

1 **New York Health Information Security and Privacy Collaboration**

2
3 **Standardized Consumer Consent Policies and Procedures**
4 **for RHIOs in New York State**

5
6 **December 21, 2007**

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11 **Invitation to Comment:**

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13 The Health Information Security and Privacy Collaborative (HISPC) is a national
14 initiative funded by the federal Office of the National Coordinator for Health IT and
15 Agency for Health Research and Quality to examine how privacy and security laws
16 impact business practices related to electronic health information exchange. The
17 purpose of this document from the New York HISPC team is to put forth for public
18 comment recommended policies and guidelines governing consumer consent for the
19 exchange of personal health information in a technology-enabled health care
20 environment facilitated by Regional Health Information Organizations (RHIOs) in New
21 York State in order to protect privacy and strengthen security. Comments received will
22 be reviewed and considered during the development of final policy guidance that will be
23 issued by the New York State Department of Health. Please submit written comments
24 utilizing the form provided on the NYS HISPC website:

25 http://www.nyhealth.gov/technology/nyhispc/phase_ii/ to the Office of Health
26 Information Technology Transformation by January 31, 2008 via email:
27
28

29 This document is divided into the following eight sections:
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1 **I. Introduction and Background**

2

3 Responding to growing evidence that interoperable health IT can support improvements
4 in health care quality, affordability and outcomes, New York State is making
5 considerable investments in transitioning its health care settings from today's largely
6 paper-based environment to an electronic, interconnected health care system.

7

8 On August 8, 2007, the State of New York announced an ambitious new initiative to
9 promote interoperable health information exchange and new tools for quality and
10 population health measurement and reporting in New York. This initiative is part of
11 Governor Eliot Spitzer's agenda to advance patient-centered care and enable
12 improvements in health care quality, affordability and outcomes for each person, family
13 and business in New York.

14

15 To launch this initiative, \$105.75 million in State funding has been committed to support
16 the implementation of health IT infrastructure. The expected benefits include:

17

- 18 • **Improvements in Efficiency and Effectiveness of Care:** Provide the *right*
19 information to the *right* clinician at the *right* time regardless of the venue where
20 the patient receives care.
- 21
- 22 • **Improvements in Quality of Care:** Harness the power of clinical information to
23 support improvement in care coordination and disease management, help re-
24 orient the delivery of care around the patient and support quality-based
25 reimbursement reform initiatives.
- 26
- 27 • **Reduction in Costs of Care:** Reduce health care costs over time by reducing
28 the costs associated with medical errors, duplicative tests and therapies,
29 uncoordinated and fragmented care, and preparing and transmitting data for
30 public health and hospital reporting.
- 31
- 32 • **Improvements in Outcomes of Care:** Evaluate the effectiveness of various
33 interventions and monitor quality outcomes.
- 34
- 35 • **Engaging New Yorkers in Their Care:** Lay the groundwork for New Yorkers to
36 have greater access to their personal health information and communicate
37 electronically with their physicians and designated care givers to improve quality,
38 affordability and outcomes.

39

40 New York's investment in health IT is significant for many reasons, chief among them
41 that it is by far the largest state investment to date in creating a public-private
42 governance and operating model to support interoperable health information exchange
43 and health IT tools for quality measurement and reporting and population health
44 improvement. As exciting as this opportunity is, it comes at a time when the health IT
45 environment is extremely dynamic. As New York charts it way through new waters, it
46 must take into account and respond to many issues, including increased consumer

1 demand for health information; a newly emerging, but largely unregulated, commercial
2 market for health information; new clinical models for personalizing care based on
3 genetic and other types of information; new care delivery models, such as the medical
4 home, which depend on streamlined information transfer to support the continuity of
5 care; and new prevention and outcome-oriented reimbursement models where
6 information is needed to measure and account for outcomes and performance. At the
7 same time, concerns about the privacy and security of all types of personal information -
8 especially health information - abound, with daily headlines alerting the public to the
9 dangers of stolen laptops containing personal health information, cyber security threats,
10 phishing and other identity theft problems.

11
12 In pursuing its health IT investment program, New York is cognizant that its success will
13 not only be measured by technical, operational, financial and clinical achievements, but
14 similarly by the policy framework and rules governing the exchange, measurement and
15 reporting of personal health information and organizations ensuring the adherence to
16 such policies. In fact, the establishment of public trust with respect to the privacy and
17 security of health information is the single most important goal of New York's health IT
18 investment program.

