

All Payer Claims Database Advisory Group Meeting Minutes

MEETING DATE	MEETING TIME	Location
November 14, 2019	1:00-3:00 PM	Webinar Only

Advisory Group Members					
Allan Hackney, OHS - Chair	X	François de Brantes		Bernie Inskeep	X
Paul Lombardo		Josh Wojcik, OSC		Victor Villagra	X
Dr. Robert Aseltine		Michael Giralmo, DHMAS	X	Robert Tessier	
Ted Doolittle, OHS		Robert Scalettar, MD	X	Easha Canada, DAS BEST	
Kate McEvoy, DSS		Matthew Katz		Krista Cattanach	
Patricia Checko	X	James Iacobellis			
Supporting Leadership					
Adrian Texidor, OHS	X	Tina Kumar, OHS	X		

Minutes			
	Topic	Responsible Party	Time
1.	Welcome and Call to Order	TINA KUMAR	1:00 PM
	Tina Kumar welcomed the Advisory Group and called the meeting to order.		
2.	Public Comment	Attendees	1:05 PM
	There was no public comment.		
3.	Review and Approval of August 8, 2019 Minutes	Council Members	1:10 PM
	There was no quorum. The August 8 th , 2019 minutes are deferred to the February 2020 meeting for review and approval.		
4.	Announcement of New APCD Advisory Group Member	Allan Hackney	1:15 PM
	<p>Allan announced that the chairperson of the APCD Data Release Committee is to become the standing ex-officio voting member of the APCD Advisory Group. Allan remarked there is a lot of value in making the direct connection between the two committees. Allan welcomed and introduced Dr. Patricia Checko, chair of the DRC and very actively involved with the APCD.</p> <p>Patricia Checko commented that she represents consumers as both the DRC chair and in her role on in the State Innovation Model as head. Pat has an extensive background in public health from over 50 years, both as a Doctorate and Master's in chronic and infectious diseases. She has always been compelled to make sure that what we do is best for the public. Pat commented that it was a pleasure working with the (APCD) group on rewriting the policies and procedures.</p> <p>Allan thanked Pat and acknowledged the incredible amount of time and energy she has put in to all of the working groups.</p>		
5.	Discussion of OnPoint Contract Renewal	Allan Hackney	1:20 PM
	<p>Allan Hackney briefed the advisors that we had transferred the relationship and oversight of the APCD from the CT Insurance Exchange over to The Office of Health Strategy months ago. As a direct consequence of that we executed a contract assignment that document which transferred the vendor management ownership and relationship for OnPoint health data, who is our outsourcing vendor for managing the APCD from the Insurance Exchange over to the OHS done earlier this year. OHS has been working with them successfully since the transfer occurred.</p>		

When the Insurance Exchange had gone to bid for the OnPoint relationship, they ultimately ended up with a renewable contract for up to a 5-year period. The 5-year anniversary which would trigger any type of renewal, arrived on November 4, 2019 anticipating that we were going to have to make a decision around renewals. OHS worked with OnPoint and The Office of Policy & Management (OPM) to extend a contract for a period of 6 months (May 2020). The reason for a 6-month renewal rather than any other permutation, is because we are working in general with contract renewals where there's effectively a full source renewal.

OPM (under Secretary McCaw) has been implementing policies that applies to all agencies that are focused on ensuring that if there are sole source renewals, then the sole source renewals can be fully justified as opposed to going out to a periodic bid (which is the norm). We are working through the increased focused on sole source with OPM. OnPoint is running the program, and maintaining the database for us, and this isn't something we can just pull the plug on. the extension of 6 months gives us time so that we can work with OPM to chart an appropriate course of action for this very important outsourcing agreement. Allan believes by the time the APCD Advisory Group meets in February, we will know the direction and will have solved any open questions that we have pending with OPM, to be able to give the advisors a pretty clear picture of where we are going with our relationship with OnPoint and the contract. Allan needs the advisors to know that this is the circumstance that we are in, and OnPoint understands this as well. Naturally, OnPoint would express the desire to move quickly to their 5-year renewal, but we need to work through the process with OPM and their focus.

