

Program Brief: Integrated Population Health Data Project
August 2017

The incoming administration should fully harness the power of the Integrated Population Health Data Project to allow for more comprehensive and smarter policy-making. Linking different datasets that already exist within social service programs is integral for a holistic understanding of patient needs and gaps in the system.

Executive Summary

- As health care costs rise and patients and providers become increasingly frustrated, solutions grounded in data and research are urgently needed. Unfortunately, multiple laws and bureaucratic hurdles significantly impede access to the types of comprehensive data needed to improve our health care system, especially for patients with complex health and social needs.*
- Signed into law on January 11, 2016 (PL 2015, Ch. 193),² the Integrated Population Health Data (iPHD) Project establishes a streamlined process for potential researchers to access health and social data that already exists. This process relies on a governing board, which reviews all research project requests. Data is provided on a project by project basis, and the iPHD Project protects the privacy and security of the data. To fully harness the power of the iPHD Project, it will take strong leadership from the next administration.
- When realized to its full potential, the iPHD Project will serve as a powerful tool to advance health and public system goals, and ultimately improve population health across New Jersey (NJ). Across the country, integrated data solutions similar to the iPHD Project have been catalysts to smart policy-making tackling some of the most expensive and complicated health issues facing our country.

I. Introduction

As health care costs rise and patients and providers become increasingly frustrated, NJ's next administration urgently needs new and innovative solutions. Patients, especially those facing complex health and social needs, rely on multiple public systems and services (e.g., health care, criminal justice, and housing). Improving health outcomes while decreasing health care spending requires understanding the influence of both health care entities and social services.

For the upcoming administration, it will be imperative to promote policy solutions that advance a holistic understanding of health. The iPHD Project will serve as a powerful tool to improve health outcomes and reduce costs by allowing the new administration to understand the forces within and outside the health service sectors that impact a person's health. Signed into law on

*A relatively small patient population for whom the current health system is ill-equipped to meet the myriad of interrelated medical, behavioral, and social challenges they may face including those often considered 'non-medical' such as addiction, housing, hunger, and mental health. They often experience poorer outcomes despite extreme patterns of hospitalization or emergency care.

January 11, 2016 (PL 2015, Ch. 193),² The iPHD Project establishes a streamlined process for potential researchers to access health and social data that already exist. This process relies on a governing board, which reviews all research project requests. Data is provided on a project-by-project basis, and the iPHD Project protects the privacy and security of the data. Linking different datasets that already exist within social service programs is essential for a holistic understanding of patient needs. Unfortunately, multiple laws and bureaucratic hurdles significantly impede data linkage. With an increasingly burdened state government, the resources available to our state agencies and support programs to do this work and/ or to meet ad hoc requests for multiple and large data sets accessible to researchers are constrained.

A well-structured and governed iPHD Project can overcome legal, financial, and bureaucratic obstacles and provide a rich resource for identifying ways to improve population health and make government programs more efficient. Across the country, integrated data solutions similar to iPHD have been catalysts to smart policy-making.

To fully harness the power of the iPHD Project, it will take strong leadership from the upcoming administration. The iPHD Project can help policy makers and the incoming governor's administration create more comprehensive policies and programs, advance health and public system goals, and ultimately improve population health across NJ.

II. How the iPHD Works

The iPHD Project establishes a streamlined process for potential researchers to access health and social data that already exist. This process relies on a governing board, which reviews all research project requests. The iPHD Project is designed to make it easier for NJ state agencies and outside researchers to gain authorized access to integrated datasets, while not creating new hurdles for those interested in using integrated data. If state agencies already have data sharing agreements in place that meet their needs, they will not be required to do anything differently. Agencies also are not required to share data exclusively through the iPHD Project.

Where is iPHD Project data housed? Rutgers Center for State Health Policy (CSHP) houses and links key state datasets for project that have been approved by the governing board and in accordance with the legislation. CSHP already has established relationships with key state agencies and has experience accessing and linking state administrative data.

What data is part of iPHD Project? The iPHD Project has expandable scope, allowing administrative datasets to be added as they are needed to address policy development, research, and evaluation priorities. The iPHD Project is being built iteratively, accessing data only on a project by project basis.