19
20 In pursuing this goal, New York benefits from policy thinking developed by several
21 important initiatives which have addressed privacy and security, including: the Markle
22 Foundation's Connecting for Health initiative; the California Healthcare Foundation's
23 policy briefs on privacy and consumer attitudes and important policy forums; studies
24 advanced by such organizations as the American Health Information Management
25 Association (AHIMA), eHealth Initiative, Healthcare Information Management Systems
26 Society (HIMSS), and National Alliance for Health Information Technology (NAHIT), the
27 Health Information Security and Privacy Collaborative (HISPC); and the Certification
28 Commission on Healthcare Information Technology's (CCHIT) work on privacy and
29 security-related product certifications. In a very real sense, New York's investment
30 program builds on the collective foundation of these policy efforts and at the same time
31 seeks to go one step further. Because New York is setting policy in the context of live
32 implementations and is doing so through a statewide public-private collaborative model
33 it presents a unique opportunity to stress test new concepts which to date have largely
34 been considered in either much smaller settings, on a theoretical basis or based on
35 proprietary and/or narrow technological approaches. Hopefully, New York's experience
36 will provide all stakeholders a much richer understanding of what works and what
37 doesn't work, and will help to inform and shape emerging state and national policy.

38 39 **Achieving Interoperability**

40 A central strategic focus of New York State's efforts is to advance interoperability
41 through the development and implementation of a shared health information
42 infrastructure based on a community-driven model available to all providers, payers and
43 patients. The State health IT framework supports common policies, technical standards
44 and protocols, as well as regional "bottom-up" implementation approaches and care
45 coordination to allow local communities and regions to structure their own efforts based
46 on clinical and patient priorities. The framework seeks to promote innovation across the

1 diversity of New York’s health care delivery settings - from solo physician offices and
2 community health centers to large academic medical centers, nursing homes and multi-
3 specialty physician practices, from Manhattan to rural upstate towns - with vastly
4 differing market conditions and health care needs.

5
6 Interoperability is essential to realizing the expected benefit from health IT; vastly
7 improving the availability and use of health information to improve patient care.
8 Perpetuating siloed information systems that do not interconnect will significantly
9 impede the adoption and effective use of health IT tools. Interoperability enables
10 patient health information to be exchanged in real time among disparate clinicians, other
11 authorized entities and patients while ensuring security, privacy and other protections.
12 Interoperability is necessary for compiling the complete experience of a patient’s care
13 and ensuring it is accessible to clinicians as the patient moves through various
14 healthcare settings. This will support clinicians in making fact-based decisions so
15 medical errors and redundant tests can be reduced and care coordination improved.
16 Interoperability is critical to cost-effective, timely and standardized data aggregation and
17 reporting for quality measurement, population health improvement, biosurveillance, and
18 clinical research. Interoperability is also needed for patients to have access to their own
19 personal health information, enabling it to be portable, not tethered to a particular payer
20 or provider.

21
22 To ensure interoperability, the State is seeking to support the implementation of three
23 interrelated components of New York’s health information infrastructure –
24 organizational, clinical and technical. The successful implementation of New York’s
25 health information infrastructure must emerge from these three intertwined capabilities
26 in order to realize the benefit of health information with respect to improving health care
27 quality, reducing costs and improving outcomes for all New Yorkers. Achieving these
28 benefits is dependent on much more than just technology. For example, interoperability
29 is as much a function of trust as technology or clinical participation, and is achieved
30 through policy and governance.

31
32 The high-level technical framework for New York’s health information infrastructure is
33 comprised of three main layers and is depicted in figure 1 below¹.

- 34
35 • **A Statewide Health Information Network for New York (SHIN-NY)** is a
36 network of networks to interconnect clinicians to exchange patient information
37 regardless of the venue in which the patient receives care in order to deliver the
38 right care at the right time in a coordinated, patient-centered manner. The SHIN-
39 NY will utilize the Internet and include common software protocols and services,
40 including security tools, and will be a part of the emerging Nationwide Health
41 Information Network (NHIN).
42

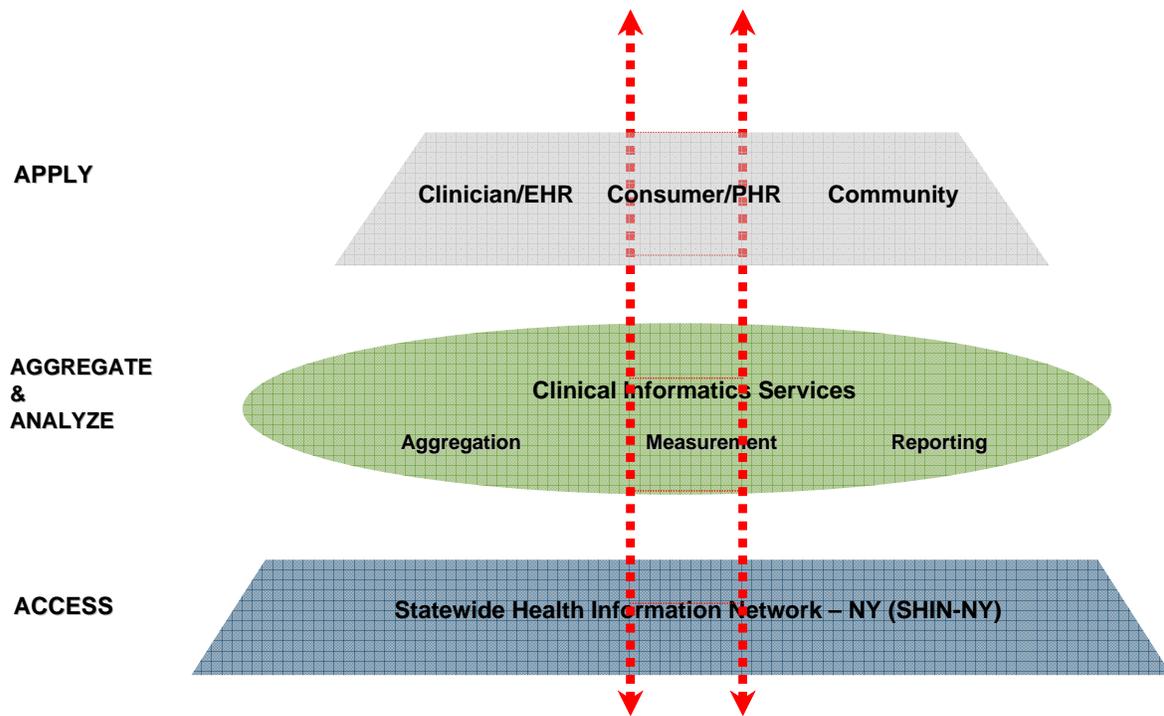
¹ For additional information, a technical discussion document published as part of the HEAL NY Phase 5 Health IT RGA is located on the DOH website: <http://www.nyhealth.gov/funding/rfa/0708160258/>

