Building an Integrated Population Health Database (iPHD) for New Jersey

New Jersey is at an exciting point in reforming its public health system to improve quality and reduce costs. The Integrated Population Health Database (iPHD) provides policymakers, researchers, Accountable Care Organizations, community groups, and other public support programs the tools they need to promote good care in New Jersey and generate cost-savings. By linking administrative datasets together, New Jersey can build upon the work its agencies, executive authorities, and legislature have already done to continuously improve healthcare delivery in the state.

Good care requires good data. As healthcare costs rise and patients and providers become increasingly frustrated with the system's failures and inefficiencies, new and innovative solutions are urgently needed. The good news is that New Jersey is at an exciting time in its journey to improve the quality and efficiency of its healthcare system.

The Good Care Collaborative (GCC), a coalition of stakeholders from across the healthcare spectrum in New Jersey, proposes that the state establish the Integrated Population Health Database (iPHD), which would integrate healthcare data already being collected from departments, agencies, and public support programs at the local, state, and federal levels with data already being collected on other services that are important to achieving good health (e.g., housing, homelessness, education, social security, transportation, employment, and criminal justice systems).

The iPHD has the potential to transform New Jersey's healthcare delivery system. Patients, especially those facing complex medical and social needs and those incurring the highest costs, rely on multiple public systems and services (e.g., healthcare, criminal justice, and housing). These systems interact in complex ways. Reducing costs and improving outcomes, therefore, requires understanding forces both within and outside the health service sectors.

The approach is supported by research demonstrating that the conditions in which we live and work have an enormous impact on our health, long before we ever

The iPHD in a nutshell

What is the iPHD? The iPHD is an integrated data system linking health data with other social administrative datasets while safeguarding the privacy and security of the data. The iPHD provides the infrastructure to link health data with social data on a project by project basis, allowing administrative datasets to be added as they are needed to address policy development, research, and evaluation priorities.

What is its purpose? To facilitate research and the development of the most effective means for improving the health, safety, security, and well-being of New Jersey residents and the overall cost-efficiency of government programs.

Why do we need it? The iPHD has the potential to transform New Jersey's healthcare delivery system. Patients, especially those facing complex medical and social needs and those with the highest costs, rely on multiple systems and services (e.g., healthcare, criminal justice, housing). These systems interact in complex ways. Reducing healthcare costs and improving health outcomes, therefore, requires understanding forces within and outside the health service sectors. By providing a more holistic understanding of health, the iPHD would help the state achieve its Healthy 2020 goals, ensure the success of the Medicaid ACO Demonstration Project, and promote population health generally.

What would it cost? The iPHD would not impose additional burdens or significant costs upon the state. Many departments, agencies, and public support programs at the local, state, and federal level already collect large amounts of data to administer their programs. The departments, agencies, and public support programs, however, lack the infrastructure and resources to link the data together to provide a fuller picture of what factors are affecting New Jerseyans' health. By linking disparate datasets, the iPHD would allow these entities to leverage their current data collection efforts without additional burdens. Similar integrated datasets in other states have been associated with saving money and improving efficiencies in the state.

How will it safeguard privacy and security? The iPHD governing board would have a formal process to review data requests made by administrators, certified Medicaid ACOs, and researchers to ensure the ethical and appropriate use of the data and that these requests meet rigorous security and privacy standards.

see a doctor. The journey to good health begins in our homes, in our schools and workplaces, in our playgrounds and parks, and in the air we breathe, the food we eat, and the water we drink. The more we see health this way, the more opportunities we have to improve it and save costs by preventing and treating medical conditions before they reach the point of expensive treatment. Linking different datasets that exist within agencies, departments, and public support programs is essential for a holistic understanding of the forces driving poor health. But, unfortunately, multiple laws and bureaucratic hurdles impede data linkage. A well-structured and governed iPHD would help overcome these challenges and provide a rich resource for identifying ways to improve population health and make government programs more efficient and effective.