Allan opened the floor to questions or comments.

Dr. Robert Scalettar asked for an overview of the highlights over the last number of years with what have and haven't worked with the vendor relationship. He appreciates the delicacy issues and asked for a general sense.

Allan explained that he divided this into three eras:

- 1) The development era under the guidance of Tamim Ahmed, under the Insurance Exchange went on for almost three years. There were some issues with the developments that the longer-term members of the Advisory group are aware of. Not all of those issues were laid at the doorstep of OnPoint, some of the issues lie closer to home. As we got to the point where we stabilized the development of activities, a lot of that happened of the beginning of era 2.
- 2) This is where Robert Blundo stepped in. Rob gets terrific credit for sorting out the remaining issues with the development of the tools and got us into a position, where all the submitters were submitting data, and the quality of the data was increasing over time. Under Rob's work, with Pat's Data Release Committee, we started releasing data. At that point, the relationship with OnPoint stabilized. This is when we began to see value out of the APCD as we started to do genuine data release.
- 3) When transfer over to OHS occurred, Rob Blundo was instrumental in getting us to the point of where the transfer could occur cleanly. Subsequent to that, we've spent a lot of time with OnPoint ensuring we had an open line of communication. There were times, where communications with OnPoint weren't always as crisp as it could have been. But we've settled into a routine where it's very clear that we are working in tandem with each other. Allan thinks this is a good a vendor relationship as he's seen in other sectors of his career. The data continues to flow, we now have a relationship with UConn, which takes a limited set of data information (this is what OnPoint delivered to Rob previously). Now in OHS where we are able more analytics on the data, and as soon as we do deep analytics, we are able to work with OnPoint to get that data cleaned up. Allan said that the relationship with OnPoint is pretty good, it took some time to get there, but right now there are serving the needs as well as any of us could ask for. There's always room for improvement but as a vendor relationship goes this one seems to be working pretty well.

Allan added that OHS & OnPoint’s relationship now is about \$685,000 a year (more or less), and there is some escalation clause in their current contract which may bump this up (i.e. cost of living) to around \$700,000 a year for their services.

Robert Scalettar recalled that as one of the peaks of the OnPoint relationship, the vendor was one of early players and national leaders in working with successful APCDs. He asked if there was an update on this. Allan said yes, OnPoint has a national presence and the last time they looked, OnPoint was operating APCDS for about 12 states (some considerably larger than CT).

6.	Update on Available OHS Resources	Allan Hackney	1:25 PM
-----------	--	----------------------	----------------

Allan recalled that when the oversight of the APCD switched from the Insurance Exchange over to the Office of Health Strategy, we lost the services of Rob Blundo. When we examined the nature of what a day in the life of Rob Blundo looked like, it was basically doing four different job activities to serve the needs of the APCD. Now, that the APCD exists in the Office of Health Strategy, we are fortunately able to distribute the work differently. We have five resources that help with the APCD: Adrian Texidor, Olga Armah, Joseph Rus, Chris Wyvill and Tina Kumar. For an overview of their roles and responsibilities, please refer to pages 8-14 in the presentation here:
https://portal.ct.gov/-/media/OHS/Health-IT-Advisory-Council/APCD-Advisory-Group/Presentations/OHS_APCD_Advisory_Mtg_Presentation_111419.pdf.

Allan introduced and welcomed all of the staff, and commented he feels we have a full contingent team. Allan asked if there was any questions or additional information from the advisors.

Pat welcomed everyone aboard and said she has been working primarily with Adrian and Tina and is looking forward to meeting and working with the rest of the team. Pat requested for the new staff to join the following APCD Advisory Group Meeting (February 2020), and Allan agreed.

