

New York State Department of Health

**Transparency,
Evaluation and
Health Information
Technology
Workgroup Interim
Report**

Interim Report to the Governor and
Legislature

December, 2014

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Workgroup Membership

Senator Kemp Hannon

Chair, Senate Committee on Health
New York State Senate

Assemblyman Richard N. Gottfried

Chair, Assembly Committee on Health
New York State Assembly

Mary Ann Christopher

President and CEO, VNS of New York

David Cohen, M.D.

Sr. Vice President Clinical Integration
Chairman, Department of Medicine
Maimonides Medical Center

Paul Francis

Board Member, NYS Health Foundation

Eugene Heslin, M.D.

Bridge Street Family Medicine

Victoria Hines

COO, University of Rochester Medical Faculty
Group

Russell Lusak

Sr. Vice President, Selfhelp Community Services,
Inc.

Luis Marcos, M.D.

CEO, Physicians Affiliate Group of NY (PAGNY)

Michael Mascari

Executive Director, AHRC

Mark McKinney

CEO, HIXNY

Larry McReynolds

President, Lutheran Family Health Centers

Theresa A. Pardo, Ph.D.

Director, Center for Technology in Government

Daniel E. Porreca

Executive Director, HEALTHeLINK

Lee Rambeau

Sr. Vice President,
Federation Employment and Guidance Services,
Inc.

Kenneth Raske

President and CEO, Greater New York Hospital
Association

Mary Kate Rolf, FACHE

President/CEO, Home Care of CNY, Inc.

Charles Scaglione

Executive Director, Bronx RHIO

Helen Schaub

Vice President, 1199 SEIU

Sanjiv Shah, M.D.

Medical Director, Fidelis Care NY

James D. Sinkoff

Executive VP Business and Information Services
& CFO, Hudson River Health Care

Susan Van Meter

VP of Federal Relations,
Healthcare Association of New York State
(HANYS)

Patricia Wang

CEO, HealthFirst

David Whitlinger

Executive Director, NYeC

State Team Members:

Courtney Burke

New York State Executive Chamber

Ian Brissette

New York State Department of Health

Mary Beth Conroy

New York State Department of Health

Jonathan Halvorson

New York State Department of Health

Johnathon Karmel

New York State Department of Health

Chris Nemeth

New York State Department of Health

Stefanie Pawluk

New York State Department of Health

Robert Pennacchia

Office of Information Technology Services

Hope Plavin

New York State Department of Health

John Powell

Department of Financial Services

Marleen Radigan

New York State Office of Mental Health

Patrick Roohan

New York State Department of Health

Anne Schettine

New York State Department of Health

Steve Smith

New York State Department of Health

Executive Summary

The Transparency, Evaluation and Health Information Technology Workgroup, convened in September 2014 consistent with Chapter 54 of the Laws of 2014, is charged with evaluating New York State's health information technology infrastructure and systems, and with submitting a report to the Governor and Legislature by December 1, 2014.

The workgroup, composed of a diverse group of consumers, payers, and providers, offers a preliminary set of recommendations which are summarized below. Given the evolving nature of health information technologies, much work has yet to be done and the workgroup will continue to meet to address outstanding issues and questions.

The State's health information technology infrastructure is multi-faceted and includes the Statewide Planning and Research Cooperative System (SPARCS), Medicaid data collection and reporting systems, the All Payer Database (APD), and the Statewide Health Information Network of New York (SHIN-NY). Each of these systems is summarized below:

- SPARCS is an all payer hospital discharge system established in 1979 as a public-private partnership between the health care industry and state government. SPARCS is a data base of hospital billing data for inpatient discharges and outpatient services, including visits to emergency departments, diagnostic and treatment centers, and extension clinics licensed for ambulatory surgery services.
- Medicaid data are collected for beneficiaries enrolled in New York State's government health insurance program for persons of all ages whose income and resources are insufficient to pay for their health care. Medicaid data are used for program administration, including quality measurement, rate setting, and evaluation activities.
- The APD, currently in development, will be the central repository for health care data across New York State. The APD will provide information about how and where health care dollars are spent, and help answer important questions for consumers, providers, employers and policy makers. Beginning with claims data, the APD will collect and integrate information to help the State understand the evolving needs of the health care system.
- The SHIN-NY is the statewide network of electronic health records collected through regional entities known as Regional Health Information Organizations (RHIOs) that will in the future be certified as Qualified Entities. The SHIN-NY provides the overarching structure and framework to support a fully interoperable system able to securely exchange health information between and among participating hospitals, providers, health plans and public health officials. The SHIN-NY, through the interconnected, statewide network of electronic health record systems is designed to improve health care for all New Yorkers by ensuring that doctors have access to information about their patients, anywhere and anytime.

Recommendations. The workgroup offers the following preliminary recommendations:

1. *Data Collection Should be Discrete, Meaningful, and Reliable.* The need to balance a desire for more data and better integrated data with privacy and security concerns was and is a central tension addressed by the workgroup with recommendations for future action.

2. *SHIN-NY Regulations*: A thorough review of comments offered as a result of the public rule-making process as well as issues and concerns noted in the body of this report, particularly those related to governance and privacy, will be considered over the coming months with recommendations published in the final report.
3. *Efforts to Promote the All Payer Database Should Continue*. The State should continue to work with stakeholders to develop and implement the APD as a means of understanding costs and quality, and to increase transparency of data for consumers, providers and payers.
4. *Minor Consent Must Continue To Be Studied And Evaluated*. Mechanisms to assure meaningful minor (ages 10-18) consent must continue to be explored and evaluated. Minor consent continues to be an outstanding issue that requires further investigation and consideration including development of policies that allow for the sharing of minor's medical records when appropriate.
5. *The State Must Continue To Promote Understanding of Opt-In and Opt-Out Provisions*. Additional work is required to evaluate how best to implement the SHIN-NY with respect to opt in and opt out provisions. For either option (opt in or opt out) consumer education will be needed to ensure that all New Yorkers understand how, when and with whom their health information is being shared.
6. *Evaluation of Provider Liability with Respect to Evolving Health Information Technology Must Continue*. Issues pertaining to provider liability should be further explored as they pertain to the potential use of erroneous data included in an electronic record, misuse of accurate information, and potential downstream breaches of data.
7. *Common Data Sets And Measures Across Payers And Providers Must Be Developed*. The State should develop a standardized scorecard that measures cost, quality and outcomes to assure that all New Yorkers have access to affordable and accessible high quality care.
8. *Mechanisms To Incentivize Use Of Interoperable, Electronic Health Records Should Be Explored*. The State should explore ways to incentivize the adoption and use of interoperable electronic health records for multiple provider types, including home care and social service providers to assure that electronic health information can be broadly shared across and between providers to promote health and wellbeing.
9. *Mechanisms For The Collection Of Non-Clinical Health Data Should Be Explored*. The State should explore options for collecting and integrating health and "non-health" data (i.e., housing) to create a more holistic picture of the individual, to address social determinants of health and to promote overall population health.

Not all issues were resolved as this report went to press. The recommendations offered provide a foundation for future policy discussions as New York continues the transformation to an integrated health care delivery system premised on a strong health information technology infrastructure.

Given the ongoing evolution of health information technologies, this workgroup will continue to meet to consider how these technologies will fit into the context of broader health care transformation initiatives, including the Delivery System Reform Incentive Payment (DSRIP) program and the State Health Innovation Plan (SHIP).

Workgroup Background & Charge

Chapter 54 of the Laws of 2014 requires the Commissioner of Health to convene a workgroup to focus on the State's health information technology infrastructure, and develop a report based on the workgroup's findings and recommendations. The charge is as follows:

"The commissioner shall:

(i) convene a workgroup to:

- A. evaluate the state's health information technology infrastructure and systems, as well as other related plans and projects designed to make improvements or modifications to such infrastructure and systems including, but not limited to, the all payer database (APD), the state planning and research cooperative system (SPARCS), regional health information organizations (RHIOs), the statewide health information network of New York (SHIN-NY) and medical assistance eligibility systems; and
- B. develop recommendations for the state to move toward a comprehensive health claims and clinical database aimed at improving quality of care, efficiency, cost of care and patient satisfaction available in a self-sustainable, non-duplicative, interactive and interoperable manner that ensures safeguards for privacy, confidentiality and security;

(ii) submit a report to the governor and the temporary president of the senate and the speaker of the assembly, which shall fully consider the evaluation and recommendations of the workgroup, on or before December first, two thousand fourteen."

