

APCD Data Privacy and Security Subcommittee Meeting Minutes

MEETING DATE	MEETING TIME	Location
April 26, 2019	9:00AM – 10:00AM	195 Farmington Ave Farmington, CT 06032

SUBCOMMITTEE MEMBERS					
Robert Scalettar	x	Sean King	x	Matthew Katz	x
Joshua Wojcik	x	Pat Checko	x	Jean Rexford	
James Iacobellis	x	Bernie Inskeep	x	Krisa Cattanach	
Dr. Victor Villagra	x				
SUPPORTING LEADERSHIP					
Allan Hackney, OHS	x	Carol Robinson, CedarBridge	x	Mark Hetz, CedarBridge	x
Rob Blundo, AccessHealth CT		Michael Matthews, CedarBridge	x	Dawn Bonder, CedarBridge	x
				Sheetal Shah, CedarBridge	x

Minutes			
	Topic	Responsible Party	Time
1.	Welcome and Call to Order	Dr. Scalettar	9:00 AM
	<p>Dr. Scalettar thanked everyone for making the time and commitment to participate in this review process. Data privacy and security policies are being reviewed as part of the transition of APCD from Access Health to Office of Health Strategy (OHS). CedarBridge Group has been engaged to assist in this policy review, and they have conducted an environmental scan of other states' APCD programs as an initial step in the review process. The basic mission this morning is to level set the work of the committee over the next 2 months and review the environmental scan.</p>		
2.	Public Comment	Attendees	9:15 AM
	<p>Dr. Susan Israel indicates she has read the materials that were online and stated that she was involved with what happened with the first APCD. She asks if this is incorrect: original legislation called for de-identified data and in looking at what is online now, it seems the intention is to change that to fully identified data that will be handled by many people without patient consent. It is listed as PHI, which means identified data and also covered by HIPAA. It also says that many people can see your identified data without consent as long as they follow rules under HIPAA. If you look at legislation over the past couple of years, CT keeps moving the goal post and giving more access to PHI.</p> <p>Dr. Scalettar thanks Susan Israel for her continued tracking of this issue and knows how strongly she feels about this. It has been very helpful for the deliberations and asks Allan Hackney to respond to this comment/question.</p> <p>Allan thanked Dr. Scalettar and said would be happy to make a comment. He thanked Dr. Israel for following this topic and the work of the HIT Advisory Council. He explained that what has given rise to this discussion is the statutory change which places oversight and administrative responsibility for the APCD with OHS. They are in the "in between" situation where the APCD is administered by the insurance exchange and this group is needed to evaluate and make recommendations to OHS on what regulatory group of policies are needed to support the transition to OHS. Dr. Scalettar asked Allan to talk a little bit about issues of transition and this will be part of conversation at the next APCD Advisory Group meeting.</p> <p>Allan knows this is an interested group of people in the APCD. The transition starts on July 1st, at which point the APCD becomes an unfunded mandate. They are taking a bidirectional approach to ensure the APCD can</p>		

continue, and, if we are successful, even expand. They have identified some carryover money that will support current operations for a while. Vicki Veltri is working with the Governor’s Office to put sufficient resources in the budget to sustain the APCD. He also thinks it is important to plan for some contingencies. In addition, having terminated the relationship with Access Health, this means that their key executive, Rob Blundo is no longer able to support the work of the APCD. So, they have an open position in OHS for a data analyst. He wants to let folks know that they are working on hard on these issues.

Matt Katz thinks that the information that was provided was fantastic and very well done by CedarBridge. However, he would like to get it earlier than the morning before the meeting. Dr. Scalettar apologized and said we will do our best to accommodate this request moving forward.

3.	Overview of Subcommittee Charge / Workplan	CedarBridge Group	9:20 AM
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Michael Matthews reviewed the agenda for the meeting. He indicated that they will go through the workplan and environmental scan. He provided an introduction to the support teams from the State and CedarBridge. He then asked members of the group to introduce themselves and share any initial thoughts or concerns they may have.

Dr. Robert Scalettar (Chair) – A retired pediatrician who is involved in health system strategies. He has been a Board Member with Access Health since its inception.

Sean King – He is participating on Ted Doolittle’s behalf. He is a senior staff attorney at the Office of the Healthcare Advocate, an independent consumer advocacy agency. They ensure folks get access to affordable health care and health care coverage. An item or question he would like to address: because the APCD is transitioning from a quasi-public agency to a formal agency in the State of CT, will that require formal adoption of regulations? Does legislation give OHS authority to promulgate regulation?

Michael thanks Sean for this question. He indicates that some of these thoughts or concerns will be flagged for future response. They will have Allan address this at the next meeting.

