Integrated Population Health Data (iPHD) Project
Governing Board (GB) Meeting Minutes
September 25, 2026

1:30 PM-3:00 PM EST

The iPHD Governing Board meeting convened in compliance with the New Jersey Open Public Meetings Act. 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), Lindsay Shea (Ex officio/ Nonvoting, Director of Rutgers Center for State Health Policy), Greg Woods (Ex officio/Designee for the NJ Commissioner of Human Services, Assistant Commissioner and Division Director, 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), Janet Currie (Appointed- Human Subjects Research Expert, Professor of Economics and Policy Affairs, Emeritus, Princeton University), and Gina Quinn (Ex officio/Designee for the NJ State Treasurer, New Jersey Department of the Treasury)

Attendees:
Margaret Koller (Rutgers Center for State Health Policy), Mark McNally (NJ Office of the Attorney General), Jacqueline D'Alessandro (NJ Office of the Attorney General), Maria Baron (NJ Department of Health), Aras Islam (NJ Department of Health), Barbara Bolden (NJ Department of Health), Kara Unal (NJ Department of Health), Geeta Real (NJ Department of Health), Darrin Goldman (NJ Department of Health), Domenica Cevallos (NJ Department of Health), Bretta Jacquemin (NJ Department of Health), Michael Toto (NJ Department of Health), Li Kuang (NJ Department of Health), Yong Lee (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), Katherine Kovacs (Rutgers Center for State Health

Policy), Julien Rodriguez (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 1:32 pm with a quorum present.
- R. Hammond acknowledged that the meeting was held in compliance with the New Jersey Open Public Meetings Act. Notices were published in the Newark Star Ledger and posted on relevant websites with registration and login instructions.

General Updates

Administrative Updates

- R. Hammond extended a formal welcome to L. Shea and G. Quinn as they joined the Board. L. Shea has been appointed as the new Director of the Center, succeeding J. Cantor. Furthermore, G. Quinn will take on the role of Designee for the New Jersey State Treasurer, taking over from D. Zeveloff.
- R. Hammond said that NJDOH is concluding its review of the iPHD annual report prepared by Rutgers and expressed hope that it will be published soon.

Meeting Minutes

- R. Hammond noted that the Meeting Minutes Subcommittee met on August 20, 2026, reviewed the July 24 meeting minutes, and approved them for publication on the iPHD website.
- E. Litten made a motion to approve the June meeting minutes. G. Woods seconded the motion, G. Quinn recused, and, upon roll call, the minutes were approved unanimously.

Applicant Survey

- M. Koller reminded the Board that iPHD previously conducted an applicant survey approximately two to three years ago to gather feedback from applicants and data recipients regarding their experiences with iPHD processes.
- K. Kovacs provided an overview of the survey design:
    - Respondents will include both approved and not approved applicants. The survey will have skip pattern for customizing questions for each group.
    - The survey will assess the following areas:
        - Interactions and communication with Rutgers iPHD staff.
        - Experience navigating and using the iPHD website.
        - The application and review process.

        - The data transfer process.
        - Data quality, documentation, and the overall utility of the data received.
    - The soft launch date for the survey is October 13, 2026, and it will remain open for 3 to 4 weeks. Results will be shared at the November Board meeting.
- K. Kovacs said that the questions are intended to gather actionable information for process improvement. M. Koller agreed, noting that the survey contributes to broader objectives, including demonstrating the impact of iPHD, planning for sustainability, shaping the agenda for an in-person research consortium scheduled for early March 2027, and identifying areas where further discussion and intervention may be helpful.

Discussion

Research Review Committee Process

- M. Koller presented an overview of the current application review workflow and the Research Review Committee (RRC) scoring framework. The RRC members assign scores ranging from 1 (strongest) to 4 (most problematic) for each domain and then provide an overall score and recommendation regarding data release.
- M. Koller proposed a few changes for rebalancing the review criteria to address the questions raised by the Board in the last meeting:
    - Adding risk assessment as a distinct decision-making factor and reporting risk separately (minimal, moderate, and high) to the Governing Board. This will require developing a formal definition of risk.
    - Placing greater emphasis on policy relevance, programmatic impacts and dissemination plans from the applications in the GB briefing materials. This may help documenting proposed impact that may further inform state decision-making.
    - Involving Data Stewards for application review when questions arise regarding data availability, feasibility of research and interpretation of findings.
    - Exploring targeted Requests for Applications (RFAs) based on agency-specific policy questions rather than relying entirely on investigator-initiated proposals. This may help inform new policies and program development.

Data Stewards Role in the Review Process

- M. Koller suggested leveraging expertise of Data Stewards for proposal review on need basis as an additional step.
    - She acknowledged M. Baron for this suggestion because there were questions about the availability of the datasets to support the research during the application review.

