RUTGERS HEALTH
Center for State Health Policy
Institute for Health, Health Care Policy and Aging Research

Data for Behavioral Health and Equity Research:
NJ Population Health Cohort (NJHealth) Study
Integrated Population Health Data (iPHD) Project

Presentation to the
Rutgers-New Brunswick Behavioral Health and Equity Task Force
October 3, 2024

NJ Population Health Cohort Study

Study Site
303 George St. (enter on New St.)

More information: **https://njhealthstudy.rutgers.edu/en** where the study design manuscript and collaboration guidelines can be found.

Funded by the Robert Wood Johnson Foundation, State of New Jersey, and Rutgers Health.

NJHealth Study Leadership

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Study Team

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Community outreach staff
Field coordinators
RA/Interview staff

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NJHealth Study Goal and Aims

Overall Goal

Generate practical, actionable knowledge and advance theory for improving health and wellbeing in the population overall and especially among diverse groups at high-risk chronic exposure to stressors, including immigrants, multi-generational families, people of color, and low-income families.

Scientific Aims

- Identify the prevalence and pathways through which **enduring and emerging stressors** over the life course contribute to health in diverse populations

- Discover novel factors that **buffer or amplify** these influences on personal and population health

NJHealth Study Ecosocial Model of Stressors and Health Over the Life Course
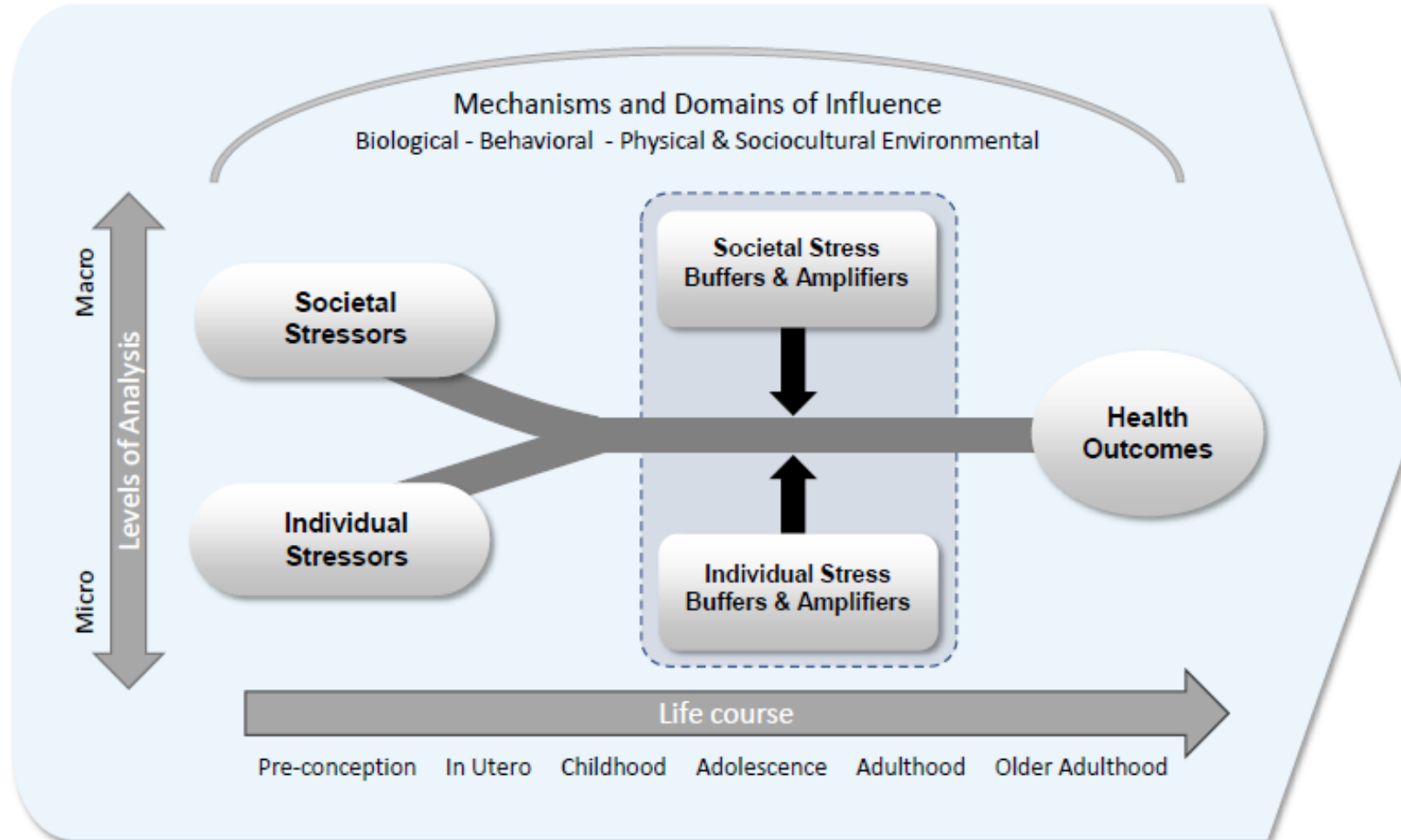
NJHealth Outcomes