The Center for State Health Policy (CSHP) at Rutgers University's Institute for Health, Health Care Policy and Aging Research would house the iPHD. In New Jersey, CSHP has already demonstrated the power of data linkage and analysis to deepen our understanding of avoidable hospital use and cost. By linking various datasets (e.g., all-payer hospital billing records, charity care data, death records, and census data), CSHP has identified the significant role that behavioral health conditions play in driving costs,[1] the persistence of hospital use among high-users over time,[2] the extent to which care of high-users is fragmented across multiple hospitals,[3] and the patients who are at the greatest risk of fragmented care.[4] Without the ability to link disparate administrative datasets, CSHP would not have been able to study these issues and arrive at its findings. The iPHD would create greater opportunities for this type of valuable research in a cost-effective and efficient manner.

The table below lists other potential projects the iPHD would support:

Project	Examples of data linkage
Study variations in the quality and outcomes of cancer care and identify best practices	• Link Medicaid, Medicare, or other claims data to the New Jersey Cancer Registry
Monitor and improve transitions to the community among vulnerable and at-risk populations	• Link jail/prison health service data to Medicaid data • Link homeless services data to Medicaid data
Evaluate the efficiency and effectiveness of ongoing public health programs	• Link jail/prison health service data to Medicaid data • Link data on Housing First program participation to community addiction services, hospital emergency department and inpatient data, workforce data, and education data.

A multitude of benefits. As described above, the iPHD would help serve as a catalyst for population health research. It would both support state commissioned studies and also attract outside research funding and talent to the state. This research, in turn, would advance population health in multiple ways. For example, it would;

- Help the state achieve many of its Healthy New Jersey 2020 goals, including:
  - Identifying statewide health improvement priorities;
  - Increasing public awareness and understanding of the determinants of health, disease, and disability and the opportunities for progress;
  - Providing measurable objectives and goals that are applicable at the state and local levels;
  - Engaging multiple sectors to take actions to strengthen policies and improve practices that are driven by the best available evidence and knowledge;
  - Identifying critical research, evaluation, and data collection needs;
  - Highlighting opportunities to improve health care efficiency.
- Promote the success of the NJ Medicaid ACO Demonstration Project by revealing new opportunities to improve the quality of health and reduce costs;
- Improve coordination among state agencies and their affiliated providers;

- Create a data rich environment allowing policymakers to make evidence-based decisions;
- Support agency, department, and public support program administrators with meeting the complex and interconnected needs of their client populations efficiently and effectively.

As a result of improving population health, the iPHD would yield a constellation of other positive spillover effects. Research from across the globe demonstrates that good health leads to increased productivity, reduced absenteeism, and higher educational attainment; all of which have a positive impact on the education system, the business community, and the economy at large.

Many benefits without additional burdens. The iPHD would not impose additional burdens or significant costs upon the state. Many departments, agencies, and public support programs, in the state of New Jersey already collect large amounts of data to administer their programs. The departments, agencies, and public support programs, however, lack the infrastructure and resources to link the data together to provide a fuller picture of what factors are affecting New Jerseyans' health. By linking disparate datasets, the iPHD would allow these entities to leverage their current data collection efforts without additional burdens. Similar integrated datasets in other states have been associated with saving money and improving efficiencies rather than imposing additional costs.

How do we build the iPHD?

House the data. CSHP would house and link key state datasets to enable valuable analyses by authorized entities, including policymakers, researchers, certified Medicaid ACOs, community groups, and other public support programs. CSHP already has established relationships with key state agencies and has experience accessing and linking state administrative data. For example, the NJ Medicaid ACO Demonstration Project calls on CSHP to provide technical assistance for the implementation and evaluation of gainsharing plans submitted by coalitions seeking state certification to become Medicaid ACOs. CSHP is also responsible for evaluating New Jersey's Comprehensive Medicaid Waiver Demonstration whereby it receives comprehensive Medicaid enrollment data, fee-for-service claims data, and managed care encounter data to conduct data analyses. CSHP was also

commissioned to use Medicaid data to help inform recommendations on improving care and reducing costs for the top 1 percent of Medicaid beneficiaries who account for a disproportionate share of program spending. Most recently, CSHP was awarded a federal State Innovation Model Design Award to help the state assess and plan population health and delivery system improvements, again drawing on analysis of Medicaid administrative data.

By collecting data for the iPHD, CSHP would have enhanced capacity to serve in its current role as technical advisor to the state and be able offer more robust and effective solutions for health improvement and cost savings.

Identify the data to be linked as needed. The iPHD would have expandable scope, allowing administrative datasets to be added as they are needed to address policy development, research, and evaluation priorities. Rather than being a single large project, iPHD would start on a small scale, accessing data only on a project by project basis.

