New York State Department of Health

Health Information Technology Workgroup Final Report

Final Report to the Governor and Legislature

December 2015

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Executive Summary

The Transparency, Evaluation, and Health Information Technology Workgroup convened in September 2014, pursuant to Chapter 54 of the Laws of 2014, is charged with evaluation of New York State's health information technology infrastructure and systems. A final report to the Governor and the Legislature is required by December 1, 2015. Background, deliverables to date, recommendations, and a summary of ongoing discussions are detailed below.

Background: This Workgroup was convened to assess and make recommendations regarding policies and initiatives that together comprise the State's evolving health information technology infrastructure. These initiatives include the New York State Planning and Research Cooperative System (SPARCS), New York's Medicaid data systems, the All Payer Database (APD), and the Statewide Health Information Network of New York (SHIN-NY) as summarized in Appendix B.

Over the past year, two major discussion topics have been considered by the Workgroup: SHIN-NY and APD regulations. In addition, evolving initiatives to promote transparency and to develop a common quality of care measure set, meaningful to payers and providers alike, have been discussed at length with corresponding recommendations noted below.

Recommendations: The Workgroup offers the following recommendations:

1. *Efforts to increase the usage of the SHIN-NY, the health information exchange for the State of New York, must continue*.

2. *The APD, which holds the promise of being a rich, comprehensive database for policymakers, consumers, researchers, and public health officials, must continue to be supported through full implementation inclusive of all payers, as well as public health data and eventual linkage with the SHIN-NY.*

3. *As technologies evolve and data collection capabilities increase, the NYSDOH must continue to ensure that data collected are discrete, meaningful, and reliable.*

4. *A common set of measures to support the "Advanced Primary Care Model", being developed as part of New York's State Innovation Model (SIM) testing grant, should be developed.*

5. *Provider liability with respect to evolving electronic health information technology must continue to be monitored and evaluated.*

6. *Mechanisms for the collection of non-clinical health data to inform population health should continue to be explored.*

New York continues to be a leader in its vision of advancing statewide innovation to strengthen population health, transform the health care delivery system, and decrease per capita health care costs. Health information technology is foundational to achieving these goals. The data that will be available through the APD, together with the SHIN-NY, will support more sophisticated analytics.

As health information technologies evolve in sophistication and capabilities, issues surrounding data governance, policy, access, privacy, security, transparency, and alignment are likely to be of critical importance. Continuing maintenance and support of the State's health reform efforts compels this Workgroup to continue meeting in an advisory role to provide guidance and recommendations that assure a vibrant, well-functioning health information technology infrastructure well suited to promoting the Triple Aim as envisioned under the State's Health Innovation Plan.

Workgroup Background & Charge

Chapter 54 of the Laws of 2014 required 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, in relevant parts, is as follows:

"The commissioner shall convene a workgroup to:

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 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;

submit an interim report to the governor, the temporary president of the senate and the speaker of the assembly, which shall detail the concerns and issues associated with establishing the state's health information technology infrastructure considered by the workgroup, on or before December first, two thousand fourteen;

and submit a report to the governor, 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 fifteen."

The interim report "New York State Department of Health: Transparency, Evaluation, and Health Information Technology Workgroup Interim Report"[1] was released in early 2015 and included a summary of the Workgroup's activities to date.

This final report fulfills the legislative 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.

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[1] The interim report is available at the following link:
https://www.health.ny.gov/technology/innovation_plan_initiative/docs/2014-12_hit_interim_report.pdf

Health Information Technology: Foundational to Health Policy, Planning, and Promotion

Health data holds the promise of a better understanding of the health status of all New Yorkers, identifies and supports best practices to promote health and well-being, and promotes efficient health system utilization and use of resources. The systems described in this report are each unique, yet they are part of a greater whole that together will inform health quality, cost, and value decisions. These evolving systems and mechanisms face 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 – and the subsections that follow is crucial for health planning and evaluation.

Table 1: 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

Promoting and Supporting Health Reform: As noted by Porter and Lee,[2] "rigorous measurement of value (outcomes and costs) is perhaps the single most important step in improving health care." Health Information Technology and its ability to collect, maintain and report data is central to proposed health care reform proposals that seek to contain costs, improve access, and save lives. In fact, almost a decade ago (2006), the Agency for Healthcare Research and Quality (AHRQ), noted that broad and consistent use of HIT will:

- Improve health care quality or effectiveness;
- Increase health care productivity or efficiency;
- Prevent medical errors and increase health care accuracy and procedural correctness;

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[2] https://hbr.org/2013/10/the-strategy-that-will-fix-health-care

- Reduce health care costs;

- Increase administrative efficiencies and health care work processes;

- Decrease paperwork and unproductive or idle work time;

- Extend real-time communications of health informatics among health care professionals; and

- Expand access to affordable care.

While much has been learned and achieved to date, much remains to be done. The availability of timely, accurate, and comprehensive health information is foundational to achieving the goals and objectives of New York's State Health Innovation Plan (SHIP), the State's Delivery System Reform Incentive Payment Program (DSRIP), as well as New York's Health Benefits Exchange, and the State's Prevention Agenda. A robust health information infrastructure, including a health information exchange (the SHIN-NY), and an All Payer Database (APD) will together provide a platform for sharing critical clinical and administrative information to support and inform consumers, providers, payers, and other health care stakeholders to promote quality and assure value.

A key focus of New York's SIM grant and DSRIP is to enhance and bring the medical home model to scale, supported by a value-based payment system, skilled workforce with a strong emphasis on primary and community-based care, and a common set of quality metrics. Performance improvement and capacity expansion in primary care will only be possible with the support of leading-edge health information technology, including an all payer database and greatly-enhanced capacities to exchange clinical data, as well as a common scorecard, shared quality metrics, and enhanced data/analytics to assure that delivery system and payment models support Triple Aim objectives.

For the New York State Health Innovation Plan, health information technology and the work of this Workgroup is foundational to the overarching plan and vision. Robust data systems are needed to evaluate access to care, develop and operate new models of care, create new payment models, and monitor population health in new and innovative ways. The systems highlighted in this report are essential to the objectives of the SHIP and are central to achieving transformation in health care with the goal of supporting the Triple Aim – healthier people, better health and consumer experience, and smarter spending.