This report fulfills this requirement and provides recommendations for the State to move toward a comprehensive health information technology infrastructure with robust data that promotes health care quality, efficiency and patient satisfaction.

Overview of New York State’s Health IT Infrastructure

Background information on each of the following health information systems provides the foundation for the evaluation and recommendations offered in this report: Statewide Planning and Research Cooperative System (SPARCS), Medicaid, the All Payer Database, and the State Health Information Network of NY (SHIN-NY). Further information about each of these systems can be found on the New York State Department of Health’s public website (<http://www.health.ny.gov/>). These information systems will provide benefits to many audiences; below are a few examples (Table 1).

Table 1: Potential Stakeholder Benefits of New York’s Health IT Infrastructure

Stakeholder	Benefit
State Policy Makers/Public Health	<ul style="list-style-type: none"> • Enable targeted public health initiatives and interventions based on strategic assessment of health care disparities; • Identify high-performing communities that provide cost-effective care; analyze that success in order to promote similar models; • Data to inform evaluation of reform efforts to identify and duplicate successful initiatives; identify new opportunities for reform; • Price transparency.
Health Plans	<ul style="list-style-type: none"> • Data on which to evaluate programs to implement improvements or expand upon successful programs; • Incentivize high quality and lower cost treatments; • Refine reimbursement models; • Measure and collect data related to safety, quality, utilization, health outcomes, and cost; • Modify contracts with providers in a geographic location based on the health needs of that area; • Compare health care facilities and providers on quality and cost.
Employers	<ul style="list-style-type: none"> • Empower businesses to design insurance products and select providers based on quality, cost, and efficiency; • Benchmark performance against peers, comparing cost and covered services of health insurance policies; • Provide access to information to enable better negotiations.
Providers	<ul style="list-style-type: none"> • Reduce collection and reporting burden due to transition to a coordinated data set; • Enhance treatment quality improvement with new coordinated feedback loops and performance benchmarking; • Strengthen quality measurement, and provide tools helping providers to better manage their entire panel of patients; • Enable clinicians and hospitals to determine fair market value for services and align operational incentives to maximize quality of care and minimize utilization and cost.

SPARCS

Background: The Statewide Planning and Research Cooperative (SPARCS) is an all payer (including self-pay and self-insured) hospital discharge system established in 1979 as a public-private partnership between the health care industry and state government. SPARCS requires reporting of hospital billing data for inpatient discharges and outpatient services including visits to emergency departments, diagnostic and treatment centers (D&TC) and extension clinics licensed for ambulatory surgery services. The enabling legislation and regulations for SPARCS are PHL§2816 and NYCRR Title 10 §400.18.

Table 2 below shows by year when data collection began for each type of SPARCS data, and the years that data are available to researchers for approved uses.

Table 2: SPARCS Data History and Years Available for Approved Use

Data Set	When Data Collection Began	Available Years
Inpatient	1982	1982 to Present
Ambulatory Surgery	1983	1983 to Present
Emergency Room	2005	2005 to Present
Outpatient Services*	2011	2011 to Present

*Hospital ambulatory surgery, emergency department, and outpatient services.

Data Uses and Oversight: SPARCS data use is established in regulation and is closely monitored by SPARCS program staff and a SPARCS Data Governance Committee. SPARCS data uses include: financial rate setting, developing and evaluating policy, epidemiology, health planning, resource allocation, quality of care assessment, health services research, surveillance, utilization review, geographic analyses (geo-coding), and linkages with other data sets, registries, such as vital statistics and the cancer registry. SPARCS data are used for calculation of patient safety, quality and efficiency metrics such as AHRQ Inpatient Quality Indicators (IQI) and Patient Safety Indicators (PSI), potentially preventable hospitalizations and readmissions.

Data Sources: SPARCS data are submitted according to designated national standardized HIPAA (Health Insurance Portability and Accountability Act) X12 837 formats. Health care facilities submit their SPARCS data in an electronic, computer-readable format through NYSDOH’s secure electronic network: the Health Commerce System (HCS). All SPARCS data must be supported by documentation in the patient’s medical and billing records

Infrastructure: SPARCS data is collected continuously, with a minimum monthly submission required by hospitals. Regulations require that data be complete, accurate and timely with all SPARCS data submitted within 180 days following the end of the month of the patient discharge/visit.

SPARCS data timeliness, quantity and quality is continually monitored by SPARCS program staff. Reports are made publicly available on the volume and completeness of data. Regulations adopted in September 2014 allow the SPARCS program to conduct quarterly quality reports for facilities reporting data, and hold facilities to compliance standards.

SPARCS Data Access: The table below shows the three levels of SPARCS data access: Identifiable, Limited and Public Use/De-identified files. The most restrictive data are the identifiable data requests, which after going through internal staff review, then go to a Data Governance Committee whose

recommendation must be ratified by the Commissioner. Table 3 below shows the three file types, contents and protocols for application and approved use.

Table 3: SPARCS Data Access

File type	Contents	Application process
Identifying/ Deniable Data Requests	Contain data elements that if disclosed without any restrictions on use or re-disclosure would constitute an unwarranted invasion of personal privacy	<ul style="list-style-type: none"> • Must submit application to the NYSDOH • Must be approved by the SPARCS Data Governance Committee and be ratified by the Commissioner • Unless exempt from payment, a fee is charged*
Limited	Data elements not defined as identifying/deniable data elements in SPARCS regulation (NYCRR Title 10 §400.18)	<ul style="list-style-type: none"> • Must submit application to the NYSDOH • Must be approved by SPARCS operations staff • Unless exempt from payment, a fee is charged
Public Use Files	Contain aggregated, de-identified data consisting of basic record-level detail. Public use files do not contain protected health information (PHI) under HIPAA	<ul style="list-style-type: none"> • No application required • Available on public websites (Health Data NY, Health Data Query System)

*The SPARCS fee may be waived in the following circumstances: (i) Use by a health care facility of the data it submitted to the SPARCS program; (ii) Use by a health care facility that is licensed under Article 28 of the Public Health Law for the purpose of rate determinations or rate appeals and for health care-related research; (iii) Use by a federal, state, county or local government agency for health care-related purposes.

Role of SPARCS in Self-Pay and Uninsured Data: SPARCS is a leading resource in hospital quality data, and is the only currently available source of claim level data for the self-pay and uninsured populations. Given that an estimated 12 percent of New York’s 19.3 million residents (or 2.27 million) are either self-pay or uninsured, SPARCS is an invaluable data resource that will be integrated into New York’s All Payer Database (APD) to ensure a holistic picture of care use by all New Yorkers.

Medicaid

Summary: Medicaid data are collected for beneficiaries enrolled in NYS government health insurance program for persons of all ages whose income and resources are insufficient to pay for their health care. With an estimated 29 percent of NYS residents covered by Medicaid, New York has the second largest Medicaid program in the nation (lead by California) with the highest per capita costs. Current enrollment is more than 5.9 million (as of November 2014). The annual cost is over \$50 billion.

Data Uses: Medicaid data are used for program administration. Some of the uses include the following: risk-adjusted payment models; service utilization monitoring; quality measurement; quality improvement and incentive programs; measuring access to needed health care services; measuring and risk adjusting health outcomes; patient safety and efficiency metrics; performance standards; disease measurement; policy and program development; fraud and abuse monitoring; drug rebate invoicing; health homes, patient-centered medical homes; and dual eligible (Medicaid/Medicare) analytics.

Types of Data:

- **Eligibility and Enrollment (Membership):** Upon enrollment, the Medicaid program collects beneficiary information including age, gender, race/ethnicity, zip code, etc. For every Medicaid beneficiary enrolled/eligible in Medicaid, monthly enrollment status information is updated.
- **Claims:** Fee-for-service (FFS) claims are transactions between a provider of care and Medicaid that includes information on the patient, the provider, diagnoses, procedures, and payment. Claim file types for Medicaid data include professional, institutional, dental and pharmacy. Claim level records include diagnosis codes, procedure codes and NDC pharmacy codes. Fee-for-service claim records contain the actual amount paid to providers, including capitation payments to health plans.
- **Encounters:** Managed care encounters are “pseudo-claims;” they look like a claim and contain almost all the same information, except no direct payment is associated with an encounter. Claims and encounters are stored in the same format and are analyzed across both FFS and managed care in a comparable manner. Managed care encounter records contain proxy costs at both the visit level and service line level, along with an indicator showing whether the proxy cost was part of a sub-capitated arrangement. Managed care encounter data, used for risk-based payment methodologies, are held to quality compliance standards. Monthly reports by category of service and other levels of aggregation are shared with health plans via the Health Commerce System (HCS) on a routine basis. Incomplete submission of encounter data may result in a Statement of Deficiency (SOD) to the health plan.

