sean Fogarty, OHS	x

Minutes			
	Topic	Responsible Party	Time
1.	<b>Welcome and Overview</b>	<b>Michael Matthews</b>	<b>1:00 PM</b>
	Michael Matthews thanked the design group members for joining the meeting today.		
2.	<b>Public Comment</b>	<b>Attendees</b>	<b>1:02 PM</b>
	No public comments at this time.		
3.	<b>Disclosure Notification Policy – Draft Review and Update</b>	<b>CedarBridge Group</b>	<b>1:05 PM</b>
	<p><i>Slide 14 - 18: Disclosure Notification Policy (NEAR-FINAL DRAFT), Responsibilities of the HIE Entity (2.1.4)</i></p> <p>Ross Martin reviewed updated language with the members. There were modifications to wording related to supporting smaller health care organizations and supporting English translation services. He indicated it is the responsibility of the participating organization, but with support. He asked for the group’s comments on what they would adopt or change.</p> <p>Susan Israel asked a question if patients would know their data is going into the HIE prior to giving consent. She did not have an issue with the language as written.</p> <p>Pat Checko indicated she reviewed the consent white paper from NY. She was curious to know what NY implemented after that extensive report.</p> <p>Rachel Rudnik expressed difficulty for organizations to update NPPs. Many organizations prefer to indicate that they participate in the HIE and direct consumers to information at another website. Nic Scibelli agreed that there are organizational barriers to updating NPPs. They take this very seriously.</p> <p>Carol Robinson mentioned that many states have taken new approaches. NY’s law is codified and the qualified entities/RHIOs provide a consent mechanism for patients/individuals to provide their consent for data to be shared across the state. She indicated this is a very complex environment and processes will evolve over time.</p> <p>Susan Israel indicated that it is not always true that patient consent is not needed for TPO. She believed they should start first with the issue of patient consent. Ross Martin indicated that the first use case is related to “care mapping,” which is understanding if a relationship between the patient and provider exists.</p>		

Susan Israel was concerned that they moved from a patient-centered situation to a statewide/provider centered perspective. Ross Martin indicated previous examples of HIEs that tried to do active patient registration were not viable.

Pat Checko indicated that she was thinking of consent and notification as two separate entities. However, believed that notification implied participation as it was described. Ross Martin indicated that they would need get through core work here and then investigate a mechanism for managing consent at a state level.

Susan Israel asked about which specific data fields would be used to identify individuals (ie SSN, race). Ross Martin indicated that this is an excellent question. There are minimum elements needed to reasonably identify an individual. Generally, the more data you can apply to the person, the more accurately you can declare that it is the right person.

Michael Matthews mentioned that the HIE entity has a governing body and it will be operating committees and subcommittees. Some of the issues this group talks about may need to be at a “guiding principles” level. They can make a broad reference that the HIE entity should provide a user-friendly tool.

Susan Israel asked if patients are notified and told what those factors are. Michael Matthews indicated it would be good to know where to go for that information. Ross Martin can draft language and think about where to add this.

Rachel Rudnik expressed concern that they are doing this work “in a vacuum.” For this use case, they would want to know the data typically involved. She believed the conversation was circular and not practical or feasible long-term.

Michael Matthews agreed with her. The HIE has not established those use cases, but the Consent Design Group wants to create meaningful policies to start. This is why references the term “guiding principles.” The group can recommend guiding principles for any potential policy or use case. In addition, they can discuss the structure and process for how stakeholder and public input is used for consideration.

Michael Matthews indicated that one of the recommendations could be that this Design Group could only do a limited amount because they do not know the use cases.

Susan Israel asked if patients could select which providers could share data. Rachel Rudnik indicated that they would also need to understand if the functionality is there. Nic Sciabelli asked how other trusted networks do this.

Ross Martin indicated that the it is difficult to know more if a document does not contain a piece of information that may be subject to particular types of consent. There are models that support it, but it is not technically feasible. Cerner and Epic have reticent to this concept.

Michael Matthews provided an example of eHealth Exchange. The policies of each participant is respected by each of the participants. If one entity is exchange with another entity, what works at one endpoint is respected.

Nic Scibelli asked if this is the basis for the HIE is being set up. Michael Matthews indicated that there will be alignment.

Michael Matthews indicated that the group can say that they do not know enough about the use cases but can opine once there is more specificity. He asked for the group’s feedback.

Rachel Rudnik did not believe they have enough information to form guiding principles. They need more information to understand what data is involved and the practicality of what is technically feasible. Susan Israel did not disagree; she would like to have more information.

Carol Robinson indicated that everything the group is saying is rational and typical of the complexity of this space. She indicated that starting with the care map and demographic data seemed like the right place to

	<p>start, as you can data from many sources – birth registry, driver’s license, health care entity, etc. There are many ways to “slice and dice” the information being sent. The next level is data shared under HIPAA Laws. The data is there legally, but there is an acknowledgement that patients can opt-out. Most HIEs operate this way. Then, there is a 3<sup>rd</sup> level of use cases – genomics or research – purposes that may not be permitted by HIPAA. She acknowledges the confusion and understands why.</p> <p>Rachel Rudnik indicated it would be help to have more information from OHS about the broader picture and the intent. That would be the best way to use the expertise of this group. It is important to step back to more meaningfully create the consent framework.</p> <p>Michael Matthews indicated that they would circle back with Allan Hackney and develop a plan. He can provide more information on the “bigger picture” and how data is going to be used. The members agreed.</p>		
<b>4.</b>	<b>Wrap Up and Meeting Adjournment</b>	<b>CedarBridge Group</b>	<b>2:50 PM</b>
	Michael Matthews thanked the group for thinking very thoughtfully through these complex issues.		

**Upcoming Meeting Schedule:** March 21, 2019; April 18, 2019, May 17, 2019

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