Dr. Scalettar asked for an update on the budget related issues. He commented that we are all unfortunately too familiar with the difficulties through the many years with how to fund the robust APCD, and the state (good news we were able to get the funds with access health grant initially) noting the number of staff and the number of requests with legislature. He wants to make sure those are not in the category of unfunded mandates and asked where the money coming out of funds for the whole APCD.

Allan explained that the relationship with OnPoint, is coming out of OHS (other expense line, appropriations line for agency). Each of the other resources are part time on the APCD and funded differently. Joseph and Chris are funded through assessments into the health ecosystem to compensate the agency for the regulatory oversight (assessment mechanism for the staff who perform those duties).

Adrian is funding through the State Innovation Model (SIM) program (today), in the future will tap into other federal funding, and a pending budget request in which is uncertain if it will be approved or not.

Tina is funded through a federal program related to Health IT advisory council and the health information exchange work. These funds are allocated to the APCD is because the advisors are a standing subcommittee HIT Advisory Council.

Allan commented that he is worried if we are going to get extra budget request from OPM, and that we will know the first week in February 2020 if we will get funding. Dr. Scalettar thanked Allan for the explanation.

Dr. Scalettar asked, that since the Data Release Committee has been active, if the sale of the data would help in the budgeting process? He is curious as to what we are finding in the way of revenue and what we are getting from data release, and what does that ultimately mean?

Allan answered to be candid the amount of revenue out of data releases we have done about 15, and we are getting a few thousand to ten thousand dollars for each of these.

	<p>Allan added we have a data release pending for Yale New Haven Health Systems, and what we have recently discovered is that the State of CT (OHS) doesn't have a mechanism to issue an invoice. We've been trying to get paid, and Yale has been anxiously trying to give us money. This is another cork in the process. If we ever get a steady rate of data requests, we will have to figure this out in a better way.</p>	
7.	<p>Update on Existing Data</p>	<p>Adrian Texidor 1:30 PM</p>
	<p>Adrian Texidor provided an update on the existing data in the CT APCD. He added that part of this discussion will also include a status update on our data use agreement with Medicare. Please refer to page 16 for Fee for Service Dates available in the next extract. All payers highlighted in green will be up to date and current with submission in CT's APCD. We have not received the September update that was due in October due to administrative and minor onboarding issues. Additionally, there was an update that was pushed out to our submitters in July 2019 that caused us to visit the timeline.</p> <p>Victor Villagra asked in reference to the chart, how the submissions are classified? Is it fee for service, HMO, etc.? He observed under the different companies a line item for HMO FI, HMO on ACAS FI, etc. to clarify the nomenclature under Anthem.</p> <p>Adrian responded that there is a breakdown for the type of plan (HMO, FI) based on the payer. Anthem is a summary file.</p> <p>Allan added that a lot of this is done this way for a matter of practicality, the insurance carriers frequently operate the plans in separate administrative platforms, or separate legal affiliates who in turn are operating separate platforms for managing the plans. For example, if you see Aetna or United Health, for a matter of convenience, they are lined up against the admin system they have. Anthem has lots of admin systems, but they tend to run APCD and claims in an aggregated form nationally. This is why Anthem looks like it's a clean fee, where others are different.</p> <p>Victor thanked Allan and asked as a follow up, if the fee includes a breakdown by product category, as it would be displayed for example in the Access Health CT list of plans for the [qhrs](sp?) offers? And, are there fields that allow you to eventually make that connection, if you wanted to see an Anthem [pto](sp?) but instead offered by Access Health?</p> <p>Adrian answered yes there is a way to do this. If you look at https://healthscorect.com/researcher, and scroll to the Data Dictionary, there is a file under the member eligibility table which will show the type of plan.</p> <p>Dr. Scalettar asked if pharmacy data was included in this database?</p> <p>Allan answered that the prescriptions are coming through the carrier feeds as opposed to directly to the pharmacies. We are getting prescriptions that are filled and picked up (due to claim), in looking at this he doesn't know the history of why <i>Caremark & Express Scripts</i> are included in the status report. And why we are specifically looking at these two. Allan predicted this is because they are operating pharmacy benefit programs but will follow up on this question.</p> <p>Bernie Inskeep from United said we had talked a lot about this early on, because there were several meetings in a row where they received pointed questions as to why Optum RX was not a line item on this. Bernie thinks it depends on how the PDM does business with the medical carriers. For Optum RX, because they give over all of the claims to the customers. For example, if they were mandated all of the Oxford and United data would submit an addition then you would double the pharmacy costs and skewed and duplicative information, that's how United handles it. So, assuming this is how the PDMS handles it where they keep their own information and submitting it themselves vs. providing it to the whomever the medical provider is.</p>	

