

# APCD Data Privacy and Security Subcommittee

## Meeting Minutes

MEETING DATE	MEETING TIME	Location
May 3, 2019	9:00AM – 10:00AM	195 Farmington Ave Farmington, CT 06032

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

Minutes			
	Topic	Responsible Party	Time
1.	<b>Welcome and Introductions</b>	Dr. Scalettar	9:00 AM
Dr. Scalettar welcomed the group. He thanked CedarBridge Group for sending the materials early. He asked if anyone would like to give a public comment.			
2.	<b>Public Comment</b>	Attendees	9:05 AM
There was no public comment.			
3.	<b>Recap of Meeting 1</b>	CedarBridge Group	9:10 AM
Dr. Scalettar provided background from the last meeting. He indicated the committee will finish reviewing the environmental scan today. He asked if there were any corrections or additions to the previous meeting minutes. He identified that Rob Blundo was in attendance at the last meeting, but this was not reflected in the meeting minutes. There were no other objections or further amendments requested. Individuals approved the meeting minutes.			
Michael Matthews briefly reviewed the agenda, support team, committee members and scope of committee. He provided a recap of the first meeting and an overview of the follow-up action items: statutory and regulatory implications, creating a grid of state level data which was circulated with the meeting materials, gathering additional information from neighboring states, engaging Mark Schaefer regarding the use of APCD data to assess quality, and a summary review of previous APCD data requests. He mentioned that the first two meetings will provide the foundation for the committee and they will focus on reviewing the privacy policy in subsequent meetings.			
Krista Cattanach asked if existing policies were sent out. Dr. Scalettar responded to let her know they were sent out towards the end of April via email from Chris Robinson.			
4.	<b>Continuation of Environmental Scan</b>	CedarBridge Group	9:15 AM
Mark Hetz reminded the committee that CedarBridge Group conducted online research and interviews with the states listed on the slide. CedarBridge Group is conducting additional follow up with the neighboring states.			
Mark Hetz shared that they will cover the last 3 characteristics today: publication of security measures, consumer online access to data and the treatment of cost (pricing) data. For the publication of security			

measures characteristic, many states did not go into depth in this area. They observed that more states are moving in the direction of offering less specificity. One reason for this is that states do not want to give bad actors a roadmap into what the state is doing. This is a trend they are seeing in health care and other industries.

Dawn Bonder reviewed the characteristic related to consumer online access to data. This characteristic refers to how much data on the website can consumers review without a request or specific permission. A number of states the team researched had some type of interactive online tool, used public use files or had a library of pre-prepared reports. Currently, a quarter of the states including CT, had none or nearly no access to data for consumers online. For states that provided interactive tools for consumers, some only provided quality data for specific procedures. They also found for states which provided pre-prepared reports, some had a reduced number of data requests because individuals could find information on the website. This could have unintended consequences with respect to sustainability. If the state is offering information publicly, the state would not be able to charge a fee for accessing data.

Dr. Scalettar paused to ask how the group would like to proceed with the presentation. The group indicated they would like to go through the presentation and then come back for questions at the end.

Michael Matthews asked if Allan Hackney or Rob Blundo would like to comment on CT's direction in relation to consumer online access to data.

Allan Hackney indicated that the statute says CT has to provide consumer information, but it does not specify how. He believed they need to provide value, develop tools people will find useful for the stewardship of their own health care, and be sustainable.

Dr. Scalettar asked for clarification. His understanding is that the website had two intentions: 1) prepared reports for consumers to get insights for health care costs and separately 2) trying to make a truly interactive tool.

Allan Hackney indicated that is correct. The statute does not dictate what CT should do. He commented that many states have a low number of consumer visits to the website. He believed an argument could be made there are more providers reviewing information to compare costs among each other.

Bernie Inskeep commented that Maine has been fairly open and done quite a bit of analysis. Their tool gets down to the payer and provider setting and product. Maine found that most of their hits come from Texas. The number of hits is not always an illustration of actual usability by state residents.

Pat Checko asked how many of these states have an active HIE and some relationship with the APCD. She indicated that CT's plans for the HIE involve a patient portal and this could help make consumers aware of the data in the APCD.

