Integrated Population Health Data (iPHD) Project

Spring Virtual Update

April 30, 2025 | 2-3pm EDT

Integrated Population Health Data (iPHD) Spring 2025 Virtual Update

Welcome!

The webinar will begin shortly and will be recorded.

Attendees will join the session in listen-only mode.

Kindly submit any questions <u>using the Q/A box</u>.

Please also <u>complete the post-event survey</u>.

Thank you!

Welcome & Project Overview

Agenda

- **Welcome & Project Overview**
  - *Rachel Hammond, Chair, iPHD Governing Board*
- **iPHD Accomplishments to Date**
  - *Joel Cantor, Distinguished Professor & Director, Rutgers Center for State Health Policy*
- **iPHD Application Process Overview**
  - *Oliver Lontok, Senior Research Manager, Rutgers Center for State Health Policy*
- **iPHD Data Sets & Linkages**
  - *Jose Nova, Associate Director of Data & Analytics, Rutgers Center for State Health Policy*
- **Fee Schedule & Funding Opportunities**
  - *Kate Scotto, Associate Director of Research Administration, Rutgers Center for State Health Policy*
- **What's Next for iPHD**
  - *Margaret Koller, Executive Director, Rutgers Center for State Health Policy*
- **Q&A Session**

iPHD Project Law (P.L. 2015, c. 193)

Enacted Sept. 11, 2016

Purposes of the iPHD

- Improve **public health, safety, security and well-being** of NJ residents
- Improve **cost-efficiency of government assistance programs**
- Promote population health research by **NJ research organizations**

"In but not of" the **New Jersey Department of Health**

More details on the **iPHD website**: https://iphd.rutgers.edu/

Why Apply to the iPHD?

- Administrative data are much more impactful when linked across data sets than when they remain isolated from one another.

- Integrated data holds the power to inform pressing population health research.

- The iPHD provides the opportunity for pilot studies that can inform future proposal development.

- The Governing Board may grant data access fee waivers to researchers at New Jersey-based institutions to expand access to iPHD data.

iPHD Governing Board

Rachel Hammond Governing Board Chair Designee, NJ Commissioner of Health *Ex Officio*	**Joel C. Cantor, Sc.D.** Rutgers Center for State Health Policy *Ex Officio*, Non-voting	**Rashmi Jain, Ph.D**. Montclair State University Gubernatorial Appointment **Large Data Systems & Data Security Expert**
Greg Woods, MPA Designee, NJ Commissioner of Human Services *Ex Officio*	**Elizabeth G. Litten, J.D.** Fox Rothschild LLP Gubernatorial Appointment **Privacy & Security Expert**	*VACANT* Designee, NJ State Treasurer *Ex Officio*
Francis Baker, J.D. Designee, NJ Attorney General *Ex Officio*	**Michele L. Norin, M.Ed.** Rutgers University, Office of Information Technology *Ex Officio*	**Kathleen Noonan, J.D.** CEO, Camden Coalition of Healthcare Providers Senate President Appointment **Advocate on behalf of persons whose data may be in the iPHD**
Jane Currie, PhD Professor of Economics and Public Affairs, Princeton University **Expert in Human Subjects Research from a NJ Research University**	**Mark McNally, J.D.** Deputy Attorney General NJ Office of the Attorney General *Board Counsel*	

iPHD
NEW JERSEY

Our Work & Accomplishments to Date

Establishing iPHD Research Priorities

| Governing Board Approval March 2019 | Approval May 2020 | Approval Jan. 2024 |

Opioid Epidemic

Informing New Jersey's integrated approach to addressing the opioid epidemic

Maternal and Infant Health

Improving maternal and infant health

Social Determinants of Health

Assuring access to physical and behavioral health services and addressing social determinants of health

COVID-19 and Other Public Health Emergencies

Conducting analyses to support New Jersey's response to COVID-19 and other public health emergencies

High Value Care

Promoting equitable access to high-value health services

Narrative description of research priorities available at: https://iphd.rutgers.edu/research-priorities

Key Considerations for Granting Data Access

1. The project will **advance the purpose of the iPHD and address one or more of the research priorities**.

2. The principal investigator, collaborators, and other **researchers are well prepared by education and experience** to conduct the project.

3. The overall research **strategy and methodology are well-reasoned and appropriate** to accomplish the aims of the project.

