

**Integrated Population Health Data (iPHD) Project
Governing Board (GB) Meeting Minutes
June 9, 2023**

3:00 PM-4:30 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), 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), Michele Norin (Ex officio, Chief Information Officer- Rutgers University), Kathleen Noonan (Appointed- Chief Executive Officer, Camden Coalition of Healthcare Providers), and Janet Currie (Appointed- Human Subjects Research Expert, Professor of Economics and Policy Affairs, Princeton University)

Attendees:

Margaret Koller (Rutgers Center for State Health Policy), Mark McNally (NJ Office of the Attorney General), Suzanne Borys (NJ Department of Human Services), Sharon Cooley (NJ Department of Health), Barbara Bolden (NJ Department of Health), Johanny Garcia (public attendee), Jose Nova (Rutgers Center for State Health Policy), Kate Scotto (Rutgers Center for State Health Policy), Oliver Lontok (Rutgers Center for State Health Policy), Jolene Chou (Rutgers Center for State Health Policy), Joe Brecht (Rutgers Center for State Health Policy), Joshua Lue (Rutgers Center for State Health Policy), David Prilutsky (Princeton University), and Manisha Agrawal (Rutgers Center for State Health Policy)

Call to Order/Opening Remarks

- R. Hammond called the meeting to order at 3:05 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 meeting time and location in the Newark Star Ledger and three websites (NJ. Com, NJ Press Association, and the iPHD website). Instructions for registration and login information were posted in the publications and the websites.

General Updates/Actions

Updates from the Chair

- In regard to the Eagleton Institute survey, R. Hammond recommended to the Board members whose initial appointment date could not be determined to enter the date they first attended a Governing Board meeting as their appointment date to the iPHD Governing Board.
- M. Koller introduced David Prilutsky, CSHP intern, who will be assisting with the iPHD annual report.
- R. Hammond provided an update on the NJDOH funding support. She said that \$400K for FY 2022-2023 will be added soon and an additional \$400K may be available for FY 2023-2024 to support fee waivers and other project activities.
- R. Hammond said that the May 8th Research Advisory Committee (RAC) orientation session was well attended, and the recording and slides were shared with the RAC members.

Meeting Minutes

- R. Hammond requested Board members review the April 14, 2023, Governing Board meeting minutes (approved by the Minutes Subcommittee on May 15, 2023).
- R. Jain made a motion to approve the April meeting minutes. G. Woods provided the second, and upon roll call, the minutes were approved unanimously.

Cycle I Progress

- M. Koller provided an update on the status of the pilot awards including:
 - Data Use Agreements (DUA's), IRB approval, and account set-up completed for three sites.
 - Assembly and transfer of datasets were completed for three approved projects. J. Nova said that 54 million records came in and the data team

conducted several processes to generate linkages. The dataset for the fourth approved project is ready and will be transferred after the DUA and IRB approvals are executed.

- o Memorial pilot projects – letters acknowledging 2 pilot projects in the memory of Colette and Ranjana were shared with their families.

RWJF's Health Data for Action (HD4A) program

- M. Koller provided an update on HD4A cycle. Some key points include:
 - o The call for proposals (CFP) will launch in late June. The CFP will provide a detailed overview of the iPHD Project and will include a link to iPHD Project video for applicants.
 - o The letter of intent (LOI) is competitive and will be due on August 1, 2023. Approved LOIs will be invited to submit a full proposal.
 - o Proposals will be reviewed by external RWJF reviewers. Reviews will be shared with the iPHD Governing Board in early 2024, and it will be the Board's decision to review and approve release of iPHD data.
 - o Final decision will be announced in June 2024. Funding is not restricted to NJ researchers and the data prep fees for up to 2 projects (\$50K per project) will be paid by RWJF to the iPHD Project.
 - o This may help promote iPHD nationally through the RWJF/AcademyHealth networks.

Cycle II Application Process

- M. Koller provided an update on the application process:
 - o Currently 75 members have agreed to participate on the RAC. Seven RAC members have a conflict as they submitted an application, and 67 members are available for Cycle II application review. The expanded RAC facilitated the reviewer assignment.
 - o CSHP hosted a virtual RAC orientation session in May, which was well attended. CSHP shared the slides and the recording with all RAC members.
 - o IPHD received 17 applications addressing diverse research priorities and from various entities including: 12 Rutgers, 2 Montclair, 1 NJIT, 1 Johns Hopkins in collaboration with NJ Attorney General's Office, and 1 Yale.
 - o Modifications to the review process based on Cycle I feedback include:

- Two RAC reviewers will be assigned to each application.
- Applications will be shared with NJDOH data stewards when there is 1) a technical question regarding the appropriateness of using the data to address the research question, or 2) a disagreement between the two reviews involving the use of the data.
- The GB Review Subcommittee will include 2 external reviewers.
- The application documents and RAC reviews will be shared with the GB Subcommittee. The GB Subcommittee will meet in August to discuss the proposal review and make recommendations, including proposal ranking, to the Governing Board. CSHP will assist in drafting the summary document (template shared in the meeting packet).
- The GB Subcommittee chair will lead the discussions during the full Board meeting in October and share the Subcommittee's recommendations and rankings for each application.
- The Governing Board will discuss the proposals and vote on the release of data and pilot funding, and fee waivers.

Discussion

Subcommittee Template

- M. Koller shared the subcommittee meeting draft template and said that CSHP will synthesize the discussions and complete this template after the meeting and subsequently share with the subcommittee members for feedback.
- J. Currie asked if the ranking of the proposals is based on the merit or on the type of request. Additionally, she inquired if the ranking should be done at the subcommittee meeting or at the full Board meeting.
- M. Koller said that ranking may provide some perspective to the members during the full Board meeting when selecting the projects. J. Currie suggested to rank the application on quality and reviewers should be agnostic of type of funding request.
- R. Jain asked if there is concern about the source of funding for self-pay applications. R. Hammond responded that it is important to know the funding source to determine the feasibility of the project. J. Currie said that it will be in the strengths and weaknesses. R. Jain said that requirements may change if there are other funding sources such as copyrights, publication requirements etc. J.

Currie said that we should require researchers to acknowledge iPHD in all their publications using the iPHD data.

- M. Koller said that researchers may have discretionary funding to pay for the data. R. Hammond responded that iPHD policies and procedures are non-negotiable. M. Koller agreed that we need to clarify the funding source for the self-pay applications.
- M. Koller said that CSHP is working on August dates for the subcommittee meeting. Similar to the last Cycle, CSHP will set up folders on Rutgers Box and share the access link with the subcommittee members.

Annual Report

- M. Koller shared the legislative requirement that iPHD is required to complete an annual report no later than 12 months following the receipt of data. The report will be shared with the Board, NJDOH, and Rutgers. Additionally, it will be posted on the website.
- R. Jain asked if there is a template. R. Hammond responded that there is no standard template, and the legislation outlined a list of items for inclusion in the report. The annual report will include a list of Cycle I projects, Cycle II applications, and a list of priorities for the coming year. M. Koller added that grantee reports and other project deliverables will be included in the later years.

Planning for 2024 Cycles

- M. Koller shared a list of additional datasets of interest for future iPHD cycles. R. Hammond introduced Sharon Cooley, Pregnancy Risk Assessment Monitoring System (PRAMS) data steward, to the Board.
- M. Koller said that CSHP will initiate discussions with Medicaid and NJDOH for the 2 approved datasets. For Medicaid, it may take more than 1 year for data transfer. R. Hammond suggested including the Medicaid privacy officer in the legal subcommittee.
- R. Hammond said the cancer registry is primarily for research, and PRAMS is important for maternal and infant health priority area. She added that Substance Abuse Monitoring System (SAMS) is subject to 42 CFR Part 2 confidentiality agreements. However, there are specific research provisions under Subpart D.
- R. Hammond said that NJDOH datasets will be reviewed by the legal subcommittee and will be added as attachments to the existing DUA. For DHS

datasets, currently there is no existing DUA and the process needs to be initiated for any DHS data transfer.

- M. Koller asked if a vote is needed for endorsing datasets. R. Hammond requested Board members to approve the datasets if CSHP is comfortable with moving forward and there are no other questions/concerns.
 - J. Currie made a motion to move forward with all 4 datasets (i.e., Cancer Registry, PRAMS, SAMS, and incarceration data). R. Jain provided the second, and upon roll call, the four datasets were approved unanimously.
- R. Hammond said the legal subcommittee will be reconvened and will include appropriate representation for each dataset approved.
- M. Koller said that the goal is to make iPHD attractive with new datasets without compromising the quality. The plan going forward is to have 2-3 application cycles per year including 1-2 data-only cycles. She added that the fee schedule will be updated for 2024.
- M. Koller provided an update that the third-party risk assessment questionnaire for the Clinical Research Data Warehouse was approved by the Homeland Security.

R. Hammond indicated that executive session is 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 4:17 pm.

- G. Woods made a motion to adjourn the meeting.
- J. Currie offered a second.
- There was a unanimous vote to adjourn the open session of the meeting.