Infrastructure: Medicaid fee-for-service claims data are received and processed in a nationally recognized format (X12-837). Medicaid encounter data are received in a proprietary format, following the X12 national standard for data elements, with some New York State specific elements required for reporting. All data are received by the state fiscal agent with validation edits applied to the data to ensure quality standards are met. Once data are received and processed by the fiscal agent, Medicaid data are then stored in the eMedNY Medicaid Data Warehouse (MDW). From the MDW, individual data marts receive eligibility, claim, encounter and provider data feeds for analytical purposes. A data mart is an analytical subset of a data warehouse specific to a single program area or department (e.g., the OHIP Data Mart) to be used for analytical and application purposes.

The Medicaid program also collects and stores individual and facility-based provider information. Both billing and non-billing provider information is collected. Provider information contains multiple identification numbers per provider, including NPIs, legacy provider IDs, tax IDs and entity IDs. Provider name and address information is also collected.

Access: Medicaid data can be used only to assist in the administration of the Medicaid program, as stated by federal law. New York has shared data with various entities to assist in enrollment, develop payment rates, and provide analytics as well as research and evaluation of specific Medicaid initiatives. Individuals interested in obtaining claim level Medicaid data are directed to the NYS Department of Health Office of Health Insurance Programs (OHIP) Medicaid Data Privacy Coordinator for more information, including data use agreements.

All Payer Database

Background: New York State legislation, enacted in the spring of 2011, allows the creation of an All Payer Database (APD). The APD will allow policymakers, providers, consumers and payers to better address the complexities of the health care system by providing comparative information about how services are accessed, provided, and paid for across public and private payers.

The All Payer Database (APD) is envisioned as the central repository for health care data across New York State. The database will be structured to meet evolving information needs for the management, evaluation and analysis of the New York State health care system. The APD will serve as a key resource for consumer health care decision making. It will also support financial analyses, policy development, the monitoring of care quality and the promotion of health care innovation. The APD will help make the cost and quality of health care more transparent, and empower decision making for all stakeholders.

Many other states have developed All Payer Claims Databases (APCDs). These are secure databases, often created by state mandate, that typically include medical, pharmacy, and dental claims data received from both private and public payers. States are using APCDs for a variety of analyses including transparency reporting, cost comparisons, disease prevalence reporting, and total cost of care analysis. New York refers to its system as an “APD”, instead of “APCD” because a future goal is to expand the data base to include clinical and administrative data as well as public health data to promote overall health and well-being for all New Yorkers. Initially, the APD will begin with claims and encounter data.

APD Uses: The APD will provide information about how and where health care dollars are being spent, and help answer important questions for consumers, providers, employers and policy makers. It will collect and integrate information to help the State understand the evolving needs of the health care system.

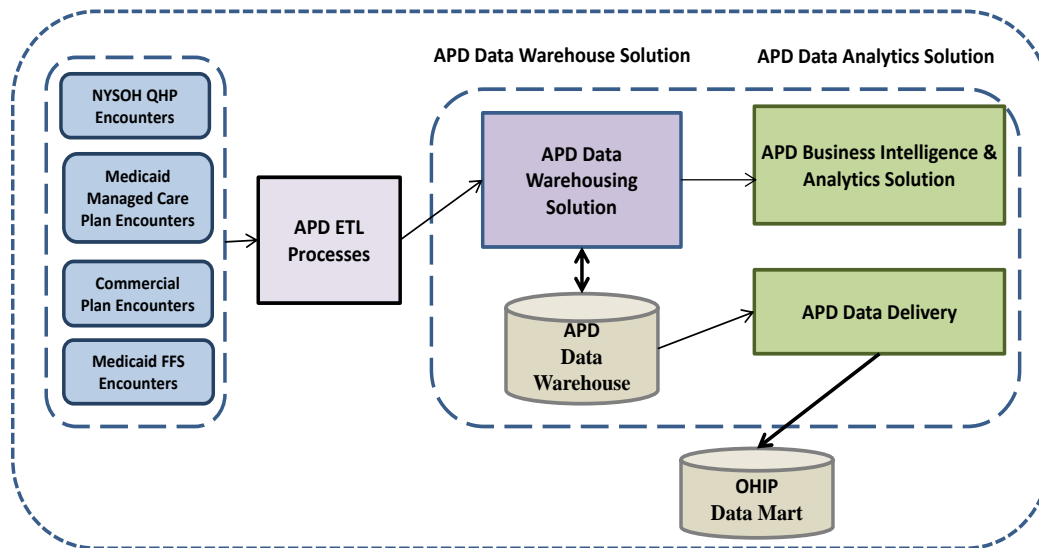
Data Sources: When fully operational, multiple data sources will populate the APD. The initial data intake strategy will focus on the collection of public payer data from the New York State of Health Qualified Health Plans (QHP). Data sources included in the APD will be expanded to include Medicaid Managed Care, Child Health Plus encounter data and Medicaid Fee for Service claims data. Medicare data will be incorporated through purchase from CMS. Large group commercial data collection will follow in 2015. As the APD evolves over time, other types of information will be incorporated, including public health repositories, and clinical and laboratory information from the Statewide Health Information Network for New York (SHIN-NY). In the long term, the APD will provide a comprehensive repository of information for all participants in the health care system, from policy makers and payers, to clinicians and consumers.

Infrastructure: The Department's approach to the development of the APD focuses on three solutions depicted in Figure 1.

1. The Data Intake Solution will collect and edit claims data from numerous health insurers.
2. The Data Warehousing Solution will store the data received from all the different sources.
3. The Data Analytics Solution will include two components: the APD Business Intelligence and Analytics solution, which will facilitate data analysis and reporting; and the APD Data Delivery solution, which will produce extracts and de-identified data sets for researchers and other stakeholders approved through a data governance process.

New York is currently developing the APD in phases. The Data Intake Solution is in development. Technology vendors will be procured for the permanent storage and analytics solutions in 2015. The State will be launching a competitive procurement process to identify a vendor who can contract with the State to build the storage and analytic components. It is anticipated that access to the APD will not begin until sometime next year. APD data governance and access will be determined through regulations, currently under internal DOH review.

Figure 1: Planned All Payer Database Technical Infrastructure



Please refer to Appendix A for a reference list of acronyms used in Figure 1.

Access: Draft regulations propose that all entities seeking APD data be required to submit a request to the NYSDOH using standard data request forms. Data users will:

- be required to take all necessary precautions to prevent unwarranted invasions of personal privacy resulting from any data analysis or release;
- be prohibited from release of any information that could be used, alone or in combination with other reasonably available information, to identify an individual who is a subject of the information; and
- bear full responsibility for breaches or unauthorized disclosures of personal information resulting from use of APD data.

Applications for APD data must provide an explicit plan for preventing breaches or unauthorized disclosures of personal information of any individual who is a subject of the information. The State will ensure access to APD data is secure and compliant with all state and federal laws including HIPAA and the HITECH Act.

Next Steps/Status: For the remainder of 2014 and early 2015, APD milestones include:

- release of the Data Warehouse and Analytics Solutions Request for Proposals (RFP);
- publication of draft APD regulations, and;
- first round testing and quality assurance for the newly developed New York State of Health (NYSoH) intake system (the first building block of the APD infrastructure).

SHIN-NY

Summary: The Statewide Health Information Network of New York (SHIN-NY) is a developing mechanism by which health care information can be exchanged among participating hospitals, providers, health plans and public health officials in a secure and trusted framework. The SHIN-NY when fully operational will provide health information exchange (HIE) services such as direct messaging and patient record look-up to all participating entities. The SHIN-NY is governed by the NYSDOH and currently facilitated by the New York eHealth Collaborative, Inc. (NYeC). The future framework is envisioned to include Qualified Health IT Entities (QEs) – formerly called Regional Health Information Organizations (RHIOs) – in regions across the state that work with and connect health care providers at the local level that in turn communicate with one-another to create a statewide network – the SHIN-NY.

