



Integrated Population Health Data (iPHD) Project Governing Board Meeting Minutes November 8, 2019 1:00 PM-3:00 PM EST

iPHD Governing Board meeting convened in compliance with the New Jersey Open Public Meetings Act. The meeting was held at the New Jersey Department of Health (369 South Warren St., Trenton).

Board Members Present:

In-person:

Rachel Hammond (Chair and Designee for the Commissioner of Health Data Privacy Officer, NJ Department of Health), Francis Baker (Ex officio/Designee for the NJ Attorney General, Deputy Attorney General, NJ Office of the Attorney General), Greg Woods (Ex officio/Designee for the NJ Commissioner of Human Services, Chief Innovation Officer, Division of Medical Assistance and Health Services Department of Human Services), Dr. Ranjana G. Madhusudhan (Designee for the State Treasurer, Chief Economist, NJ Department of the Treasury), Joel Cantor (Ex officio/ Non-voting, Director of Rutgers Center for State Health Policy), Kathleen Noonan (Appointed- Chief Executive Officer, Camden Coalition of Healthcare Providers), and Elizabeth Litten (Appointed- Legal & Privacy Expert, Partner and HIPAA Privacy & Security Officer, Fox Rothschild LLP)

By-phone:

Michele Norin (Ex officio, Chief Information Officer- Rutgers University)

Attendees:

In-person:

Margaret Koller (Rutgers Center for State Health Policy), Mark McNally (NJ Office of the Attorney General), Judith Persichilli (NJ Department of Health – Acting Commissioner), Arundhati Mohankumar (NJ Office of the Attorney General), Eileen Troutman (NJ Department of Health), Suzanne Borys (Division of Mental Health & Addiction Services), Carolyn Daniels (NJ Department of Health), Yong Sung Lee (NJ Department of Health), Barbara Bolden (NJ Department of Health), Tim Seplaki (NJ Department of Health), Yannai Kranzler (NJ Department of Health), Niurca Louis (NJ Department of Children and Families), Chris Rein (NJ Office of Information Technology), Jon Tew (Camden Coalition of Healthcare Providers), Shelby Klein (New Jersey Innovation Institute), Jose Nova (Rutgers Center for State Health Policy), Cliver Lontok (Rutgers Center for State Health Policy), Manisha Agrawal

(Rutgers Center for State Health Policy), and Omna Syed (Rutgers Center for State Health Policy)

Call to Order/Opening Remarks

- R. Hammond called the meeting to order at 1:06 pm with a quorum present.
- R. Hammond acknowledged that the meeting was being held in compliance with the 1975 NJ Open Public Meetings Act and that there was a publication of meeting time and location in two NJ print publications (Newark Star Ledger and The Times of Trenton) and on the Rutgers Center for State Health Policy website.

General Updates/Actions

Updates from the Chair

- R. Hammond introduced Francis Baker, the newly appointed designee for the NJ Attorney General. She thanked Arundhati Mohankumar, who will soon be taking maternity leave, for her services on the Board.
- R. Hammond acknowledged the strong representation by the DOH at the Governing Board meeting, including Judith Persichilli, the Acting Commissioner.
- R. Hammond provided a recap of the activities accomplished last year and a progress/status of the Board's three subcommittees (Legal, Technical & Communications).
- M. Koller noted some progress in filling the vacant Assembly Speaker's Board appointment with an expert in human subject's research. Professor Janet Currie from Princeton University is currently being vetted for the seat.

Meeting Minutes

- R. Hammond requested board members review the September 20th Governing Board meeting minutes (approved by Minutes Subcommittee on November 1, 2019)
- M. Norin made a motion to approve the September meeting minutes. G. Woods provided the second and, upon roll-call, the minutes were approved unanimously.
- F. Baker and E. Litten abstained from voting as a result of their absence from September's meeting.

Subcommittee Updates

Technical

- M. Norin shared that a preliminary crosswalk of NJ OIT and RU policies was completed in July 2019. In September 2019, an in-depth comparison was initiated to identify areas of inconsistency. The Rutgers team is currently categorizing the policies into four (4) tiers, prioritized by security risk for the iPHD. The top tier is now targeted for completion in advance of the next technical subcommittee call on December 13th. A total of 36 policy domains are being reviewed.
- M. Koller mentioned the crosswalk analysis would be used to harmonize all agreements for subsequent board approval. R. Hammond recommended translating the crosswalk into a checklist upon completion.
- J. Nova of Rutgers CSHP has reached out to Eileen Troutman, CIO at NJ DOH, to discuss next steps for the "dummy data" transfer process. No identifiable data can be transferred until the data use agreement has been executed. A call has been scheduled for the week on November 11th.
- M. Koller said that Rutgers Institute for Health's IT Director, Tom Regan, has shared the draft of the DUA with the Rutgers Compliance Office and Denise Romano from RU OIT for their review.