Jean Rexford wanted to remind the committee that this is a new process. She wanted consumers to access whatever they need, but she believed it was too early to have this discussion.

Dawn Bonder reminded the committee of the legislative mandate. It does not evaluate how information should be presented or clarify the scope of tools used. The CedarBridge Group is researching if other states found correlations that lead to value. The efforts related to release of cost/pricing data are varied. To date, the best efforts have been in CO, ME, NH and WA, as they offer robust data on cost and quality. Their tools are interactive/consumer friendly, especially if one is looking for specific health care procedures. With respect to the comment on HIEs and APCDs, the CedarBridge Group did research states with a relationship

between the two. From these states, they learned that the data is so different between the HIE and APCD. It was very challenging to match the fields and parse the data. There are efforts underway to integrate this data, Virginia may be one example, but they are in a very nascent stage from a technology stand point.

Dawn Bonder indicated there is a shared recognition that this data is valuable, reinforcing the use and importance of the APCD. Over time, healthcare organizations become more accepting of published price data by the APCD program. States also release pricing data in a highly curated way to address payer and provider concerns.

Dawn Bonder shared that the environmental scan highlighted the need for states to be cognizant of the levels of stakeholder trust, confidence, and commitment. Trust of stakeholders is essential; and it takes time to build. There must be trust in the APCD data quality, accuracy of data reports, processes used to develop policies and procedures, application of those policies and procedures, and fairness of APCD data availability and data use policies and procedures. As stakeholder trust and confidence in an APCD program builds, new opportunities for expanding the use of APCD data can be considered and sources of funding may increase. As trust in privacy, security and accuracy of data increases, the value increases. Ultimately, increased value leads to sustainability.

Dr. Scalettar asked to reference one of the comments mentioned earlier about states releasing provider and procedure level cost data. He has not visited the CO or WA sites recently. However, in the past, he did not see provider level data. He did see data at the procedure level and some based on geography.

Dawn Bonder will take a follow up action to provide links to the state websites with “high marks” in this area. Dr. Scalettar thought this is a great idea and thanked her.

Bernie Inskeep provided an industry perspective from United Healthcare. She mentioned that the presence of an interactive website is an expensive proposition. She also indicated that these websites cannot be as accurate as the information from the plan. There are really good reasons for why the data is not as accurate: APCD contains post-adjudicated claims which are aged and they do not have real-time accumulators for an individual’s co-pay, deductible or out-of-pocket max. The APCD is a static approximation and always less accurate than the member’s website. The component that gives the most “heartburn” to the industry is the disparity in price. It is not meant to criticize what any state is doing, but it has been an ongoing conversation in the states referenced.

Ted Doolittle thanked CedarBridge Group for the presentation. He had two questions. The first is related to the publication of security standards. While he understands the philosophy of “less is more,” he is curious to know how CT can “stay honest.” He asked if there is a periodic audit or review and how should the committee propose to stay up-to-date on the appropriate security standards.

Mark Hetz indicated it is best practice to have an annual audit of privacy policies and procedures and engage in some type of penetration testing (technical audit) with an independent group.

Ted Doolittle understood and assumed that CT would provide recommendations along those lines.

Dr. Scalettar indicated, that if most agreed, they would recommend this.

Ted made a comment related the 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program proposed rule. HHS/ONC is seeking comment on promulgating a rule

that would not allow price information to be blocked. He thought it was interesting and that others may want to review. It seemed as if the norms of the last 15 years are changing rapidly.

Pat Checko asked to speak to Bernie Inskeep's comments related to the construction of data fields. There were two data requests approved for SIM. One is related to access of APCD data as a separate element. The second looked at APCD data from the perspective of CDAS, a more permanent database for population health. She asked Rob Blundo if it would be worth reaching out to the SIM team for their perspectives.

Rob Blundo asked Michael Matthews if the SIM team would be willing to provide commentary on this. Michael Matthews replied that he will follow up with the SIM team to learn how they are using data for FQHCs and ACOs. He asked if Allan Hackney would like to make a comment on the implications of the APCD with respect to CDAS.

Allan Hackney replied he would like make comment once the group is at the regulations portion of the meeting.