Figure 1: The State Health Innovation Plan – Pillars and Enablers

Goal	Delivering the Triple Aim – *Healthier people, better care and individual experience, smarter spending*				
Pillars	**Improve access to care for all New Yorkers, without disparity** Elimination of financial, geographic, cultural, operational barriers to access appropriate care in a timely way	**Integrate care to address patient needs seamlessly** Integration of primary care, behavioral health, acute and post-acute care, and supportive care for those that require it	**Make the cost and quality of care transparent to empower decision making** Information to enable individuals and providers to make better decisions at enrollment and at the point of care	**Pay for health care value, not volume** Rewards for providers who achieve high standards for quality and individual experience while controlling costs	**Promote population health** Improved screening and prevention through closer linkages between primary care, public health, and community-based supports

Enablers			
Workforce strategy	A	Matching the capacity and skills of our health care workforce to the evolving needs of our communities	
Health information technology	B	Health data, connectivity, analytics, and reporting capabilities to support clinical integration, transparency, new payment models, and continuous innovation	
Performance measurement & evaluation	C	Standard approach to measuring the Plan's impact on health system transformation and Triple Aim targets, including self-evaluation and independent evaluation	

Measuring Cost and Quality: Widespread Electronic Health Record (EHR) adoption and implementation within clinical practices, together with cost and claim data available from the APD, is intrinsic to the State's 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, policy makers, 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. Electronic solutions to protect and secure data continue to evolve, including the emergence of approaches that allow individuals to control consent to others to access 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 tenet addressed by the Workgroup with recommendations for future action. The Workgroup noted the importance of ensuring that data collection is discrete, meaningful, and reliable.

NYS Data Sources: A Vision of the Future

Health 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 such as HIV and cancers.   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 vision is a comprehensive and integrated data set capable of supporting and promoting health policies and programs throughout the State.

The information to be included in the APD will initially include claims and encounter data from Medicaid and the Qualified Health Plans in the New York State of Health (NYSoH), the State's health plan marketplace. In subsequent waves, commercial data and Medicare data will be added.

While many other states have "All Payer Claims Databases (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 (i.e., Minimum Data Set (MDS), Uniform Assessment Tool (UAT) and the Outcome and Assessment Information Set (OASIS)), public health datasets (i.e., birth data, immunizations), and non-health data (i.e., housing, criminal justice). The State should integrate these data sources into the APD, and these additional datasets will need to be evaluated and prioritized in a meaningful manner. Currently, systems in NYSDOH are siloed – Medicaid, SPARCS, public health data follow a format similar to Figure 2, as stand-alone data systems. The APD will change this approach and have a more comprehensive "patient-centric" view of the data (see Figure 3).

To link these varying data sources, a master patient index (MPI) will need to be developed, as well as data governance rules regarding matching, linking, and releasing data for specified purposes. The APD procurement includes a project task to create a MPI, as well as tools to mask and encrypt data.   For most research, a de-identified data set is sufficient. One of the goals of the APD design is to allow matching of identifiable data sets to occur in a secure environment, and to release only de-identified data to users.   This model is scalable, as new data sets could be added through time that will be matched in the secure environment.

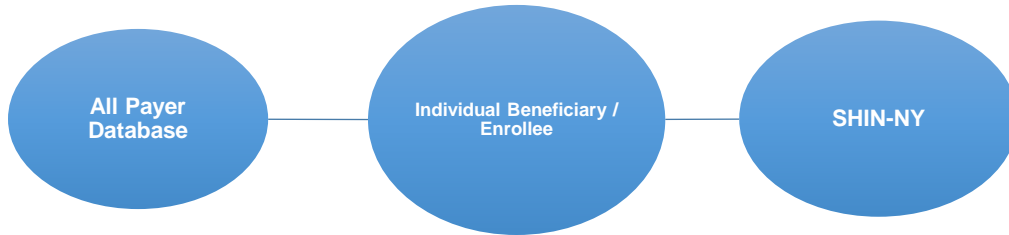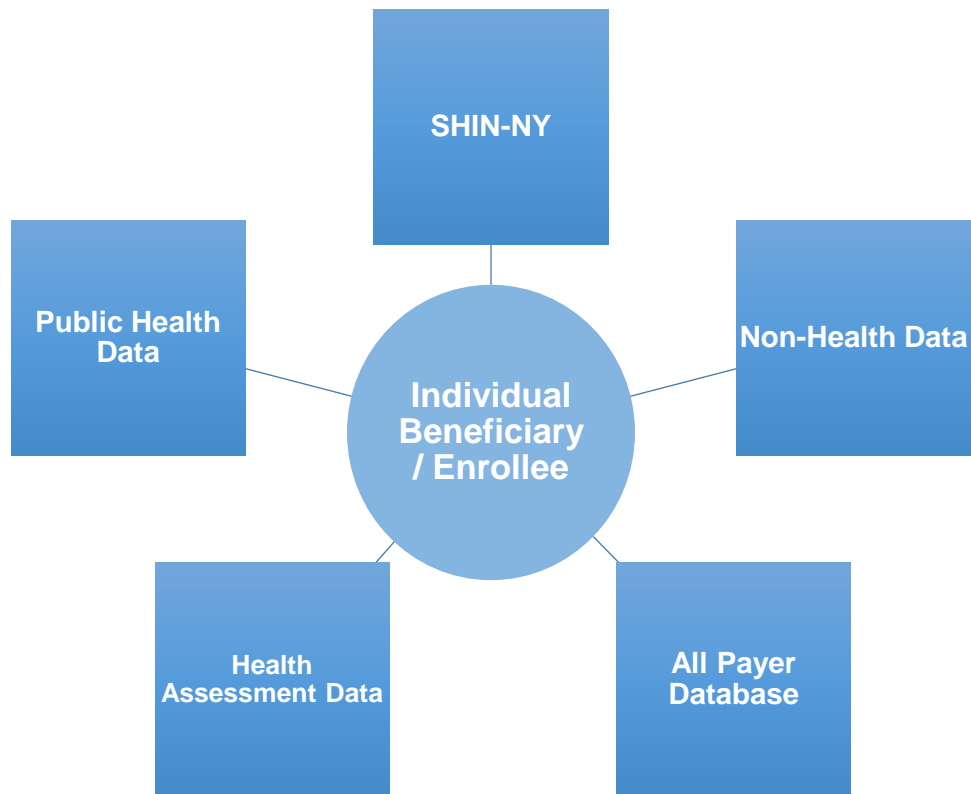**Figure 2: Initial Design with APD and SHIN-NY Unconnected**

