

# Consent Policy Design Group

## Meeting Minutes

MEETING DATE	MEETING TIME	Location
September 17, 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	X	Susan Israel, MD	X	Nic Scibelli, MSW	X
Pat Checko, DrPH	X	Rob Rioux, MA		Rachel Rudnick, JD	X
Carrie Grey, MSIA					
SUPPORTING LEADERSHIP					
Allan Hackney, OHS	X	Carol Robinson, CedarBridge	X	Sheetal Shah, CedarBridge	X
Tina Kumar, OHS	X	Michael Matthews, CedarBridge	X	Tim Pletcher, Velatura	
Sean Fogarty, OHS	X	Chris Robinson, CedarBridge	X	Lisa Moon, Velatura	

Minutes			
	Topic	Responsible Party	Time
<b>1. Welcome and Overview</b>		<b>Allan Hackney</b>	<b>1:00 PM</b>
	Michael Matthews welcomed the group and provided an overview of the agenda. Michael introduced Sean Fogarty, a new program manager with OHS.		
<b>2. Public Comment</b>		<b>Attendees</b>	<b>1:02 PM</b>
	There was no public comment		
<b>3. Review and Approval of Meeting Minutes</b>		<b>Attendees</b>	<b>1:05 PM</b>
	Pat Checko created the motion to approve the meeting minutes from July 23, 2019. Nic Scibelli seconded the motion and it was approved without objections or abstentions.		
<b>4. Questions &amp; Answers from Previous Meeting</b>		<b>Allan Hackney</b>	<b>1:10 PM</b>
	Allan Hackney thanked Susan Israel and Pat Checko for presenting questions and statements regarding the previous meeting's presentation. Starting with questions from Susan Israel, Allan first wanted to ensure there was a common understanding of the HIE Trust Framework and the use cases. Allan indicated that the Trust Framework is a modular framework and will allow for the creation of a HIPAA Business Associate relationship and allows for any number of individual use case exhibits that permit the sharing of data in accordance with the purpose and instructions of the use case. The framework requires the participating organization to sign onto a master agreement, in which no data is exchanged, but for which a legal connection is established with the HIE. Once this legal connection is established, organizations can sign-on to specific use case exhibits, based on their organizational needs. Only once a use case exhibit is signed will data be exchanged. Allan said it is important to understand that patients have no input with respect to an organization signing on to the HIE as a HIPAA Business Associate. This is a business decision and participation in the HIE is mandated by statute. Hospitals and clinical labs have one year to participate, and other clinical organizations have two years. Allan said that with respect to use cases, he believes it is the recommendation of this group that the consent requirements would be incorporated into the use case exhibits. Allan thinks this is a reasonable recommendation and guiding principle.		

Allan said that it is correct that public health data may be sent to the HIE without further patient consent, as dictated and outlined by the use case exhibit, once it is developed. For example, OHS will ask for funding from the SUPPORT Act to connect PDMP data to the HIE. Doctors and other caregivers can query the systems from within their clinical workflow before they issue a prescription for controlled substances. Patients do not have the ability to dictate whether these prescriptions are entered into the PDMP or whether these records are accessed from the provider's electronic health record system. This is an example where the law is dictating the use case. There are other use cases where consent is entirely appropriate, but there may be cases where data flows through the HIE without patient consent.

Pat Checko clarified one point relating to public health data and reporting, specifically related to reportable diseases and conditions. Pat said that the law clearly states that this must happen and has never required patient consent. Allan agreed and said he was going to give another example relating to measles reporting and public health surveillance. Susan Israel commented that public health reporting was historically conducted in a very small department and there was limited access to the data.

Susan Israel asked for further clarification about the use case for identity and care mapping and whether or not patient's will be allowed to consent to the incorporation of their identity data into the HIE. Allan Hackney indicated that identity and care mapping is not a use case; it is a core function of the HIE and is a central function that any use case will utilize. Susan Israel believes that the public needs to understand that their identity information will be matched with their care providers. Furthermore, Susan indicated that she believes that HIPAA treatment, payment and operations (TPO) is extremely broad, and this means that patients will have limited ability to consent.

Nic Scibelli commented on provider and patient matching. From his understanding, this is something that DSS has been doing for a long time for the Medicaid population. Nic said that this is not new and is not limited to one small department at the state. Allan Hackney agreed and indicated that this is true regarding identity matching. Additionally, Allan said that this is the same system utilized by the health insurance exchange (AccessHealth CT) for eligibility and is also used by the Early Childhood Development Offices. Nic wanted to make sure that this point was clarified and that the HIE's participation in this would be limited compared to what the state has been doing for quite some time.