When fully operational the SHIN-NY will connect hundreds of hospitals, thousands of medical providers and millions of people who live in or receive care in NYS. The SHIN-NY will be a secure, interconnected, statewide network of electronic health record systems designed to improve health care for all New Yorkers by ensuring that doctors have access to information about their patients, anywhere and anytime. For instance, the network would allow an emergency room doctor treating an unconscious patient in Buffalo to instantly receive the patient's full medical history, including past procedures and relevant allergies from her primary care physician in Brooklyn. The network will be governed by federal HIPAA and State privacy and security policies and standards.

The regional organizations (Qualified Health IT Entities, currently RHIOs) that form the SHIN-NY have successfully built robust networks over the last several years by collaborating with community stakeholders to make sure their local communities are best served. Today, current adoption rates (connections to a RHIO and sharing information) are approximately as follows:

- 83% of New York State hospitals
- 78% of Federally Qualified Health Centers (FQHCs)
- 56% of public health departments
- 35% of home care agencies
- 26% of long-term care and post-acute providers
- 18% of ambulatory physicians
- 14% of clinical practice sites

History and Background: Since 2006, New York State has invested in technology and operational capacity to mobilize statewide health information exchange (HIE) to improve the quality of patient care, reduce costs, and realize the vision of more effective, collaborative care. Through the Health Care Efficiency and Affordability Law of New York (HEAL-NY) grant program, New York State invested more than \$400 million to advance health IT adoption and develop a statewide health IT infrastructure as part of its strategy to transform New York's health care delivery from a siloed, paper-based system to an electronic, interconnected system.

A primary focus of the investment has been on the existing RHIOs located across the state. These not-for-profit organizations evolved individually under the direction of local stakeholder boards of directors. Their focus has been to address the needs of their local communities. While the entire geography of the

State of New York is serviced by at least one RHIO, there has not been a consistent, standardized statewide approach to the delivery of health information exchange services. To create this statewide approach the Department contracted with the New York eHealth Collaborative (NYeC)) to help support the State in its development and implementation of a statewide health information technology and exchange strategy. NYeC has facilitated the Statewide Collaboration Process (SCP) that brings stakeholders together to recommend policies and standards for health information exchange to the Department.

On September 3, 2014, the Department, under Public Health Law §206(18-a)(b) published a Notice of Proposed Rule Making to add a new Part 300 to Title 10 (Health) of the New York Codes, Rules and Regulations. The proposed regulation delineates the following:

- Legal requirements for the State Designated Entity, the QEs and the QE Participants (including health care providers and health plans that access patient information using the SHIN-NY).
- Codifies SHIN-NY policy standards including policies that had been incorporated into the HEAL-NY grant contracts and continue to be updated under the statewide collaboration process.
- A governance structure and process for operation of the SHIN-NY to advance health information technology adoption and use on a statewide basis for the public good.
- Introduces the concept of a Qualified Health IT Entity (QE) as a not-for-profit entity (i.e., a RHIO) that has successfully completed a certification process to ensure that it meets minimum technical standards for the sharing of health information in a secure and confidential manner and provides a standard set of technical and member-facing services to its constituents.

Future Uses: By providing a standard set of technical and member-facing services, the proposed QEs will make it possible to immediately share health information through electronic health records to:

- Ensure that doctors can provide the best quality care by having complete access to a patient’s medical history, including medication, laboratory and radiology reports. This can be critical in emergency room situations, if a patient is unconscious or unable to communicate.
- Improve quality care for chronically-ill patients who need several doctors to collaborate while addressing different aspects of their disease or illness.
- Serve as a mechanism to facilitate achieving the goals and objectives of a number of state initiatives such as SHIP, DSRIP and Performing Provider Systems, Patient-Centered Medical Homes, ACOs, etc.

Data Sources and Infrastructure: Under the proposed regulation, hospitals and hospital-based physician practices and clinics that utilize certified EHR technology will be required to connect to a QE within two years from the date of promulgation of the final regulation. Health care providers across the United States are adopting certified EHR technology under the federal Health Information Technology for Economic and Clinical Health Act (HITECH), which is providing ‘meaningful use’ incentive payments under Medicaid and Medicare. The SHIN-NY is intended to dovetail with the federal effort to create a nationwide health information exchange system under the auspices of the United States Office of the National Coordinator for Health Information Technology.

Access to the Data: The proposed regulations are consistent with the section of HITECH codified in 42 USC § 17938, and permit sharing of patient information among disparate health care providers. The QEs must enter into and adhere to participation agreements with providers that comply with federal requirements for “business associate” agreements under HIPAA and for “qualified service organization” agreements under 42 CFR Part 2. The regulations stipulate that written authorization would be required to access patient information made available through the QEs. Exceptions to this authorization requirement would be made when an emergency condition exists under the doctrine of implied/presumed consent; health care providers may “break the glass” and access information as needed to provide emergency treatment. The proposed regulations incorporate legal requirements related to disclosure of patient information, including certain disclosures without consent, such as those currently mandated to be reported to the government for public health and health oversight purposes.

Next steps: Comments submitted in response to publication of the proposed regulations, published in the September 3, 2014 NYS Register, will be reviewed along with comments and recommendations offered by members of the HIT Workgroup. As the regulatory analysis is being completed, the RHIOs will continue to prepare for QE certification. Certification includes compliance with established minimum technical and administrative services. Upon full QE certification, statewide patient record look-up (PRL) will be fully available across NYS, as well as direct messaging, and notifications/alerts. These services have the potential to greatly support the work that needs to be done by the PPSs created under DSRIP and as part of health system redesign as envisioned under the SHIP.

Provider adoption continues to be a primary focus. Currently about 83% of NYS hospitals and 78% of Federally Qualified Health Centers utilize EHRs and are connected to a RHIO for the sharing of patient information. Private practice adoption is much lower. While approximately 79% of NYS physicians utilize EHRs, only about 18% are connected to a RHIO and share information. During SFY 2014-2015, the RHIOs will continue to reach out to providers (approximately 7,000) to promote connection to a RHIO.

The Promise of Big Data: How These Systems Fit Together

Health data, particularly “big data” that can grow exponentially, holds the promise of a better understanding of the health status of all New Yorkers, support of best practices to promote health and well-being, assure efficient health system utilization and reduce costs. The systems described in this report are each unique, yet they are part of a greater whole that will inform health quality, cost and value decisions. At the same time, these evolving systems and mechanisms face great challenges with respect to confidentiality, security and appropriateness of data collection, access and use. This vast array of data – as described in the taxonomy below - is crucial for health planning and evaluation.

Table 4: Taxonomy Used by HHS Data Crucial for Health Data and Statistics Planning

(SOURCE: Adapted from HHS Data Council (2007))

Health Data	Elements
Demographics and Socioeconomic Data	Age, sex, race, ethnicity, education, and related demographic/socioeconomic variables
Health Status Data	Individual health status, including morbidity, disability, diagnoses, problems, complaints, and signs and symptoms as well as behavioral and health risk factor data
Health Resources Data	Capacity and characteristics of the provider, plan, or health system
Health Care Utilization Data	Nature and characteristics of the medical care visits, encounter, discharge, stay, or other use of health care services. Includes time, data, duration, tests, procedures, treatment, prescriptions, and other elements of the health encounter
Health Care Financing and Expenditure Data	Costs, prices, charges, payments, insurance status, and source of payment
Health Care Outcomes	Outcomes of prior or current prevention, treatment, counseling, or other interventions on future health status over time in a cyclical, longitudinal process
Other Factors	Genes and proteins, environmental exposures

Widespread EHR adoption and implementation, together with cost and claim data available from an APD, is intrinsic to future ability to measure cost and quality, and to use this information to drive improvements (better care, improved outcomes and lower costs, or at least more affordable cost). Critical to this endeavor (achieving the Triple Aim) is the ability to effectively share data with all who will benefit – providers, payers and consumers -- and to ensure security and confidentiality.