Dr. Scalettar asked if there has been any insight or information on impact or outcomes from a research perspective. He was curious to know if there are any metrics regarding the problem for consumers and if this has been used to benefit policy or program development.

Dawn Bonder indicated this is an excellent question. They did not conduct research for literature on the outcomes of having data available to consumers. This is something the CedarBridge Group could review but her personal belief is that it is too early to have a meaningful study. Dawn Bonder also mentioned the CedarBridge team heard, from multiple states, there is recognition that this data can provide good opportunities for research, quality improvement and is a step forward for more engaged/informed consumers who can use data to make better health care decisions. This is a widely held opinion by individuals from states with more mature APCD programs. In order to fund these programs, it is critical to create broad based support and appreciation for the program. She will look for research with respect to outcomes and impact for consumers.

5.	<b>Follow-up Items from Meeting 1</b>	<b>CedarBridge Group</b>	<b>9:40 AM</b>
	With the time left remaining, Michael Matthews indicated he will quickly go through the remaining follow-up items. Regarding statutory and regulatory implications, he asked Allan Hackney to comment.		
	Allan Hackney shared that there are multiple dimensions to this area. Based on his experience, there is no APCD in the country with a sustainable business plan because of the value it is adding to the environment. In this context, the "environment" could be the state, consumers, or researchers. The APCD as a function is struggling with funding models because there is not always a direct link between the availability of data and value. One of the states singled out as a "best effort" was WA, however he knows WA is losing their funding or their funding is in jeopardy. As CT thinks about the statutory and regulatory environment, he would like the group to think about the competing interest of privacy with the need to use this data to attract funding. As an example, if CT is able to tie APCD data to something related to the Medicaid Meaningful Use program, CT could attract federal funding from the HITECH Act to maintain a portion of the APCD. To do this, it would mean making APCD data available in ways the committee has not yet contemplated. He asked the committee to be conscious of this balance.		
	Allan Hackney also wanted to provide another comment which was alluded to by Ted Doolittle. He believed the committee should receive material to help understand what is happening at the federal level. In the 21 <sup>st</sup> Century Cures Act, the federal government concluded that there is a lack of health care data availability to support better health outcomes across the nation. As part of this, new rules will emerge through the Trusted Exchange Framework and Common Agreement (TEFCA) for how data will be made available across the		

country. There are other rules in the rulemaking process which are likely to be adopted and impact the work of this committee. As the committee thinks about the CT environment, they should be informed and made aware of how federal changes will impact landscape.

Michael Matthews thanked Allan Hackney for his comments. He provided a quick update on the remaining follow-up action items. With regard to the state level grid of responses, committee members should reach out if they have additional questions on the assessment. Related to the use of APCD data for quality measurement, Michael Matthews mentioned that Mark Schaefer from SIM is about to implement a public scorecard which is intended to enable quality comparison among all the state's Advanced Networks (ACOs) and FQHCs. In addition, SIM will also be calculating state level benchmarks. If the group is interested, they can ask Mark Schaefer to spend more time on this area. Lastly, related to the summary of data requests, Michael Matthews provided an overview of the data release process. Of the 15 applications received to date, three-quarters have been approved, one was not approved, two were scheduled for DRC review, and one has been submitted to the APCD. The last three slides provide a breakdown of each data request. Rob Blundo can review this information in more detail at a later meeting if the group would like.

Next Steps & Adjournment	9:55 AM
Dr. Scalettar believed there is enough information and discussion to make this a longer meeting. He asked the group if they can change the meeting time from 1 hour to 1.5 hours. No one is opposed.	
Michael Matthews provided a review of next steps: change the meeting to 1.5 hours, review information from neighboring states, spend more time on quality of APCD data if the committee is interested, review the privacy policy and begin to identify areas for improvement.	
Pat Checko made a request to have an offline conversation to better understand how data is being used by the APCD. Allan Hackney indicated that he plans to share this information during the APCD Advisory Council meeting on May 9 <sup>th</sup> .	
Dr. Scaletter thanked everyone for the time and thoughts. He is looking forward to the next meeting on May 17 <sup>th</sup> from 9-10:30am.	

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