

**Integrated Population Health Data (iPHD) Project  
Governing Board (GB) Meeting Minutes  
March 22, 2024**

**1:00 PM-2:30 PM EST**

*iPHD Governing Board meeting convened in compliance with the New Jersey Open Public Meetings Act and all participants attended the meeting virtually.*

**Board Members Present:**

Rachel Hammond (Chair and Designee for the Commissioner of Health Data Privacy Officer, NJ Department of Health), Joel Cantor (Ex officio/ Non-voting, Director of Rutgers Center for State Health Policy), Rashmi Jain (Appointed- Big Data/Security Expert, Chair of Information Management and Business Analytics, Montclair State University), 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), Elizabeth Litten (Appointed- Legal & Privacy Expert, Partner and, Chief Privacy & HIPAA Compliance Officer, Fox Rothschild LLP), Kathleen Noonan (Appointed- Chief Executive Officer, Camden Coalition of Healthcare Providers), and Michele Norin (Ex officio, Senior Vice President & Chief Information Officer- Rutgers University)

**Attendees:**

Margaret Koller (Rutgers Center for State Health Policy), Mark McNally (NJ Office of the Attorney General), Maria Baron (NJ Department of Health), Darrin Goldman (NJ Department of Health), Kara Unal (NJ Department of Health), Rick Hall (NJ Department of Health), Jose Nova (Rutgers Center for State Health Policy), Kate Scotto (Rutgers Center for State Health Policy), Jolene Chou (Rutgers Center for State Health Policy), Joshua Lue (Rutgers Center for State Health Policy), Oliver Lontok (Rutgers Center for State Health Policy), Joseph Brecht (Rutgers Center for State Health Policy), and Manisha Agrawal (Rutgers Center for State Health Policy)

## **Call to Order/Opening Remarks**

- R. Hammond called the meeting to order at 1:05 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 the meeting time and location in the Newark Star-Ledger and three websites (NJ. Com, NJ Press Association, and the iPHD website). The iPHD Governing Board meeting was convened in compliance with the New Jersey Open Public Meetings Act. Instructions for registration and login information were posted in the publications and the websites.

## **General Updates/Actions**

### *Updates from the Chair*

- R. Hammond reminded the GB that the existing MOA set to lapse in March 2024 will now extend until March 2026. An extra \$800,000 in funding has been secured, split evenly between FY 2023 and FY 2024 (\$400K each). This supplementary funding is intended to bolster the project's deliverables.
- R. Hammond informed the Board that the Senate confirmed DOH Commissioner Dr. Kaitlan Baston.

### *Meeting Minutes*

- R. Hammond requested Board members review the January 26, 2024, Governing Board meeting minutes (approved by the Minutes Subcommittee on March 7, 2024).
- K. Noonan made a motion to approve the January 2024 meeting minutes. M. Norin provided the second, and the minutes were approved unanimously upon roll call.

### *iPHD Fee Schedule*

- M. Koller informed the Board that the iPHD fee schedule shared in the last meeting was approved by Rutgers Cost Accounting. The new fee schedule will result in an average 43% reduction in data fees, depending on the project's specifics. This new schedule will be effective for two years.

## Discussion

### *New Research Priority*

- M. Koller shared the revised language of the new research priority approved in concept by the Board on January 26<sup>th</sup>. E. Litten requested an explanation of high-value vs. low-value care in the last meeting.
  - *Promoting Equitable Access to High-Value Health Services* – Assuring equitable access to high-value health services, defined as high-quality care delivered at the lowest feasible cost while also reducing the delivery of unnecessary and low-value care, is a persistent challenge in the healthcare system. Analyses of iPHD data to inform healthcare financing and delivery innovations and clinical recommendations that advance access to high-value care and identify opportunities to reduce unnecessary and low-value care are encouraged.
- Some members of the Board proposed adjusting the language for grammatical accuracy. M. Koller mentioned that an updated version would be circulated among the Board members, and she noted that this research priority would be included in the upcoming RFA.

### *2024 Cycle 1*

- M. Koller provided an update on the LOIs received for 2024 Cycle 1:
  - Overall, 13 LOIs were received, including 8 Rutgers applications, other universities include Princeton, Oregon Health and Science University, Bentley, Georgia State, and one family health center. Two 2023 Cycle applicants submitted an LOI for consideration.
  - In line with research priorities, including addressing the social determinants of health (11 LOIs), enhancing maternal and infant health (8 LOIs), conducting analyses to aid New Jersey's response to COVID-19 and other public health crises (3 LOIs), and addressing the opioid epidemic (2 LOIs). She also noted that full proposals are expected by next week.
  - M. Koller said that CSHP received an inquiry from a Rutgers researcher for access to preliminary iPHD data to inform her proposal for pursuing grant funding. The work will use iPHD data in the future. She added that CSHP will get more clarification from the researcher to accommodate her needs.
- M. Koller said that a policy for sharing preliminary data is needed for future requests. The policy should clearly define criteria and limitations for supporting proposal development, and it will be shared on the iPHD website. J. Cantor said

that this type of request is permissible under the iPHD Acceptable Use Guidelines. M. Koller said the draft language will be shared with the Board in the next couple of months for the Board's review and approval.