Who provides oversight of the iPHD Project? Oversight of the operations of the iPHD Project is vested in the governing board, which has a formal process for reviewing projects. The governing board deliberates the plausibility and merits of each proposal, and either approves or rejects the projects. It is comprised of ten members (nine voting; one non-voting). One of whom shall be the Director of CSHP, who shall serve as a non-voting, ex-officio member; one of whom shall be a

public member appointed by the President of the Senate, representing an organization capable of advocating on behalf of persons whose data may be received, maintained, or transmitted by the iPHD Project; one of whom shall be a public member appointed by the Speaker of the General Assembly with experience as a researcher and with service on an Institutional Review Board (IRB) charged with oversight responsibility for ensuring compliance with standards defining the ethical conduct of research; and two of whom shall be public members appointed by the Governor, as follows: 1) an individual with legal expertise and interest in protecting the privacy of individually identifiable information and 2) an individual with technical expertise and interest in the creation of large data systems and data security.

The five remaining voting members are ex-officio members representing the Secretary of the Department of State; the Commissioner of the Department of Human Services; the Commissioner of the Department of Health; the Department of Law & Public Safety, office of Attorney General; and the Chief Information Officer of Rutgers University.

What are the responsibilities of the governing board? The governing board is charged with ensuring that the iPHD Project receives, maintains, and transmits only data that is appropriate to meet its legislative purpose. In addition, the governing board facilitates executing any needed data use agreements (DUAs) or business associate agreements (BAAs) in compliance with all applicable privacy and security standards.

The governing board adopts policies and procedures for the efficient and transparent operation of the iPHD Project, including: 1) privacy and security policies complying with the applicable federal and state privacy and security statutes and regulations (e.g., HIPAA); and 2) data access policies and procedures allowing access by an agency, department, or third party, including research organization, certified Medicaid Accountable Care Organizations, and other public support programs, only when such request meets the standards in the data access policies and procedures approved by the governing board.

Each year, the governing board publishes an annual report that identifies the sources and types of data received and maintained by the iPHD Project over the prior 12 months; describes IRB-approved disclosure of data sets by the iPHD Project; lists all publications and reports that have been published based on iPHD Project data; and includes any other information deemed appropriate by the Governing Board.

How does the iPHD Project protect privacy and security? Protecting the privacy and security of the data in the iPHD Project is paramount. CSHP relies on state-of-the-art safeguards, which are compliant with legal and ethical standards at the federal, state, and local levels. These mechanisms mitigate the risk of privacy and security breaches.

How does the iPHD Project ensure ethical and appropriate use of data? Research using the iPHD Project data shall not proceed without the approval of a federally authorized and independent IRB. Further, the governing board, data-system administrators, and outside researchers are required to follow ethical protocols, as outlined in local, state, and federal regulations, to ensure ethical and appropriate use of data maintained in the iPHD Project. Ethical

and appropriate use entails protecting the security and confidentiality of data and requires that the researcher: 1) has the skills to organize and handle the data; 2) understands the limits of the data; and 3) and appropriately and adequately interprets the findings. The data shall only be used for research in accordance with the legislation.

III. How the iPHD Project Can Advance Population Health Under a New Administration

The iPHD Project will help serve as a catalyst for population health research. It will support both state commissioned studies as well as other externally funded research projects that are reviewed and approved by the governing board. The NJ iPHD Project has the potential to transform health care and service delivery in our state. By improving health and well-being, other positive impacts will also likely result. Research demonstrates that a healthy population leads to increased productivity across the economy; reduced absenteeism from jobs; and higher educational attainment. These improvements have a positive impact on the education system, business community, and the economy at large.

Below are specific ways that the iPHD Project can advance population health in New Jersey:

- Identify statewide health improvement priorities.
- Increase public awareness and understanding of the correlates of health, disease, and disability.
- Engage multiple sectors to take actions to improve practices that are driven by the best available evidence and knowledge.
- Identify critical research, evaluation, and data collection needs.
- Highlight opportunities to improve health care efficiency.
- Provide the opportunity to study a wide array of issues, from quality outcomes of cancer care and identifying best practices, to monitoring the transitions from the jail to the community among vulnerable and at-risk populations.
- Promote local health care innovation that uses data to identify what community needs must be met.
- Create a data rich environment that allows policymakers to make evidence-based decisions, as well as allocate resources to health care and social service interventions that will most efficiently and effectively improve health outcomes and well-being.
- Support agency, department, and public program administrators with meeting the complex and interconnected needs of their client populations by showing decision makers the unmet health and social needs of their clients.