Create a governing structure. Oversight of the operations of the iPHD would be vested in the governing board, which would have a formal process for reviewing projects. The governing board would deliberate the plausibility and merits of each proposal, and either approve or reject the projects. It would be comprised of ten members (nine voting; one non-voting). Four of these members would be public members appointed by the Governor with advice and consent of the Senate and would include:

- An individual representing an organization capable of advocating on behalf of persons whose social services data may be received, maintained, or transmitted by the iPHD;
- An individual with legal expertise and interest in protecting the privacy of individually identifiable information;
- An individual with technical expertise and interest in the creation of large data systems and data security;
- An individual 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.

The five remaining voting members would be 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. The Director of the Rutgers Center for State Health Policy would serve as an ex-officio non-voting member.

The governing board would be charged with ensuring that the iPHD receive, maintain, and transmit only data that is appropriate to meet its legislative purpose. In addition, the governing board would facilitate executing any needed data use agreements (DUAs) or business associate agreements (BAAs) in compliance with all applicable privacy and security standards.

The governing board would adopt policies and procedures for the efficient and transparent operation of the iPHD, including) 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 ACOs, 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 would publish an annual report that identifies the sources and types of data received and maintained by the iPHD over the prior twelve months; describes IRB-approved disclosure of data of data sets by the iPHD; lists all publications and reports that have been published based on iPHD data; and includes any other information deemed appropriate by the Governing Board.

Protecting privacy and security. Protecting the privacy and security of the data in the iPHD is paramount. CSHP would use state-of-the-art safeguards, which are compliant with legal and ethical standards at the federal, state, and local levels. These mechanisms would mitigate the risk of privacy and security breaches.

Ensuring ethical and appropriate use of data. No research using the iPHD data would proceed without the approval of a federally authorized, independent IRB. Further, the governing board, database administrators,

and outside researchers would be 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. Ethical and appropriate use entails not only protecting the security and confidentiality of data, but also requires that the researcher: 1) has the skills to organize and handle the data; 2) understands the limits of the data; and 3) and interprets the findings applying adequate information. The data would be used only for research in accordance with the iPHD legislation.

Creating streamlined processes. The iPHD governing board would establish standardized application and review procedures, which would improve efficiency in the process for reviewing applications for authorized use of data.

The iPHD is designed to make it easier for New Jersey state agencies and outside researchers to gain authorized access to integrated datasets, and it would not create 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.

Let's consider an example: How the iPHD works

You are a member of a research team working closely with the state to promote and evaluate state health policies. The Department of Human Services (DHS) is interested in exploring the linkages between housing and health. DHS asks your research team to evaluate housing projects targeting the chronically homeless who also heavily rely upon the hospital system. DHS is specifically interested in questions on the impact of new supportive housing programs on hospital utilization, Medicaid costs, and total public spending.

Your team has already received approval from your University's IRB to conduct this research project, but is now having trouble accessing the relevant health and social data sets. Your team decides to submit a proposal to the iPHD governing board, requesting the linkage of health data with other social services data. Your proposal clearly delineates how such linkage will advance population health research and good public health policies in the state.

The iPHD governing board convenes and proceeds with a formal process deliberating the feasibility and merits of your proposal in accordance with the purpose of iPHD. The iPHD approves the project as the proposal clearly delineates how such research seeks to improve public health, safety, security, and wellbeing of New Jersey residents as well as to improve the overall cost-efficiency of government assistance programs.

Upon approval, the governing board facilitates the development of any necessary data use agreements or business associate agreements between state agencies contributing data and the data users in compliance with all applicable privacy and security standards. The governing board does not allow data to be moved into the iPHD until the state agencies are satisfied that applicable legal standards have been met.

To link and prepare the data, only trained, designated Rutgers CSHP staff have access to the data needed to execute linkages. To protect the data, this select staff use state-of-the-art privacy and security 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. Once the data is cleaned and linked, CSHP staff strip all personal identifiers from the linked dataset and then send the linked dataset, in accordance with iPHD policy and procedures, compliance with all applicable data use and business associate agreements, and adherence to approved IRB protocols, to your team, which can now analyze the data.

In its annual report, the iPHD governing board publishes a brief summary of your research project, explains the purpose of your project, which datasets were used for analysis, and any research publications that have resulted from your analysis.