Dr. Scalettar added that most people are familiar with the National Data Repository or nonprofit called HCCI. He noted that the Anthem Blue cross Association threw their lot in with HCCI and raised an issue with Jim Iacobellis who had challenged the transition group to try and reckon with it. He questioned how will we think about the issue with what's on the screen? With CT based data, how will we think about our role in participating with others in terms of sharing the data outside of the state as a New England collaborative or a national effort which might come out of an HCCI? Allan said there's a set of discussions in the New England state to look at reciprocal data sharing. The conversation started predominately with the data that each state calls it different, but the people that regulate health care access and certificate of need programs, etc. are able to share data under reciprocal agreements, in some states this includes APCD data, in some it does not. Olga Armah added that this is moving at a snail's pace.

In our statute we are authorized to do data sharing across state lines, as long as they are reciprocal.

Dr. Scalettar commented that it sounds like this is an ongoing conversation, and that there's a statutory guidance or requirement on how this will play out. He asked if the group needed to be involved in this.

Allan said no, not at this time. We may have to come back to the advisory board on how they want to proceed.

Pat added that during the process in working on policies and procedures, believes that the issue of reciprocal data sharing and the national concept was eluded to in a positive way in the report. Allan agreed with this.

Bernie shared that last week she attended the National Association of Health Data Organization, and to level set with the group that one of the largest barriers of data sharing is that every state has a different format, and even if the format is similar some of the definitions for fields that may have the same name or sound the same actually contain different data. When it gets down to actual data sharing, it is not as straightforward as one might imagine. Allan added he thinks there's an effort with wanting to find a standard.

Bernie agreed that we have one state that is adopting it. United is 100% behind this, because as a payer that's in every single APCD the variability is onerous for them and it creates a lot of churn organizationally. A common data layout would help but would take a lot of time and would need to go through the legislative process. Allan agreed yes, this is a long process.

Victor asked that in looking at the table on the screen-he sees there is one start date that is common, what is the white and gray cells-what do they mean? And do we have a table that tells us every year since the first data submission. What data you have received. But just getting a sense for what has happened historically...

Adrian answered that they grey signifies the last month of data submission.

Victor asked if this is the first time that the data has been submitted, or has it been submitted every year. He also asked if there was a cumulative report.

Adrian said yes, it is a cumulative report. For example, in first column Aetna Health Insurance HMO FI We have data in the CT APCD right now ready for use from 01/2012-9/2019. Victor said this is helpful.

Allan commented that we are working through a data use agreement for access to the Medicare data, which is tied to the state's SIM program, the SIM program comes to an end in Jan 31, 2020. An agreement was reached to extend the data use agreement through the end of April 2020. However, what happens to the Medicare data after that is unknown to us at this point; whether they would continue to offer access to this data in the absence of a SIM program is unclear and we are working our way through that. There is a possibility that we may lose the data access agreement for Medicare data.

Adrian continued to discuss the data use agreement status.

Adrian said that for each and every use of Medicaid data for OHS related purposes, we have to obtain approval from the States Medicare department, which is housed at the Dept. of Social Services (DSS).

Currently, we are seeking approval to use pharmacy claims to support our work relative to our work PA 18-41. Also, working with DSS to establish Medicaid approval for non OHS data release requests that flow through the APCD Data Release Committee.