All Payer Database — Individual Beneficiary / Enrollee — SHIN-NY

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

SHIN-NY

Public Health Data

Non-Health Data

Individual Beneficiary / Enrollee

Health Assessment Data

All Payer Database

Data Type	Data Contents
Individual Beneficiary / Enrollee	Enrollment, Eligibility
SHIN-NY	• Clinical Data from Electronic Health Records • Meaningful Use Data Set • Laboratory Values • Other Clinical Detail
Public Health Data	• Birth Data • Immunization Registry • Cancer Registry • HIV Registry • Death Data, etc.
Health Assessment Data	• Minimum Data Set (MDS) • Outcome and Assessment Information Set (OASIS) • Uniform Assessment System (UAS) • Office of Mental Health Assessments, etc.
All Payer Database	• Medicaid Fee for Service Claims • Medicaid Managed Care Encounters • Medicare • Commercial Claims/Encounters • Child Health Plus • Qualified Health Plan Encounters
Non-Health Data	• Social Determinants of Health Data

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/) and in Appendix B. These information systems provide benefits to many audiences for numerous purposes; below are a few examples (Table 2).

Table 2: Potential Stakeholder Benefits of New York's Health IT Infrastructure

Stakeholder	Benefit
State Policy Makers/ Public Health	• Enables targeted public health initiatives and interventions based on strategic assessment of health care disparities; • Identifies high-performing communities that provide cost-effective care and analyze that success in order to promote similar models; • Creates a source of data to inform evaluation of reform efforts; • Provides information to promote evaluation of care and services based on price and quality data.
Health Plans	• Provides source(s) of data to evaluate plans and programs to implement improvements or expand upon successful programs; o Incentivize high quality and lower cost treatments; • Refines reimbursement models; • Measures and collect data related to safety, quality, utilization, health outcomes, and cost; • Modifies contracts with providers in a geographic location based on the health needs of that area; • Compares health care facilities and providers on quality and cost.
Employers	• Informs Benefits Managers on how to select and purchase insurance products based on quality, cost, and efficiency; • Benchmarks performance against peers, comparing cost and covered services of health insurance policies.
Providers	• Reduces collection and reporting burden through use of standardized measures; • Promotes quality care with timely information and performance benchmarking; • Helps providers understand the cost of services in a value based purchasing environment; • Enables clinicians, institutional, home, and community based providers to determine fair market value for services and align operational incentives to maximize quality of care and minimize utilization and cost.
Consumers	• Provides information on quality and cost to assist with making informed health care decisions including selection of providers and plans.
Researchers	• Provides comprehensive data to allow for meaningful analysis of the State's health care system, health payment models, health delivery mechanisms and consumer engagement.

Findings and Recommendations

1. ***Efforts to increase the usage of the SHIN-NY, the health information exchange for the State of New York, must continue.***

The SHIN-NY has developed over time, originally with HEAL 5 funding, to support health information exchanges and with the establishment of the statewide collaboration process, established policies and operational standards for Regional Health Information Organizations (now QEs) to securely exchange health information. This has led to development of a certification process to ensure the QEs meet the minimum core requirements to exchange data, along with security and privacy policies and procedures. A significant amount of provider and hospital participation has already been achieved throughout the state.

As a result of comments on the initial proposed rule, released September 2014, establishing the SHIN-NY in regulation, the NYSDOH's most recent proposed rule, released November 2015, includes significant policy revisions from the earlier version. Changes include a greater focus on SHIN-NY transparency and performance, removing guidance documents that had previously been incorporated by reference, and removing the concept of "state designated entity" from regulation. These changes are intended to allow flexibility for QEs, participants, and the NYSDOH in implementing technology and policy guidance in support of the SHIN-NY.   A new proposed rule was released on November 4, 2015 which outlines:

- The NYSDOH's activities in establishing the SHIN-NY including reporting on functionality, security, and performance of the SHIN-NY and establishing a network to support statewide patient record look-up.
- Requirements of QEs in maintaining a minimum set of core services, connecting to services established by the NYSDOH to support statewide patient record look-up, reporting to the NYSDOH on performance, adoption, and usage along with submitting to audits by the NYSDOH and a certification process.
- Patient consent requirements for access to data on the network, including how information resulting from minor-consented health services could be shared and exceptions to consent requirements in instances allowed by Public Health Law such as for communicable disease control and emergencies where a patient is unable to consent.
- A requirement for certain health care facilities to participate in the SHIN-NY if they use Meaningful Use certified electronic health record technology. Those facilities include Article 28 facilities, long term care, hospice, and home care. This provision also allows the Commissioner to grant waivers for those facilities who are unable to connect due to technical or economic reasons.

Beyond the key issues addressed in the regulation, patient consent issues are a top priority to resolve; specifically the key areas of minor consent and community wide consent. The SHIN-NY must establish a way to deal with minor consented health information to ensure that data can be appropriately shared among health care providers. The HIT Workgroup discussed information about two interim methods to ensure that minors receiving minor consented health services, such as treatment for sexually transmitted diseases, mental health services, or family planning services, can consent to have their health information accessed by providers and ensure that sensitive health information is protected from inappropriate disclosure. While the desired goal is to have a technical solution to segment and isolate

this and other sensitive data types, that solution is years away from widespread deployment. The SHIN-NY regulations allow, but do not require, providers to restrict the release of their data. If implemented by health facilities, this would enable patients to restrict the release of sensitive health information including minor consented information.

Although there is a desire to implement community wide consent among some stakeholders, significant federal legal barriers exist. The Workgroup discussed multiple consent models to ensure patients can easily consent access to their health information while maintaining security and confidentiality, including opt-out, community-wide opt in, multi-participant consent and individual participant consent. Federal consent requirements regarding the sharing of alcohol and substance abuse treatment information limit the ability to implement community wide consent where an individual may consent to allow current and future providers to access their data. Therefore, the current methods of individual participant consent and multi-participant consent are the only methods that adhere to federal law and can be used in the SHIN-NY.