    - CSHP will share the RRC flagged applications with Data Stewards for additional clarification.
- G. Woods asked whether involving Data Stewards would slow the review process. M. Koller responded that this will be only on need basis and would not impact on the timeline.
- R. Hammond supported this approach and said that this would strengthen decision-making without materially delaying the review process.
- J. Currie asked whether all applications would be reviewed by Data Stewards or only those raising specific questions. M. Koller clarified that the Data Steward consultation would be triggered only when technical or data-use questions arise.

Fee Award Criteria Review

- M. Koller reviewed the current fee award criteria, which allows up to two awards of up to $25,000 per cycle to support approved projects. Three additional considerations were suggested:
    - Potential impact on New Jersey policy or population health.
    - Early-stage investigator status.
    - Applicant PI is an iPHD data contributor.
- E. Litten raised concerns that if the iPHD data contributor criterion is added, the agency representatives from contributing organizations on the Board might face conflicts of interest and need to recuse themselves when there is an application from their agency. She suggested separating funding discussions from data-release decisions. J. D'Alessandro advised that agency representatives could recuse themselves out of an abundance of caution.
- E. Litten stated that data release should be evaluated solely on project merits before financial considerations are introduced. She proposed that the fee award request be withheld from the Board until the decision regarding data release has been made. This approach would ensure that applications are evaluated solely on their merits for data release. R. Hammond and M. Koller agreed the change appeared feasible and would not significantly alter the workflow.
- With regards to adding policy relevance criterion, J. Currie said that by the time results are available, policy priorities may have changed. She suggested exploring ways to engage subject matter experts who already have expertise using iPHD data to answer more immediate policy questions. Additionally, it would be advantageous to evaluate their interest in serving as consultants to facilitate more responsive, real-time analyses that could inform the development of new policies.
- The Governing Board agreed to postpone the discussion of fee waiver criteria for a future meeting.

Rutgers Capacity and Application Volume

- M. Koller reviewed Rutgers' operational capacity and outlined a two-tier framework:
    - Tier 1: This tier involves iPHD-only or non-person-level linkages, which are considered relatively straightforward. The estimated capacity is 12 to 15 projects annually.
    - Tier 2: This tier consists of third-party person-level linkages that require external datasets and additional agreements. The estimated capacity for this tier is approximately four projects annually. While these projects provide significant value, they demand more staff time and extend release timelines from about 9 months to 12-15 months. As the complexity of applications increases, resource limitations may eventually affect turnaround times.
- R. Hammond suggested adding Rutgers capacity to the data release criterion, so it is officially considered during the application review. Additionally, she suggested managing demand proactively by including language in the RFA during specific application cycles rather than denying applications after submission.
- M. Koller agreed and said that this approach would manage expectations upfront rather than forcing the Governing Board to reject applications later.
- E. Litten supported this approach and recommended using clearer terminology than "person-level linkage" so applicants better understand eligibility requirements.
- J. Nova confirmed that capacity concerns are compounded because many previously approved projects remain active, creating ongoing administrative responsibilities. He agreed that temporarily limiting certain application types during high-capacity periods could help manage workload.
- R. Hammond asked whether Rutgers capacity should become an official criterion in data release decisions.
    - Moved by: E. Litten
    - Seconded by: J. Currie
    - Vote: The Governing Board unanimously approved the motion.

Privacy and Risk Considerations

- E. Litten asked whether Data Stewards should also assess privacy risks issues such as:
    - Small cell sizes
    - Re-identification risk
    - Unique data characteristics that could increase disclosure risk
- R. Hammond clarified that the proposed data steward review was intended to address feasibility questions:
    - Whether the dataset contains the required information

    - Whether the research question can be answered from the requested datasets
- R. Hammond asked if the RRC should assess risk. E. Litten responded that RRC may not have the necessary expertise to assess risks comprehensively.
- R. Hammond noted that all data releases inherently carry some degree of risk, even after de-identification requirements are met. She said that more clarity may be needed regarding how the RRC evaluates and communicates risk concerns.
- E. Litten suggested that if privacy or disclosure concerns arise, the RRC could flag them for further review rather than conducting a full risk assessment themselves. She added that increased use of linked datasets may elevate privacy concerns.
- M. Koller referenced a chat comment from K. Kovacs describing two primary categories of risk discussed by the RRC:
    - Risk of re-identification: possibility that released data could lead to identifying individuals.
    - Scientific or research Risk: risk that studies could generate misleading or inaccurate findings due to:
        - Weak research design
        - Inadequate methodology
        - Researcher qualifications or limitations
- M. Koller noted that while scientific risk exists in all research, peer review processes help mitigate some of those concerns. However, the Board decided to discuss the following questions at the next meeting:
    - Who should assess the data release risk?
    - Should privacy and privacy and scientific risks be evaluated separately?
- L. Shea raised an additional consideration based on experience with data linkages involving autism, disability, and other rare conditions. She asked whether established methodologies, including the Safe Harbor method and other data-processing approaches, could help address re-identification concerns.
- J. Nova explained that iPHD releases data to researchers only as either de-identified data or a limited data set. He also noted that iPHD has policies concerning cell size in research outputs. However, the risk may depend on how researchers eventually stratify, subset, or otherwise “cut” the data for their analyses.
- E. Litten asked if Data Stewards could address cell-size concerns. R. Hammond agreed that very small populations could raise both a privacy issue and a scientific/generalizability issue.