Matthew Katz – He is the EVP and CEO of the State Medical Society. He was part of the APCD from its creation. The Medical Society has the same concerns that Dr. Israel mentioned. They do have concerns about identifiable data, but it needs to be accessible. Beyond patient protection, they want to ensure cost and quality are clearly defined. They want to ensure the data is clear before it is displayed.

Josh Wojcik – He is the Assistant Comptroller at the Comptroller Office. To reiterate, he believes it is the job of this group committee to review any potential risks for patients having identifiable PHI available, but it is also important to review policies and procedures to balance the protection of PHI and leverage this data for important uses, such as setting state policies. At times, there are data elements required to get that done. He thinks it is important to strike that balance, protecting patients but also ensuring we have data available.

Pat Checko – She is delighted that this is happening. She learned an incredible amount reading the materials that were sent yesterday. They were enlightening given that she is Chair of the Data Release Committee. In practice, she thinks it is important that people understand that the level of information CT is allowed to release is pretty low. While she did not hear everything Josh said, it is important to re-look at the best use of the data and always keep confidentiality and the patient in mind.

Jim Iacobellis – He is the Senior VP of Government and Regulatory Affairs with CT Hospital Association. He worked on legislation and implementation for the APCD. He is going to align with what he has heard from other people’s concerns regarding privacy and de-identification and would like to amplify the quality component as it is a significant issue as well. He complimented the materials that were put together. He

thinks the group should challenge themselves to look at what is best from a non-budget mindset. They should think about what is best for the APCD and then work through the budget concerns. He thinks they should let good policy and strategy drive them upfront, and then lay out the budget concerns.

Bernie Inskeep – She is APCD Program Director for United Health Group. They participate in all the APCDs nationally. Her responsibilities include advocacy, participation, compliance, and submissions. She participates in many data release processes countrywide. United submits 3100 files annually for APCDs. She has a depth of understanding of this topic that is intense and well established. One of her concerns is that there does not seem to be a clear delineation between the rights/authority of the State accessing data vs. an outside entity, particularly a commercial entity. When they talk about data release and data use, there are obvious privacy concerns on the member level. They should also address the DOJ safety zone rule 3 about anticompetitive behavior, and keep in mind that there are some allowable uses for regulatory agencies for accessing data, that may not be afforded to an outside entity with an appropriate IRB.

Victor Villagra – He is a non-practicing internist and has been involved with the APCD from its inception. His overarching concern is that although he absolutely understands and respects the need for privacy and confidentiality, he is very concerned that all the restrictions to use – some of what Pat Checko had mentioned – and all the other barriers to sharing the incredibly useful data renders the data of minimal or no use. He thinks there is so much access to this data that already exists, for example the payer community has the data accessed by hundreds of people. Through appropriate privacy, confidentiality, HIPAA and IRB rules, he wants to make data available to groups like his who are interested in health disparities; otherwise he is concerned it may not be too useful.

Michael Matthews indicates that we need to ensure the group understands the Committee’s charge. The group will look at applicable policies and the impact of transferring the APCD to OHS. They will review and comment on existing policies, review policies and practices from other states, concerns from staff or data recipients, define policy recommendations and next steps, and present these recommends to the APCD Advisory Group.

There will be a total of five meetings, with the focus today being the environmental scan. Depending on time, some of the information may need to carry over to the next meeting. For this conversation, Michael indicates that the team will be providing a lot of foundational information and that there will not be as much time for Committee input in the first couple of meetings as there will be meetings after that. However, if a member has a comment or question, they are encouraged to speak up. Michael turned the presentation over to Mark Hetz to begin the presentation of the environmental scan.

4.	Environmental Scan	CedarBridge Group	9:30 AM
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Mark Hetz is a former health system CIO (mid-size health system in Oregon), Board member for a regional HIE, Board member for the Oregon’s hospital association’s for-profit data management subsidiary, and participates in Oregon’s HIT Oversight Committee. But most of his work has been on hospital and clinic IT front. In conducting the environmental scan, the team reviewed the APCD processes and policies for 15 states. They did a deeper dive on interviews and spoke with representatives on the APCD Council and the National Association of Health Data Organizations (NAHDO).

As they went through the scan, they were looking at the following characteristics: treatment of protected health information, data release governance, data release process, transparency of data request/release, publication of security measures, consumer on-line access to data, and treatment of cost (pricing) data. For most of those characteristics, they are able to identify general categories where each of these states and CT.

In going through this, some states do not store PHI, some have strict prohibition against any release, but most fall into the category of HIPAA-based release. A number of them use a much more rigorous or defined processes. One of the things they found for states that are releasing PHI: they are getting more value out of the APCD. That is not to say that they are selling PHI, but they are getting more utilization of APCD data. For those that do not have PHI in their APCD, they are not able to integrate claims data or utilize it for value-based purchasing. Mark paused for any questions.