Carol Robinson requested to clarify one aspect from Susan's comments. If the individual's identity and care providers are collected and mapped within a central utility of an information system. This does not necessarily mean that the individual would not have means to consent or decline consent for information being shared to their providers. Susan asked a question regarding which providers can see care summaries and if this is covered under HIPAA TPO. From her perspective, there is nothing in the guiding principles that allow for patient consent on items covered by HIPAA TPO. She does not know if the average person in the state would want this information in the state's database. Carol Robinson indicated that based on her experience across the country, it is imperative to ensure fidelity and safety of all individuals in the state. There are limited ways to protect the health and safety of a total population without effective data sharing. This is the conundrum they are facing. One has to view the needs of the overall population, as well as individual rights, and think about appropriate policies and technology.

Susan Israel said that as she read through the guiding principles, it is her understanding that when a patient goes to a doctor and agrees to treatment, then you are also agreeing to participation in the HIE. She indicated that we should be clear on this because she is concerned about the safety of data. Pat Checko said that an important reason for creating the HIE was to give patients access to their own information and to be able to share it with their care givers. Pat said that she does not think we should be sharing data until we do a large educational campaign to educate the consumer on what will be

taking place. Allan agreed and mentioned that the Health IT Advisory Council deliberated on this point and concluded that patients absolutely need access to their data through their HIE, but there needs to be scale. The game plan was always to connect, build scale and that do exactly what Pat described.

Susan Israel asked if there is a “complete” opt-out of the HIE. Allan responded no, there is not the ability to opt-out of the HIE under certain use cases. Allan said that within one of the impending federal funding requests, there is funding available to develop a consent management system and have always viewed consent as integral to the HIE. The funding is meant to provide enough thoughtful planning and design for a consent management solution that attaches to a particular person. He added that consent management is not about limiting access to data for certain people, the intent is to more readily share data thoughtfully with appropriate providers.

Allan referenced Susan’s question regarding notifications and consent. Susan Israel indicated that when ones goes to a doctor, there is really no consent, outside of their agreement to receiving treatment. She clarified that she is not against having an HIE, she is only talking about patient consent. Nic Scibelli indicated, historically, these notifications were built to inform the patient and ensure they understand the data is being exchanged with the insurance carrier. This is not exclusive to exchanging information with a HIE under HIPAA TPO.

Allan Hackney next addressed Susan’s comment on the identity key and transferring data without names. Allan said that they are only exchanging data with providers who already know who the patient is and have an established relationship. The purpose of the common key is to increase the certainty that the HIE is linking the right individual’s data to the right record. This is an operational aspect of the HIE.

Allan Hackney said that the clinical care summary is full of clinical data, but the use case exhibits will stipulate which data will be used and exchanged. He does not want anyone to think that the HIE intends to store all of the data with respect to clinical care summaries. The only data that is stored would be clearly specified by the use case exhibits, and it would only be used for this specific purpose. Susan Israel asked about discharge summaries. Allan indicated that it is important to bring this back to the use case exhibits. If there is a transition of care use case, it is appropriate to exchange data from one caregiver to another. Allan said that the clear communication of this could be a guiding principle that the group can consider.

Pat Checko said that it is important to recognize what is good for the consumer. From her perspective, this group has spent a lot of time deliberating about people who do not want their data shared, as opposed to those that will find great value from the services of the HIE.

Allan Hackney indicated that the federal government just announced that The Sequoia Project will oversee the deployment and implementation of the Trusted Exchange Framework and Common Agreement (TEFCA). Allan said we should absolutely align to TEFCA. Allan is very supportive of the idea of patient responsibility and the concept of informed consent is very important.

As it related to item 4 from Pat Checko’s comments, Allan indicated there will be an Operations Advisory Committee formed within the HIE, based on participants that sign onto the long form of the master agreement. This group is operational, and this concept has been discussed at previous meetings. Allan explained that the priorities will be driven by organizations that have funding or specific policy levers. Allan had a discussion with DSS about this topic. As it related to item 5 from Pat’s comments, Allan Hackney indicated that the patient has always been the “north star” in all considerations and deliberations. As it related to item 6, Allan Hackney offered to provide a demonstration of the Core Data Analytics Solution (CDAS) over at UConn AIMS.

