





# Integrated Population Health Data (iPHD) Project Governing Board (GB) Meeting Minutes October 13, 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), 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 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), Maria Baron (NJ Department of Health), Darrin Goldman (NJ Department of Health), Bretta Jacquemin (NJ Department of Health), Stella Tsai (NJ Department of Health), Tim Seplaki (NJ Department of Health), Aaron Rosenbaum (NJ Department of Health), Pamela Lilleston (NJ Department of Children & Families), Jose Nova (Rutgers Center for State Health Policy), Kate Scotto (Rutgers Center for State Health Policy), Joshua Lue (Rutgers Center for State Health Policy),

Oliver Lontok (Rutgers Center for State Health Policy), Joe 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 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 the 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

- R. Hammond informed the Board that DOH has a new Acting Commissioner, Dr. Kaitlan Baston.
- R. Hammond said the DOH will soon modify the MOA for an additional \$400K in funding for FY 2023 and another \$400K in funding for FY 2024. This additional funding will be used to support future fee waivers and potential additional project deliverables.
- R. Hammond said that the DOH will also amend the DUA between DOH and Rutgers to add the DOH datasets (PRAMS, COVID-19 vaccine data) approved by the Board. This will allow the transfer of these two datasets to iPHD.

#### Meeting Minutes

- R. Hammond requested Board members review the June 9, 2023, Governing Board meeting minutes (approved by the Minutes Subcommittee on July 20, 2023).
- R. Jain made a motion to approve the June meeting minutes. K. Noonan provided the second and, upon roll call, the minutes were approved unanimously.

#### EMS Data Transfer

• J. Nova said that CSHP received the EMS data and the team is now organizing, cleaning, validating and doing test linkages with the data. CSHP team thanked T. Seplaki for facilitating discussions with the data vendor.

## RWJF Health Data for Action (HD4A)

- M. Koller shared that the HD4A program received 20 brief proposals requesting iPHD data. The proposals will be reviewed by RWJF and Academy Health reviewers and the approved proposals will be invited to submit a full proposal. We anticipate that two proposals could be funded. A diverse group of researchers, including both NJ-based and out of state organizations have applied, enhancing iPHD's national visibility and extending its impact in the state.
- J. Cantor added that CSHP is reviewing applications for fit and purpose of the iPHD, and alignment with the research priorities. The initial review will be shared with Academy Health. After the applications are selected for funding by RWJF/Academy Health, they will be brought to the Board for discussion and approval.

# Cycle I Additional Data Request

- M. Koller presented a grantee's request for additional data years and outlined several considerations that this request raises for the Board:
  - The additional data years are not included in the application approved by the Board.
  - Fees apply for additional data years, and consideration must be given to how the fees for processing additional data years is accounted for.
    - Raises the question of developing iPHD guidelines for future project enhancement requests. J. Currie said that additional years of data may raise a confidentiality issue as it will be easier to identify people if you follow them over time. It is important to get an updated IRB approval before additional data is transferred. J. Cantor agreed and said that would be the first step. R. Jain said that this also raises questions about additional responsibilities for researchers for handling data. E. Litten also agreed with the concerns raised.
    - Concerning the question on setting boundaries for additional data requests, R. Jain proposed either implementing a time-bound or volume-bound approach. Failure to do so may result in open-ended proposals and further requests for additional data years from researchers. J. Cantor mentioned the obligation for iPHD to charge fees for additional requests. R. Hammond questioned the fee, and J. Cantor explained that CSHP would ask for a formal request for additional data years from the grantee, subject to Board review at

the next meeting. The Board will then decide on the fee waiver based on available resources for the data processing fee. R. Hammond agreed that the matter should be returned to the Board for approval of any data transfer and discussions on fee costs. She added that this will require modifications to the current DUA between the researcher and Rutgers. J. Cantor highlighted the need for clarification on the fee structure for additional requests. He indicated that there is a higher fee for initial linkage and lower costs for additional data years. The data team will assess the effort required for processing additional data years and present their recommendation to the Board.