Electronically available health data today includes claims data and clinical data that can be linked across sources to provide a more holistic picture of health and health care. This affords an opportunity to assess clinical outcomes over time, but also creates the risk of data being linked in a way that could jeopardize privacy, employment, or insurance eligibility. To address these concerns, sources and holders of electronic health information are expanding beyond HIPAA protections for personal health records (PHRs). Additionally, in areas such as personal EHRs, electronic solutions to protect and secure data

continue to evolve, including the emergence of approaches that allow individuals to control consent to others to follow their data.

The need to balance a desire for more data and better integrated data with privacy and security concerns was and remains a central tension addressed by the workgroup with recommendations for future action. The group noted the importance of ensuring that data collection is discrete, meaningful, and reliable.

NYS Data Sources. Data collected by the State fall into two broad categories: administrative and clinical. Administrative data includes claims data such as that collected through Medicaid, the APD, and SPARCS. In addition to these systems, the NYSDOH collects vital statistics data on births and deaths, as well as surveillance data to monitor outbreaks of certain diseases. Clinical data includes the information provided in an EHR, or in a medical record and can be both electronic and paper based. The SHIN-NY will be the primary source of clinical data across the state.

The information to be included in the APD will initially focus on claims and encounter data from Medicaid, commercial insurers, and Medicare. Some of this information is currently captured in SPARCS and the Medicaid Data Warehouse. The APD will include new data from the Qualified Health Plans in the New York State of Health (NYSOH), the State's health plan marketplace, as well as data from commercial insurers once regulations are finalized.

While many other states have "All Payer Claims Data Bases (APCDs)," New York's intent is to have an "All Payer Database" that will include numerous data sets that go far beyond claims and may include clinical data from the SHIN-NY (i.e., laboratory values, Meaningful Use measures), health assessment data, public health datasets (i.e., birth data, immunizations), and non-health data (i.e., housing, criminal justice). The State will need to determine its authority in integrating these data sources into the APD, and these additional datasets will need to be evaluated and prioritized in a meaningful manner. To link these varying data sources, a master patient index will need to be developed, as well as data governance rules regarding matching, linking, and releasing data for specified purposes.

Figure 2: Initial Design with APD and SHIN-NY Unconnected

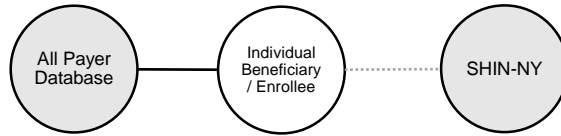
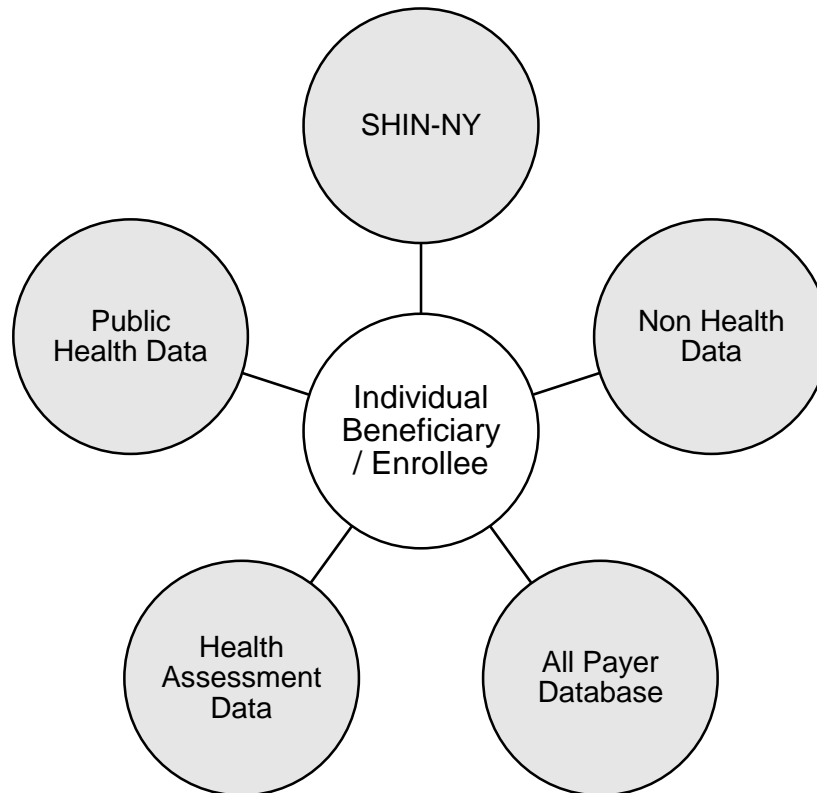


Figure 3: The Future: Systematic Integration of Data Sets to Evaluate and Drive Program and Policy



Data Type	Data Contents
Individual Beneficiary / Enrollee	Enrollment, Eligibility
SHIN-NY	<ul style="list-style-type: none"> • Clinical Data from Electronic Health Records • Meaningful Use • Laboratory Values • Other Clinical Detail
Public Health Data	<ul style="list-style-type: none"> • Birth Data • Immunization Registry • Cancer Registry • HIV Registry • Death Data, etc.
Health Assessment Data	<ul style="list-style-type: none"> • Minimum Data Set (MDS) • Outcome and Assessment Information Set (OASIS) • Uniform Assessment System (UAS) • Office of Mental Health Assessments, etc.
All Payer Database	<ul style="list-style-type: none"> • Medicaid Fee for Service Claims • Medicaid Managed Care Encounters • Medicare • Commercial • Child Health Plus
Non-Health Data	<ul style="list-style-type: none"> • Social Determinants of Health Data <ul style="list-style-type: none"> ○ Criminal Justice ○ Housing ○ Etc. • Employment Data

Future Policy Considerations

Creation of a single, cross sector health dataset inclusive of claims and clinical data will provide a wealth of information that can be used to inform health policy from a holistic perspective. While potentially quite powerful, care must be taken to ensure privacy, prevent misuse or abuse, and assure use in a manner that promotes overall health and well-being.

Effective implementation of the frameworks and taxonomy discussed in this report is made challenging by the wide distribution of data across systems and the significant fragmentation of the data on varying software platforms. Currently, data are collected and held in many places—by the patient, provider(s), payers, and government repositories for public health and planning purposes. Few places today have comprehensive, longitudinal views about individuals. The inability to connect data that may include risk factors, medical history, and interventions in a comprehensive way is a fundamental flaw in existing EHR systems. This challenge is being addressed in New York State by the Statewide Health Information Network of New York and the All Payer Database, which together, will help integrate clinical data.

Data challenges also include disparate collection mechanisms. Some of the data collected—such as diagnosis codes (ICD), procedure codes (CPT), medication (National Drug Code or NDC), and other administrative data as required in HIPAA administrative and financial transactions—are high quality, coded, and computerized. Laboratory data are becoming increasingly standardized and codified. However, most other data are not available in a computerized form, or are generally in free unstructured text even when it is saved in electronic format. EHRs offer the opportunity for computerization and codification of additional key data elements in structured data fields; however, EHR penetration is not universal.

After three workgroup meetings, one meeting of the legal sub-workgroup, and numerous communications through email, a number of issues, challenges, and opportunities were identified. The workgroup recognizes that these issues and challenges require continued conversation. A summary of outstanding issues is provided below.

A. LEGAL CONCERNS

Legal issues associated with evolving health information technologies and data bases span multiple systems and initiatives. A legal sub-workgroup was convened to investigate and evaluate issues related to consent, liability, security, and confidentiality. Each topic area is highlighted below.

(1) Consent

Consent, particularly with respect to specific groups or individuals such as adolescents or persons with HIV infection, continues to be a concern. As currently structured, EHRs do not allow for “data segmentation.” As a result, providers have full access to the complete patient record or none at all. Conflicting perspectives on how to best address this situation persist and an appropriate solution has yet to be developed.

Under New York law, minors may generally receive medical treatment only with the consent of a parent or guardian.ⁱ However, New York has long recognized that minors, under certain circumstances, must have the ability to control certain aspects of their medical care and to consent to their own treatment in certain circumstances. Additionally, certain categories of minors have a

broader right to consent to any and all medical care. Married minors,ⁱⁱ pregnant minorsⁱⁱⁱ and minors who are parents themselves^{iv} have a statutory right to consent. New York law also gives emancipated minors the right to make their own health care decisions without the consent of a parent or guardian.^v

When minors consent to their own medical treatment, they generally have the right to withhold information about such treatment from *their parents or guardians*. However, each minor consent service is governed by a different law or regulation. Whether health care providers may disclose information about minor-consented treatment to *other health care providers* for treatment purposes without that minor's consent depends on the type of information being disclosed.

