



**DRAFT  
MEETING MINUTES**

**Rhode Island All Payer Claims Database  
Data Release Review Board Meeting  
Wednesday, February 11<sup>th</sup> 10:00 am – 12:00 pm  
Room 401, RI Department of Health  
3 Capitol Hill, Providence, RI 02908**

**Members Present:**

Monica Neronha  
Solmaz Behtash  
Cory King  
Betsy Stubblefield Loucks  
Kenny Alston  
Michael Lichtenstein  
Ira Wilson  
Amy Black  
Patrick Tigue  
Kimberly Paull

**Members Absent:**

Lawrence Rothstein

**Staff Present:**

Nicole Alexander-Scott, Director, Department of Health  
Alyssa Ursillo, Freedman HealthCare  
Samara Viner-Brown, Department of Health  
Melissa Lauer, Executive Office of Health and Human Services  
Amy Zimmerman, Executive Office of Health and Human Services  
Linda Green, Freedman HealthCare

**1. Welcome and Introductions**

The meeting was convened by Alyssa Ursillo, Project Manager for the RI APCD, at 10:05 am with roll call.

**2. Approve January Meeting Minutes**

Ms. Ursillo presented the January meeting minutes. The Board approved the minutes as presented.

**3. Approve Annual Meeting Schedule**

Ms. Ursillo presented the annual meeting schedule. There was some discussion about whether the meetings could be held in the afternoons. In the end all Board members said either time 11am – 1pm or 1 – 3pm on the third Friday of each month was fine. Ms. Ursillo will check schedule these meetings.

**4. Board Chair Nominations**

Ms. Ursillo reviewed the role of the Board Chair. This person will take roll call, facilitate approval of meeting minutes, and facilitate discussion and voting for recommendations. The APCD staff will

continue to draft and post meeting agendas and minutes, communicate with members, and lead informational presentations. Ms. Ursillo asked for nominations. Michael Lichtenstein, Dr. Rothstein, and Dr. Behtash were nominated. Dr. Alexander-Scott will appoint a Chair before the next meeting.

#### 5. Discuss Board Operating Procedures

Ms. Ursillo facilitated the discussion for determining the Board's procedures for making recommendations to the Director. The Board discussed the three options used in other states – recommend for approval, recommend for approval if certain conditions are met and recommend to not approve and have applicant reapply. Dr. Wilson emphasized the need to reduce the number of mechanical reasons for denial and suggested developing examples of successful applications.

The Board discussed their role in asking the applicant to meet certain conditions or telling the applicant to reapply. Mr. Tighe pointed out that if the Board asks for certain conditions to be met, this is similar to sending it back to the applicant to reapply. Dr. Wilson noted he thought the second option was for minor issues. Ms. Ursillo confirmed this. Ms. Neronha pointed out that the Board's role would not be to reject an application but to recommend it be rejected to the Director. Dr. Alexander-Scott noted that she would prefer the Board send the application back to the applicant with the list of deficiencies and include this in her recommendation - she can then choose to overturn this. Ms. Ursillo will draft a process for the next meeting.

The Board also discussed whether an applicant should come to the meeting when their application is being reviewed. Dr. Behtash asked if the person can call in. Ms. Ursillo will get legal clarification on this for the next meeting. Mr. Lichtenstein noted they could have a limited time to present and ask questions. Other Board members noted the applicant would not present, but would be present for the Board to ask them questions if needed. The Board generally agreed that the applicant should be encouraged to come, but that it would not be required.

#### 6. Review Level 2 Data Sets Format

Ms. Ursillo presented the format of the Level 2 data sets for the Board to review. She reviewed how Level 2 data sets differ from Levels 1 and 3, the purpose of Level 2, examples of how the data could be used, and the need to balance patient privacy, usability and cost with this level of data. She noted that Level 2 data presents a very small risk of re-identification. Dr. Wilson asked how this was a risk. Ms. Ursillo noted that if there was someone with a very rare diagnosis, and you had certain information about their claim, such as their city, hospital they went to, diagnosis, etc. you could potentially identify them. However, this risk with Level 2 would be very, very minimal.

