



# Integrated Population Health Data (iPHD) Project Governing Board Meeting Minutes April 9, 2021

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

*iPHD Governing Board meeting convened in compliance with the New Jersey Open Public Meetings Act. All participants attended the meeting virtually due to the Covid-19 pandemic restrictions.* 

#### **Board Members Present:**

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), 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), 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 Janet Currie ((joined 1:20pm) 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 (Division of Mental Health & Addiction Services), Tim Seplaki (NJ Department of Health), Darrin Goldman (NJ Department of Health), Christine Campbell (Office of Information Technology), Barbara Bolden (NJ Department of Health), Jody Ruiu (NJ Department of Health), Darrin Goldman (NJ Department of Health), Natassia Rozario (NJ Department of Health), Stephen Firsing (NJ Department of Health), Shelby Kehoe (Camden Coalition of Healthcare Providers), Eileen Troutman, (NJ Department of Health), Bhavani Sathya (NJ Department of Health), Jose Nova (Rutgers Center for State Health Policy), Oliver Lontok (Rutgers Center for State Health Policy), Jolene Chou (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 1:10 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 new iPHD website. Information regarding transition from an in-person to virtual meeting due to the Covid-19 pandemic was posted in the publications and on the iPHD website.

# **General Updates/Actions**

# Updates from the Chair

- R. Hammond mentioned that with the appointment of J. Currie and R. Bartolone, the Board is fully appointed. She recognized Katherine Kovacs, former project consultant at CSHP for her contributions to the iPHD implementation planning.
- R Hammond mentioned that public health emergency is still in place and as of April 19<sup>th</sup>, all adults 16 or older will be eligible for vaccination. She highlighted the resources/information available on the NJDOH COVID-19 Information Hub.
- R. Hammond said that MOA modification with CSHP is in the final stages and it will extend the MOA through June 30<sup>th</sup>.
- R. Hammond said that DOH is getting a lot of inquiries from researchers for the COVID (CDRSS) and the vaccination data. She mentioned the possibility of adding the vaccination data to iPHD. This will be discussed in the next Board meeting.

# Meeting Minutes

- R. Hammond requested board members review the January 8, 2021 Governing Board meeting minutes (approved by Minutes Subcommittee on February 19, 2021).
- R. Jain made a motion to approve the January meeting minutes. G. Woods provided the second and, upon roll call, the minutes were approved unanimously.

### Website launch

- R. Hammond mentioned that the website launch was timely and will serve as a primary mode of vehicle for disseminating information about the iPHD's launch. She inquired about posting the bylaws and the Data Use & Access and Acceptable Use Guidelines policies on the website.
- M. Koller responded that plan is to post the bylaws and the project charter. The data use polices will be not posted on the website for security purposes.
- R. Hammond asked to ensure that GB members have access to all the documents.
- M. Koller said that the plan is to review the Data Use and Access and Acceptable Use Guideline documents and make sure they are consistent with recent implementation decisions. The revised document will be shared with the Board before the next meeting.

# Research Advisory Committee (RAC) invitations

- M. Koller said that the draft letter will be shared with R. Hammond for her review. Invitation will come from J. Cantor and R. Hammond. She added that the invitation letter will be sent in the next two weeks.
- M. Koller mentioned that the RAC list is broader than outlined in the policy documents. There was earlier discussion about extending the invitation to the out of state reviewers.
- R. Jain mentioned that several examples were discussed and it is good to have out of state reviewers. R. Hammond added that it is valuable to have a mix of instate and out of state reviewers, specifically for conflict of interest situations.

### Discussion

# Request for Applications

Letter of Intent (LOI)

- M. Koller mentioned that the consensus was not to use a tiered approach and simultaneously accept applications for both funding requests and data only.
- M. Koller said that with the tiered approach, LOI was made optional. If we accept all applications from the date of launch, then requiring an LOI will assist in resource planning.
- J. Currie said that it is good idea to make LOI mandatory and make the process consistent for both funding and data only applications. R. Jain added that it will

also provide good information on current research interests. R. Hammond also suggested making it mandatory.