- K. Noonan inquired whether the preliminary data release necessitated a formal Board review. J. Cantor clarified that such requests for preliminary data did not mandate Board approval. The purpose is primarily to ascertain the cell sizes for variables within the dataset. He further explained that it aligns with iPHD's business interests, ensuring operational efficiency, as larger grant applications, such as those to NSF or NIH, require researchers to demonstrate adequate sample sizes in their datasets. M. Norin mentioned similar data requests received for information stored in the Clinical and Research Data Warehouse (CRDW) and highlighted efforts to accommodate these requests despite resource limitations.
- J. Nova introduced an idea inspired by initiatives in other states like Massachusetts, where a structure like iPHD exists for data sharing. He proposed offering researchers a dataset shell, without actual data or containing fabricated data, allowing them to develop and test their code for potential queries. Researchers would then submit their code to iPHD, which would be executed on the authentic dataset to generate the required information. While this approach would demand the time and effort of a data analyst, it presents a promising avenue to address certain inquiries.

#### *2024 Timeline*

- M. Koller shared the 2024 iPHD timeline with the Board:
  - The subcommittee meeting for 2024 Cycle 1 will be in July 2024, and the full Board meeting will be in August 2024.
  - 2024 Cycle 2 RFP release (self-pay only): May 2024.
  - 2024 Cycle 3 RFP release (fee-waivers and self-pay): September 2024.

#### *Subcommittee Additions*

- J. Cantor reminded the Board that the Review Subcommittee reviews all proposals, and the RAC reviews and develops recommendations for permissible data release for the Board. He added that K. Noonan, R. Jain, and J. Currie served on the committee in the last two cycles. J. Currie is not available this year. For the last cycle, two external reviewers were added, and it worked well.
- J. Cantor suggested reconstituting the committee in J. Currie's absence. K. Noonan and R. Jain confirmed their participation, and the two external reviewers will be contacted to confirm their availability. He shared the plans to add one external reviewer to the subcommittee. A list of potential reviewers with bios and links was shared with the Board for review. He added that he has been

providing technical assistance to the applicants, and he will have too many conflicts if he joins the subcommittee.

- R. Hammond mentioned that according to the bylaws, only one Board member is required for the subcommittee, which is a significant commitment. Board members can take turns participating on a rotating basis. R. Jain expressed her interest in participating for academic purposes and has already received confirmation from CSHP. K. Noonan acknowledged that it's a substantial commitment but affirmed her willingness to continue participating, having confirmed her involvement with M. Koller.
- J. Cantor extended appreciation to K. Noonan and R. Jain for their invaluable insights as subcommittee members. M. Koller noted that their respective strengths complement each other well, leading to high productivity. Expanding the team's expertise would be beneficial, especially with three cycles scheduled for this year, allowing for a more evenly distributed workload among reviewers.
- M. Koller commended both external reviewers for their outstanding performance in the previous cycle and mentioned that she would reach out to confirm their availability for this upcoming cycle. R. Jain concurred, emphasizing how their expertise streamlined the process and led to concise and effective discussions. M. Koller added that we'll initiate outreach and engagement with individuals on the list to assess their interest in taking on the role.

#### *RWJF Health Data for Action*

- J. Cantor provided an update on the HD4A application review process:
  - RWJF conducted a peer review process under its HD4A national program. Two outside reviewers were assigned to each application. Five applications requesting the iPHD data were received, and the external reviewers selected three finalists.
  - RWJF is willing to fund up to two applications requesting iPHD data. CSHP is reviewing the applications and will meet with RWJF and the AcademyHealth staff on March 29th to select the finalists.
  - Materials for up to two selected finalists will be available for the Board's review and consideration for data release at the May 17th meeting (or to schedule a special meeting if needed).
  - M. Koller said that RWJF will provide funding only to new researchers. iPHD will receive data preparation fees from RWJF (\$50K/application).
- J. Cantor noted the necessity of obtaining permission from RWJF to disclose the applicant's information during the full Board meeting. K. Noonan proposed utilizing subcommittee review if necessary. J. Cantor indicated that further details

would be provided following the March 29th meeting. M. Koller inquired with M. McNally about the permissibility of sharing an update with the Board via email, to which M. McNally confirmed its permissibility.