Similar Databases

Throughout the country, integrated data systems (IDS) similar to the iPHD have been created to improve public programs and social services. These programs have taken their cues from some of the most successful companies and organizations in the world, which have leveraged the power of integrated data sets to design products and services to better serve customers and constituents. 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.

Washington State. The Washington State Department of Social and Health Services manages the Integrated Client Data Base (ICDB).[5] Compliant with HIPAA and strict confidentiality standards to protect personal client information, the ICDB links various social and health datasets. The database has streamlined the department's capacity to conduct research aiming to enhance service delivery and policy outcomes across the state and has also saved money and improved lives. State agencies and qualified external entities are able to access this information to conduct rigorous policy analysis, which has helped the state identify whether programs are working. Through the ICDB, the Department's Research & Data Analysis Division has produced over 350 reports on a wide spectrum of issues, including behavioral health and substance abuse, housing, education, employment, and foster care. These reports have bolstered the state's ability to efficiently analyze outcomes, costs, and needs of government-funded health and social services and has created a robust policy laboratory. For example, one seminal report[6] evaluated the state expansion of treatment for mental and substance and abuse disorders, which showed an impressive return on investment. Under conservative estimates, the evaluation demonstrated 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.

South Carolina. The State of South Carolina Health and Demographic Section runs an integrated database with the tag line "We make government better by turning data into information and information into knowledge."[7] Through their IDS, the Health and Demographics Section is able to 1) receive, process, distribute, and interpret health, demographic, and census data statewide; 2) develop GIS (small-area mapping) infrastructure enabling users to obtain health, socio-economic 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. With the ability to track patients over time, their IDS makes it easier to calculate readmission rates, hospital

inpatient use, and emergency room visits, disaggregated by county of residence, age, race, and gender group.

Rhode Island. The State of Rhode Island has established a Data Hub that collects administrative data from state agencies and links data together to produce high quality information for social science researchers and program administrators.[8] In addition to linking data sets for administrators and researchers, the Data Hub creates "Data Stories," illustrating the value that linking data can produce. These Data Stories have focused on such topics as substance abuse, at-risk youths, and chronic absenteeism. One Data Story highlighted the educational costs of housing problems in the state of Rhode Island,[9] illustrating how unhealthy housing contributed to increased absenteeism, a higher probability of repeating a grade, a higher likelihood of needing special education, and poorer test results. All of which not only impose strain upon students and their families, but also stress on the state's fiscal wellbeing.

New York City. The City of New York has established an integrated database under The Center for Innovation through Data Intelligence (CIDI), which is a research/policy center located in the Office of the Mayor of the City of New York.[10] The vision of CIDI is "to make data come alive to inspire change." CIDI conducts citywide interagency research to identify areas of service need in the City, 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, including demand "hot spots." For example, CIDI recently evaluated a supportive housing program for at-risk youth in NYC.[11] Relying upon administrative data from different agencies, the study compared outcomes for youth enrolled in the supportive housing program with those youth who applied and were eligible, but ultimately not placed in the program. Controlling for other factors, the analysis found that program participants were 36 percent less likely to have a stay in the single adult shelter system and 55 percent less likely to go to jail during this time period.[12]

In addition to the research agenda, CIDI provides analytic support for the Children's Cabinet and Immigrant Health Task Force.[13]

Maryland. With the leadership of its Governor, the State of Maryland established, through legislation,[14] the Maryland Longitudinal Data System Center, which links education with workforce data for every student in the state to provide a clearer picture of student performance and their preparation for higher education and the workforce.[15] The System is established jointly by the State Department of Education, the Department of Labor, Licensing, and Regulation, the Maryland Higher Education Commission, the University System of Maryland, Morgan State University, and St. Mary's College of Maryland.