(2) Liability

Liability for providers using data in their EHR was identified as a potential concern. Providers may want to be guaranteed from the incorrect use of good and accurate data as well as the correct use of inaccurate data that they provide for the SHIN-NY. In addition, concerns related to possible malpractice and the potential for downstream breaches of PHI were noted. As more data becomes available through the SHIN-NY and a provider's EHR, assurance of reliability and confidentiality are needed to protect providers from unwarranted liability.

(3) Security

Security of information stored in electronic health data systems is critical to ensuring public trust and the proper use of data. The State must have in place the utmost protections against security breaches, especially regarding private health information and identifiable personal information. When procuring new IT services, the State must ensure that vendors are prepared to abide by stringent security standards with processes in place to avoid breaches. Security is critical to the success of all components of the State's technology infrastructure and is a priority with regard to the SHIN-NY, SPARCS, APD, and Medicaid data.

(4) Confidentiality

Like security, confidentiality is critical to the success of these systems. Measures are currently in place to ensure that an individual cannot be identified by anyone who does not have authority to access such information.

Confidentiality is an issue for providers, hospital systems, and payers who may supply sensitive information that should not be shared due to its status as a trade secret and confidential information. In developing and implementing these emerging data systems, every effort must be taken to ensure appropriate confidentiality protections.

(5) Sharing of Price Data – Trade Secret and Antitrust Concerns

A. Trade Secrets. The State's authority to collect price data from health plans, as proposed under the All Payer Database, was questioned by the group with respect to trade secret protections. More specifically, the authority for the state to legally supersede existing contracts between providers and payers that stipulate confidentiality (i.e. negotiated prices that cannot be disclosed pursuant to

contract or statute). Additional analysis is required to determine how, when and if price data may be shared.

B. Anti-Trust. Anti-trust concerns were raised with respect to the state’s authority to collect and share price data through the All Payer Database. Initial discussion by the legal sub-workgroup suggest that key to this determination is how information would be made available, to whom and its intended use(s). If the intended use of data is benign the state is the entity collecting and sharing data, and there is no collusion, anti-trust is not likely to be a concern. Furthermore, if anti-competitive behavior is noted, it would be policed in the normal manner under state law.

Other states, including Massachusetts, do collect and share price information. New York will meet with representatives from Massachusetts and other states to better understand issues encountered with respect to releasing price information and discuss these issues with stakeholders in New York.

(6) APD Data Collection and Release

A. Self-insured data. Does NYS have the authority to require third party administrators to submit claims data to the APD? Collection of data for persons who are self-insured is currently the subject of ongoing litigation in the State of Vermont. New York will need to monitor the lawsuit closely and discuss the collection of such data with employer groups and coalitions in the State. It should be noted that through SPARCS, the State has and continues to collect hospital discharge data from patients who may be covered under a self-insured plan.

B. Private Physicians. When the APD is expanded to include population health and clinical data, how might the Department compel private physicians to submit data? The authorizing legislation provides broad authority for the collection of data.

C. Hospital and Provider pricing data. The legal sub-workgroup will continue to evaluate the state’s authority to post this information publicly. New York will look to other states collecting and posting this information for additional guidance and best practices.

B. PROGRAMMATIC CONCERNS

(1) Need for Common Data Sets/Measures Across Payers and Providers

Workgroup members noted a need for common datasets across multiple providers and payers. More specifically, commonalities across Medicaid performing providers systems (PPSs), were noted as needed to ensure consistent measurement and reporting and to reduce administrative reporting burden. In addition, alignment between physical and behavioral health measures and the importance of including non-traditional providers (i.e. social services, housing, etc.) in future data collection efforts were recognized as important future goals.

It was noted that an important goal for the State is to produce an analytical resource that offers evidence-based assessments of different payment reforms, in order to identify those that produce better outcomes, lower costs, and a better experience of care.

(2) Data Resources for Community-Based Providers

A key consideration for future action is the current limitation faced by community-based organizations in their ability to collect and share data. Lacking infrastructure and resources, these providers, who are key to the success of many emerging health delivery systems including PPS's, are currently not able to share or connect with systems such as the APD or the SHIN-NY. Currently this data is often collected outside the EHR but can be useful in demonstrating good outcomes. This type of technology should be further explored for its relevance to the goals of DSRIP.

(3) Electronic Health Records (EHRs) for Post-Acute and Community-Based Providers

Lack of EHR funding for post-acute and community-based providers was noted as a barrier to participation in evolving health information systems. It was recommended that the State explore funding mechanisms for home care, case management, housing, and senior centers to ensure that they are able to participate in evolving health information systems. It was noted that these providers have been slower to adopt EHRs due, in part, to ineligibility for federal meaningful use incentives and limited access to other technology funding programs such as HEAL-NY.

Funding for client based in-home technologies was also noted as a challenge. Currently, client based in-home data for tracking patient progress is collected outside the EHR, which is problematic because it can be useful in demonstrating good outcomes. It was suggested that this type of technology be explored.

(4) Creation of a Master Patient Index

As the state begins to link data across multiple sources, a Master Patient Index (MPI) will need to be developed to measure health delivery and outcomes across providers on a patient-specific basis. The MPI is needed to link data among sources like the SHIN-NY, APD, and SPARCS, and eventually with public health data sets and social determinants of health data. If the State develops an MPI, it must solve for the following issues:

- a. *Data integrity*: Not all data sources can be used for real time clinical decision support. Data may be inaccurately entered by a patient in the home, or measured and reported inaccurately.
- b. *Strength of the match*: Use of patient-specific information for treatment decisions requires a high level of confidence in the data. In contrast, use of patient-specific data for broader research and evaluation may require slightly less strength or confidence that data across systems for a specific individual has been matched accurately. Matches of varying strength and accuracy are likely to have different possible uses.
- c. *Prioritization of datasets for linking*: Possible datasets for linking across systems should be prioritized, with a potential roadmap for other datasets and growing linkages.
- d. *Data Governance*: Access to the MPI data and how to maintain confidentiality of the data is of critical import.

(5) All Payer Database (APD)

Outstanding questions related to creation, implementation and operation of the APD include the following:

- a. *Data on the uninsured.* Since the APD will include data collected from health plans, the uninsured individuals' data will not be captured in the APD. Because SPARCS collects data on hospital discharges, the State may be able to account for those receiving hospital care without insurance. The State should consider other ways to capture the uninsured population in the APD.
- b. *How to include* and link data that is not claims data such as data related to social determinants of health. The State will need to explore other data sources that might be included as part of or linked to the APD. New York's All Payer Database is envisioned to become a larger database where other sources of data could be included, beyond claims data. The State will need to consider if it has the authority to link data across disparate collection mechanisms to support the social determinants of health, including housing and employment data, and how difficult it shall be to operationalize and link these data sources.
- c. *Use of APD in evolving reimbursement methodologies.* The State will need to explore how new reimbursement methods such as full capitation and bundled payments will fit into the APD since some models will 'mask' some details that may be useful to evaluating quality, costs and outcomes.
- d. *Sustainability.* In developing the APD, supporting regulations, and strategies to support a changing system, special attention should be paid to sustainability. Benefits of the data may not be realized if costs for providers and other data users are not affordable.
- e. *Data Collection and Reporting Burden.* Workgroup members recommended that special thought be given to ensuring data collection does not cause a reporting burden. To mitigate reporting burden it was suggested that the State evaluate the most efficient methods of data collection.

(6) Medicaid Data

Appropriate sharing of Medicaid data, consistent with privacy protections, across providers and sites of care is noted as an ongoing concern. This is particularly important given evolving programmatic and organizational structures such as PPS, which seek to better integrate and communicate across providers and sites of care, and for entities to be responsible (fiscally and programmatically) for individual health outcomes that are dependent on services provided by a wide array of providers.