Coordinated care activities, including those related to Performing Provider Systems (PPSs) in DSRIP and value-based purchasing activities, should use the SHIN-NY as the vehicle for clinical data exchange to improve care. Ensuring that providers in different care settings have access to clinical information, such as care plans, medications, problem lists, diagnoses, and other items, will be vital to care improvement.

Finally, the NYSDOH should accelerate its efforts to promote multiple provider types to connect to and exchange clinical data through the SHIN-NY. While over 90 percent of hospitals are currently connected to a QE and sharing data, physician adoption is currently at low levels. Urgent care centers, home health, nursing home, and social service providers should also be incentivized and assisted in exchanging data via the SHIN-NY. The State is using various mechanisms to promote adoption of the SHIN-NY and health information exchange overall, including a requirement of all Article 28 facilities to be connected to the SHIN-NY in the proposed regulations. The NYSDOH is looking into other mechanisms to promote adoption, including through contracts and quality incentive programs. The Medicaid program is also committed to having all PPS networks connect to their regional QE.

2. ***The APD, which holds the promise of being a rich, comprehensive database for policymakers, consumers, researchers, and public health officials, must continue to be supported through full implementation inclusive of all payers, as well as public health data and eventual linkage with the SHIN-NY.***

The Workgroup Interim Report recommended that the State continue to work with stakeholders to develop and implement the APD as a means of understanding costs and quality, and to increase healthcare transparency for consumers, providers, and payers. It acknowledged that the All Payer Database will be an important tool to monitor quality of care, population health, and care cost trends. Subsequent to the Interim Report, the APD data intake system began collection of data from the New York State of Health (NYSoH) Qualified Health Plans, as well as Medicaid and Child Health Plus managed care health plans. In 2016 the data intake system will be further expanded to collect commercial data and Medicaid Fee-for Service claims. Medicare data acquired from the Centers for Medicare and Medicaid Services (CMS) will also be integrated into the APD. Additionally, a vendor for data warehousing and analytics has been selected by the NYSDOH as the result of a competitive procurement process; a vendor award package is under Executive review.

Development of proposed regulations has been an ongoing effort since fall 2014. The enabling legislation for the APD is found in the 2011 renewal of SPARCS legislation containing enhanced language that expands data collection to health care claims data and provides for new operating components set to function as separate systems. Draft APD regulations seek to further define the new system with parameters for health care payer submission of data and for release of data to requestors and policymakers.

Major regulatory issues were researched, analyzed, and presented to the workgroup and included: the extent to which payer or provider identifiable information is shared with requestor, particularly where claims payment information is involved; how review and approval of data requests will be managed by a governance process; under what circumstances and parameters the NYSDOH may charge fees for access to APD data; and the appropriateness of including certain provider payment data. The workgroup discussed recommendations which were considered by the DOH when editing draft documents.

Throughout the regulations development process, there has been a strong emphasis on stakeholder input and feedback, including interagency collaboration between the NYSDOH and the Department of Financial Services, feedback from the national APCD Council and an informal APD advisory group, and regular presentation of updates and development issues at HIT Workgroup meetings. Work continues to secure further stakeholder input and feedback.

In May 2015, a regulatory concept paper for the APD was presented to the NYSDOH Regulatory Advisory Committee and a set of documents for submission of a formal regulatory package was completed in July 2015. The NYSDOH has finalized the formal APD regulatory package and it is expected that they will be available for a formal public comment period in February 2016.

3. *All health data collected must 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.

- Regardless of source, data needs to be reliable, valid, and auditable to insure its usefulness. Ongoing efforts will be needed to assure that the data collected is assessed for completeness, timeliness accuracy and that the State has adequate oversight measures in place to address data anomalies.

4. *Development of a common set of measures to support the "Advanced Primary Care (APC) Model that is being developed as part of New York's State Innovation Model testing grants must continue and should adhere to the following principles:*

- Measures need to fit the purpose of the APC model. Measures need to evaluate whether APC standards are in place and working effectively, as well as measuring patient experience, clinical quality, and avoidable costs.
- Measures used in APC should strive toward alignment and parsimony. Measures should be aligned across payers, serve multiple purposes within APC and without, and are aligned with other federal, state, and regional collection and reporting programs (e.g. Meaningful Use, QARR).

- Measures should be valid, reliable, tested and used, and endorsed by the National Quality Forum (NQF), the National Committee for Quality Assurance (NCQA), or other endorsing organizations.
- Measures need to be meaningful to patients, payers, and providers.
- Measures need to provide opportunity to improve health and measures that will influence the health care delivery system.
- Measures need to be balanced between acute and chronic measures and process and outcome measures.

A review of current measurement sets in New York, as well as from other states and nationally, was conducted by NYSDOH to select a core set of 20 measures as a starting point. A copy of the 20 measures is included in Appendix D. These 20 measures are being discussed and vetted with the State Health Innovation Plan's Integrated Care Workgroup, one of the several workgroups being convened under SIM, and the process will continue through the rest of 2015 to fine tune this list of measures. Feedback overall has been favorable.

5. **_Provider liability with respect to evolving electronic health information technology must continue to be monitored and evaluated._**

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. Further clarification and legal review is needed to better understand the responsibilities of data partners in the use of data by downstream providers.

6. **_Mechanisms for the collection of non-clinical health data should continue to be explored_**.

The State will continue to 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. The state will also assess non-traditional health care data such as personal health devices and in-home technologies to determine their effect on population health management.

Conclusion

New York is a leader in health information technology and in its vision of advancing statewide innovation to strengthen population health, transforming the health delivery and payment systems, and promoting the most efficient use of health care resources. Health information technology is one of the building blocks 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 data sources will create and support an analytical resource that offers evidence-based assessments of evolving 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, issues surrounding governance, policy, access, privacy, security, and alignment are likely to continue. To ensure the systems described in this report support the State's health reform efforts as enumerated in the SHIP, support the development of aligned measurement, and evolve health transparency efforts, this Workgroup will continue to meet in an advisory capacity, specifically to support the ongoing evolution of health information technologies in the context of broader health care transformation initiatives in the State. The Workgroup will advise and support the State in creating a statewide HIT infrastructure that supports the goals of the Triple Aim through the implementation of the SHIN-NY and APD and through the alignment of measures and technology to evolving needs for the State.