Medicare access is tied to the SIM program, we do have extended use of the data through April 2020. OHS just renewed their data use agreement with Medicare, working through adding additional scopes of work to the DUA with some work relative to the cost estimator and pharmacy claims.

There is some discussion at the Medicare level with CMS to find out if we can receive Medicare data in the future and how much that cost will be (approximate quote current \$130K). CMS may have some post SIM programs in the works which may reduce that cost or eliminate the costs entirely, and we are waiting to hear back.

Dr. Scalettar asked regarding the data use agreements, have there been any requests for Medicaid data, to date that has been approved by the two authorities-DSS and the Data Release Committee (DRC)?

Pat answered that have had the DRC has received a number of requests for the data when it comes available, but we do not have access to the data. We've tried to put someone from DSS on the committee itself, and we've tried to create a process where they could come one to say yes or no to the application request.

8.	Demonstration on Cost Estimator Feature	Adrian Texidor	1:40 PM
-----------	--	-----------------------	----------------

Adrian provided a brief demonstration on the Cost Estimator tool featured on Healthscore CT.
<https://healthscorect.com/>

Allan said the purpose of this demonstration to give the advisors a peak at one the uses of APCD data and using it in new way that extends beyond the traditional data release. Allan added that as a caveat when we put this data in the cost estimator live on Healthscore CT. We received a lot of query from provider groups, in particular the hospital groups who are running the off campus facilities where they are doing procedures like MRI, cat scans, etc. What has become evident as we've looked at the data, is the way the provider organizations are grouping the claims to arrive at the median costs of claims, this doesn't 100% line up with the way we've been doing grouping.

For the purposes of today's meeting, Allan would like the advisors not to draw any conclusions from the actual data because we are in process of validating the data with a couple of hospitals in particular and may revise the groupings. But would like advisors to see that we have a way of visualizing the data. Adrian proceeded to walk through the [cost estimator](#). OHS received a few comments on the healthcare community itself, which led us to determine we had a particular grouping product.

Victor asked if he can talk a bit about the development plan of making this cost estimator more granular or a timetable in the next year in terms of enhancing this to be more useful.

Allan said there is a long list, to some extent this was formed by statute. The statute that gives rise to having this estimator gives rise to about six different topics in it (highlight pharmacy costs, other cuts of data etc.) there will be layers of different drop down and filtering and cuts of the data going forward. All of this will start after we settle with the grouping. Also, OHS will conduct consumer focus groups, as this is oriented towards consumers to receive feedback on what's useful, how data is displayed, and how the filters work. As a long-term plan, we want to bring the quality score card with the cost information so that there is a unified picture to see how cost and quality work together.

Dr. Scalettar said that given that we are in open enrollment now, is this a way to evolve from someone to choose a health plan vs. using this to determine where to go if someone needs a hip replacement or other service? Allan said we try to be very clear that these are ranges and medians, and if you are going to get a knee replacement, colonoscopy, etc. that you can get a sense on relative costs for the facilities near you. But you have to go back to your payer, because these are medians, and your situation is indicated by multiple factors: i.e. nature of plan, high deductible, hmos, Co-pays unique to plan. We try to direct people back to their insurance plan, because that's where you receive the full information on what the procedure would cost. And by using this as a guidance tool to ask the right questions.

Victor asked which grouper are we using? Allan answered 3M's.