Providers in the workgroup requested timely Medicaid eligibility data for serving high need populations who may be eligible for Medicaid but are not currently enrolled. The accessibility and timeliness of such data could support attribution and enrollment, thereby promoting population health. Delays and limited data currently are a barrier to effective implementation.

(7) Electronic Health Records (EHRs)

Workgroup members noted that many EHR vendors exist (nearly 150 vendors), but most EHRs don't communicate well with one another, despite the existence of data standards. EHRs that lack the ability to connect with other EHRs or the SHIN-NY compromise their effectiveness. Members emphasized that the State must continue to play a role in promoting national EHR standards, and leverage the expansion of existing standards where possible.

(8) The Statewide Health Information Network of NY (SHIN-NY)

Workgroup members recommended that the SHIN-NY requirements and Meaningful Use (MU) phases be better coordinated and aligned to ensure that hospitals, physicians and other providers are eligible for the Medicare and Medicaid EHR Incentive Payment Programs, and not subject to penalties.

The role of the SHIN-NY in supporting many of the goals and objectives of DSRIP was noted as a critical issue. An ability to share data between and among PPS providers was noted as key to the provision of coordinated care for the population. It was suggested that PPS's may want to utilize relationships with their local QEs to access the SHIN-NY and facilitate more effective data sharing. The State should facilitate such relationships. Other suggestions included a recommendation that SHIN-NY and tele-health be further explored by the State and that rigorous and transparent performance benchmarks are needed for all entities participating in the SHIN-NY to ensure trust in the SHIN-NY and predictability for QE participants.

Recommendations

The following recommendations are offered for consideration by the workgroup. In many instances, additional work is required to ensure that we meet our ultimate goals of delivering high quality, high value care that promotes optimal health and well-being for all New Yorkers.

1. Data Collection Must be Discrete, Meaningful, and Reliable

The need to balance a desire for more data and better integrated data with privacy and security concerns remains a central tension addressed by the workgroup with recommendations for future action. The group noted the importance of ensuring that data collection is discrete, meaningful, and reliable.

2. Public Comment and Workgroup Recommendations Regarding Proposed SHIN-NY Regulations Must be Rigorously Reviewed and Evaluated.

A thorough review of comments offered as a result of the public rule-making process as well as issues and concerns noted in the body of this report, particularly those related to governance and privacy, is recommended. This review should address and resolve at a minimum the following considerations prior to issuing a Revised Rule Making:

- SHIN-NY Governance models
- Confidentiality of data collected and shared. It was suggested that State indemnification and appropriate legislative protection from liability for breach be explored.
- Sharing of and access to patient information
- Transparency and accountability
- Patient consent
- Financing of the SHIN-NY
- SHIN-NY technical standards
- Minor consent
- Clear and transparent SHIN-NY performance benchmarks to ensure trust in the SHIN-NY and predictability for QE participants.

3. Continue to Develop and Promote the All Payer Database

The APD is an important tool that will provide payers, consumers, and providers' information on which to base informed decisions. It was recommended that NYS continue to work with stakeholders to develop regulations to guide APD implementation. Some workgroup members expressed concern about the collection and potential release of pricing information at the provider level, and urged careful thought and consideration moving forward. It was also recommended that the State explore lessons learned from other states with increased price transparency and consumer tools, and provide a forum for stakeholders to discuss and deliberate the models in place and how they could be implemented in New York. Some members of the workgroup suggested that the state consider alternatives to "prices" such as proxy pricing, based on derivatives of RBRVS, DRGs, etc., to provide information on cost and quality.

Additional areas identified by the workgroup that will require consideration as the APD is developed include:

- a. Mechanisms for capturing data on the uninsured
- b. How best to capture non-health such as data from community-based providers
- c. How to overcome instances, such as bundled payments, that will 'mask' some details that may be useful to evaluate quality, costs and outcomes
- d. Long-term sustainability of the system
- e. Structuring data collection and reporting mechanisms to minimize burden on the reporting entity and to avoid duplication where possible.

4. Continue to Evaluate Minor Consent

Mechanisms to assure meaningful and appropriate minor (ages 10-18) consent must continue to be explored and evaluated. Minor consent requires further investigation and consideration including development of policies that allow for the sharing of minor's medical records when appropriate as well as technological advances that support segmenting of records. Minor consent, specifically when minors receive confidential health care services, continues to be an outstanding issue. These issues must be addressed within the context of the SHIN-NY regulations.¹ Several possible minor consent options raised by workgroup members are highlighted below:

Rochester Model:

- Allows for parental consent for non-minor consented services.
- Allows for minor consent for minor-consented services.
- If minor denies consent, no information is available (i.e. minor denial "overrides" parental affirmative consent).
- If minor doesn't consent; interrupted as a yes.

Let the Data Flow Model:

- Parental consent is consistently maintained.
- When receiving minor-consented services, a minor can override a parent's negative consent on a case-specific basis, temporarily giving information access to provider of minor-consented services.
- Protection of inappropriate disclosure of minor-consented services is dependent on:
 - i. Provider education regarding appropriate disclosure;
 - ii. Providers of minor-consented services seeking waiver from DOH from the requirement to upload their data to a QE; and

¹ The proposed SHIN-NY regulation states: "QEs and Participants may, but shall not be required to, subject Sensitive Health Information to certain additional requirements, including but not limited to providing patients the option to withhold certain pieces of Sensitive Health Information from access via the SHIN-NY governed by a QE. In the event that a QE or a Participant has provided a patient the option to withhold certain pieces of Sensitive Health Information from access via the SHIN-NY governed by a QE, and the patient has exercised that option, the patient's record when accessed via the SHIN-NY governed by a QE may, but is not required to, carry an alert indicating that data has been withheld from the record." Privacy and Security Policies and Procedures for Qualified Entities and their Participants in New York State, Version 3.1, June 2014. Section 1.4.2. Any recommendation should permit QEs and Participants to do what this section 1.4.2 explicitly permits them to do.

- iii. Additional information included on records of patients from ages 10-18 regarding the fact that records on the SHIN-NY contain information that should not be disclosed to others in order to protect confidentiality.

Rochester/Let the Data Flow Hybrid Model:

- Parent consents for non-minor consented services and gets access through the patient portal.
- A health care provider, using professional judgment, may give a minor patient over the age of 12 the opportunity to object to consent. If the patient objects to consent, the health care provider may flip the no consent flag if the provider determines that SHIN-NY access may be detrimental to the patient (see PHL § 18 (2)(c) and PHL § 18 (3)(c)).
- If minor denies consent, no information is available, including through the patient portal (i.e. minor is treated as an adult for purposes of giving consent).
- If minor doesn't object, interrupted as a yes, i.e. minors must opt out.
- Protection of inappropriate disclosure of minor consented services is dependent on:
 - iv. Provider education re: appropriate disclosure
 - v. Additional re-disclosure message on records of minor patients regarding potential of records on the SHIN-NY containing non-re-disclosure information and need to protect confidentiality.

Another model the State might consider would be one in which the parent can consent to share health information of minors other than “minor consent patient information” and minors can consent to share minor consent health information. For example, a parent could consent to allow a 17-year old daughter’s health information to be accessed via the SHIN-NY, but if the daughter received medical care without her parents’ knowledge, the daughter could withhold the records concerning her treatment and bar access via the SHIN-NY, based on her statutory right; the remainder of the daughter’s data would continue to flow.

In general, it was noted that minor consent solutions should be workable in the current and emerging technology environment and avoid the unintended consequence of preventing parents from helping their minor children access quality care. EHRs currently in use generally include all of a patient’s medical record or none of it, and they do not permit data segmentation of a patient’s medical record. Therefore, even if model (d) is recommended, QEs may need to use model (a), (b) or (c) as an interim solution.

Consent to mental health treatment for minors was also noted as an area worthy of further discussion. Under Mental Hygiene Law, section 33.21, in certain circumstances a clinician can provide mental health treatment to a minor without the consent or knowledge of the parent, on the basis of the clinician’s judgment, not based on a right of consent or confidentiality held by the minor patient. In this circumstance, only the treating clinician is in a position to judge whether release of treatment data to the SHIN-NY, or anyone else, is in the child’s best interest, and therefore permissible.