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

1. Transparency, Evaluation, and Health Information Technology Workgroup Interim Report – December 2014: https://www.health.ny.gov/technology/innovation_plan_initiative/docs/2014-12_hit_interim_report.pdf

2. HIT Workgroup Meeting Materials are available at the following link: https://www.health.ny.gov/technology/innovation_plan_initiative/workgroups.htm

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Appendix B: Infrastructure Overview

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.[3]

Table 3 below shows by year when data collection began for each type of SPARCS data and the years that data has been available to researchers for approved uses.

Table 3: 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 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 and 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.

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[3] The enabling legislation and regulations for SPARCS are PHL §2816 and NYCRR Title 10 §400.18.

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 to 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 then be ratified by the Commissioner. Table 4 below shows the three file types, contents, and protocols for application and approved use.

Table 4: 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	• 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)	• 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	• 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; or (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 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 received by all New Yorkers.

Role of SPARCS in Self-Insured Data: SPARCS is currently the only statewide claim level data resource for the self-insured population in New York State. Estimates on commercially insured, self-funded Employee Retirement Income Security Act (ERISA) benefit plan arrangements range from 30-50 percent of the state population.

Medicaid

Background: Medicaid data are collected for beneficiaries enrolled in NYS government health insurance program for persons of all ages who meet established income and eligibility criteria. With an estimated 29 percent of NYS residents covered by Medicaid, New York has the second largest Medicaid program in the nation (led by California) with the highest per capita costs. Current state enrollment is more than 6.1 million (as of July 2015).

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.

Infrastructure: Medicaid fee-for-service claims data are received and processed in a nationally recognized format (X12-837). In September 2015, Medicaid encounter data collection was changed from a proprietary format to the X-12-837 format as part of the APD Encounter Intake System. 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 prescribed in 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.

All Payer Database

Background: New York State legislation, enacted in the spring of 2011, provided for the expansion of SPARCS to allow 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 all public and private payers in the State.

The APD is envisioned as the central repository for a wide array of health care data across New York State. When fully functional, the APD will facilitate integration of claims and clinical data principally held in the SHIN-NY together with public and population health data to support a holistic picture of the quality and cost of health care in the State and the well-being of all New Yorkers. 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.

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: Multiple data sources will populate the APD. The initial data intake strategy has focused on the collection of public payer encounter data from the New York State of Health Qualified Health Plans (QHP), Medicaid Managed Care, and Child Health Plus. Public payer data sources included in the APD will be expanded in 2016 to include Medicaid Fee for Service claims data and Medicare data incorporated through anticipated purchase from CMS. Large group commercial data collection will also commence in 2016. As the APD evolves over time, other types of information will be incorporated, including public health registries, 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 NYSDOH's approach to the development of the APD focuses on three solutions depicted in Figure 4.

1. The Data Intake Solution – to collect and edit claims/encounter data from numerous health payers.
2. The Data Warehousing Solution – to aggregate, de-identify, and store the data received from all the different sources.
3. The Data Analytics Solution – this includes 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 and implementing the APD in phases. The Data Intake Solution is in early production for public payers, with emphasis on ensuring optimal system performance and compliance with submission requirements, and in design and development for others. A procurement

for a technology vendor for the permanent data warehousing and analytics solutions has been underway since spring 2015, with an anticipated contract award in December 2015. It is expected that the system will not be fully operational until late 2016. APD data governance and access will be determined through regulations, currently pending formal regulatory review, and associated policy documents to be developed after finalization of regulatory language.

Figure 4: Planned All Payer Database Technical Infrastructure
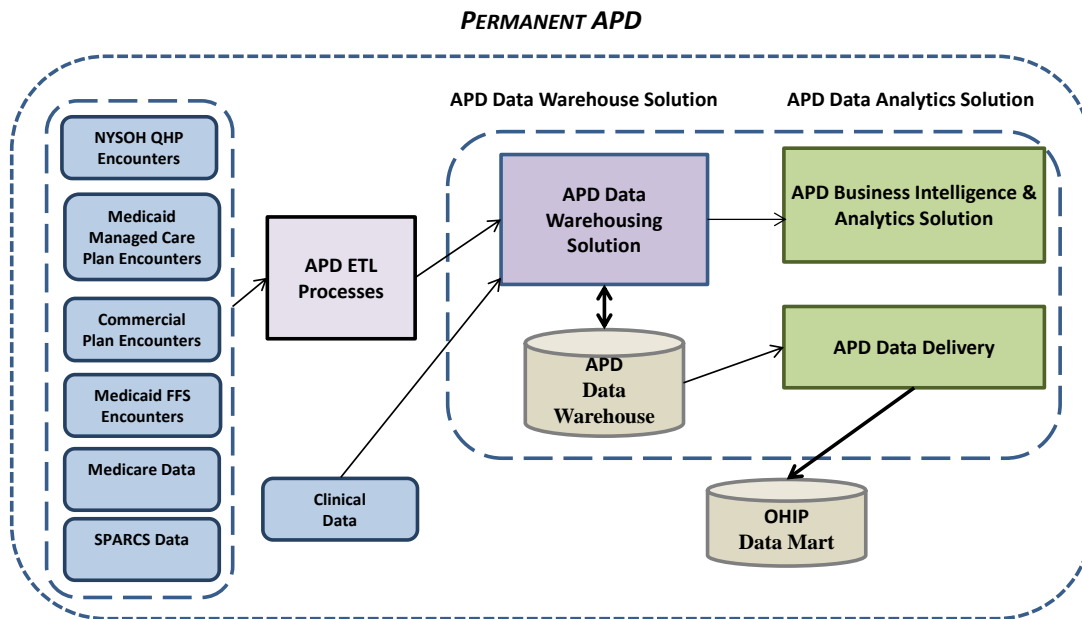
Please refer to Appendix C for a reference list of acronyms used in Figure 4.

Access to data: Draft regulations propose that release of APD data will follow all appropriate privacy and confidentiality safeguards. All entities seeking detailed APD data will be required to submit a request to the NYSDOH through a formal data release process similar to that used to access SPARCS data. The process will address privacy and confidentiality concerns by requiring that data users:

• 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 will be required to 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.