9.	Discussion of the APCD Data Release Committee Survey	Patricia Checko	1:55 PM
<p>Pat said that to address the Medicaid issue raised before, she cannot speak to the larger OHS agreement that will be ongoing in terms of acquisition of data from them and their ability to gain access to data. Pat will speak to it primarily in terms of how it relates to the Data Release Committee and the release of deidentified data sets. As a quick overview, there was a bumpy history to get started, Pat came aboard in 2017 when they were beginning to start the process. As it relates to Medicaid, when people make an application, they assume it's available and most of them do request it. We have had to respond with, "sorry we do not have access to the Medicaid data," and their response is usually, "can you send it when it does become available." People do want Medicaid data, and we know that it plays an important role in comparison not only terms of cost but also, issues related to outcome.</p> <p>As this relates to the DRC, any one who has had the experience of ever trying to utilize Medicaid data, are aware that it is very usage specific. It is not an overall blanket access that is given. The way it is set up on the federal level (dependent on commissioner), is related to the overall good outcome and benefit for people on Medicaid. The outcome certainly will depend on OHS' final negotiation. Currently, they would be required to have a separate permission from the DRC itself, and then a second review and permission from Medicaid. It is in our interest, from both the DRC and on behalf of any applicant who may want to work through this process, to make this process as unpainful as possible. In the policy and procedure amendment that the board voted on, we recommended adding a member of DSS to the committee to include a Medicaid representative. Our hope in these deliberations, is that whoever the DSS representative is would be given the ability to make that decision on behalf of Medicaid as part of that overall process. For example, someone who is looking for deidentified data sets in the hypothesis is looking for Medicaid, and right now we can not respond to that. Once this is settled, we hope it won't take as long in getting the data out of the APCD, that the person would come to the meeting (in person/phone) and participate in the process, and the individual from Medicaid would have ability to question along with rest of members. At the time, we vote if the Medicaid individual votes yes along with members, then the individual would have access to Medicaid data. However, if the individual voted no, they can still have access to the data, but not to the Medicaid data. This is where the issue lives, other APCD's have figured out how to do it, so we certainly can. Pat noted that Kate McAvoy is the director of Medicaid would be the person who reacts to any Medicaid data request.</p> <p>Pat asked if there were any questions or comments.</p> <p>Victor asked if Pat had catalogued the mechanisms that other states have used to make Medicaid data available? Pat responded no but will pursue this. *Action item* To look at how other states have made Medicaid data available.</p> <p>Allan shared an anecdote from when he attended a health IT conference in Baltimore and was asked earlier this year to chair a panel discussion on best practices around APCDs across the country. He had an epiphany in the course of the discussion of where 15 states were represented, that CT is in a unique and enviable position compared to other states. The revelation there was all about the fact that CT has all of the commercial carriers in scope and actively submitted and records going back to about seven years. We fought the battle for four years to try get the Medicaid data. Most of the other 15 states were in the opposite position, they were jealous of CT's position of having the commercial claims because they couldn't get them. The reason they couldn't get the commercial claims is because they were housing the APCD, in one of the various forms of health and human services agencies. It was a revelation to Allan that we are battling Medicaid, where many of the others are battling commercial carriers to get their data.</p> <p>Pat briefly discussed the Data Release Committee survey. Pat said to date we have had 15 data release applications and have had the transition of having it housed in OHS. During this time, the process has been evolving.</p>			

The brevity of the application itself, was to the point that there was no way you can make a decision without bringing the individual to the meeting to discuss their hypothesis and application. The application does not give us enough information as it stands alone. The statute only authorizes us to allow for the use of the deidentified data set, and we now have more specific OHS proposals or have an MOU.

Pat said that as we've looked at what people have requested, and their questions about, what happened? What was data they were given? Was the data useful? Etc. We have also had the opportunity to talk to one of the two individuals who have had access to both the deidentified data and limited data set. Pat said it is very clear that both people who have used it, and to us on the committee that when looking at the deidentified data sets, you cannot get a zip code, and where dates are masked, you cannot get this.

The third issue is the sustainability of the APCD would be based on fees reserved for using the data. We have not had any new proposals since the one. It has become very clear, that as written the deidentified data set is inadequate to anyone with any serious research questions to utilize.

The DRC Survey team agrees that we need and want to have greater use of the data. We are beginning to put together the process, starting with a survey that will look at all applications to date. Any applicants who started the process and never finished it, through what data is accessible. We were never aware of what the DUA was, if the work was completed. A small group is working with Tina and Adrian to come up with a survey that we would send out to all of the applicants and ask them if they would like a follow up with the ability to discuss further. This will be the beginning of our evaluation of the process and its usefulness and hopefully we will begin to create the data and the experience that will allow us to move forward and bring to advisor's attention. The hope is to bring this to the APCD advisory group for consideration of changing the statute that is willfully inadequate that will respond to the initial goals of the legislation.