### *Data Expansion Strategy*

- M. Koller provided an update on the data expansion plan for the iPHD:
  - Current iPHD datasets included birth, mortality, hospital discharge, Communicable Disease Reporting and Surveillance System (CDRSS) (COVID-19 PCR Reports), and EMS data. M. Koller thanked T. Seplaki and R. Masiello for their support with the EMS data.
  - Datasets previously approved by the Board included the Pregnancy Risk Assessment Monitoring System (PRAMS), COVID Vaccine, Cancer Registry, NJ Medicaid, NJ Substance Abuse Monitoring System, incarceration data, cardiac catheterization data, cardiac surgery data, and trauma registry data. Ongoing discussions with data stewards of PRAMS, COVID Vaccine, and the Cancer Registry datasets.
  - For Medicaid data, CHSP is meeting quarterly with G. Woods and the NJ Medicaid team to discuss the process and the appropriate agreements. The review process needs to be modified for applications requesting Medicaid data. G. Woods said that there is still a fair amount of work to be done to figure out all the details, but it is on a good trajectory.
  - E. Litten asked for a broad description of Medicaid data that will be transferred to CSHP. G. Woods responded that Medicaid already shares data sets with CSHP for the existing work. The dataset includes service claims and encounter data. J. Cantor added that it would be the same data but with identifiers, so there are several HIPPA questions to be addressed.
  - J. Cantor indicated that once approved, the Medicaid data would promptly become accessible as they have already been transformed into research files. This development has the potential to significantly impact the landscape, particularly regarding inquiries into iPHD social determinants of health research priority, which currently lack comprehensive coverage without ambulatory care data. With approximately 2 million individuals included in the Medicaid files, this integration stands to substantially enhance the utility of iPHD.
  - E. Litten suggested State Health Benefits Program (SHBP) dataset as another potential dataset for iPHD. J. Cantor responded that there are about 800,000 covered lives in that dataset.
  - M. Koller mentioned two additional datasets from the NJ Department of Children and Families for the Board's consideration to add to the iPHD

Project: 1) The Children's System of Care (CSOC) Cyber Data: CSOC provides comprehensive mental health services, substance use and addiction services, and services/supports for youth with intellectual and developmental disabilities, as well as their families. 2) Child Protection and Permanency (CP&P): CP&P is responsible for investigating allegations of child abuse and neglect and, if necessary, arranging for the child's protection and the family's treatment. She added that DCF is willing to share their data, they have leadership approval, and they are willing to move reasonably fast. R. Hammond had conversations with colleagues at DCF. M. Koller asked if there were any questions or concerns about including this data.

- E. Litten asked if there would be a perceived privacy concern regarding identifiable data related to children. There may not be a legal issue but just a perception issue. M. Koller responded that both the director of research and the privacy officer at DCF are involved in the discussions. She added that K. Stoehr, First Deputy Commissioner, and P. Lilleston, Director of Applied Research and Evaluation at DCF, attended a couple of early Board meetings.
- J. Cantor said that there is a precedent around the country regarding sensitive data about minors. We can check with places such as the University of Wisconsin data system to find out whether there are additional protections. E. Litten said that they may have some statements or protections in place specifically recognizing the sensitivity of children's data.
- R. Hammond said that children's data are included in our current iPHD datasets. She added that E. Litten raised an important point because the datasets discussed involve children receiving mental health services and child abuse data, which requires another level of sensitivity and privacy. Furthermore, this is something to think about for all datasets that have children's data.
- R. Jain asked for more clarification on the Child's Protection and Permanency data. J. Cantor responded that it concerns children being removed from dangerous households. DCF shares these datasets with the Rutgers School of Social Work. They have a rich data dashboard available for basic trends. Additionally, DCF already shares these datasets with outside researchers. It will be much richer with iPHD data linkages.
- M. Koller said that DCF discussed the application review process. They were not interested in duplicating the work but just wanted to ensure that it met their standards.
- R. Hammond remarked that it would be interesting to see the details of the DUA between DCF and Rutgers. She requested the Board members to make

a motion to add the two DCF datasets listed above if there were no other questions or concerns. She added that our existing data sets have a higher level of restrictions and share only de-identified or limited datasets, and additional protections could be added for these datasets.

- E. Litten agreed that it is appropriate to include these datasets with the right purpose and protections in place.
- R. Jain made a motion to approve the addition of the two DCF datasets to iPHD. G. Woods provided the second, and upon roll call, the inclusion of CSOC and CP&P datasets was approved unanimously. R. Hammond said that this will kick off the legal review and the DUA process.

**R. Hammond indicated that the executive session was not needed. R. Hammond asked if anyone would like to make a public comment. There were no comments, and the open session of the Governing Board meeting was adjourned at 2:12 pm.**

- E. Litten made a motion to adjourn the open session of the meeting.
- G. Woods offered a second.
- Unanimous vote to adjourn the meeting.