Legal

- E. Litten provided an update on the activities of the Legal Subcommittee. On October 30th, she, Rachel, and Margaret held a conference call with Sarah Polites to discuss the mortality data legal memo. They provided feedback to Sarah on the structure of the memo, particularly about the applicability of HIPAA when the data is in motion to/from NJDOH. Sarah is scheduled to complete the memo by the week of November 18th.
- E. Litten mentioned that the committee is exploring the possibility of having Jim Lloyd from the Center for Health Care Strategies revise the current draft of the UB data memo.
- E. Litten stated that the goal is to have all memos completed by the middle of Q1 (i.e., February 2020).
- M. Koller shared that she and Joel had a conversation with Jim Lloyd, who is in the final stages of preparing a statutory crosswalk memo for the Medicaid data. The expected time frame for completion is mid-November. She

- reiterated that, to date, the Medicaid data has not been approved for inclusion in the iPHD.
- R. Madhusudhan inquired how the iPHD process fared relative to best practices for integrated data projects.
- R. Hammond replied that, based on the Actionable Intelligence for Social Policy (AISP) conference, the iPHD project is in lockstep with similar projects.
- K. Noonan added that, in her experience, the iPHD project is developing well, and reflects a methodical process, enabled by state legislation and governed by a thoughtful and committed board.
- C. Rein said the iPHD project had applied the National Institute of Standards
 of Technology (NIST) used by the Department of Homeland Security, which is
 a best practice. He also noted that the Rutgers Institute for Health scored
 above the state average on the NJ Cyber Security Self-Assessment.

Discussion

iPHD Launch and Communications Strategy

- A slide presentation highlighting key achievements and a high-level launch timeline was shared with the group with the discussion led by R. Hammond.
- M. Koller reviewed milestones of the Board from 2017 through 2019. K. Kovacs
 presented a proposed launch plan and highlighted critical path items required to
 launch in Q3 2020. J. Cantor discussed strategic launch options and pilot funding.
 He recommended defining the iPHD launch as when research applications can be
 accepted.
- After discussion by the Board, it was agreed to launch with a minimum of three data sets: birth, mortality, and UB (hospital discharge).
- J. Cantor also presented the Board with two options regarding pilot funding: 1) Funding a single research priority, such as Opioids, or 2) Funding all three research priorities.
- K. Noonan recommended that we open applications for all three research priorities, and the Board agreed.
- R. Hammond listed key items that needed to be addressed prior to launch: (1) a secure environment for researchers to access data, (2) the ability to link iPHD data with other data sets, and (3) establishment of a fee schedule.
- K. Noonan stated the importance of communicating fees associated with iPHD access at launch, even if the fees are initially subsidized or waived because of

- DOH launch funding. M. Koller suggested adding information on fees and waivers to the iPHD FAQs.
- R. Hammond stated the ultimate goal is to make the iPHD self-sustainable. K.
 Noonan agreed and expressed a belief that researchers should pay for the data sets to the extent possible.
- R. Hammond shared that universities are currently the primary applicants for DOH data. Applicants are charged a nominal fee of \$5 for a limited data set.
- Y. Lee also noted that additional fees could be assessed for IRB approval.
- J. Cantor said the iPHD statute includes language on the development of an NIHlike fee schedule for cost recovery. He also mentioned his preliminary conversations with select organizations regarding future funding.
- J. Cantor stated that researchers applying to the iPHD would be required to receive IRB approval prior to applying, even if the projects are ultimately considered exempt.
- O. Lontok noted that the iPHD Governing Board could identify the minimum level of risk researchers' IRB applications must meet in order to be considered for dataset access.
- R. Hammond mentioned DOH's IRB approval is conducted through Rowan University and has an \$800 expedited processing fee.
- R. Hammond noted that each of the initial DOH data sets will be identified in the pending DUA to enable execution of one agreement.
- In the context of launch timing, J. Cantor commented that including the EMS data set could add three (3) to four (4) months to the initial launch timeline.
- In response to a question from C. Rein about the reasons for the delay, J. Nova said the EMS dataset is large and not created for research purposes; therefore, it may require additional time to incorporate with other data sets.
- T. Seplaki noted that work was recently completed on the EMS data set with the last two years of data now "research ready."
- J. Nova noted that we would like to obtain 10 years of EMS data history. E. Troutman shared two years is more realistic.
- G. Woods asked if there is a meaningful difference between launching with three or four data sets. M. Koller noted the high demand for EMS data, as well as the associated implications for the iPHD communications strategy at launch.
- The Board decided to launch with as many datasets as are research-ready, focusing on a minimum of three.

- K. Noonan stated the focus should be on all priorities as they are all important. The iPHD should be open to accepting all applications and see what comes in.
- G. Woods asked if there is a process set for awarding the pilot money.
- J. Cantor responded that it is up to the Board to approve the awarding of the pilot funding, with decisions informed by input from the Research Advisory Committee.
- M. Koller shared that the Communications Subcommittee has a call scheduled for November 21st. One of the goals of the meeting is to initiate strategic planning of the iPHD research consortium meeting mandated by statute.

Schedule for Upcoming Meetings

- R. Hammond proposed to continue with quarterly in-person meetings in 2020:
 March, June, September, and November for the third Friday of the month at 1 o'clock.
- With no objections, O. Syed to follow up.

The General session of the Governing Board meeting was adjourned to Executive Session at 2:24 pm.

Next Steps & Adjourn

- K. Noonan made a motion to adjourn.
- E. Litten offered a second.

The Governing Board meeting was adjourned at 2:27 pm.