4. The **scientific environment** in which the work will be done **is conducive to the successful completion of the project**.

iPHD Impact by the Numbers

80 million
Data records processed

20 million
Individuals' records linked

10+
Data sets in process for inclusion

26
Approved research projects

30+
Applicant institutions

500+
Mailing list contacts

200+
Average monthly website visitors

70+
Expert RAC members

$200K+
In fee waivers distributed

iPHD Impact in the Literature, Media

Rokicki, S. (2024). Perinatal Depression Associated with Increased Pediatric Emergency Department Use and Charges in the First Year of Life. Health Affairs, 43(4), 477-485.

Milbank Blog
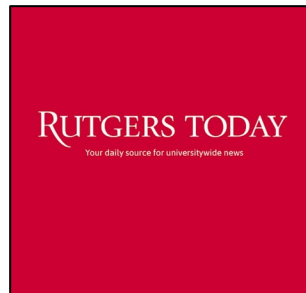
Rutgers Today

Healthcare Innovation

AJMC News

Healthtech Analytics

Selected Projects Approved for Data Access

Perinatal Depression and Emergency Department Visits in the Postpartum Period: A Quasi-Experimental Analysis

Prevalence of and Trends in Opioid and Cannabis Co-Use Among Inpatients in New Jersey

Effects of Legacy Pesticides on Maternal, Infant, and Child Health in New Jersey

Integrating EMS and Prison Release Data with Hospital, Mortality, and Geographic Data to Identify Opioid Overdose Patterns Across Settings in New Jersey Communities

Enhancing AgFF Injury Surveillance Using Big Data and Machine Learning

Application Process Overview

Who is Eligible to Apply for iPHD Data?

- Any qualified researcher whose proposal aligns with the approved purpose and priorities of the iPHD
  - Only New Jersey research institutions are eligible to apply for a waiver of data access fees
  - Data access fees apply to approved applications with the exception of funded fee-waivers
- Students are eligible with faculty supervision
- The iPHD Project seeks a diverse pool of applicants
- Formal application process
- Forms and guidance at https://iphd.rutgers.edu/iphd-application-review-process

How to Apply for iPHD Data Access

1. IPHD RELEASES A REQUEST FOR APPLICATIONS

iPHD will post a Request for Applications to open the application cycle - sharing it on the project's website, social media, and with our e-mailing list.

2. RESEARCHER SUBMITS LOI DURING APPLICATION CYCLE

A non-binding Letter of Intent (LOI) is required in order to submit a full application.

3. RESEARCHER SUBMITS APPLICATION

- Application & Data Request Form
- Research Abstract & Narrative
- Curricula Vitae of PI & All Other Investigators

Letter of Intent

Submit via email to
iphd@ifh.rutgers.edu

Full Application

Submit via the iPHD website
(iphd.rutgers.edu/iphd-application-review-process)

Submitting Your Application*

* Only accessible during announced application cycles

New Resources for Researchers – iphd.rutgers.edu

App Process Infographic & Sample Materials

Funding & Fee Schedule Page

iPHD Application Review Process

- **Research Advisory Committee (RAC) Review**
  - Panel of 75 subject matter, research, and data experts
  - Each application assigned to at least two members

- **Governing Board Subcommittee Review**
  - Panel of four members including two Governing Board and two external reviewers
  - Synthesize RAC feedback and make recommendations to the Governing Board for data release

- **Governing Board Determination**
  - Consider, but not bound by, RAC and Subcommittee recommendations
  - Applications deliberated in public session

iPHD Data Sets & Linkages

Data Sets Currently Available

Five initial NJ DOH Data Sets Approved by the Governing Board

NJ Birth Data	NJ Mortality Data	NJ Hospital Discharge Data	NJ CDRSS Data	NJ EMS Data
(2000-2021)	(2000-2021)	(2010-2022)	(2020-2022)	(2017-2022)

Please visit https://iphd.rutgers.edu/data for data dictionaries and available variables.

iPHD Value Added
- Create longitudinally linked data at the individual person level
- Prepare project-specific, de-identified and limited datasets for approved projects
- Provide limited technical assistance

Building Data Processing & Linkage Capacity

About 80 million records reviewed to date

- 2000-2021 – NJ Birth Data, 2.4M individuals/records

- 2000-2021 – NJ Mortality Data, 1.7M individuals/records

- 2010-2022 – NJ Hospital Discharge Data Collection System, 13.4M individuals / 59M records

- 2020-2022 – NJ CDRSS Data, Covid 19 PCR Positive, 2.3M individuals / 2.5M records