- 1 • **Clinical Informatics Services (CIS)** are community-based health IT tools which
2 aggregate, analyze, measure and report data in a standardized and valid manner
3 for various uses, including quality and population health initiatives, available to all
4 payers, providers and public health officials.
5
- 6 • **Information Tools (3Cs)** are Electronic Health Records for **Clinicians**, Personal
7 Health Records for **Consumers** and **Community** Portals for clinicians and public
8 health officials, collectively the **3Cs**, providing: (i) clinicians with information tools
9 when and where they need them to guide medical decisions, (ii) New Yorkers
10 with greater control over and access to their health information and (iii) Public
11 Health Officials with the ability to survey, report and respond to population health
12 events.
13

14 **Figure 1**
15

Framework for New York’s Health Information Infrastructure

“Cross-Sectional” Interoperability – People, Data, Systems



16
17
18
19

The Role of Regional Health Information Organizations

20 Underlying this infrastructure and central to its successful implementation are Regional
21 Health Information Organizations (RHIOs). RHIOs, working with other RHIOs,
22 governments and other organizations, must create an environment that assures

1 effective health information exchange both organizationally and technically through a
 2 sound governance structure. While the term RHIO is not presently defined in federal or
 3 state law, RHIOs are defined in New York State HEAL NY Phase 5 Request for Grant
 4 Applications as “a non-governmental, multi-stakeholder organization that exists as a
 5 New York State not-for-profit corporation to advance interoperable health IT in the
 6 public’s interest through a transparent governance structure with an overall mission to
 7 improve health care quality and safety and reduce costs.” RHIOs are not technology
 8 organizations, do not develop software and are not proprietary regional health
 9 information exchange (HIE) networks. They are regional “exchange organizers or
 10 governors” which set policies and ensure adherence to such policies to *enable* the
 11 implementation of the SHIN-NY, and ensure other components of the technical
 12 infrastructure such as the CIS and EHRs are interoperable. The term health information
 13 exchange is a verb defining the act or function of mobilizing and sharing health
 14 information and the term SHIN-NY defined above is New York’s name for health
 15 information exchange. The term Health Information Service Provider (HISP) is a vendor
 16 company which develops health information exchange software and services and/or
 17 supports the implementation of such software and services.

18
 19 As described more fully below in Figure 2 below, there are seven critical components of
 20 the definition of a RHIO.