SHIN-NY

Background: The Statewide Health Information Network of New York (SHIN-NY) is a network that supports the secure and confidential exchange of health information among participating hospitals, providers, health plans, and public health officials to increase the quality of care, reduce costs, and increase population health. The SHIN-NY is made up of eight regional health information organizations and the New York eHealth Collaborative (NYeC) that provides statewide services and collaborates with the State to develop the policies and agreements that support the secure exchange of information. The SHIN-NY provides health information exchange (HIE) services that include secure direct messaging between health care providers and record query services that allow providers to look up patient records among all participating entities. These services are provided at the local level by Qualified Health IT Entities (QEs) (formerly known as Regional Health Information Organizations (RHIOs)) that connect health care providers in secure local networks. All QEs connect to a statewide network to allow their participants to search for information anywhere statewide.

Master Patient Indexes (MPI) sit at the center of secure and appropriate exchange within and between QEs. Each QE operates a MPI that enables the matching of demographics from medical records and enables consent-based query of medical records among the participants of that QE. A statewide MPI (sMPI) matches demographics from QE master patient indexes to ensure that patient information can be queried between QEs.

The SHIN-NY will connect hospitals, medical providers, and consumers who live in or receive care in New York State. For instance, the network is designed to allow an emergency room doctor treating an unconscious patient in Buffalo to access the patient's full medical history, including past procedures and relevant allergies from her primary care physician in Brooklyn. The network is governed by federal HIPAA, federal Substance Abuse and Mental Health Services Administration regulations, and state law and privacy and security policies and standards.

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

- 86% of New York State hospitals

- 84% of Federally Qualified Health Centers (FQHCs)

- 65% of public health departments

- 53% of home care agencies

- 34% of long-term care and post-acute providers

- 14% of clinical practice sites

History: 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 an unconnected, paper-based system to an electronic interoperable system that connects health care providers in a network.

A primary focus of the investment has been on the QEs located across the State. These not-for-profit organizations evolved individually under the direction of local stakeholder boards of directors. While all regions in the state are serviced by at least one QE, there had not been a consistent, standardized statewide approach to the delivery of health information exchange services. To create this statewide approach, the NYSDOH 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 NYSDOH. However, QEs often provide services above and beyond the minimum set of services, including analytics.

Figure 5: SHIN-NY Structure
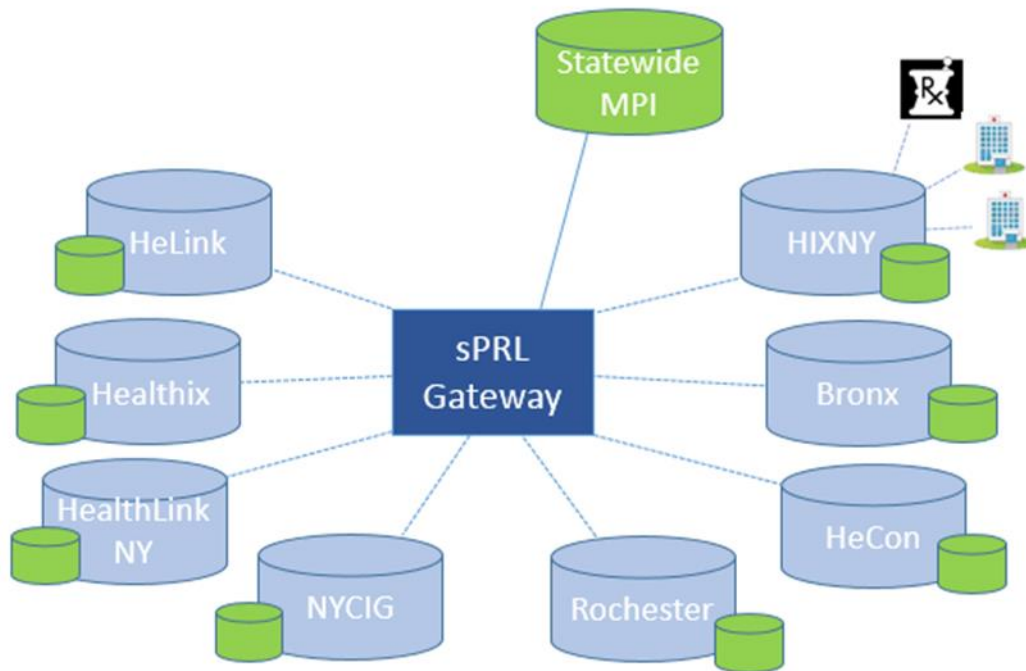
On September 3, 2014, the NYSDOH, under Public Health Law §206(18-a)(b) published a Notice of Proposed Rule Making to add a new Part 300 to Title 10 (Health) of the New York Codes, Rules and Regulations. The Workgroup received draft regulations for comment and the NYSDOH considered the recommendations of the Workgroup. The proposed rule:

- Establishes legal requirements for QEs and the QE Participants (including health care providers and health plans that access patient information using the SHIN-NY).

- Establishes that QEs will submit information on system performance, security, provider participation and usage.

- Establishes that the NYSDOH will use the statewide collaborative process to ensure stakeholder feedback on policies that govern the SHIN-NY.

- Codifies the concept of a Qualified Health IT Entity (QE) as a not-for-profit entity 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 minimum set of services to its constituents.

Uses: The SHIN-NY, through the regional QEs, will make it possible to share health information through electronic health records to:

- Ensure that physicians and other clinicians are able to 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, particularly those with multiple diagnoses, 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 the State Health Innovation Plan (SHIP) and the Delivery System Reform Incentive Payment (DSRIP) program by providing key information needed to ensure timely delivery of quality care that will promote the health and well-being of all New Yorkers.

Data Sources and Infrastructure: Under the proposed SHIN-NY regulation, 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. Hospitals will be required to connect within one year. 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 aligns with the federal Department of Health and Human Services' effort to create a nationwide health information exchange system.