- **Behavioral health conditions** including depression, anxiety, suicidality, and substance use disorder

- **Other illnesses and conditions** such as dementia/cognitive decline, stroke, heart disease, cancer, liver disease, kidney disease, chronic pain, and injuries

- **Disability related conditions** such as and hearing or vision loss

- **Factors that increase risk** for new conditions such as high blood pressure, diabetes, high cholesterol, and trauma

NJHealth Study Population

New Jersey community residents (n≈**8,000**) aged 14 and older

- **Statewide random sample** (n≈4,000)
  - Designed to represent the state & ensure inclusion of multi-generational, minority, and low-income families

- **Immigrant samples** (n≈4,000)
  - Ten focal groups: Chinese, Korean, Asian Indian, Filipino, Dominican, Mexican, Haitian, Jamaican, Nigerian, and Immigrants with Special Status (i.e., refugees, asylum seekers, parolees)
  - Recruited via outreach and referral

NJHealth Data Sources

- **Interviews** (n≈8,000)
  - Telephone, Zoom, in person, or on-line
  - Existing, enhanced, and new scales/assessment tools
  - Extensive battery of questions about stressors, stress buffers and amplifiers, health & wellbeing assessment
  - Cognitive assessment (ages 50+)

- **Activity and movement** (n≈1,000)
  - Two-week assessment with actigraphy watch
  - Measures movement & sleep

- **Biological markers**
  - Saliva DNA (all consenting participants)
  - Plasma biomarkers for stress and other conditions (n≈2,000)

- **Linked health records and administrative data** (all consenting participants)

- **Environmental data**
  - Home environment, neighborhood conditions, local policies, etc.

NJHealth Timeline

- N>1,100 participants recruited to date, complete cohort recruitment near the end of 2025

- Study site opening this week for plasma and biometric data collection

- Preliminary findings
  - To support R01 development
  - Non-technical presentations and brief, lay language reports

- Initial R01 submissions this month, more planned

Opportunities for Collaboration

We are interested in developing collaborative work that…

- Is consistent with NJHealth Study aims
- Contributes to study sustainability (~20% of proposed direct costs, including in-kind)
- Shares data with other NJHealth investigators

Early emphasis on collaboration with experienced R01 investigators and well-prepared early-stage investigators with strong senior co-I/mentor support

Broader data sharing planned once baseline data are fully collected

Full guidelines at: https://njhealthstudy.rutgers.edu/en/researchers

More information**: https://iphd.rutgers.edu/**

Funded by the NJ Department of Health and the Robert Wood Johnson Foundation.