21

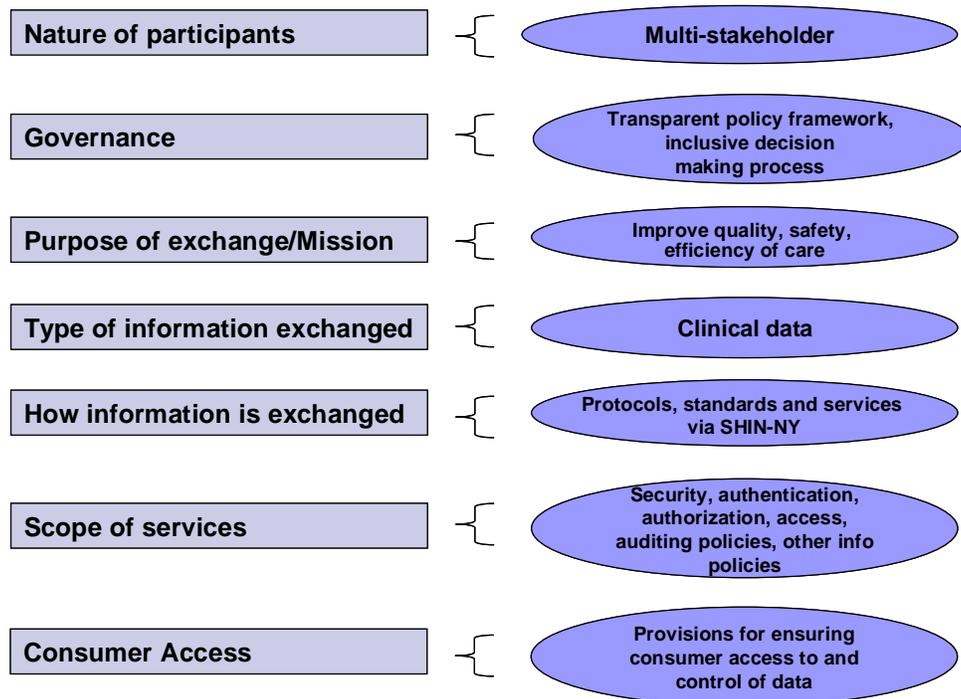
22 **Figure 2**

23

24

25

Seven Critical Components of the RHIO Definition



26

1

2 One of the main functions of a RHIO is to act as a governor or trusted broker to
3 establish, maintain and enforce privacy and security policies for multiple entities and for
4 multiple purposes. Establishing a trusted broker for health information is not merely a
5 matter of implementing a technical solution compliant with State and federal law. It
6 requires developing consensus and trust around value-laden policy decisions, which are
7 then translated into business procedures and eventually reflected in contractual
8 relationships between RHIO participants.

9 The purpose of this paper is to provide guidance to RHIOs and their participants
10 regarding a crucial component of interoperable health information exchange: patient
11 consent. Patient consent must be implemented through a suite of common policies to
12 ensure informed and trusted patient consent.

13 While this paper is focused on patient consent policies, it is important to emphasize that
14 consent policies must be accompanied by a full range of privacy and security
15 protections to earn patient trust and enable successful health information exchange.
16 The consent policies outlined in this paper must be buttressed by additional policies for
17 privacy and security, including authentication of provider/consumer identity,
18 authorization for access, consumer and provider identification, transmission security,
19 data integrity and administrative and physical security, all of which remain a priority for
20 New York State and are encompassed in the policy framework.

21
22 It also is important to recognize that the recommendations in this paper provide a
23 starting point for a longer discussion. While the recommended policies outlined below
24 are often specific and directive in nature, more detailed guidance will be necessary to
25 enable full implementation.

26

27 **Consumer Access Services - Supporting the Right of New Yorkers to Have** 28 **Greater Control Over and Access to Their Personal Health Information**

29

30 As we advance health IT in New York, there is a significant opportunity to expand the
31 way in which we have traditionally thought about consumer rights to access and use
32 their own personal health information. Consumer access to and use of their personal
33 health information is necessary to realize the full potential of the range of
34 technologically-enabled care advancements. Redefining consumers' rights, however,
35 will require a paradigm shift in how we think about health information – supplementing
36 the current legal structure which focuses on clinician control over the medical record
37 and under what circumstances disclosures of such information are permissible - with a
38 new legal structure that affirmatively provides consumers with the right to gain access to
39 their personal health information, regardless of the source of such information, and
40 supports the consumer's ability to maintain such information for his or her personal use.
41 While consumer access services and personal health records are not the focus of this
42 paper, it is important to note that RHIOs can, and hopefully will, play an important role in
43 enhancing consumer access to their own personal health information.

44

1 **II. The Health Information Privacy and Security Collaboration (HISPC): Project**
2 **Goals and Work Plan**

3 HISPC is a national initiative funded by the federal Office of the National Coordinator for
4 Health IT and Agency for Health Research and Quality to examine how privacy and
5 security laws impact business practices related to electronic HIE. The stated objectives
6 of HISPC are to:

- 7 • Preserve privacy and security protections in a manner consistent with
8 interoperable health information exchange;
 - 9 • Promote stakeholder identification of practical solutions and implementation
10 strategies through an open and transparent consensus-building process; and
 - 11 • Create a knowledge base on privacy and security issues in electronic health
12 information exchange in states and communities that endure to inform future HIE
13 activities.
- 14

15 **NY HISPC Phase I**

16 In 2006, New York State was one of 34 States and territories awarded a HISPC
17 contract. The New York State Department of Health (NYS DOH) served as the lead
18 agency for this project in New York State. Phase I spanned from March 2006 to April
19 2007 and involved a comprehensive assessment of health privacy legal and policy
20 issues in New York State. Major findings of NY HISPC Phase I included the following:

- 21 • **Human Judgment in Information Exchange:** Information exchange currently
22 relies heavily on human judgment and interaction to ensure security and privacy
23 of health information
 - 24 • **From One-to-One to Many-to-Many:** Moving to a broad transfer of information
25 to many persons or entities may require layers of sophisticated permissions and
26 controls.
 - 27 • **Informed Patient Consent:** Informed patient consent that is meaningful,
28 tracked and monitored is a key requirement to earning patient trust in HIE.
 - 29 • **Sensitive Data:** Differing regulations governing specially protected health
30 information present challenges for staff education and compliance.
 - 31 • **Appropriate Scope of Disclosure:** There is a need to more clearly define who
32 needs to see what information and to understand how to accommodate
33 appropriate access in an electronic environment.
 - 34 • **Patient Care and Patient Privacy:** There exists a delicate balance between
35 patient privacy and the need for information for treatment.
 - 36 • **Security in an Electronic World:** There is a heightened sense of vulnerability
37 regarding identifiable health care information in electronic form.
 - 38 • **Patient Control:** There is an opportunity to create an environment that supports
39 the right of consumers to control the use of their own personal health information.
- 40

- 1 • **Role of Regional Health Information Organizations (RHIOs):** RHIOs can play
2 an important role in HIE by acting as a trusted broker to establish and maintain
3 privacy and security policies.
4

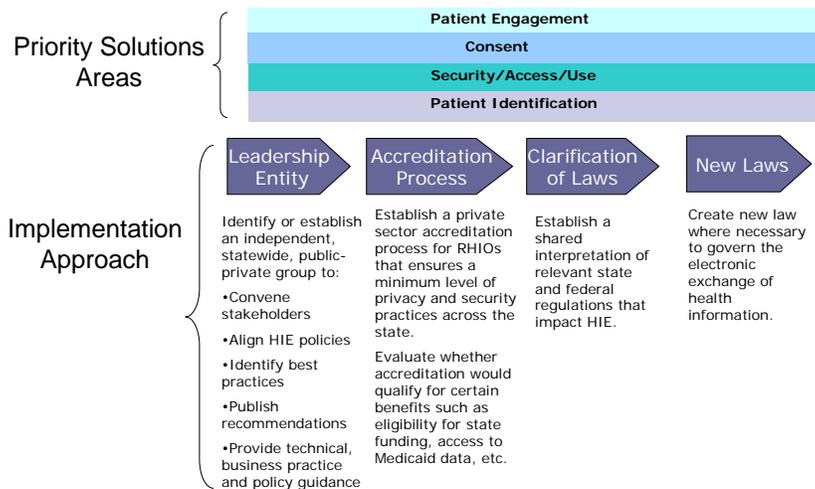
5 A central finding of phase one of HISPC was that strong policies that protect the privacy
6 and security of health information are crucial to achieving interoperable health
7 information exchange. Current laws governing HIE and the resulting business practices
8 were developed in the context of a paper-based health care setting where decisions on
9 what to communicate, how and to whom are generally made on a one-to-one basis by
10 clinicians. The current laws attempt to serve the patient’s privacy interests by restricting
11 what can and cannot be shared and the terms on which sharing takes place. Human
12 judgment and personal relationships play a major role, as clinicians attempt to act as
13 the guardian of their patients’ information. Moving from a paper to an electronic health
14 system changes the information sharing dynamic. An interoperable health system
15 facilitates a many-to-many relationship, enabling different information technology
16 systems and software applications to exchange information accurately, effectively, and
17 consistently. This offers new opportunities for patient access to and control over their
18 health care information, as well facilitating the safety, quality and efficiency of their care.
19 However, it also demands new approaches for protecting patient privacy and security,
20 including policies addressing the disclosure and use of health care information, and
21 technologies that address patient identification, authentication, record location, identity
22 management, and storage of special classes of information.
23

24 The NY HISPC Phase I advanced an “Implementation Framework” highlighted in Figure
25 3 below. One of the four priority solution areas was consumer consent – ensuring that
26 consumers are able to provide informed and meaningful consent and that holders of
27 consumer health information adhere to State and Federal privacy and security laws as
28 they exchange health information electronically.

1 **Figure 3**

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3

NY HISPC Phase I Implementation Framework



4
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6 **NY HISPC Phase II**

7 The second phase of NY HISPC began in June 2007, with NYS DOH as the lead
8 agency, and has focused on implementing a patient consent solution through the
9 development of a standardized consent process. The goal of this standardized process
10 is to promote consistency across NYS RHIOs, as exchange organizers and governors
11 of the SHIN-NY, in obtaining consent and addressing consumer privacy concerns about
12 electronic exchange of health information. Specifically NY HISPC Phase II project goals
13 are to:

- 14 • Advance health information exchange via the SHIN-NY through the development
15 of a standardized consent process implemented through and facilitated by RHIOs
16 in NYS
- 17 • Ensure that consumer consent is informed and knowing
- 18 • Provide clarity on and ensure consistency in consent process
- 19 • Give RHIOs standing to address patient consent on behalf of physicians,
20 providers and New Yorkers
- 21 • Enable incentives and protections to encourage RHIO participation.