There was some discussion around balancing the usability of the data sets with patient privacy. Dr. Wilson brought up the possibility of linking the data to 9-digit zip codes from census data to add in socioeconomic data to make it more useful, and then deleting the zip codes from the data set before making it available. The APCD staff noted they would explore this possibility. Mr. King asked if these files would be pre-determined or if they can be customized. Ms. Ursillo clarified these would be pre-determined, but if someone wanted a customized file that fell within the level 2 privacy parameters, the Board could recommend these requests be filled without Board review. Ms. Paull emphasized the need to provide streamlined access to data. Dr. Wilson noted because the data sets did not allow for someone to do their own crosstabs which decreased their usability, the State should not charge for them. Ms. Ursillo noted you can calculate rates and averages and other metrics. Ms. Neronha emphasized there will never be a data set that is everything everyone wants, but the role of the Board is to protect patient privacy. Ms. Ursillo noted the staff will be soliciting user feedback and that the point

of level 2 is providing data that is meaningful to the public while protecting patient privacy, as there are privacy concerns when extracts have a line for each individual. Mr. Tigie noted these data sets would be very valuable to advocacy organizations, industry, and policy makers – they do not need a higher level of sophistication. Ms. Neronha agreed. Mr. King emphasized that there needs to be another level between 2 and 3. Ms. Black noted this is an iterative process that the Board can continue to help define.

Ms. Ursillo presented the privacy guardrails for Level 2 data sets, including:

- No member IDs, 5-digit zip codes or service dates;
- Agreement to terms and conditions required to access the data; and
- Certain aggregated metrics, such as member and visit counts

She explained that the terms and conditions required the user to adhere to the CMS cell size suppression policy in any publication, prohibited attempts to re-identify individuals, and prohibited the user to re-distribute the data in its original form.

Dr. Alexander-Scott clarified this process is separate from the IRB process but asked the Board to think about whether IRB approval should be part of the DUA for those projects that qualify as human subjects' research. Ms. Ursillo noted this will come up with the Level 3 application.

The Board discussed the cell size suppression policy. There was some confusion around whether the State would suppress small cell sizes in the data set, or whether the State would release the data sets with small cell sizes but require the user to adhere to cell size suppression policies. Ms. Ursillo and the APCD staff clarified that the State may release data with small cell size to users who are under the agreement to terms and conditions, but that user must adhere to cell size suppression policies in any disclosure or publication of the data. Dr. Wilson asked how a cell could be less than 11 with this format; Ms. Ursillo and other members of the Board clarified that a row of data with a rare diagnosis could result in a member count of less than 11. Ms. Neronha and Ms. Behtash asked if it created technical barriers to suppress every cell. Ms. Ursillo noted it would be more burdensome, but without the ability for the user to do cross tabs it should be pretty straightforward.

Ms. Neronha noted that she felt small cell sizes should not be included at this level of data. Ms. Paull pointed out that the EOHHS General Counsel had reviewed the information and determined it was appropriate to give out this data under a DUA that was similar to when an IRB approved access to this kind of data. This offered legal protection. Ms. Neronha said she understood for level 3 there were more stringent protections and a DUA and this data could be given out, but that she was worried it was not the intention when this legislation was being written to allow the kind of access being proposed for Level 2 when there is any risk of re-identification. Ms. Behtash agreed.

Dr. Alexander-Scott noted that there may be more needed to learn and understand this level of data before a final decision could be released. Dr. Wilson and Mr. Tigie asked for clarification on the actual format of the data. Ms. Ursillo pointed to the sample data set and explained data sets would have member, visit and claim counts for certain categories of members or services. She reviewed the proposed types of data sets, including inpatient, outpatient, professional and pharmacy services, and reviewed the definitions of these. Dr. Wilson noted there would be no way to cut or cross tab the data. Mr. King noted there should be a way to tabulate the data and have a more interactive user interface.

Dr. Alexander-Scott re-directed the Board to think about whether the proposed elements in the proposed format presented any patient privacy concerns. Ms. Paull pointed out that it seemed the decision was around whether the State should include small cell sizes, or suppress small cell sizes in the

data sets it released. The Board agreed this was the question. Dr. Wilson noted that without the ability to do cross tabs, suppressing small cell sizes made no difference to the usability of the data set.

#### 7. Public Comment

There were no public comments.

#### 8. Recommendations for Level 2 Format

Ms. Ursillo asked if the Board felt comfortable making a recommendation on whether the State should release Level 2 data sets with small cell sizes. The Board members agreed to take a vote. The Board voted to recommend to approve the format on the condition that the State suppressed any cell with less than 11 observations in the data sets to be made available.

Members in favor of approving with condition to suppress small cells:

Monica Neronha  
Solmaz Behtash  
Cory King  
Betsy Stubblefield Loucks  
Kenny Alston  
Michael Lichtenstein  
Ira Wilson  
Patrick Tigie

Members not in favor of approving with condition to suppress small cells:

None

Members abstaining from vote:

Kimberly Paull  
Amy Black

#### 9. Next Steps and Adjourn

The Board will meet on March 18<sup>th</sup> to confirm the process for making recommendations. The APCD staff will present further clarification of Level 2 data sets to answer questions raised during this meeting.