 M. Koller said that J. Nova has been providing guidance and technical assistance to the grantees. She acknowledged DOH data stewards for their support.

#### Discussion

## Cycle II Proposals

- M. Koller provided an overview of the review process.
  - iPHD received 17 applications for this cycle.
  - CSHP completed the first review of all applications for completeness and compliance.
  - Applications were assigned to two Research Advisory Committee (RAC) subject matter experts.
  - The GB Subcommittee (comprised of three Board members and two external reviewers), reviewed applications and met to discuss application strengths and weaknesses, RAC reviews, and made recommendations for the Board to consider.
- R. Hammond requested all non-Board members attending to mute themselves until the public comments section of the meeting.
- R. Hammond requested the Board members with conflict of interest to recuse themselves from that proposal discussion. She instructed them to stay in the virtual room, turn off their camera, and mute themselves for that portion of the meeting. She added that they will be called back into the virtual meeting for discussion of subsequent agenda items. She mentioned the recusals listed below:

- J. Cantor (non-voting member) and E. Litten will recuse from all proposals,
   R. Jain will recuse from the Montclair proposals, and F. Baker will recuse from the Office of Attorney General's proposal.
- R. Hammond suggested that K. Noonan will report on the subcommittee recommendations and the Board members will vote on data release for each proposal. She added that the Board needs to develop some criteria for selecting proposals for funding. iPHD will fund up to two pilot projects and waive data fees for up to two approved proposals in this cycle. There will be a roll call vote for each proposal for documentation.
- R. Hammond requested K. Noonan to go through each application and share the subcommittee's recommendations. K. Noonan shared a few initial thoughts on the review process.
  - The goal of the sub-committee was to synthesize reviews from the external RAC reviewers and make recommendations to the Governing Board for data release. The sub-committee did not rank the proposals as it was decided that funding criteria needed to be established and that was under the purview of the Governing Board.
  - The subcommittee also tried to harmonize the reviews in instances when there was disagreement between reviewers. The subcommittee played the role of "umpire" and worked with the two external reviewers to help with the process.
  - The summary sheet includes 6 projects highlighted in light green for which there was consensus from the subcommittee that data should be released. These were projects deemed: 1) to align with 1 or more of the research priorities, 2) be grounded in good science, 3) be well written, and 4) present a feasible analytic plan.
  - K. Noonan said that the subcommittee thoroughly reviewed each proposal as well as the individual RAC reviews and provided a summary of the six projects approved by the subcommittee. R. Jain said that all subcommittee members agreed on these six for approval and didn't find any concerns for data release for these proposals. J. Currie said that compared to the first round, RAC reviews were more useful and aligned. M. Koller added that the subcommittee members were blinded from the funding request, so discussions were focused on the merits of the proposals.
  - R. Hammond outlined the process for considering the six proposals recommended by the subcommittee: The Board is expected to secure a motion and a second for each proposal endorsed by the subcommittee, express any comments they may have, and then proceed with a vote or any

ensuing discussions. It was noted that the motion could be adjusted if necessary.

