Consent Policy Design Group
Meeting Minutes

MEETING DATE	MEETING TIME	Location
June 18, 2019	1:00PM – 2:00PM	**Join Zoom Meeting:** https://zoom.us/j/269726549 **Dial:** +1 646 876 9923 US **Meeting ID:** 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			
Carrie Grey, MSIA	x	Rachel Rudnick, JD	x		
SUPPORTING LEADERSHIP					
Allan Hackney, OHS		Chris Robinson, CedarBridge	x	Tim Pletcher, Velatura	
Carol Robinson, CedarBridge	x	Ross Martin, CedarBridge	x	Lisa Moon, Velatura	
Michael Matthews, CedarBridge	x	Sheetal Shah, CedarBridge	x	Sabina Sitaru, HIE Entity	x

Minutes			
	Topic	**Responsible Party**	**Time**
1.	**Welcome and Overview**	**Michael Matthews**	**1:00 PM**
	Michael Matthews welcomed the workgroup members and provided an overview of the agenda.		
2.	**Public Comment**	**Attendees**	**1:02 PM**
	There was no public comment.		
3.	**Roadmap Review**	**Ross Martin**	**1:05 PM**
	Ross Martin indicated that they were about halfway through the process to develop draft consent policies and a structural process for advancing this work on go-forward basis. He reminded members that there are certain areas which are out of scope for this specific workgroup, such as the security of the data. This group is focused on initial use cases of identity and care maps. They reviewed the specific meeting topics on slide 2. Pat Checko asked for clarity related to consent for identity and care maps. From her perspective, this means sharing data on providers responsible for delivering care to individuals. This helps establish the foundation for other use cases. As she understands it, they may not need separate consent policy for identity and separate consent policy for care map. Ross Martin concurred.		
4.	**Disclosure Notification Policy Draft Review**		**1:15 PM**
	Disclosure Notification Policy – Slide 14 Ross Martin reviewed the disclosure notification policy. The purpose is 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. The purpose is also 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. It is foundational to all use cases. *Disclosure Notification Policy – Slide 15* Ross Martin reviewed the specific language in this section of the policy. He indicated that it details the specific obligation of the entity. This was drafted based on comments during the last meeting. He asked if there were any particular changes to the wording.		

Prepared By: CedarBridge Group

Pat Checko asked about the non-English language support and whether this just applies to materials, or to the broader services. She asked if there was an expectation that the HIE would have to provide translational services.

Ross Martin indicated that they may not dictate how materials get translated. This is the responsibility of the HIE.

Susan Israel asked if they were generally referencing "consent" on the slide and if this was intentional. She indicated that the actual policy (opt-in vs opt-out) had not been decided yet. Ross Martin indicated this was correct.

Carrie Grey indicated that she did not want to set an expectation that all languages are offered. Carol Robinson agreed and indicated that they can develop recommendations that would later need prioritization.

Disclosure Notification Policy – Slide 16

In this section of the policy, Ross Martin indicated that the HIE will maintain a website and customer service capability to address patient and caregiver questions about the details of the services offered and the rights and responsibilities of patients.

Nic Scibelli mentioned that he feels this wording is very thorough. He indicated that he thinks everything is covered and is not sure what else could be added. It meets his expectations based on what they discussed last time.

Pat Checko indicated that she does not want to put the entity in the position to communicate 1:1 with the patient. She believed this is the responsibility of the provider. Ross Martin said this is a great point. He did not envision this to be a 24/7 service. However, most providers will have little insight into how the HIE technically functions, so this would be viewed as a "secondary line of defense" or response.

In Maryland, Ross Martin indicated that the HIE has patients and providers calling to ask questions. Over time, they developed a customer care team that answers the phone which is focused on helping providers get connected and enrolled, as well as answering questions from patients and caregivers. They have developed a set of standard operating procedures for addressing certain questions.

Nic Scibelli appreciated the explanation.

Susan Israel wanted to raise a concern she had with the use of the word "certain", but she did not want to discuss it now.

Disclosure Notification Policy – Slide 17

Rachel Rudnik asked for clarity on the concept of the "use case factory" Ross Martin indicated that it was a methodology or process to predictably create artifacts for all types of use cases. It will allow providers and hospitals to decide which use cases they participate in.

Pat Checko asked to explain the customized reports for identity validation. Ross Martin explained that if a patient signs up, they could get an automated periodic message that lays out who among their care team is participating in each of the use case. It's their providers and the use cases that they are participating in.

Disclosure Notification Policy – Slide 18

Ross Martin indicated that this section of the policy speaks to displaying information about HIE participation in patient-accessible locations.

Rachel Rudnik indicated that there would be significant cost to create new postings and would request flexibility in the way it is done. Ross Martin agreed, he indicated this is an issue for HIEs to maintain and there is no "one size fits all."

Michael Matthews agreed. They are concerned with the burden to providers. He added that once this group has formulated an approach, they will seek more feedback from a physician group.

Disclosure Notification Policy – Slide 19

Ross Martin indicated that the proposed language in this section will ask organizations to include information about their participation in the HIE entity as part of their Notice of Privacy Practices.

Susan Israel asked if they could put patient data in the HIE before they received consent from the patient. Ross Martin indicated that this is a good question and something this group has to grapple with.

Pat Checko indicated that they have been through the discussion of what HIPAA allows in terms of sharing information between providers without consent. From her perspective, she may only see her physician 3 times a year. If the physician is referring her to a specialist, he should have that information to share. This is one example when consent of patient is not required.

Rachel Rudnik indicated that asking larger institutions to update their Notice of Privacy Practices is a heavy lift and not practical. She believed it is more practice to changing it online and knowing that the organization is participating in HIE as a means of TPO. Additionally, it will be important to keep in mind that a provider organization may still share information with other physicians, for TPO, just not through the HIE.

Ross Martin indicated that this question warrants a longer discussion. This is a very complicated area and it has been implemented in different ways arounds the country. In preparation for the meeting 2 weeks from, he asked the design group members to exchange thoughts and comments among the group. Lastly, he indicated that they can also create a minority report that gets added to the final report and recommendations.

Nic Scibelli agreed with the administrative burden, feasibility and related compliance issues if we wait for a patient's agreement. He also believed they may be covered on Part 2 data with this approach.

5.	Wrap-up and meeting Adjournment	Michael Matthews	2:00 PM
	Michael Matthews asked for the group's preference in scheduling additional time: two additional meetings or 1.5 hours for the next two meetings. There was consensus in updating the next two meetings to 1.5 hours. The meeting was adjourned.		

Upcoming Meeting Schedule: July 9, 2019; July 23, 2019