- M. Koller proposed developing a written strategy for Governing Board consideration at the next meeting. This strategy is intended to provide clarity on several key points:
    - When a data steward should be consulted.
    - What questions should be posed to the data steward.
    - Addressing concerns related to small-cell size and the potential for re-identification.
- R. Hammond supported that proposal and raised an additional question: Who should be responsible for evaluating the level of data-release risk? She questioned whether data risk should be a criterion for the Governing Board to consider, rather than something the Research Review Committee is expected to assess.
- E. Litten responded that even if the Governing Board ultimately makes the determination, it still needs access to the underlying facts and subject-matter expertise necessary to make an informed decision. R. Hammond agreed technical input should still be maintained even if responsibility for the ultimate risk determination sits with the Governing Board.
- R. Hammond opened the meeting for public comments and invited M. Baron to share her thoughts.

Public Comment from Data Steward

- M. Baron described situations in prior reviews where assumptions had been made about:
    - Availability of specific data elements
    - Population sizes
    - Denominator construction
    - Feasibility of answering research questions
- M. Baron stated that Data Stewards often have immediate access to factual information that can answer such questions. She suggested that data steward input could prevent:
    - Incorrect assumptions about data availability.
    - Rejection of valid proposals based on misunderstandings.
    - Unnecessary delays or debates during review.
- The Board agreed that Data Stewards should not review every application but should be consulted when specific technical questions arise about dataset contents, availability, and limitations. This should be viewed as a quality improvement strategy rather than an additional approval layer.

DCF IRB Requirements

- M. Koller explained that two approved DCF projects raised questions about whether DCF's internal Research Review Committee could satisfy iPHD IRB requirements. She added that DCF has a rigorous review process.
- M. Koller highlighted Section 7.23 of the recently approved Data Use and Access policy, which allows a contributing state agency to use iPHD data for analyses that are not intended to produce generalizable research. Instead, these analyses are conducted to enhance program performance and operations. DCF plans to evaluate its own programs rather than engage in research aimed at generating generalizable findings. M. Koller pointed out that this type of program evaluation is generally exempt from IRB review. Furthermore, the Board's approach could set a precedent for similar situations in the future.
- R. Hammond stated that if DCF's committee is making exemption determinations for non-human-subjects activities, the Board could accept that documentation. However, if a project qualifies as human subjects research, IRB approval would still be required.
- J. Currie agreed and noted that the Board should not suggest that an alternative process could substitute for IRB review when human subjects review is required.
- E. Litten recommended ensuring that if projects evolve into human-subjects research, DCF would be obligated to obtain IRB review. She emphasized the importance of protecting iPHD and suggested that responsibility remains with DCF for affirming that its activities are not research and do not involve human subjects.
- R. Hammond asked whether these protections should be incorporated into DUA. She suggested addressing circumstances in which a project evolves into research intended to contribute to generalizable knowledge or publication, in which case the project would need to proceed to an IRB. M. Koller agreed that the DUA would be the appropriate document for capturing such requirements.
- E. Litten noted that the existing agreement might already contain adequate protections but recommended reviewing it specifically to ensure that it addresses changes in the nature or scope of a project.
- R. Hammond stated that these issues may arise more frequently as additional agencies submit requests involving program evaluation and potentially public health surveillance. She recommended revisiting the matter at a future meeting after the current issue had progressed.
- M. Koller said that CSHP will reach out to DCF for additional clarification and provide an update to the Board.

Adjournment

R. Hammond indicated that the executive session is not needed. R. Hammond asked if anyone would like to make additional public comments. She added that each commentor has a maximum of three minutes to share their comments. There was no other public comment.

Motion to Adjourn

- **Moved by:** J. Currie
- **Seconded by:** E. Litten

Vote

The motion carried unanimously. The meeting adjourned at approximately 2:50 PM.

Action Items:

- Develop formal data risk framework and definitions.
- Draft proposal defining when and how Data Stewards will be consulted.
- Separate data-release and funding-review materials.
- Clarify DCF IRB/exemption documentation requirements.
- Revisit fee-waiver criteria in October meeting.