Proposal information		Motion	Second	Voting for Data Release			
Title	PI/Institution	Wiotion	Second	Yes	No	Recused	
Opioid-related overdose and mortality among pregnant and postpartum individuals in New Jersey	Elizabeth Suarez, PhD Instructor Rutgers Center for Pharmacoepidemiology and Treatment Science	J. Currie	R. Jain	R. Hammond K. Noonan J. Currie G. Woods R. Jain F. Baker	0	E. Litten	
Impact of "Opt for Help and Hope" on drug overdose deaths among NJ criminal defendants, 2020-2025	Kelly Levy, JD DAG, Acting Director New Jersey Department of Law & Public Safety, New Jersey Office of the Attorney General	J. Currie	G. Woods	R. Hammond K. Noonan J. Currie G. Woods R. Jain	0	E. Litten F. Baker	
The impact of severe maternal morbidity (SMM) on mother and children's hospitalization/ED use one year after birth	Sze Yan Liu, PhD, MPH Assistant Professor Montclair State University	K. Noonan	F. Baker	R. Hammond K. Noonan J. Currie G. Woods F. Baker	0	E. Litten R. Jain	
Integrating EMS Data with hospital, mortality, and geographic data to identify opioid overdose patterns across settings in New Jersey communities	Stephen Crystal, PhD Distinguished Research Professor Rutgers Center for Health Services Research	K. Noonan	J. Currie	R. Hammond K. Noonan J. Currie G. Woods R. Jain F. Baker	0	E. Litten	
Linked administrative data as surveillance of overdose crisis and drug-related adverse health events in New Jersey	Grant Victor, PhD Assistant Professor Rutgers School of Social Work	R. Jain	J. Currie	R. Hammond K. Noonan J. Currie G. Woods R. Jain F. Baker	0	E. Litten	
Prophylactic salpingectomy use at the time of postpartum sterilization	Xiao Xu, PhD Associate Professor Yale University School of Medicine	R. Jain	J. Currie	R. Hammond K. Noonan J. Currie G. Woods R. Jain F. Baker	0	E. Litten	

• K. Noonan informed the Board that the subcommittee recommended additional review and discussion for four proposals highlighted in yellow. The primary reasons were methodological weaknesses, and the subcommittee leaned towards a "no" for these proposals. She invited the Board to decide whether they wanted further discussion on these four proposals.

- G. Woods commented that data should be made available to proposals with some methodological weaknesses. J. Currie emphasized that there is always some possibility, even if small, of privacy violation with every data release. Proposals must meet a certain threshold of scientific merit before they are deemed worthwhile to accept any associated risk. The reason for the "maybe" category for these proposals was a combination of methodological weaknesses and concerns about reidentification. R. Jain added that in addition to these issues, conclusions drawn from a poorly designed study may not be scientifically grounded and have implications. R. Hammond agreed and said that one of the goals of the iPHD is to inform future programs and for that, we need reliable information.
- K. Noonan said that iPHD needs to have some standards for the review process. G. Woods suggested an alternative framework that considers: (a) is this a cogently defined research project that has some value? (b) will this proposal likely generate meaningful results? He said if this information is sufficiently persuasive, then the Board should consider for data release.
- J. Cantor made a general comment that it takes a great deal of methodological expertise to conduct causal inference research. He added that descriptive studies, e.g., the geographic distribution of a problem that could influence the distribution of resources to address the problem, are valuable for supporting planning. He encouraged the Board to approve descriptive studies if confidentiality or other concerns are not an issue. Lastly, the applicants who weren't chosen will receive RAC comments and can certainly resubmit their proposals in the upcoming cycle.
- K. Noonan asked if CSHP can process the data requests if more proposals are approved. M. Koller responded that it will only impact the timing of the data transfer to the approved projects and that should not be the driver for approving applications. J. Nova agreed and said that CSHP is planning data linkage for all data sources for all the years and the only implication is that volume may impact speed with which the limited data sets can be released.
- K. Noonan suggested taking a vote on the four "maybe" proposals and the decision on data release will be based on the majority votes. K. Noonan made a motion to take a roll call vote for each of the four proposals in the "maybe" category on data release. G. Woods offered a second and the motion was approved unanimously.