Patient Confidentiality and Consent in the SHIN-NY: Physician-patient confidentiality is a basic tenet of medical ethics.[4] In New York, the following is professional misconduct for a physician: "Revealing of personally identifiable facts, data, or information obtained in a professional capacity without the prior consent of the patient, except as authorized or required by law."[5] The federal law and regulations known as HIPAA do not preempt state laws that prohibit health care providers from disclosing patient

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[4] American Medical Association Code of Medical Ethics Opinion 5.05 – Confidentiality.
[5] Education Law § 6530(23).

information to third parties without patient consent, including disclosures to other health care providers for the purpose of treatment of the patient.[6]

Even though health care providers may not disclose patient information to third parties without a patient's consent, under the legal principle of agency, health care providers may allow members of their workforce and contractors to create, receive, maintain, and transmit patient information on their behalf without patient consent.[7] Thus, health care providers do not need patient consent to enter into qualified entity (QE) participation agreements that allow QEs to facilitate the electronic exchange of patient information, for the same reason that health care providers do not need patient consent to place paper medical records in the hands of a FedEx courier.

1. *General Consent: A Routine Health Care Data Sharing Scenario*

To illustrate consent under the SHIN-NY, assume a patient sees a primary care physician (PCP) for a sinus infection. The PCP prescribes an antibiotic. The PCP also refers the patient to an ear, nose, and throat specialist (ENT), and the referral from the PCP is required in order for the patient's insurance to cover the ENT. In this situation, the patient typically would have consented in writing to allow the PCP to disclose patient information for the purpose of "treatment, payment, and health care operations" when the patient was first seen by the PCP. But even if the patient did not do so, if the patient asked the PCP to bill the patient's insurance company, this course of conduct implies consent to allow the PCP to disclose to the insurance company the information that the insurance company requires to pay a claim. If the patient takes the referral to the ENT, this again implies consent to allow the PCP to disclose the patient's medical history of sinus infections. In addition, the patient would have consented to the disclosure of patient information to the insurance company in the patient's enrollment agreement with the insurance company. This type of consent can be referred to as a "general" consent for the release or disclosure of medical information.[8]

Under various laws, a general consent is sometimes insufficient to release certain kinds of medical information. When the medical records indicate that the patient is HIV positive, Public Health Law Article 27-F may require a provider to get written authorization that specifies that the medical records include HIV-related information and that specifies to whom disclosure is authorized. There are similar requirements under Mental Hygiene Law § 33.13 for clinical records maintained by health care providers licensed under Mental Hygiene Law Article 31 and under 42 CFR Part 2 for federally-regulated alcohol and drug abuse treatment records.

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[6] 45 CFR § 164.506(b). The term "patient information" is being used here to mean the medical record of diagnosis and treatment created and maintained by the health care provider. See Public Health Law § 18; Education Law § 6530(32). The information that health care providers submit to health plans, including the Medicaid program, is referred to as "claims data."

[7] The Department believes that this principle was taken for granted prior to the implementation of HIPAA, since health care providers have always used contractors, from the sole practitioner who uses a medical transcriber to the large general hospital that uses a warehouse to archive medical records. This principle is made explicit in HIPAA, which allows disclosures to a "business associate" for "health care operations" without patient consent, and in 42 CFR Part 2, which allows disclosures to a "qualified service organization."

[8] See, for example, Public Health Law § 2780(9).

QE participants can access a patient's entire medical record, for treatment, payment, and health care operations, including for quality improvement purposes. This is consistent with the federal program that allows Medicaid and Medicare providers to receive incentive payments for making meaningful use of interoperable health information technology and qualified electronic health records.[9] In order to comply with all applicable laws, the patient must sign a written authorization that specifies that the patient gives permission to disclose HIV records, mental health records, and alcohol and drug abuse treatment records and that specifies to whom disclosure is authorized.[10] The New York State Medicaid program, as a health plan, has programs intended to improve the use of its claims data to provide services for recipients.[11] Medicaid providers providing care management services may be QE participants. Medicaid Health Homes may also be QE participants.[12] A Performing Provider System (PPS) may also be a QE participant in order to carry out the goals of the New York State Delivery System Reform Incentive Payment (DSRIP) program.[13]

2. *SHIN-NY Opt-In and Opt-Out Consent Models*

Three different opt-in models (single-participant consent, multiple-participant consent, and community-wide consent) and an opt-out model have been considered to allow consent to access patient information using the SHIN-NY. Each is described in detail below. In the descriptions below, even though the shorthand terms "single-provider" and "multiple-provider" are being used, the consent is for both health care providers and health plans that are QE participants.

a. *Single Participant Consent-* Each QE participant that accesses patient information gets its own consent to access. The advantage of this approach is that it is very clear that there is legal authority to disclose the patient's information to that QE participant, but this approach places the burden on the QE participant accessing the information to get the patient to sign a written authorization.

b. *Multiple-Participant Consent-* Multiple QE participants, or even all of the *current* QE participants can be listed on a single consent form. There is still widespread consensus that this legally allows all of the current QE participants listed to access the patient's information, even though the patient may well have forgotten that the patient authorized a particular provider to access medical records if the patient only gets services from the provider years after signing the consent. With multiple-participant consent, the patient does not have to sign the same consent

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[9] See https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html.

[10] Two form that satisfy all applicable requirements are OCA Form No. 960 http://www.nycourts.gov/forms/hipaa_fillable.pdf and DOH-5032 http://www.health.ny.gov/forms/doh-5032.pdf.

[11] Federal law allows the Medicaid program to use Medicaid claims data to provide services for recipients. 42 USC § 1396a(a)(7); 42 CFR Part 431, Subpart F. In addition, the Medicaid program has obtained consent to use claims data in this way when individuals apply for Medicaid. See https://www.health.ny.gov/forms/doh-4220all.pdf.

[12] See https://www.health.ny.gov/forms/doh-5055.pdf; https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/docs/hhsc_5201.pdf.

