

APCD Data Privacy and Security Subcommittee

Meeting Minutes

MEETING DATE	MEETING TIME	Location
May 31, 2019	9:00AM – 10:30AM	195 Farmington Ave Farmington, CT 06032

SUBCOMMITTEE MEMBERS					
Robert Scalettar	x	Ted Doolittle	x	Matthew Katz	x
Joshua Wojcik		Pat Checko	x	Dr. Victor Villagra	x
James Iacobellis	x	Bernie Inskeep	x	Krista Cattanach	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
		Chris Robinson, 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 joining the call. He thanked the CedarBridge team for circulating materials in advance of the meeting.</p> <p>Dr. Scalettar asked if there were any revisions to the previous meeting’s minutes. Pat Checko asked for a revision on page five of the minutes. The group accepted the revision. Matthew Katz asked for the minutes to be displayed on the screen so members could review the updated format together. The members accepted the new format with a tracking log and the revised meeting minutes.</p>		
2.	Public Comment	Attendees	9:10 AM
	No public comments at this time.		
3.	May 17 Meeting Recap	CedarBridge Group	9:15 AM
	<p>Michael Matthews reviewed topics that were flagged during the May 17 meeting for further review:</p> <ol style="list-style-type: none"> 1. Further discussion regarding how to move process related items from the policy to a procedural document to ensure there was oversight and transparency when the process and procedures were changed; and 2. Ensuring there was a connection between the DRC, OHS, APCD Staff, and the APCD Advisory Group going forward. <p>Pat Checko, Allan Hackney, and Michael Matthews had a conversation on May 30th that provided greater insight on how to achieve this coordination.</p> <p>Dr. Scalettar asked the members to consider these two items before moving to the Privacy Policy.</p>		
4.	Follow-up Discussion on Issues from May 17 Meeting	CedarBridge Group	9:20 AM
	<p>Regarding point 1, Michael Matthews shared Allan Hackney’s suggestion to differentiate internal procedures, such as relatively minor “housekeeping” items, from external facing procedures. The external facing procedures would require some level of oversight from the Data Privacy and Security Subcommittee or APCD Advisory Group.</p> <p>Ted Doolittle believed the approach would be workable. He also recommended including definitions or descriptions of which procedures could change internally compared to ones which would require additional review.</p>		

Matthew Katz supported Ted Doolittle's recommendation related to definitions. He also suggested defining the various documents clearly to reduce confusion. For example, internal mechanics could be labeled as a "process" and external things as a "procedure."

Bernie Inskip suggested looking at OHS' current documentation to see if there was a naming convention for other OHS documents of this nature that could be extended to these documents for transparency and consistency.

CedarBridge was tasked with developing language based on the discussion and Dawn Bonder agreed to get the meeting materials out to committee members with as much advance time as possible. She indicated CedarBridge could put together the revised recommended policy and consolidate the areas that needed to be updated or wordsmithed. There was consensus on this approach.

Matthew Katz asked for clarification on the process for the next meeting. CedarBridge agreed to bring a proposal back to the group for consideration.

Dawn Bonder invited members to send any thoughts on specific language to her for inclusion in the policy.

Michael Matthews indicated he would touch base with Allan Hackney to ensure overall alignment with his operations within OHS.

Dr. Scalettar asked the committee to provide any input in advance of the next meeting.

Michael Matthews described the vision for the format of the final report and recommendations. He indicated it would detail the background and purpose of this review process, including the transition to OHS, formation of this committee, process for review, and environmental scan which led the subcommittee to the findings and recommendations, including conclusions and next steps. Additionally, it would describe how procedures will be developed and finalized. It will not simply be a final redlined policy.

Michael Matthews asked Pat Checko to elaborate on the ongoing communication and engagement amongst the Data Release Committee (DRC), OHS/APCD staff, and the APCD Advisory Group.

Currently, there is no formal connection between the DRC and the Advisory Group, and Pat Checko believed there needs to be a formal connection between the two bodies. One suggestion is to have the Chair of the DRC be a member of the Advisory Group. As issues arise that may be problematic to both groups, it is imperative to have a formal connection between the two. To date, they have been working as two separate silos.

Dawn Bonder indicated the desire to have this link may need to be a recommendation. CedarBridge will work with Allan Hackney to understand how ongoing communication and coordination can function at the APCD Advisory Group level and be worked into the governance of both groups.

Dr. Scalettar really appreciated Pat Checko's comments and insight. He is supportive of a better link between the groups.

Dr. Scalettar referred the group to the state level grid that was developed during the environmental scan. The second of the five criteria is data release governance. There were several categories, one being "multiple committees." The issue of multiple committees caught his attention. He would like to know how to link these efforts to more than just the Data Release Committee.