	Allan thanked everyone on this design group for their willingness to discuss these complicated topics collaboratively. These are tough topics and appreciates everyone.	
<b>5.</b>	<b>Discussion of Guiding Principles</b>	<b>Attendees</b>
	<p>Michael Matthews indicated that this discussion has helped illuminate the need to shift to the guiding principles. CedarBridge Group circulated an initial draft to give Design Group members an idea of what types of things could be considered. Michael emphasized that these were in draft form and there could be additional items added. The concept of guiding principles has been used by the Health IT Advisory Council for strategy and policy development in the past.</p> <p>Michael asked Pat Checko and Nic Scibelli, who have participated in previous design groups, to share whether or not they believe this is a workable approach for this group. Pat Checko mentioned that each use case will be unique, and that more specificity will be needed to develop a consent policy. Therefore, she believes that the guiding principles should be reviewed each time a use case is created. She believed this will help in developing “rules of the road.” Nic Scibelli agreed. He discussed his experience participating in the eCQM Design Group. In his experience, he wanted to dive into more details and had great concern around the prioritization of which quality measures would be analyzed. That group formed principles for certain components or processes, and it ensured behavioral health was included as a guiding principle. He believed developing guiding principles will be the best use of this group’s time and will produce the best product.</p> <p>Michael Matthews asked Rachel Rudnick for her input. Rachel believed that this group cares about consent policy, informed consent, notice, choice and fair information privacy principles as a whole. However, without having clarity on the actual use cases, she believes that they are left with a little confusion and the group has differing perspectives. In her experience, she thinks about “privacy by design” but this is hard to do. Michael Matthews indicated that the intent with guiding principles is that they are applied equally to all of the HIE’s use cases. He believed the lack of specificity is preventing the group from developing a consent policy. The guiding principles will also help with use cases that have not been contemplated yet. Rachel Rudnick indicated that she would need to understand where the state wants to be. There are some things in the guiding principles she would accept whole-heartedly and other areas where she could see pitfalls. She would like to see something more concrete.</p> <p>Susan Israel said that before discussing the guiding principles, she would like to know what would be included under HIPAA TPO. For example, if identity and care mapping is automatic, she would like that delineated. Based on this question, Michael Matthews asked Susan if she could contemplate what a guiding principle would be and add it to the document. He would like to see if there are elements that have majority support.</p> <p>Nic Scibelli added that this group is not the “decision-maker” but has an opportunity to inform the decisions that will be made. Michael Matthews concurred with this statement. He added that Allan Hackney went through the likely roadmap for the use cases, however they may not be at the level of granularity to develop a specific consent policy. With the group understanding the first 4-5 use cases, this would be enough to support development of guiding principles and an opportunity to inform decision makers governing health information exchange.</p> <p>Rachel Rudnick commented that a general principle is the HIE is used to facilitate sharing by applicable laws and to facilitate TPO. There is no difference whether one is working between a health information management or medical record office. She believed the group could probably complete this exercise with the guiding principles, but with some hesitation and some confusion. She mentioned that she has stated multiple times that she is unsure if this group could reach consensus.</p>	<b>1:45 PM</b>

	<p>Michael Matthews asked this group to review the principles and add additional guidelines. He asked the members to think about if they accepted the principle, accepted it with changes or modification, or state that it is not something they could support. Rachel Rudnick requested to add a fourth choice as “undecided” or “unable to comment.” Michael Matthews agreed and believed this was a great suggestion.</p> <p>Sabina Sitaru asked Michael Matthews to comment on how the guiding principles will inform the HIE entity’s operations. Michael Matthews responded that the HIE will have a Board, Operations Advisory Committee, and a Privacy Policy Committee, each with infrastructure to support. One of the principles could be that every single use case would have a single consent policy review.</p>
<b>6. Wrap Up and Meeting Adjournment</b>	<b>Michael Matthews</b> <b>2:25 PM</b>

As a next step, the CedarBridge team will circulate a user-friendly format of the guiding principles. They will add a fourth option for “unable to respond.”

The group deliberated on subsequent meeting dates. The next meeting will be on September 24<sup>th</sup> at 1pm. The group will aim to send their feedback by Friday or over the weekend. Then, the CedarBridge team will compile and circulate the responses by Monday morning. A contingency meeting will be scheduled for October 15th at 1pm.

Michael Matthews indicated that these are difficult conversations and appreciated the members for their thoughtfulness.

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