22

23 The duration of the project is from June 2007 through January 2008; the process is
24 represented in Figure 4, below:

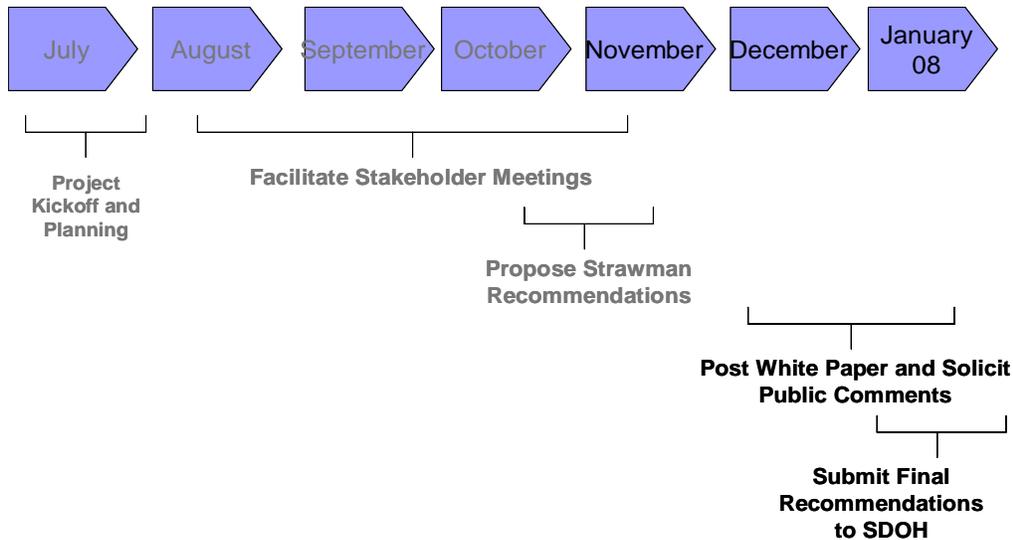
1 **Figure 4**

2

3

4

NY HISPC Phase II Project Timeline



5

6

7 To engage in a statewide dialogue on consent, three stakeholder meetings were held in
8 September and October 2007 to identify consent-related issues and gain consensus on
9 a standardized approach. The meetings were attended by consumer advocates, health
10 care providers, RHIO executive and clinical leadership, representatives from the City
11 Department of Health, and others. The first meeting was dedicated to understanding the
12 current state of RHIO policy development regarding consent in New York. The second
13 meeting sought to elicit discussion on the key policy questions that a new consent policy
14 for RHIOs would need to address. The key questions that provided the basis for this
15 discussion are outlined in Figure 5 below:

16

1 **Figure 5**

2
3 **Key Questions for Developing RHIO Consent Standards**

4
5
6 Activities: What are the activities with respect to health information
7 exchange we are seeking to govern and support?

8
9
10 Obligations: What are the core obligations of a RHIO governing health
11 information exchange via SHIN-NY with respect to consumer consent?

- 12 • Uses of information
- 13 • Sensitive information
- 14 • Where and at what point consent is obtained
- 15 • Standardized consent process
- 16 • Durability and revocability
- 17 • Consumer engagement
- 18 • Audit and transparency

19 Benefits/Penalties: What are the consequences, including benefits and
20 penalties, of meeting the obligations defined above?

21 Adoption/Compliance: How and by whom will compliance be enforced?
22

23
24 At the third meeting, “straw model” recommendations were proposed and discussed.
25 The policy guidance described in this document is the result of the discussion during
26 those three meetings.

27
28 This document outlines a standardized consent process, related roles and
29 responsibilities of RHIOs and participants as trusted custodians of health care
30 information, and consumer protection safeguards required to prevent inappropriate use
31 or disclosure of consumer health information. The policies described are still under
32 development. As such, public comments are strongly encouraged.

33
34
35 **II. The Need for a Standardized Consent Process for RHIOs in New York State**

36
37 RHIOs across the State are struggling to define what constitutes adequate and
38 meaningful patient consent. Broad variation in opinion exists among stakeholders as to
39 what is required legally, what is appropriate for risk management purposes, what
40 constitutes the best public policy, what is best for New Yorkers and what is feasible from
41 an implementation perspective. Standardized consent policies will help earn patient
42 trust, provide clarity regarding compliance with New York law and ensure
43 interoperability via the SHIN-NY enabled and governed by RHIOs.

44
45 **Standard Consent Policies for RHIOs are Necessary to Ensure Complete and**
46 **Consistent Health Information and Earn Patient Trust**

1 Electronic health information exchange represents a paradigm shift in the way
2 information is exchanged between a consumer's health care providers. In today's
3 largely paper-based world, exchange of health information between providers generally
4 is managed by the consumer. In order for Provider A to obtain health information from
5 Provider B, the consumer must tell Provider A that they are receiving care by Provider B
6 and would like their health information to be shared. The consumer in effect is the
7 gatekeeper of a one-to-one relationship among various providers who are responsible
8 for their care.

9
10 RHIOs usher in a new world by enabling the free flow of information, but fundamentally
11 change the one-to-one paradigm that exists in a paper-based world. RHIOs allow
12 providers for the first time to reach out to large networks of clinicians and providers
13 independent of the consumer to see what information is available and use it to aid in
14 that patient's care. This brings obvious benefits to the patient – eliminating the burden
15 of gathering and transporting paper records, avoiding duplicative tests and procedures,
16 and ensuring their providers have the best information available to make medical
17 decisions and coordinate care. It also, however, takes away a measure of patient
18 control, and for some, brings a heightened sense of vulnerability related to the
19 transmission of identifiable health information across networks of providers in electronic
20 form.