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

Statutory Goals
- 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**

Implementation
- Oversight by a Governing Board
- Integrated New Jersey state administrative data resources
- Operated by Rutgers Center for State Health Policy/Institute for Health
- Releases Limited Data Sets for approved research projects

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

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iPHD Integrated Data Sets

iPHD Data Sets (updated annually – dates shown reflect expected availability for the coming application cycle)
- NJ Birth Data (2000-2022)
- NJ Mortality Data (2000-2022)
- NJ Hospital Discharge Data Collection System (2010-2023)
- Communicable Disease Reporting and Surveillance System (CDRSS), PCR Laboratory Confirmed COVID-19 Case Reports (2020-2023)
- Emergency Medical Services (EMS) Data (2017-2023)

Governing Board Approved for Future Addition (selected)
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Perinatal Risk Assessment (PRA)*
- COVID Vaccine Registry
- NJ Cancer Registry
- Children's System of Care (CSOC)
- Child Protective and Permanency (CP&P) Data

*pending

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iPHD Data Access

- **Three annual application cycles**
  - Application materials and instructions: https://iphd.rutgers.edu/application-process
  - **Next deadline: Oct 16 for required letter of intent & Nov 6 for full applications**

- **Review process**
  - CSHP completeness review
  - Scientific review by external Research Advisory Committee
  - Governing Board subcommittee review (analogous to NIH Council)
  - Full Governing Board review and final approval authority

- **Approved projects**
  - Access fees apply (competitive fee waivers in some application cycles)
  - Requires IRB approval and Data Transfer and Sharing Agreement
  - CSHP prepares and transfers Limited Data Set
  - Reporting and accountability requirements

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Supplemental NJHealth Slides

- Conceptual framework

- Interview and assessment domains
  - Health and wellbeing
  - Stressors
  - Cognitive assessment
  - Actigraphy and movement
  - Biomarkers
  - Data linkages

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Health & Wellbeing Interview and Assessment Domains

- **Cognitive function**

- **Functional status**
  - Activities of daily living
  - Activity limitations
  - Physical performance measurement

- **Physical health**
  - Health conditions, medical history
  - Height, weight, waist, hip measures
  - Self-assessed health
  - Self-assessed changes in health

- **Mental and behavioral health**
  - Alcohol, cannabis and other substance use
  - Tobacco dependence
  - Anxiety symptoms
  - Depressive symptoms
  - Suicide risk

- **Health-related behaviors**
 - Physical activity
  - Sleep
  - Vaccination

Individual-Level Stressor Interview Domains

- **Life events & experiences**
  - Adverse childhood events
  - Bullying
  - Caregiving
  - Criminal justice involvement
  - Elder mistreatment
  - Grandparent burden
  - Intimate partner violence
  - Race/ethnic discrimination experiences

- **Social determinants of health**
  - Financial and material hardship
  - Food insecurity
  - Housing quality and stability
  - Utility security

- **Perceptions of societal stressors**
  - Role of social media in society
  - Growing income gap
  - State of race relations
  - Rise in damaging weather events
  - State of immigration
  - Amount of gun violence

- **Perceived stress scale**

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Stress Buffers & Amplifiers Interview Domains

- **Health services access & use**
  - Barriers to care
  - Health insurance status
  - Usual source of care (US and overseas)
  - Healthcare utilization (US and overseas)

- **Socioeconomic status**
  - Education
  - Employment
  - Family income and wealth

- **Psychological factors**
  - Life satisfaction
  - Loneliness
  - Meaning in life
  - Optimism
  - Personality
  - Rumination

- **Psycho-social factors**
  - Health risk and service use attitudes
  - Religious practices

- **Social circumstances and engagement**
  - Civic engagement
  - News media engagement
  - Social network size
 - Social support
  - Volunteerism
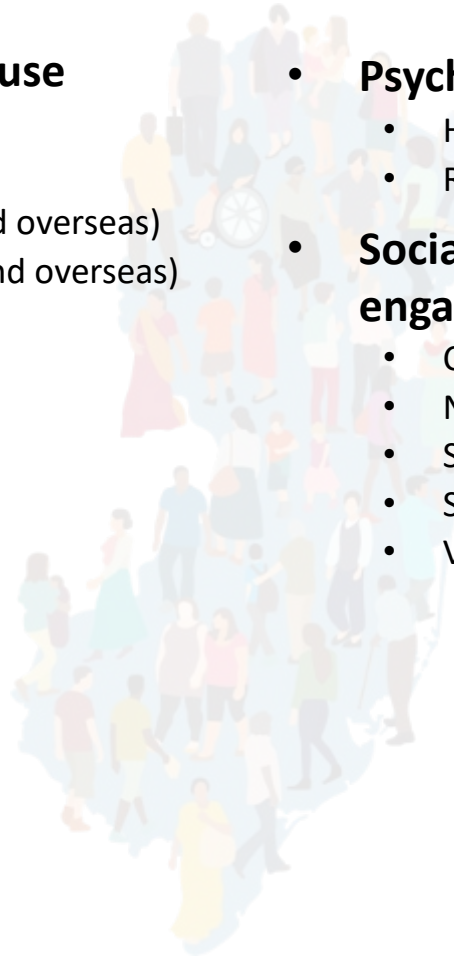
Cognitive Measures