5. Promote Understanding of Opt-In and Opt-Out Provisions

The State Must Continue To Promote Understanding of Opt-In and Opt-Out Provisions. Additional work is required to evaluate how best to implement the SHIN-NY with respect to opt in and opt out provisions. For either option (opt in or opt out) consumer education will be needed to ensure that all New Yorkers understand how, when and with whom their health information is being shared.

New York State is currently an opt-in state for access to personal health information available via the SHIN-NY. This means that although a patient's data is uploaded and available via a QE, explicit patient consent must be provided in order for a provider to access that information. Consent is done at the QE Participant level, meaning that before a provider can access a patient's data, they are responsible for obtaining patient consent to do so. While many individuals have chosen to opt-in (approximately 33% of all New Yorkers have provided consent to one or more providers and 97%-98% have been affirmative) there are concerns that individuals' understanding of the options available may not be as robust as possible, and additional education may be appropriate.

6. Evaluate Provider Liability with Respect to Evolving Health Information Technology

Provider adoption of EHRs, connecting to a QE and sharing information via the SHIN-NY is critical to a number of NYS initiatives (i.e. DSRIP, ACOs, PCMHs, etc.). Providers expressed concerns that information provided to the SHIN-NY may be inappropriately utilized by other SHIN-NY participants. It was recommended that the State address potential liability concerns associated with inappropriate use of information accessed through the SHIN-NY as well as inaccurately reported or recorded information and the potential for downstream breach of confidentiality.

7. Assure Common Data Sets/Measures Across Payers and Providers

A standardized scorecard to measure the impact of innovative reform efforts on cost and quality across all payers was recommended. The scorecard can then be modified by individual providers or payers to meet unique needs, goals and objectives.

It was also recommended that the State explore mechanisms to support an analytical resource that offers evidence-based assessments of different payment reforms, with the goal to identify those that produce better outcomes, lower costs, and a better experience of care.

8. Incentivize Use of Electronic Health Records

Interoperable EHRs are the foundation of value-based payment programs and health care transformation. They allow tracking of services to patients by different providers, give insurers and providers quality of care information, and enable insurers to link provider reimbursement to the quality of care. But infrastructure development requires investment and training. Because capital needs are high, all avenues of investments should be explored and shared. DOH, in conjunction with DFS, other state agencies, and stakeholders, can develop targets for increased EHR investments and development.

The State should explore ways to incentivize the adoption and use of interoperable electronic health records for multiple provider types, including home care and social service providers to assure that electronic health information can be broadly shared across and between providers to promote health and well-being. In addition it was recommended that the State explore mechanisms for providing funding to support EHRs for home care, social service providers, and entities that may not have been eligible for Meaningful Use or HEAL-NY funding.

9. Promote Mechanisms for the Collection of Non-Clinical Health Data

Non-clinical health data was discussed frequently during workgroup meetings as important drivers of health. These types of data are increasingly being utilized by PPS's and others seeking to include the social determinants of health in efforts to promote population health and improve individual health outcomes. It was recommended that the State explore options for collecting and integrating health and "non-health" data (i.e., housing) to create a more holistic picture of the individual, to address social determinants of health and to promote overall population health.

Conclusion

New York is a leader in not only health information technology, but also in its vision of advancing statewide innovation to strengthen population health, transform the health delivery system and decrease per capita health care costs. Health information technology is one of the tenets to achieving these goals. The rich sources of data that will be available through the APD, together with the SHIN-NY, will support more sophisticated analytics. For example, this information can be used to evaluate and inform policies related to outcomes, costs and quality. Together, these rich sources of data will create and support an analytical resource that offers evidence-based assessments of different delivery and payment system reforms, with the goal to identify those that produce better outcomes, lower costs, and a better experience of care.

As technology and health care delivery systems continue to evolve, outstanding issues remain. To bring further resolution to the areas listed in this report, members of this workgroup have expressed an interest in continuing to meet. There is much to gain for the State, providers, payers, and consumers in having a robust health information technology infrastructure on which to support clinical integration, transparency, new payment models, and continuous innovation to promote health and well-being for all New Yorkers.

Appendix

Appendix A: Resources

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Appendix B: Summary of Acronyms and Abbreviations

The following table contains a comprehensive listing of all the acronyms and abbreviations used in the Health Information Technology Report to the Legislature.

Acronym/Abbreviation	Description
AHRQ	Agency for Healthcare Research and Quality
APCD	All Payer Claims Databases
APD	All Payer Database
Article 28	Article 28 facility refers to licensed hospitals which are established, operated, and regulated under Public Health Law Article 28 and the DOH regulations in Title 10 of the Codes, Rules and Regulations of the State of New York.
Article 31	Article 31 are New York State Mental Hygiene facilities.
CAHPS	Consumer Assessment of Health Providers and Systems
CFR	Code of Federal Regulations
CPT	Current Procedure Terminology
DFS	Department of Financial Services (New York State's Insurance Department)
DSRIP	Delivery System Reform Incentive Payment Program
EHR	Electronic Health Records
eMedNY	New York's Medicaid Management Information System (MMIS)
ETL	Extract, Transform, Load
FFS	Fee-for-Service
HCS	Health Commerce System
HEAL	Healthcare Efficiency and Affordability Law
HEDIS	Healthcare Effectiveness Data and Information Set
HHS	Health and Human Services
HIE	Health Information Exchange
HIPAA	Health Insurance Portability and Accountability Act
HIT	Health Information Technology
HITECH	Health Information Technology for Economic and Clinical Health
ICD-9-CM	International Classification of Disease Coding Methodology
ID	Identification Number
IQI	Inpatient Quality Indicators
IT	Information Technology
MDS	Minimum Data Set
MDW	Medicaid Data Warehouse
MPI	Master Patient Index
MU	Meaningful Use
NDC	National Drug Classification Code
NPI	National Provider Identification Number
NQF	National Quality Foundation
NYeC	New York eHealth Collaborative

Acronym/Abbreviation	Description
NYSDOH	New York State Department of Health
NYSOH	New York State of Health (New York’s Health Insurance Marketplace)
OASIS	Outcome and Assessment Information Set
OHIP	Office of Health Insurance Programs
OMH	Office of Mental Health
OQPS	Office of Quality and Patient Safety
PCP	Primary Care Provider
PHI	Personal Health Information
PHR	Personal Health Record
PPS	Performing Provider System
PSI	Patient Safety Indicators
QE	Qualified Entity
QHP	Qualified Health Plans
RFP	Request for Proposals
RHIO	Regional Health Information System
SDE	State Designated Entity
SHIN-NY	Statewide Health Information Network of New York
SOD	Statement of Deficiency
SPARCS	Statewide Planning and Research Cooperative
UAS	Uniform Assessment System
USC	United States Code
X-12	The nationally recognized format for electronic claim submission.

ⁱ See *Bonner v. Moran*, 126 F.2d 121, 122 (D.C. Cir. 1941) (“[T]he general rule is that the consent of the parent is necessary for an operation on a child.”); *Alfonso v. Fernandez*, 606 N.Y.S. 2d 259, 262 (App. Div. 2d Dep’t 1993) (recognizing the common law rule requiring parental consent of the provision of health services to a minor); *In re Rosebush*, 491 N.W. 2d 633, 683 (Mich. App., 1992) (“It is well established that parents speak for their minor children in matters of medical treatment.”).

ⁱⁱ N.Y. Pub. Health L. § 2504(1) (“[A] minor who...has married may give effective consent to medical, dental, health and hospital services for himself or herself, and the consent of no other person shall be necessary.”). Because the law applies to a minor who “has married,” a minor who is divorced should also be able to consent to his or her own care. As of yet, NY courts have not ruled on this issue.

ⁱⁱⁱ N.Y. Pub. Health L. § 2504(3) (“Any person who is pregnant may give effective consent for medical, dental, health and hospital services relating to prenatal care.”)

^{iv} N.Y. Pub. Health L. § 2504(1).

^v Under the Family Health Care Decisions Act adopted by New York in 2010, an “emancipated minor” is defined as either a person 16 or over and living independently from their parents, or a minor who is a parent him or herself. N.Y. Pub. Health L. § 2994-a(8) (2010). However, outside the context of health care decision-making for an incapacitated patient, emancipation is understood to be a much broader category. Under New York case law, a minor is deemed emancipated when they marry; when they enter the armed services; or if they become economically independent through gainful employment or the parents of the minor seeking emancipation have defaulted on their parental support obligations to the minor.