21
22 Because of the paradigm shift inherent in health information exchange, an essential
23 cornerstone of New York State's health IT policy is to ensure that consumers are
24 appropriately educated about how their health information can be shared and to provide
25 consumers with the informed opportunity to decide whether or not they desire to have
26 their information accessible via the SHIN-NY governed by RHIOs. If consumers are
27 not informed of the new paradigm, they have no way of understanding to what they are
28 consenting. Thus, from a consumer trust perspective, new consent policies which
29 clearly define the role of RHIOs (and clinicians, providers and payers participating in
30 RHIOs), coupled with significant provider and patient education programs, are crucial to
31 ensuring that consumers are provided with the opportunity to make informed decisions
32 with respect to with whom and for what purpose their personal health information is
33 shared and used.

34 35 **RHIO Consent Standards will Facilitate Interoperability via SHIN-NY**

36 New York State offers a fragmented State legal and regulatory framework on consumer
37 consent. Unlike HIPAA, New York's extensive legal requirements governing the
38 collection, storage and exchange of health information are not organized into a single
39 regulatory scheme. State law governing health information is spread across dozens of
40 statutory and regulatory provisions. The result is a patchwork of requirements and
41 exceptions that vary greatly depending on the nature of the entity, type of information
42 involved and purpose of the disclosure. Gaps in legal/regulatory guidance result in
43 varying interpretations and diverse consumer consent policies across RHIOs. This is
44 apparent in the current HEAL NY Phase 1 funded projects, which have come to differing
45 conclusions about the mandates under state law, and are implementing a wide range of
46 patient consent policies as a result. Diverse consent policies are a barrier to

1 interoperability. A standardized consent process will enable consistency across RHIOs,
2 eliminate interoperability barriers and reassure consumers that all RHIOs adhere to
3 minimum privacy standards with regard to exchange of their health information.

4 5 **Consumer Consent is Currently Necessary under New York Law**

6 New York State law requires that hospitals, physicians and other health care providers
7 and HMOs obtain patient consent before disclosing personal health information for non-
8 emergency treatment. Unlike HIPAA, New York State law provides no exception to this
9 requirement for treatment, payment or healthcare operations. While consent may be
10 verbal or even implied for most types of health information, this is not the case for
11 certain classes of specially protected health care information, including information
12 related to HIV status, mental health and genetic testing, which require written consent.
13 These laws reflect a desire to ensure that patients are protected from unauthorized uses
14 of personal health information and provide both a legal and normative guidepost for
15 developing consent policies for information exchange governed by RHIOs in New York.
16 Thus, under any circumstances, affirmative consent from the patient to exchange health
17 information via SHIN-NY governed by a RHIO is required under existing state law for
18 non-emergency treatment.

19 20 **State and Federal Law Provide an Insufficient Framework for the Regulation of** 21 **RHIOs**

22 It is crucial that the state ensure adequate policies and standards are in place to protect
23 the integrity of RHIO activities and the privacy of the public. HIPAA applies only to
24 “covered entities,” which include certain health care providers, health plans and health
25 care clearinghouses. RHIOs are not health care providers, health plans or
26 clearinghouses². Accordingly, at the present time, it does not appear that any of the
27 RHIOs will be covered entities.

28 Under HIPAA, a business associate is an organization that assists a covered entity in
29 performing certain health-related or administrative functions, and receives, creates or
30 maintains protected health information in connection with these activities. To date, most
31 if not all RHIOs in New York have been structured as business associates of RHIO
32 participants under two basic models:

- 33 • **“Peer-to-Peer” Model:** The RHIO supports technology that enables providers to
34 exchange data directly with one another. The RHIO may facilitate access to
35 each provider’s data to ensure the proper functioning of the system. There is no
36 central data repository (CDR) governed by the RHIO. Under this model, the
37 RHIO *is* a business associate of each provider.

² A health care clearinghouse is an entity that converts electronic HIPAA-covered transactions (i.e., claims processing and other transactions between health care providers and health plans) from non-standard to standard formats (or vice versa). By definition, RHIOs in New York are not performing such data conversion activities.

- 1 • **“Custodial CDR” Model:** The RHIO supports a CDR in which each provider’s
2 data is stored. Each provider continues to own its data. The RHIO holds the
3 data on behalf of each provider as a custodian, and has no ownership rights in
4 the data. If a provider leaves the RHIO, the provider’s data must be returned or
5 destroyed. Under this model, the RHIO *is* a business associate of each provider.

6 A potential third model for health information exchange is an “Owner CDR” Model.
7 Under this model, the RHIO (or other entity facilitating health information exchange)
8 would **not** be a business associate of the participants in the data exchange. Instead,
9 the RHIO would own the data in its care. To implement this model, each provider would
10 be required by federal law to obtain a HIPAA authorization from each patient permitting
11 the transfer of his or her protected health information to the RHIO or other entity. The
12 HIPAA authorization itself would be required to state that the RHIO is not a covered
13 entity and therefore not required to comply with HIPAA.