Dawn Bonder indicated, with “multiple committees”, it varied based on the types of data being released. Some states would have one committee review a request and approve if it was for a standard release. For the next level of sensitive data, some would have a committee recommend and then another that would approve or deny the request. This would be a departure from the way it is currently being done, but something to consider if this committee felt it more appropriate to recommend another level of review. Dawn Bonder also reminded members that every layer of review adds time to resolving the request. There should be a consideration between checks and balances with responsiveness.

Dr. Scalettar appreciated the issue and did not want to slow down the process unnecessarily. He asked Pat Checko if there has been a reasonably efficient process from the time the DRC received an application to the time they provide a decision.

Pat Checko indicated that they had the process in place since Rob Blundo has been there. She believed the group does its due diligence and a number of people have experience. The DRC provides conditional approvals. She also mentioned the human investigations committee model at the Department of Public Health. There is a Chair and number of people on the committee. They are set up to review the release of any confidential Department of Public Health data. It was started around the tumor registry. The “leg work” is deciding who does what. Rob Blundo did most of the work to ensure an application was ready for review. They ask every applicant to appear in-person. She believed it comes down to expediency and whether you trust the composition and integrity of the DRC to carry out an appropriate review.

Dr. Scalettar asked if others have thoughts on this issue.

Bernie Inskip shared that she is on the DRC for Delaware’s APCD. It consists of physicians, hospitals and payers, as well as the agency that runs the APCD. Requests have to be distributed to all stakeholders in order to be considered. Stakeholders are involved and it achieves its purpose. She views the CT model as similar, but there is less than 2 weeks to review completed documents. United feels comfortable that there is a lot of stakeholder review and they are within the statutory intent of APCD.

Victor Villagra wanted to build on that comment. He believed the goal of a mechanism for communication and coordination is to support OHS as a coordinator of state strategy, beyond just the goal of the APCD. He believed it would be beneficial to concentrate mostly on the mechanism by which OHS would receive communication and pursue their coordinating role. It may be good to get input from OHS on the mechanics, forum and timing for the DRC to communicate with OHS, in addition to reports. In parallel, there should be a mechanism to keep the APCD Advisory Group informed of all the moving pieces. He had some ideas on templates.

Dr. Scalettar agreed with all the comments. He also asked if it passed the consumer and transparency test. He asked if there were enough checks and balances.

Dawn Bonder suggested reviewing some of the sections contained in the second half of the privacy policy as the review would potentially answer Dr. Scalettar’s questions. She suggested that they keep a list of topics they want to address that do not get captured in the policy.

Jim Iacobellis believed this was a good way to proceed. He also wanted to add the issue of working with a consortium of APCD entities.

Dawn Bonder indicated she would add this to this list. The current policy does not speak to this concept.

Pat Checko added that there were many moving pieces with regard to the issue of raising consumer confidence. She believed, that as they move forward, OHS will need a plan for how they educate and work with consumers, so they understand, appreciate, accept and trust all the different data systems being put in place. There is one strong guiding principle which is the patient as the “north star.” She believed the APCD is one piece that is part of the process to address the consumer.

Dr. Scalettar appreciated the comment and is glad to hear this conversation is happening in multiple places.

5. Privacy Policy Review CedarBridge Group 9:45 AM

Dawn Bonder wanted to add two notes before they started the review. She indicated they had a conversation with the State Medicaid Director and Medicaid has its own policy for data release. There will need to be alignment between the APCD policy and Medicaid policy. All Medicaid data released from the APCD needs to be released for a purpose that benefits Medicaid recipients. She would suggest having a seat for the Medicaid Director on the DRC to ensure the data being released meets the Medicaid policy intent. She asked the group if the Medicaid Director should be added as a member. This would increase the number of voting members to eight.

Pat Checko indicated that she would like to have someone from Medicaid on the committee. She said that it was very seldom that they have a no-vote. Usually, by the time an application is ready for a vote, they have addressed everyone’s concerns or issues. She does not believe that having eight people would present an issue.

Dr. Scalettar agreed that he would want a Medicaid representative on the Data Release Committee. He added that including Medicaid data was an ongoing discussion and negotiation with DSS. Moreover, since there is a separate approval process for DSS, it is critical to have Medicaid represented on the group.

Michael Matthews indicated that there must be sign off and approval of DSS when Medicaid data is involved. This is a good example of the breakout between policies and procedures. A detailed delineation of the procedure will not be a part of the group’s overall recommendations, but they will identify areas where procedures need to be developed. They want to ensure alignment and integration between DSS and OHS. They do not want the requestor of that information to be “bouncing around.”

