



# Integrated Population Health Data (iPHD) Project Governing Board Meeting Minutes November 20, 2020

### 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:**

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), Dr. 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), Michele Norin (Ex officio, Chief Information Officer- Rutgers University), Robert J. Bartolone (Designee for the State Treasurer, Chief Accountability Officer, NJ Department of the Treasury), 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 (Division of Mental Health & Addiction Services), Tim Seplaki (NJ Department of Health), Darrin Goldman (NJ Department of Health), Jon Tew (Camden Coalition of Healthcare Providers), Yannai Kranzler (NJ Department of Health), Christine Campbell (Office of Information Technology), Jose Nova (Rutgers Center for State Health Policy), Oliver Lontok (Rutgers Center for State Health Policy), Jolene Chou (Rutgers Center for State Health Policy).

# **Call to Order/Opening Remarks**

- J. Cantor chaired the meeting in the absence of R. Hammond and called the meeting to order at 1:05 pm with a quorum present.
- J. Cantor 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 (CSHP) 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 CSHP website.

# **General Updates/Actions**

Updates from the Chair

- J. Cantor welcomed R. Bartolone and J. Currie to their first Governing Board meeting.
- J. Cantor mentioned additional \$400,000 in funding from New Jersey Department of Health (NJDOH) to support iPHD implementation activities over the next year. Additionally, CSHP will carry over the remaining funds from the current budget for the coming year.
- M. Koller mentioned that K. Kovacs is stepping back from her consulting position to pursue another opportunity. CSHP is assessing staff needs to fill potential resource gaps.

#### **Meeting Minutes**

- J. Cantor requested board members review the August 21, 2020 Governing Board meeting minutes (approved by Minutes Subcommittee on September 18, 2020).
- K. Noonan made a motion to approve the May meeting minutes. E. Litten
  provided the second and, upon roll call, the minutes were approved
  unanimously. M. Norin, R. Bartolone and J. Currie abstained from voting as they
  were not present at the last meeting.

## Subcommittee Updates

M. Koller provided the subcommittee updates. There were no subcommittee meetings since the last Governing Board meeting in August. However, work continued involving members in smaller groups as needed.

- Technical: Tom Regan, Director of IT for Rutgers Institute for Health, is working
  with Rutgers IT on refining the iPHD policies, and documenting all changes made
  to the IFH environment. Rutgers IFH/CSHP met with J. Pullen, Cybersecurity
  Analyst at New Jersey Office of Homeland Security and Preparedness, last week.
  IFH/CSHP is in the process of completing the State of NJ Security Due Diligence
  (SDD) third-party security information questionnaire.
- **Legal:** J. Chou and K. Kovacs completed standardization of the data privacy memos. They will be shared with the appropriate data stewards, if requested, to facilitate data transfer.
- Communications: Progress on the website has continued. Zivtech resumed
  working on final testing and deployment of the website. The planned period for a
  soft launch will be early next year.

## Meeting Schedule for 2021

J. Cantor mentioned that the Governing Board meetings will continue on a quarterly schedule. The first meeting is scheduled for January 8, 2021. All meetings will be virtual until further notice.

## Discussion

### Fourth Research Priority

- J. Cantor mentioned that the fourth research priority was approved in the last Governing Board meeting. A small sub-committee worked on drafting a description for this priority. The description of the priority was approved by K. Noonan, E. Litten and R. Jain on September 2, 2020 via email communication.
- J. Cantor requested members make a motion to approve the description. R. Jain made a motion, G. Woods provided the second and, upon roll call, the description was approved unanimously by the full Governing Board.
- J. Cantor said that the work of COVID-19 and other Public Health Emergency subcommittee is completed and it seems appropriate to disband the subcommittee.
- M. Koller added that plan is to create a data working group including data stewards and other experts outside the Governing Board to advance this research priority.

 R. Jain made a motion, M. Norin provided the second and, upon roll call, the motion to disband the COVID-19 and other Public Health Emergency subcommittee was approved unanimously.