Matthew Katz noticed that CedarBridge did not talk to neighboring states, but rather reached out to those that are farther away. CT typically looks at their neighbors and having information from those states would be a great idea, like MA, NY, RI, ME.

Mark Hetz indicates that the CedarBridge team solicited opportunities to have discussion and tried to schedule a meeting. Carol Robinson said that in some cases they have had multiple discussions with folks from ME and RI. They were bringing in some historical knowledge and can bring that knowledge in as well.

Dr. Scalettar indicates that Matt makes a good point and he knows that folks at CedarBridge have historical knowledge. He is wondering if the APCD Council can help with some follow up so they can get more current and direct information. Another thing that may be helpful is to take the pie charts on all the different topics and create a grid aligning all the states on one axis and attributes on the other, so they can get a picture of those other states in their full horizontal view. Mark indicates that they can do that.

Mark indicates that data release governance really speaks to what process is in place with the committee, if they advise or approve, and in some instances, if multiple committees are involved.

Matthew Katz asks if they have heard any concerns about the composition of their Data Release Committee or if they needed another review. He wants to understand how the current Data Release Committee is going. Do people have concerns that they have the right people? Do they need to review and make modifications to the process?

Pat Checko indicates that they have not had a ton of applications. One of the things that they found really lacking is the form itself. They did not get enough information from the applicant to know what they want. Rob ends up talking to them in every case. We invite them in to learn about what they are doing and ask a lot of questions. The committee feels really strongly that we need to change that process. In terms of composition, they have the right people, but some people do not come to meetings. Overall, the process works and really pleased to be involved in this group.

Mark Hetz returned to the trends and observations for data release governance. He indicated there is a wide variety and multiple types and complexities with data requests. The process can be much more complicated if it involves PHI. Having broad stakeholder representation is very important and more states are including an IRB approval.

Rob Blundo asked to make a comment on the previous slide related to the process. Currently, CT only releases de-identified data. If you look at other states and the way they structure the process, states have abilities to release data at different levels. If they move to identifiable data, the process is even more intense. If you look at de-identified data and consider it less risky, they usually have a higher-level process. It is important for the group to look at the policies in place; they only allow for de-identified data and minimum necessary to be released. It may require a deep look into how the Data Release Committee process works for more risky data.

Mark Hetz indicates that is exactly right. The states that had the simplest process also had the most restrictions on what data could be released. As they said, it is complicated. They were able to identify some trends. One thing that is similar is with these types of requests: they are seeing more robust online forms and pre-approved criteria that take some administrative tasks off data release committees. The process CT has in place is very common: if it does not fit a simple model of request, they have a form, but it is followed up with some level of conversation. It is an iterative process and dialogue is involved. They are also seeing more robust data use agreements and data management plans required from the requestors.

There is an interesting trend around transparency of data request/release – they are being published online. Most states are not doing this at present, but many states are. Of the states that are doing this, most are publishing a request as it is submitted and have a period for public comment.

Rob Blundo asked if it may be valuable to see what data requests have come in so far? They can view a high-level summary of for what data is being used. He was not heavily involved in this process 2-3 years ago, but a 2-year review would be a good topic for getting the group up to speed.

Mark Hetz agrees, if they can get that compiled, it can be put it into the slide deck for next discussion. They could look at the degree to which they were approved, not approved or modified. If they have that information, that would be great. Rob Blundo would be happy to support that. Dr. Scalettar thinks that would be useful at the next APCD Group upcoming meeting as well.

Mark Hetz indicates that they are seeing this transparency as an increasing trend. They also heard that as the level of transparency increased the number of requests characterized as “challenging” was reduced. The other interesting thing was public comments were from other payers or providers, rather than consumers.

Pat Checko provided a comment related to consumers. She does not think consumers know about the APCD or what it does. That could change with increased awareness with the HIE.

Michael indicated that it is time to wrap up and that they will follow up on a couple of items from the discussion.

5. Next Steps & Adjournment

Dr. Scalettar

9:55 AM

There were no additional comments. CedarBridge was thanked for all that it has done to give the group useful information so they do not have to reinvent the wheel and can learn from others.

James Iacobellis requested for the next meeting, can they set out specific goals so the conversation can stay in the lane for solving the goal? The information can take them in a variety of different lanes, but if they know the specific goal than they can do what they need to in 5 short meetings.

Dr. Scalettar agrees.

Upcoming Meeting Schedule: May 3, 2019; May 17, 2019; May 31. 2019