SECTION	RECOMMENDATION(S)	OUTCOME
6.e.i.5	KEEP AS-IS AND DELETE LAST SENTENCE	Preliminary accepted
6.e.i.6	KEEP AS-IS	Preliminary accepted

Section 6.e.i.7.b: Conditional Approval

Bernie Inskeep asked to discuss conditional approval. Dawn Bonder asked if conditional approval is necessary if a requestor is denied, she assumed that they can re-apply.

Bernie Inskeep believed that conditional approval is really important, particularly if they add Medicaid. It may be fine if they were not asking for Medicaid data. Additionally, there may be implications with application fees.

Pat Checko indicated that they do give conditional approvals and believed it is important to keep in.

SECTION	RECOMMENDATION(S)	OUTCOME
6.e.i.7.b	DISCUSS IN FURTHER DETAIL	Keep Conditional Approval section as-is

Section 6.e.i.7.c: Denial

SECTION	RECOMMENDATION(S)	OUTCOME
6.e.i.7.c	KEEP AS-IS	Delete section

Section 6.e.ii: Veto Authority

The policy currently states the Chief Executive Officer can veto any decision of the DRC. Dawn Bonder asked how this section would change.

Pat Checko asked about the intent. She asked if this role would transfer to the OHS Executive Director or to the HITO. From her perspective, she could not imagine a situation where they could not come to an agreement.

Dr. Scalettar wanted to provide background. When the APCD was under the Exchange, not a government agency, the ultimate liability lied with the Exchange and an adverse judgement could negatively impact Access Health in its entirety. It may not have application as a state agency.

Matthew Katz concurred with this explanation.

Michael Matthews indicated he was thinking about this question yesterday. He mentioned that Allan Hackney would look to this group for guidance. Aligning the DRC and APCD DPS subcommittee underneath the APCD Advisory Group may be the most logical and straightforward structure.

Matthew Katz agreed. However, he indicated that they are suggesting a change but do not call out this change specifically in the document. They went through a legal analysis in the past and the Data Release Committee had to flow separately. He suggested that it should be a workgroup that reports to OHS.

Bernie Inskip indicated that OHS is definitely over the APCD Advisory Group. This committee is a subcommittee of the APCD Advisory Group. This subcommittee should be accountable to other committees and clear communication delineated.

Dawn Bonder suggested that she would talk to Allan Hackney on actual details of language. If the subcommittee suggests a different reporting structure, this committee cannot authorize that. Members were inclined to retain veto authority with the Executive Director of OHS as a safeguard.

Matthew Katz believed there has to be ultimate responsibility, but he is concerned that using specific titles is problematic because titles change often.

Dawn Bonder indicated that they use the title it is called today and add language, such as “successor title”, if that should change to “future-proof” the document. The HITO is on the DRC, so somebody above the HITO should have veto authority.

Matthew Katz recommended the OHS agency head.

Pat Checko asked for clarification. As she reads the document, she believed it would only occur when the committee approves something that the CEO did not feel met all the requirements. It does not look like it would come into fruition if the DRC disapproved a request.

Matthew Katz indicated that is correct. It was a liability issue; it was never to approve something that was disapproved by the committee.

SECTION	RECOMMENDATION(S)	OUTCOME
6.e.ii	KEEP AS-IS AND DISCUSS IN FURTHER DETAIL	Preliminary accepted; CEO changed to OHS head

Section 6.e.iii: No Right of Appeal

Ted Doolittle would like to see this section included. Bernie Inskeep and Dr. Scalettar agreed.

SECTION	RECOMMENDATION(S)	OUTCOME
6.e.iii	DISCUSS IN FURTHER DETAIL	Keep section as-is

Section 6.e.iv: Opportunity for Resubmission of Data Release Application

Dawn Bonder did not believe this information should be placed in this section. To streamline the section, she thought it was better to pull it out.

Pat Checko agreed. She indicated if there was evidence that the requestor had previously violated terms, they should probably not be allowed to apply again.

SECTION	RECOMMENDATION(S)	OUTCOME
6.e.iv	DISCUSS IN FURTHER DETAIL	Move information to another section
7.a.i	KEEP AS-IS	Preliminary accepted
7.a.ii	KEEP AS-IS	Preliminary accepted
7.a.iii	KEEP AS-IS	Preliminary accepted

Section 7.b: Form/Manner of Access

Dawn Bonder indicated that these sections can move to a procedural document. Members concurred.

SECTION	RECOMMENDATION(S)	OUTCOME
7.b	KEEP AS-IS; DELETE	Preliminary accepted
7.b.i	MOVE TO PROCEDURAL DOCUMENT	Preliminary accepted
7.b.ii	MOVE TO PROCEDURAL DOCUMENT	Preliminary accepted
7.c	KEEP AS-IS	Preliminary accepted
7.d	KEEP AS-IS	Preliminary accepted

Section 7.e: Access Fees

Dawn Bonder indicated that this language is mandating the APCD not have the option to make a profit. It may foreclose options for how the APCD structures a sustainability plan. She recommended that it be left out. Dr. Scalettar and Bernie Inskeep agreed. There was no opposition to removing language.