[13] The Medicaid program allows a PPS to use Medicaid claims data unless a Medicaid recipient opts out of allowing such use. See https://www.health.ny.gov/health_care/medicaid/redesign/dsrip/consumers/docs/english_optout.pdf. The PPS may get consent to access patient information as a QE participant, but this may not be possible in practice, because the PPS may not have any direct relationship with the Medicaid participant. In many cases, the Medicaid recipient will not even know which PPS is serving the Medicaid recipient.

form at multiple providers, so there is less burden on the providers to get consent. If new providers become QE participants after the consent is signed, a new consent is still needed to list the new QE participants. However, this is often the most logistically complex process to implement by the QEs to ensure that they coordinate with participants and continuously maintain updated lists of all participants. It also requires that QEs provide knowledge on which patients have provided consent.

c. *Community-wide Consent*- Allows all QE participants to access patient information, including health care providers or health plans that become QE participants after the consent is signed. This "one and done" approach is, without question, the least administratively burdensome approach, but by its very nature it does not comply with the requirement for federally-regulated alcohol and substance abuse treatment records that a written authorization must contain the "name or title of the individual or the name of the organization to which disclosure is to be made."[14] Thus, under current law and technology, QEs that use community-wide consent may not allow QE participants, that are not specifically named/listed in the consent, to access Part 2 data. Likewise, the QEs that include Part 2 data cannot allow QEs that use community-wide consent to access Part 2 data under their control. In the long term, the NYSDOH expects widespread inclusion of Part 2 data in the SHIN-NY. Therefore, community-wide consent could only be used if federal law changes, for example if H.R. 2646 (114th Cong., 1st Sess., 2015), were enacted into law; or if Part 2 data was segregated from the other patient information and the patient consented separately to disclosure of Part 2 data.

Although single-provider consent requires patients to consent multiple times with multiple providers, it may not add much burden to an individual provider's workflow to give the patients the option to sign one more piece of paper when the patient is first seen by the provider. Single-provider consent is the solution that is most protective of patient rights and allows the provider to access all of the patient's information.

d. *Opt-out Consent*- The SHIN-NY Policy Committee and other stakeholders have considered opt-out as a possibility for consent in the SHIN-NY. However, there are a number of legal restrictions that preclude using this method to access data via the SHIN-NY. It has been determined that opt-out consent for clinical data would limit types of data that would be available through the SHIN-NY including behavioral health, substance abuse and other data types. Therefore this could not support activities such as DSRIP.

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[14] 42 CFR § 2.31(2). Even though Public Health Law Article 27-F is modeled on the federal regulations for alcohol and substance abuse treatment records, the Department believes that community-wide consent can comply with State law, which is worded to require that a release of confidential HIV-related information "specify to whom disclosure is authorized." Public Health Law § 2780(9). First, the Department believes that a community-wide consent can specify exactly what the patient is consenting to. Second, both the law and public policy have changed since Article 27-F was first enacted, and the Department is strongly committed to ending the AIDS epidemic by facilitating patient linkage and retention in care. See, for example, Public Health Law § 2135. Third, the overarching aim of privacy laws is to give patients greater control over the use and disclosure of patient information, and the Department believes that patients should be allowed to give community-wide consent if they want to.

3. *Minor Consented Health Care Services*

Data derived from minor consented healthcare services continues to be an issue for all health information exchange activities across the country. According to state and federal law, people under 18 can access and consent to certain health care services including STD diagnosis and treatment, prenatal care, or any care if they are married or have borne a child. Minors can also receive mental health services without parental consent under limited circumstances. During the receipt of those services a minor, or his/her clinician, in the case of mental health services, should have the opportunity to consent to allow a provider to access information available through the SHIN-NY even if a parent has declined to allow health care providers to access information in the past. Additionally, information derived through minor consented services should be protected from view of a parent if the child does not want that information to be accessed by the parent, or if the treatment has been provided without parental consent. Currently the technology is not widely implemented that would allow electronic health records to tag sensitive health information and ensure it is segregated from less sensitive information.

The SHIN-NY Policy Committee has evaluated two methods for dealing with minor consented information and to ensure confidentiality of that information. One model can be used for 42 CFR Part 2 data and allows a minor who consents to health care services to also override a parent's consent to allow other providers to access all of the minor's health information through the SHIN-NY. The other model cannot be used for 42 CFR Part 2 data because it does not allow a minor who consents to healthcare to override a parent's consent, or refusal of consent, to allow other providers to access all of the minor's health information through the SHIN-NY. Both methods allow minors to consent to have their information accessed for the purpose of minor consented health care and both methods seek to address how minor consented information could be protected from access by the parents of the minor. However, these are interim processes for dealing with minor consented data until a time when data segmentation is widely available to filter out data that can be tagged as sensitive health data derived from access to minor consented services.

Appendix C: 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
CMS	Centers for Medicare and Medicaid Services
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
MAPP	Medicaid Analytics Performance Portal
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
NYSDOH	New York State Department of Health

Acronym/Abbreviation	Description
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
PHHPC	Public Health and Health Planning Council
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 Organizations
SDE	State Designated Entity
SHIN-NY	Statewide Health Information Network of New York
SOD	Statement of Deficiency
sPMI	Statewide Master Patient Index
SPARCS	Statewide Planning and Research Cooperative
UAS	Uniform Assessment System
UAT	Uniform Assessment Tool
USC	United States Code
X-12	The nationally recognized format for electronic claim submission.

Appendix D: Draft Advanced Primary Care (APC) Core Measures – SHIP

Draft APC core measures

PRELIMINARY as of October 2015

Proposed core measure

Prevention	1. Colorectal Cancer Screening* 2. Chlamydia Screening* 3. Influenza Immunization - all ages* 4. Childhood Immunization (status)* 5. Fluoride Varnish Application
Chronic Disease (Prevention and Management)	6. Tobacco Use Screening and Intervention* 7. Controlling High Blood Pressure* 8. Diabetes A1C Poor Control* 9. Appropriate Medication Management for People with Asthma* 10. Weight Assessment and Counseling for nutrition and physical activity for children and adolescents and adults*
BH / Substance Abuse	11. Depression screening and management* 12. Initiation and Engagement of Alcohol and Other Drug Dependence Treatment
Patient Reported	13. Record Advance Directives for 65+ 14. CAHPS Access to Care, Getting Care Quickly*
Appropriate Use	15. Use of Imaging Studies for Low Back Pain 16. Avoidance of Antibiotic Treatment in Adults with Acute Bronchitis 17. Avoidable Hospitalization* 18. Avoidable readmission* 19. Emergency Dept. Utilization*
Cost of Care	20. Total Cost of Care

* DSRIP measures