Los Angeles County. In the county of Los Angeles, the Adult Linkages Project (ALP) links data on publically funded health, mental health, social and corrections services.[16] ALP has helped restructure the Los Angeles County General Relief Program—a cash assistance program for indigent adults. General Relief participants frequently need more than just cash assistance. Many experience homelessness, have disabilities, or face other challenges requiring housing and additional forms of assistance. Recognizing this complex nexus, the Los Angeles County's Homeless Preventive Initiative partnered with ALP to monitor and analyze the participants use of various services, including health, social, and law enforcement. In one pilot project, they found that providing homeless participants with rent subsidies and help accessing essential supportive services reduced homelessness, increased employment, and increased SSI approval of rates, leading to significant cost-savings of $11 million for pilot participants over two years

University of South Florida. At the University of South Florida, the Florida Mental Health Institute (FMHI) relies on its integrated database to study and promote several service system reforms for people with mental illness.[17] A Miami judge has worked with FMHI to analyze patterns of behavioral health services utilization and incarceration in the Miami-Dade County criminal justice system.[18] This study identified a group of mentally ill individuals who were "heavy-users" of behavioral health services and cycled frequently through the criminal justice system. Many of these individuals were unable to access care in the community. Left with no choice, they often accessed care through the most inefficient and most expensive points of entry including emergency rooms, acute crisis services, and ultimately the juvenile and criminal justice systems. As a result of

this analysis, Miami-Dade County is creating a sentencing alternative for those individuals in the heavy-user group who have committed minor crimes. These individuals will begin in a higher-security area, but eventually will move to a different part of the building for treatment to encourage their re-entry and reintegration back into society and to prevent recidivism.

Federal Agencies. 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 publically subsidized housing and whether supportive housing interventions will affect their health care utilization patterns.[19]

[1] Chakravarty, S., Cantor, J. C., Walkup J.T., & Tong, J. (2014). Role of Behavioral Health Conditions in Avoidable Hospital Use and Cost. New Brunswick NJ: Center for State Health Policy.

[2] Chakravarty, S., Cantor, J. C., & Tong, J. (2014) Avoidable Hospital Utilization, High Use and Cost: Analysis by Payer. New Brunswick NJ: Center for State Health Policy.

[3] Hempstead, K., DeLia, D., Cantor, J. C., Nguyen, T., & Brenner, J. (2014). The Fragmentation of Hospital Use Among a Cohort of High Utilizers: Implications for Emerging Care Coordination Strategies for Patients With Multiple Chronic Conditions. *Medical care*, *52*, S67-S74.

[4] Ibid.

[5] See Washington State Department of Health and Social Services Website, https://www.dshs.wa.gov/sesa/rda/research-reports/saving-costs-and-transforming-lives-through-integrated-case-management-washington-state-human-services.

[6] Mancuso, D. and Felver B., Bending the Health Care Cost Curve   by Expanding Alcohol/Drug Treatment (RDA Report 4:18,2010): https://www.dshs.wa.gov/sites/default/files/SESA/rda/documents/research-4-81.pdf

[7] AISP Network Site, State of South Carolina, http://www.aisp.upenn.edu/network-site/

[8] AISP Network Site, Rhode Island, http://www.aisp.upenn.edu/network-site/providence-plan/

[9] RI HUB, The Educational Costs of Unhealthy Housing, http://ridatahub.org/datastories/educational-costs-of-unhealthy-housing/1/

[10] AISP Network Site, New York, http://www.aisp.upenn.edu/network-site/cidi-nyc/

[11] NYC CIDI (2014). Paving the Way for a More Prosperous Future for Young Adults: Preliminary Results of an Outcomes Study of the Chelsea Foyer at the Christopher, http://www.nyc.gov/html/cidi/downloads/pdf/CIDI_Brief_Foyer_5_2014.pdf

[12] Ibid.

[13] AISP Network Site, New York, http://www.aisp.upenn.edu/network-site/cidi-nyc/

[14] See Chapter 190, Acts of 2010, http://mgaleg.maryland.gov/2010rs/chapters_noln/ch_190_sb0275e.pdf

[15] Maryland Longitudinal Data System Center Website, http://msa.maryland.gov/msa/mdmanual/25ind/html/50longitudf.html

[16] Morena, M. et al. (2009), The General Relief Housing Subsidy and Case Management Pilot Project: An Evaluation of Participant Outcomes and Cost Savings.

[17] University of Florida AISP Network Site, http://www.aisp.upenn.edu/network/network-sites/fl-university-of-southern-florida/

[18] Supreme Court of Florida (2007). Report on Constructing a Competent Criminal Justice, Mental Health and Substance Abuse Treatment Program.

[19] Executive Office of the President (2013), Office of Management and Budget, Next Steps in the Evidence and Innovative Agenda.