- 2017-2022 – NJ EMS, 7.7M individuals / 10M records

De-identified vs. Limited Data Sets

De-identified data: Section 164.514(b) of the HIPAA Privacy Rule provides the standard for de-identification of protected health information. De-identified datasets using the "Safe Harbor Method" **excludes** 18 specific identifiers of individuals or of their relatives, employers, or household members of the individual, as listed below:

1. Names	7. Device IDs & serial numbers	13. Biometric identifiers
2. Address, City, and ZIP	8. Email addresses	14. Health plan beneficiary IDs
3. All dates (except year)	9. Web URLs	15. Full face & comparable images
4. Telephone numbers	10. Social security numbers	16. Account numbers
5. Vehicle IDs & serial numbers	11. IP addresses	17. Certificate/license numbers
6. Fax numbers	12. Medical record IDs	18. Any other unique identifier

De-identified vs. Limited Data Sets

Limited data set (LDS): Pursuant to 45 C.F.R. § 164.514(e) (2), an LDS excludes most of the 18 identifiers described but **may** include one or more of the following:

- Dates such as admission, discharge, service, date of birth, date of death;
- Municipality, state, zip code; and
- Ages in years, months or days or hours

Limited data sets released by the iPHD will include only the minimum necessary information needed to complete the approved research project and use of the LDS will be governed by a Data Use Agreement.

Fee Schedule &
Funding Opportunities

iPHD Project Fee Schedule

	Tier 1	Tier 2	Tier 3
Up to 3 years of data	$2,000	$2,800	$4,500
4-6 years of data	$2,400	$4,800	$10,000
7-10 years of data	$3,200	$7,200	$15,500
More than 10 years of data	$4,000	$9,500	$20,000

Special request or technical assistance: $500/hour

Tier 1	Birth data (Vital Information Platform, VIP)
Tier 1	Mortality data
Tier 2	Hospital Discharge Data Collection System (HDDCS)
Tier 2	COVID-19 surveillance data all years combined (CDRSS)
Tier 3	National Emergency Medical Services Information System (NEMSIS)

We are asked to re-evaluate our rates every few years and the current fee schedule is effective January 2024 through December 2026. The fees charged to an awardee are current at the time of data transfer and not at award notice.

Understanding Data Access Fees

Example 1:

Description	Tier	Dates	# Years	Rate
NJ Birth Data	1	2010 to 2021	12	$ 4,000.00
NJ Mortality Data	1	2010 to 2021	12	$ 4,000.00
NJ Hospital Discharge Data Collection System	2	2017 to 2022	6	$ 4,800.00
NJ EMS	3	2017 to 2022	6	$ 10,000.00
			Total Due	$ 22,800.00

Understanding Data Access Fees (cont.) + Special Hours

Example 2:

Description	Tier	Dates	# Years	Rate
NJ Birth Data	1	2000 to 2021	22	$ 4,000.00
NJ Mortality Data	1	2000 to 2021	22	$ 4,000.00
NJ Hospital Discharge Data Collection System	2	2010 to 2022	13	$ 9,500.00
Special Request Hours	$500/hr		8 hours	$ 4,000.00
			Total Due	$ 21,500.00

All external linkages should be discussed with our data team to determine feasibility and compliance with governing legislation.

Opportunity for Fee Waivers in Cycle 6

- Up to two data fee waivers being offered by DOH

- Maximum of $25K per applicant

- Must be a NJ Institution

- When an applicant receives a data waiver, no monetary transaction is required for the data applicant unless the fees exceed $25K

- Awarded at the discretion of the Governing Board

What's Next for iPHD?

iPHD Application Cycles in 2025

Cycle 6	Cycle 7
RFA Release: May 7, 2025	**RFA Release:** September 3, 2025
LOI due: May 28, 2025	**LOI due:** September 24, 2025
Full applications due: June 18, 2025	**Full applications due:** October 15, 2025
Governing Board decision: October 2025	**Governing Board decision:** February 2026
Data transfer: Early 2026	**Data transfer:** Mid-late 2026

Planning for a Fall Research Consortium

- Planning to convene an in-person meeting early in the fall 2025

- Continuing to explore effective strategies for enhancing actionable population health research

- Opportunity to revisit current research priorities and priority for data set migration

- Please complete your post-meeting survey, including items for discussion at Research Consortium

Question & Answer Session

Thank you!

Please reach out to iPHD at iphd@ifh.rutgers.edu
with any additional questions!