- Pilot Funding Eligibility
  - M. Koller asked if collaboration with a non-NJ researchers was allowed for pilot projects funding.
  - E. Litten said that it is important to allow collaboration. This will increase the visibility for the iPHD beyond NJ.
  - J. Currie asked if there is a rationale for limiting it to NJ researchers. Most states make their data available to all researchers.
  - R. Jain said that cross-institution collaboration is very important. Make the language specific that prime recipient is a NJ institution.
- Eligibility for Fee Waivers
  - M. Koller asked about the criteria and eligibility for waiving fees for data only applications.
  - J. Currie said that it seems justified to provide waivers to NJ institutions but it should be need based. She suggested using a different fee schedule for junior and senior researchers.
  - J. Cantor said that we should consider merit of application for fee waivers. He added junior researchers could be given a subsidy. iPHD will follow NIH fee schedule.
  - R. Hammond mentioned that the final goal of iPHD is to be become selfsustaining and fees will cover the administrative costs.
- Application Cycle
  - M. Koller asked about the number of cycles for accepting applications. Is quarterly cycle a good option?
  - R. Jain said that proposals generally follow a seasonal pattern. It depends on CSHP resources. Maybe twice a year??
  - M. Koller said that we are trying to be responsive to the needs of the state as a lot of research will focus on COVID and vaccination data. CSHP will be hiring a data analyst to support the iPHD.
  - R. Hammond suggested, per Rutgers CSHP resources, to start with a quarterly cycle and adjust as needed.
- Eligibility for Applications Outside of the Approved Research Priorities

- M. Koller asked for input on the eligibility criteria for proposals that fall outside of the approved research priority.
- R. Hammond said that iPHD will be a valuable resource in the future. Projects coming to DOH may transition to iPHD and no complete application should be turned down prior to the Governing Board meeting. All applications with merit could be discussed in a Board meeting. If needed, Board may decide to expand/add new research priorities.
- R. Jain said that research priorities are broad so that should accommodate a wide range of proposals.
- E. Litten said we could require reference to the research priority being addressed in the LOI.
- M. Koller summarized the discussion that all applications will be evaluated based on the approved research priorities. For application that fall outside of the approved priorities, applications with merit will be shared with the Board. The Board can then decide whether to approve based on the quality of the proposed study.

# Checklist

- M. Koller asked if both funding and data only applications will be discussed in the open public session.
- R. Hammond said that all applications will be discussed in the open public session as there are limited exceptions to meeting in closed session under the Open Public Meetings Act. She suggested to confirm with M. McNally in Executive Session.

# Data Request Form

- M. Koller asked if iPHD will release single datasets. It will require resource planning and it was not the intent and original purpose of iPHD.
- R. Hammond responded that release of single datasets should be allowed. From a privacy perspective, iPHD will be only releasing limited or de-identified dataset.
- J. Cantor said that data coming to iPHD will be enhanced for research purposes, as even as a single data set, it will have value.
- J. Currie said that if researchers are linking datasets to other data, it is important to have proper safeguards in place to prevent reidentification.

- R. Jain added that data provenance is an issue and researchers need to have a proper data management plan.
- R. Hammond asked if researchers will receive the data or they will login to a server and download the data file.
- M. Koller responded that initial plan is to send the data files to the researchers. There are different costs involved. Server login will likely be available in the next phase. She added that strong DUAs and checks and balances will be in place before and after data transfer. Researchers will be required to submit a data management plan for monitoring policies and practices.

# Scoring Sheet

- J. Cantor said that the scoring sheet is modeled on the NIH process. Each RAC member will review the application and complete the scoring sheet.
- J. Currie agreed that it was good to use the NIH format. Problem is with the "innovation" category. She asked, if someone wants to do a replication study, how it will be scored on innovation. She suggested to wrap it under scientific merit so as not to disadvantage a strong project that is replicating another study.
- R. Jain suggested to broaden "innovation" to include new tools, methodologies etc. Modeling is used for a lot of analyses and researchers may use novel techniques.
- R. Hammond asked if the same scoring sheet will be used for both funded and data only projects.
- J. Cantor said that for data only projects, there may be less need to provide a ranking to the proposal as there will be no limit to the number of data sets that can be provided. The only consideration would be the potential delays that would be experienced if there were a very high number of qualified applications.

# Data Security Plan

- R. Hammond said that researchers need to have a proper data security plan implemented by their privacy officer and chief information office and comply with the guidelines in the DUA.
- J. Currie said that for IRB approval, researchers need to provide a detailed plan to the IRB, report any breach and renew the approval every year.
- R. Hammond asked if attestation should be requested for the data security plan.
- J. Currie said that most cases may not give useful information. However, it is good to ask.
- J. Cantor suggested mirroring protection of human rights section from NIH. It is not part of the scoring sheet-mainly yes/no question.

The open session of the Governing Board meeting was adjourned to executive session at 2:37 pm.

- J. Currie made a motion to adjourn.
- G. Woods offered a second.
- Unanimous vote to adjourn the open session.

Executive session was concluded at 2:53 pm with an immediate vote taken to adjourn the meeting.

- K. Noonan made a motion to adjourn.
- J. Currie offered a second.
- Unanimous vote to adjourn the meeting.