Victor asked how are other states doing this and what are the best practices?

Pat said when we were doing the PMP review and creating the new policy and procedure that folks voted on we looked at some of this but not all of it. That will also be apart of what we will do.

Victor recalled that those reports were mostly a catalogue of what others were doing, but it didn't go to the next step to say that this allows a majority of submissions that requested to go forward to allow researchers to actually use the data.

Pat thinks it will be interesting as to what happens if we continue to receive requests for deidentified data, or whether people have used it will be unhappy. We are looking to see how well the data has been used, and if it was able to do what the researchers were trying to do. Pat said she would welcome anyone to participate in the survey committee.

Victor commented that in looking ahead, if the only path forward is a legislative initiative to amend the current law. Pat said the statute is extremely clear and limiting. Allan said yes, this in black and white and we have all of these limitations, much more than seen in other states.

Pat asked if Bernie had a perspective on this. Bernie responded, that when the initial statute is written that is when this is extremely important. Once there are limitations in the statute, then that creates a whole host of limitations to change how this is accomplished. The statutory authority is pretty key.

***Action Item* Allan suggested Tina to send out a copy of the link of the updated legislation to the advisors when distributing minutes.**

Pat said we will keep group apprised, hoping to get this out of the gate by January, and will come back for recommendations.

Victor suggested if we can get some guidance as to any additional limitations for using the data. For example, we had a fairly robust discussion about issues regarding transparency, but some concerns as to how far deep into data sets people can go and report without concern from the hospital or provider. The insurance

company that this is getting to close to confidential or proprietary. What were the stops in terms of the extent to which the data can be used to public consumption or policy making?

Pat answered that the for use of safe harbor variables, and the concept of the deidentified data. We have never been party to the actual discussion of the level of what variables you can actually receive. Certainly, in the discussion around the HIV proposal, it was clear we had the authority to say we will give the provider/pharmacy address. The people who put this in place had a lot of concerns and reluctance to have some of this data utilized. Adrian and Pat will look into what people have received, and we do ask people what they need and what variables they have. Pat thinks the data dictionary is a place to start.

Bernie says she can understand that there is interest in a researcher getting language, but health plans are not the best place to get that (federal anti-discrimination law, statement 6 says, that we can collect what's voluntarily provided to us) generally speaking have 2% of the time and can create a lot space to collect that. Some of these things are aspirational and might need to be collected from different source, but not necessarily the reason they re not. Pat agrees with her.

Victor agrees with Bernie, that we've had the discussion, not in terms of language but about race and ethnicity. Victor said they've been told that large insurance companies don't need race and ethnicity to pay claims, but referring back to Bernie's comment earlier, that when the statute gets written he thinks there is a higher level of reluctance that may come in from different groups that can be embedded in the language that puts limitation on the use of the data. If we are aiming for the greatest amount of transparency and use for the researchers, we need to be vigilant about not embedding limitations that are detrimental to researchers in terms of their research.

Bernie said that for legitimate researcher when you have very identifiable data, even if it could be used for anti-competitive purposes, but within the application process when they talk about how they are going to use the research and publish it, you may have to look at data elements to conduct the research. It is much more important as to how its going to be used and published.

Victor added that he appreciates other laws that promote transparency where there's certain information that cannot legally be suppressed, but we have to find a way more user friendly for researchers.

Pat thanked for the group for the opportunity for beginning this discussion.

Wrap-Up Meeting and Adjournment

ALLAN HACKNEY

3:00 PM

Allan Hackney asked for a motion to adjourn the meeting. Patricia Checko made a motion to adjourn. None opposed. The meeting adjourned at 3:00 pm.

Upcoming Meeting Schedule: February 13, 2020