# **Pilot Application**

- J. Cantor mentioned availability of the resources in the budget to support four pilot applications (\$30K-\$40K) for initial iPHD data. In addition to the funding, the application fee will be waived for the pilot applications.
- J. Currie asked if researchers will be allowed to apply for only data (if they are not looking for funding).
- J. Cantor said that plan is to sequentially implement. First will be pilot projects followed by unfunded projects. The pilot proposals will be reviewed for compliance, scientific rigor and alignment with research priorities.
- J. Currie asked for the reasoning for sequential implementation. She expressed that we should maximize impact by allowing applications for both funding and data at initial launch.
- J. Cantor responded that the plan was to stagger the initial workload and make sure that the pilot funding was addressed first. Preliminary plan was to have a single deadline for pilot applications and four deadlines for non-funded applications (or may be on a rolling basis).
- G. Woods said that there are three potential outcomes: (1) approved for both funding and data, (2) approved for data without funding, and (3) not approved.
- R. Jain suggested post-pilot application requirements for researchers applying for data to make it easy for reviewers:
  - O What previous research this builds upon?
  - O What future possible research this will lead to?
  - List the unique contributions of your research.
  - Study limitations.
- J. Cantor said that more weight will be given to applications that will build new knowledge for state policies.
- J. Currie asked if the researchers will be required to share the code for any novel contributions so that it can be replicated.
- J. Cantor responded that if we make it a requirement, it should be added to the policies.

- E. Litten asked if this will be self-limiting. Will there be reluctance from researchers because of the requirement?
- J. Currie responded that researchers are reluctant to share data but less reluctant to share code. Some peer review journals now require researchers to share code.
- E. Litten suggested framing it as an expectation rather than a requirement.
- R. Jain said that if the application is novel there will be more reluctance to share the code.
- E. Litten suggested to not make it a requirement but promote sharing of code. Researchers should provide reasons If they are not sharing.
- M. Koller mentioned that any obligation in exchange for using the data would need to be addressed in the DUA.
- G. Woods asked if all data linking will be completed at CSHP and only deidentified data will be shared.
- J. Nova confirmed that all linkage will be completed by CSHP and researchers will receive a limited dataset. Therefore, it will be unlikely that researchers will be in the position of contributing any linkage code to the iPHD.
- J. Cantor said that the expectation for any sharing any science, e.g., list of measures, should be discussed further with the Board, including whether to include such a requirement in the pilot application.
- J. Cantor responded that transparency is important and will try to strike a balance. He requested Board members to send comments on the pilot application.

# Research Advisory Committee (RAC) Recommendations

- In reviewing the draft list of RAC members, J. Cantor mentioned that the RAC will review and make recommendations to the Governing Board for approval. Plan is to mirror the NIH Study Section procedures.
- Both K. Noonan and R. Jain said that the list looks like a good mix of experts.
- J. Currie asked if it was intentional to not include experts from Rutgers/Princeton University.
- J. Cantor responded that this is still a work in progress. No intention of excluding Rutgers/Princeton University experts. Tried to broaden beyond Rutgers.
- J. Currie said that she will follow up with some additional technical and subject matter experts.

- G. Wood suggested to include someone from Medicaid as Medicaid data will be added in the future.
- E. Litten suggested adding someone on bio-ethical issues.
- J. Cantor said we need to broaden the pool to maintain flexibility and go beyond three reviewers if the topic is complex.
- J. Currie asked if there is a procedure in place for instances when reviewers don't provide a review on time.
- J. Cantor responded that the plan is to assign three or more reviewers to each application. The reviewers will be paid consistent with NIH study section policies.
- M. Koller said that we will add the recommendations from the Board to the list and share it with R. Hammond. The updated list will be shared before the January Governing Board meeting.

## Website deployment

- M. Koller mentioned that Zivtech is engaged again and is working on finalizing small updates to the website. "Soft launch" of website will be in February. Final deployment will be early summer.
- M. Koller will share the website link with the Board members for their review.
- J. Cantor mentioned that already inquiries are coming in. The soft launch will allow us to provide a project overview to interested parties.

# Timeline for Launch

- J. Cantor said that the DUA is under review at AG's office. Timing of the launch is dependent on DUA approval. Ongoing discussions with data stewards for transferring data with identifiers.
- The MOA between Rutgers and the Governing Board is also under review at AG's office with expected completion by the end of 2020.
- J. Cantor added that as soon as the DUA is signed, CSHP will start bringing in the data. However, no limited data sets can be shared with researchers until there is an MOA indemnifying the Governing Board and an executed DUA between Rutgers and the researchers.

The open session of the Governing Board meeting was adjourned to executive session at 2:26 pm.

- G. Woods made a motion to convene executive session.
- E. Litten offered a second.
- Unanimous vote to go into executive session.