VI. Preliminary Recommendations

The iPHD Project requires commitment and leadership to become fully implemented and utilized. The following preliminary recommendations will help activate the iPHD Project so that the state can benefit from the data system:

- Review the iPHD Project research agenda to determine alignment with new administration's goals.
- Incorporate the iPHD as part of routine policy decision-making to advance population health.
- Appoint experts to the iPHD Project governing board in a timely manner. The iPHD Project governing board comprises of four public members who have expertise in the following areas: 1) legal requirements for data privacy and security, 2) "big data" analysis and security, 3) advocacy on behalf of persons whose data may be included in the iPHD Project, and 4) a New Jersey university-based researcher with expertise in human subject research. Timely appointments to fill any present or future vacancies will be important in ensuring the appropriate experts are able to advance the objectives of the governing board. The iPHD Project is presently awaiting the appointment of one more public member.
- Support the Department of Health and other departmental leadership and engagement. The iPHD Project has been able to move forward thus far in large part due to the commitment and leadership by departmental officials who are invested in the potential impact and value of the iPHD Project.
- Consider state funding for priority projects and endorse the iPHD Project as a high priority initiative for grant support among NJ foundations (in partnership with CSHP).
- Promote and enable cross-agency coordination and collaborative initiatives by leveraging iPHD Project driven research; for example, Medicaid for supportive housing and addressing the opioid crisis.

APPENDIX: Other Integrated Data Systems across the Country

Throughout the country, integrated data systems similar to the iPHD Project have been created to improve public programs and social services. The following examples showcase the power of integrated data to bring together diverse actors, spark innovative and evidence-based projects, and improve quality and efficiency of programs.

A. Washington State

Washington State uses the Integrated Client Data Base (ICDB) to link various social and health datasets. State agencies and qualified external entities are able to access the ICDB to conduct rigorous policy analyses, which has helped the state identify whether health and social programs are working. Through the ICDB, the state has produced over 350 reports on various issues, including behavioral health and substance abuse, housing, education, employment, and foster care. For example, one seminal report evaluated the state expansion of treatment for mental and substance and abuse disorders, which showed a return on investment of two dollars saved in medical and nursing facility costs for every dollar invested in the first four years of implementation.

B. South Carolina

The State of South Carolina Health and Demographic Section runs an IDS to 1) receive, process, distribute, and interpret health, demographic, and census data statewide; 2) develop mapping infrastructure enabling users to obtain health, socioeconomic and demographic analysis for planning, intervention and evaluation of programs; 3) educate policy makers and other data users about the availability and appropriate use of information; and 4) establish collaborative partnerships with agencies and research groups to conduct studies research projects related to health and socio-economic issues in South Carolina.

C. New York City

New York City has established an integrated database under The Center for Innovation through Data Intelligence (CIDI). The CIDI conducts citywide, interagency research to identify areas of service need in NYC, including child welfare, public assistance, juvenile delinquency, homelessness and education. CIDI has helped identify and analyze utilization patterns of programs and services; program costs and benefits; overlap in programs and services; linkages within and among systems; entry points into particular systems; and geographic distributions in services.

D. Federal Agencies

Federal agencies have used IDS to improve the livelihoods of Americans. For example, the Department of Housing and Urban Development (HUD) has partnered with the Department of Health and Human Services (HHS) to match HUD administrative data with Center for Medicare & Medicaid data. The linked data will improve understanding of how senior citizens live in publicly subsidized housing and whether supportive housing interventions will affect their health care utilization patterns.

Endnotes

¹ Good Care Collaborative. (2015). *Building an Integrated Population Health Database (iPHD) for New Jersey*. Retrieved from <http://www.goodcarecollaborative.org/wp-content/uploads/2015/11/iPHD-white-paper-final.pdf>

² Rutgers Center for State Health Policy. (2016). *The New Jersey Integrated Population Health Data (iPHD) Project*. Retrieved from <http://www.cshp.rutgers.edu/content/nj-iphd>