- Compared across HRS/HCAP, ARIC, NACC
  - MoCA, Craft Story (logical memory), forward/reverse digit span, TMT B, MINT, category fluency (animal), Benson reproduction

- Every participant over the age of 50
  - English & Spanish
    - Country of origin-specific normative data
  - Mandarin Chinese – validated battery and norms developed from on-going Rutgers-Stanford Chinese Older Adult STudy (COAST)
  - Asian Indian – validated Rutgers conversion of English age, sex, education-adjusted Z-scores
  - Korean

- Future studies may include MRI assessment

Actigraphy & Movement Measurement

- N≈1,000 participants

- Two-week data collection

- Actigraph CentrePoint watches
  - Raw tri-axial accelerometer data + Actigraph activity counts
  - Physical activity (i.e., MVPA, Bouts, Steps, Wear Time)
  - Sleep (i.e., Total sleep time, Awakenings, Wake After Sleep Onset, Sleep Efficiency)

- Daily sleep and movement questionnaire
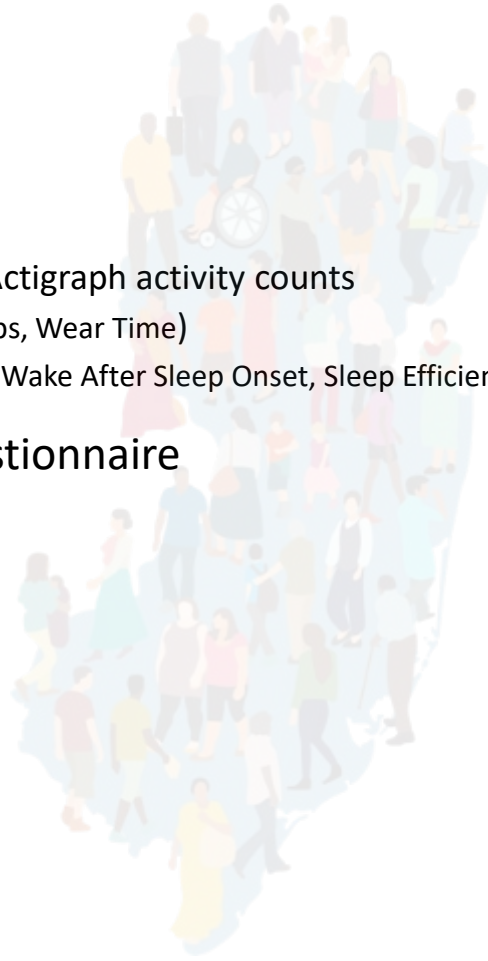
Biomarkers