Proposal information		Motion	Second	Voting for Data Release		
Title	PI/Institution	IVIOLIOII	Jecona	Yes	No	Recused
A case-control study to understand the clinical correlates and relative risk of suicide and kidney disease in New Jersey	Elissa Kozlov, PhD Assistant Professor Rutgers School of Public Health	K. Noonan	G. Woods	0	R. Hammond K. Noonan J. Currie G. Woods R. Jain F. Baker	E. Litten
Using GIS to connect maternal morbidity, social determinants of health, and environmental characteristics to guide the development of tailored perinatal interventions to improve maternal health outcomes in NJ	Patricia D. Suplee, PhD, RNC-OB, FAAN Associate Professor Rutgers School of Nursing, Camden			0	R. Hammond K. Noonan J. Currie G. Woods R. Jain F. Baker	E. Litten
Neighborhood environmental stressors and maternal and perinatal outcomes in New Jersey	Stephanie Shiau, PhD, MPH Assistant Professor Rutgers School of Public Health			G. Woods	R. Hammond K. Noonan J. Currie R. Jain F. Baker	E. Litten
Identifying Neonatal Opioid Withdrawal Syndrome (NOWS) treatment pathways and care outcomes among infants in New Jersey	Yu-Lun Chen, PhD, OTR Associate Research Scientist Kessler Foundation			K. Noonan G. Woods	R. Hammond J. Currie R. Jain F. Baker	E. Litten

- R. Hammond said that based on the majority votes, data will not be released to the four applications listed above.
- K. Noonan proposed to have one vote for the proposals in the "do not release" category. She added that this was a strong "no" from the members of the Subcommittee. R. Hammond said that R. Jain has to recuse herself if this is done as a block vote. She asked the Board members if they had any concerns with the block vote for the proposals marked "do not release.".
  - R. Hammond requested the Board members to make a motion for a block vote for these seven proposals which were not recommended for data release. G. Woods made a motion and J. Currie offered a second and, upon roll call, the motion carried. R. Hammond listed the applications that will be voted on under block vote. E. Litten and R. Jain were recused from voting.

Proposal information		Motion	Second	Voting for Data Release		
Title	PI/Institution	IVIOLIOII	Second	Yes	No	Recused
Equity motivated modeling for pandemics: integrating local sociodemographic data with SIR models and Markov Chains for COVID-19	Benedetto Piccoli, PhD Joseph and Loretta Lopez Chair Professor of Mathematics Rutgers University, Camden	G. Woods	J. Currie	0	R. Hammond K. Noonan J. Currie G. Woods F. Baker	E. Litten R. Jain
The Incidence, outcomes, and risk factors associated with opioid co-use with other Substances in New Jersey	Christine Ramdin, PhD RBHS Instructor Rutgers New Jersey Medical School					
Association of school climate and neighborhood environment with youth suicidal behavior and suicide	Christina Kang-Yi, Ph.D. Associate Professor Rutgers School of Health Professions					
Investigating disparities in health outcomes from micromobility-related injuries	Hannah Younes, PhD Post-Doctoral Research Associate Rutgers University Edward J. Bloustein School of Planning & Public Policy					
Rural health in New Jersey: social determinants of health, barriers, and access	Devon Ziminski, MS Senior Project Administrator Rutgers University, Camden					
Needs and preliminary assessment of hospital-based violence intervention programs in New Jersey	Sheetal Ranjan, PhD Professor Montclair State University					
Socioeconomic vulnerability, environmental injustice and maternal and infant health outcome disparity under the threats of severe storms and flooding in New Jersey	Zeyuan Qiu, Ph.D. Professor New Jersey Institute of Technology					

R. Hammond said that the Board members voted unanimously for not releasing data for the seven proposals listed above. Due to time limitations, the discussion on selecting applications for pilot funding/fee waiver/self-pay was deferred to the December 8<sup>th</sup> meeting. K. Noonan asked if the voting could be done by email.
 R. Hammond responded that the voting has to be recorded in an open public meeting. She will confirm the process with M. McNally. J. Cantor said that this will

require some discussion, so it is better to meet to decide on funding for six approved proposals. CSHP will work with Board members to schedule a meeting before December 8<sup>th</sup>.

• Recused Board members were asked to return and turn on their video and audio.

# R. Hammond indicated that the executive session is not needed. The open session of the Governing Board meeting was adjourned at 4:35 pm.

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