SECTION	RECOMMENDATION(S)	OUTCOME
7.e	DELETE AND DISCUSS IN FURTHER DETAIL	Preliminary accepted

Section 7.f: Posting of Data Release Application Disposition on APCD Website

Dawn Bonder indicated that they can add this language to an earlier section of the policy and retain requirement to update the disposition once a decision has been made.

Pat Checko believed this made sense but had a question. Given that they are supposed to post, she would like to know where they post this information. She does not believe there is a public facing website where information gets posted.

Victor Villagra indicated he was looking for applications that have been approved but could not find information.

Matthew Katz agreed with Pat Checko. They would get an update from the Former Executive Director through the APCD materials.

Pat Checko mentioned that this goes back to the discussion with Allan Hackney and Michael Matthews. There was an old website, but it did not have data. She was not sure if it was within the purview of this group to be addressing the public facing website.

Dawn Bonder indicated that it had always been in the policy, but it does not mean it was implemented. The question is if OHS is prepared to pick up that responsibility and if it will happen the way it should. They want to ensure their program can implement that.

Dr. Scalettar mentioned, during the last meeting, he asked Rob Blundo about the public facing website. His response led him to believe that it was always the intent to have the information publicly displayed, but it never happened under Access Health.

SECTION	RECOMMENDATION(S)	OUTCOME
7.f	DISCUSS IN FURTHER DETAIL	Move to different section

6. Next Steps and Adjournment

Dr. Scalettar

10:25 AM

Dawn Bonder indicated that she will make notes of the areas that warranted further discussion, so they are ready for the next discussion.

Michael Matthews added that CedarBridge team’s recommendation is to stay on a 2-week cadence. The last meeting is June 14th, so they will send another meeting invite for June 28th.

Dr. Scalettar asked if Mark Hetz had learned anything new from the additional interviews with neighboring states. He would like to see that information incorporated sooner rather than later.

Mark Hetz indicated that he had conversations with New York and Vermont; and a call with Massachusetts is scheduled for early next week. NY is still in the development process and forming Data Release policies. They will ingest commercial data for testing in mid 2020. They are not looking at releasing data until the end of 2020, at the earliest. Vermont was not different than what was identified through the environmental scan. The one area that was interesting is that they are prohibited from charging for release of information by statute. As a result, they have not put a lot of resources into the program.

Matthew Katz asked, when they did the original market assessment, they saw Vermont as one of the best of breeds but assumes that changes a bit. They may have been fast to set up but have not done some of the things CT has conceptualized doing.

Mark Hetz indicated that was correct. Vermont had a legislative mandate, but there are prohibitions on what they can do. It is a highly curated process.

Dr. Scalettar confirmed if they were all in accord and accepted adding a June 28th meeting. Bernie Inskip and Pat Checko said yes. No one disagreed.

Upcoming Meeting Schedule: June 14; June 28, 2019.

Appendix: Change Log Summary

SECTION	RECOMMENDATION(S)	5/31 MEETING OUTCOME
6.e.i.4	KEEP AS-IS	Preliminary accepted
6.e.i.5	KEEP AS-IS AND DELETE LAST SENTENCE	Preliminary accepted
6.e.i.6	KEEP AS-IS	Preliminary accepted
6.e.i.7	KEEP AS-IS AND MOVE TO PROCEDURAL DOCUMENT	Preliminary accepted; keep Conditional Approval section as-is
6.e.ii	KEEP AS-IS AND DISCUSS IN FURTHER DETAIL	Preliminary accepted; CEO changed to Executive Director
6.e.iii	DISCUSS IN FURTHER DETAIL	Keep section as-is
6.e.iv	DISCUSS IN FURTHER DETAIL	Move information to another section
7.a.i	KEEP AS-IS	Preliminary accepted
7.a.ii	KEEP AS-IS	Preliminary accepted
7.a.iii	KEEP AS-IS	Preliminary accepted
7.b	KEEP AS-IS; DELETE; MOVE TO PROCEDURAL DOCUMENT	Preliminary accepted
7.b.i	MOVE TO PROCEDURAL DOCUMENT	Preliminary accepted
7.b.ii	MOVE TO PROCEDURAL DOCUMENT	Preliminary accepted
7.c	KEEP AS-IS	Preliminary accepted
7.d	KEEP AS-IS	Preliminary accepted
7.e	DELETE AND DISCUSS IN FURTHER DETAIL	Preliminary accepted
7.f	DISCUSS IN FURTHER DETAIL	Move to different section