- Salivary DNA collected from all consenting participants

  - Genotype ~800,000 single nucleotide polymorphisms (SNPs) plus *APOE*

- Fasting plasma collected for biomarker analysis

  - Selected participants (N≈2,000) interested & able to participate in future add-on studies (e.g., brain MRI)
  - 100 inflammatory cytokines and their soluble receptors (250 uL)
  - Alzheimer's biomarker (p-Tau$_{181}$)
  - Plasma will be stored long-term in 250 uL aliquots at –80°C for future discovery/validation work
    - Rutgers investigators
   - External investigators
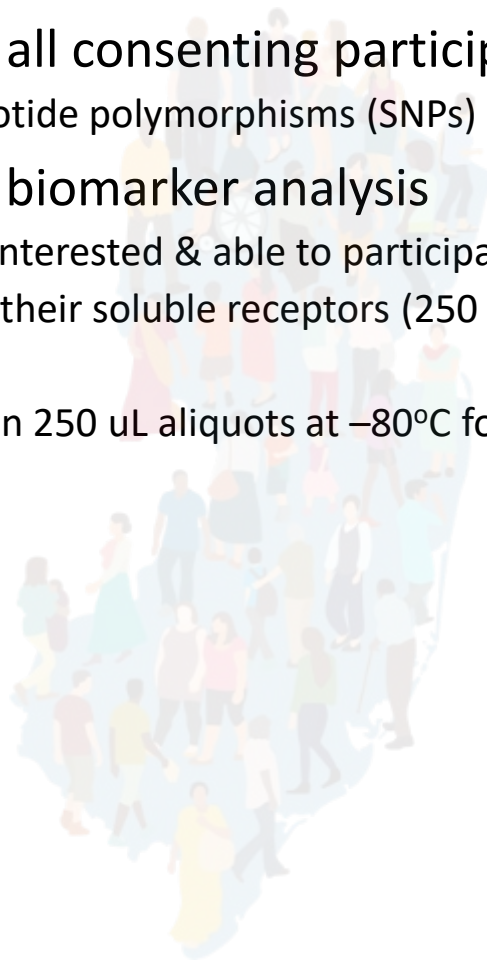
Planned Participant-Level Linked Data

- **Health insurance claims and encounter data**
  - Medicare, Medicaid, private insurance*
  - All-payer hospital billing records (inpatient and emergency department care)*
  - Emergency medical services encounters*

- **Clinical measures**
  - Birth records*
  - Death records
  - EMS records*
  - Electronic health records (diagnoses, laboratory values, ambulatory visits)**
  - Cancer and COVID-19 public health registry data*

- **Social services enrollment and use***
  - Food assistance (SNAP)
  - Cash benefits (TANF, general assistance, emergency assistance)

- **Employment and education***
  - Wage history
  - Unemployment insurance benefits
  - K-12 and higher education history

*Available for NJ only
**:From selected NJ-based health systems

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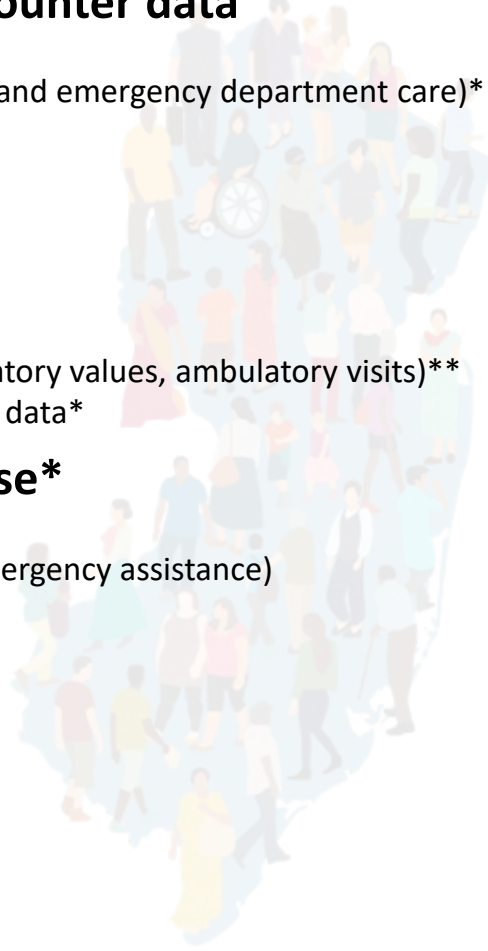
Examples of Area-Level Linked data

Local conditions (household, neighborhood)

- Crime rates, hate crimes
- Deprivation indices
- Ethnic enclaves
- Extreme weather events
- Food, alcohol, tobacco, cannabis outlets
- Household and environmental toxin exposures
- Physical activity opportunities, walkability
- Racal/ethnic segregation

Public Policies

- Local government budgets (e.g., police, social services)
- School policies (e.g., curricular, speech)
- Library offerings (e.g., book bans, services available)