14 It is not prudent to mandate that all SHIN-NY and CIS pilot projects be structured in a
15 manner that qualifies the RHIO as well as vendors and other technology service
16 offerings as a business associate of the participating providers. Such a mandate may
17 stifle innovation, such as new business models designed to create integrated data sets
18 comprised of data contributed by multiple providers to support disease management
19 and other quality interventions. At the same time, however, permitting the aggregation
20 of substantial amounts of health information in an entity that is outside the scope of
21 state or federal privacy regulation raises significant privacy and consumer protection
22 concerns, even if data is transmitted to the entity pursuant to patients’ HIPAA
23 authorization.

24 To address these competing considerations, the State should avoid dictating the
25 manner in which RHIOs fit within the HIPAA regulatory scheme, and instead, create a
26 cohesive State regulatory framework that applies directly to RHIOs. This framework
27 would include relevant aspects of HIPAA as a floor and other privacy laws to establish a
28 set of requirements governing the use and disclosure of information, security
29 safeguards, patient access to data and other matters.

30

31 **III. Key Principles and Stakeholder Priorities**

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33 The recommended policies for obtaining consumer consent to exchange personal
34 health information via the SHIN-NY governed by RHIOs were guided by several key
35 principles, summarized in Figure 6.

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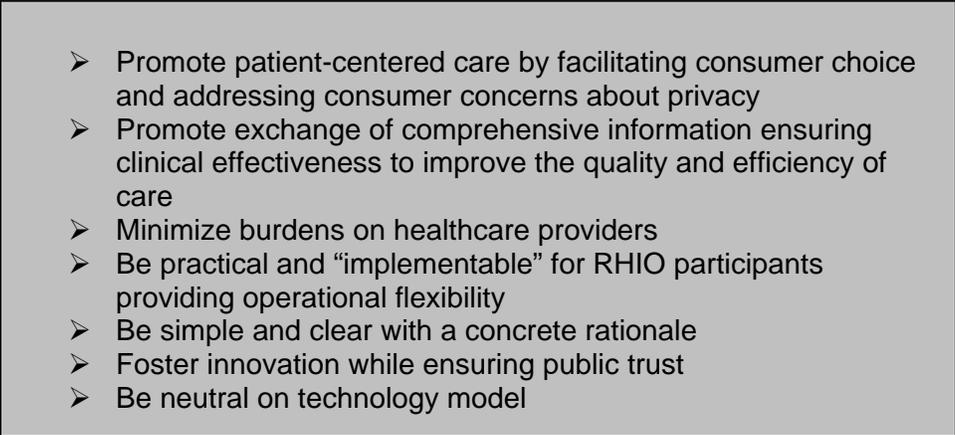
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1 **Figure 6**

2
3 **Key Principles of New Consent Policies and Procedures**

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- Promote patient-centered care by facilitating consumer choice and addressing consumer concerns about privacy
 - Promote exchange of comprehensive information ensuring clinical effectiveness to improve the quality and efficiency of care
 - Minimize burdens on healthcare providers
 - Be practical and “implementable” for RHIO participants providing operational flexibility
 - Be simple and clear with a concrete rationale
 - Foster innovation while ensuring public trust
 - Be neutral on technology model

15
16 These principles outline the core policy aspirations and practical considerations
17 necessary to implement interoperable health information exchange. Buy-in from
18 multiple stakeholder groups is important, and throughout the course of the public
19 meetings it was clear that stakeholders approach RHIOs with a host of pressing needs.

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- **Consumers:** Consumers seek assurance that they have a meaningful level of control over who is able to access their protected health information. They want choices and they want to have enough information in the consent process to make that choice meaningful and knowing. Consumers want to know that those who have access to their information use it to improve the delivery and quality of their care, and do not use it in a way that could cause them embarrassment or harm. Consumers are particularly concerned that their sensitive health information is protected and only viewed by authorized individuals for whom they enable access.
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- **Clinicians:** Clinicians want to ensure clinical effectiveness and high quality care. They want access to a consumer’s complete medical record at the point of care to enable the provision of consistent, high quality and safe medical care. They are equally concerned that consent requirements do not impose heavy burdens on them and their staff, especially for doctors in small practice settings.
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- **Provider Organizations:** Provider organizations want assurance that additional consent requirements do not impose heavy administrative, technical and/or financial burdens on their organization and its resources. Such institutions often already have internal information systems and want to ensure that new systems can be implemented in harmony with existing work flow and other requirements related to internal systems.

- 1 • **Payers:** Payers increasingly are taking an active role in helping support
2 improvements in health outcomes for their members by employing personal
3 health records and disease management initiatives. With this in mind, payers
4 want access to clinical information on their members for the purpose of
5 delivering care management services, improving quality and reducing cost.
6 Payers also note that they are being asked to contribute to the cost of RHIOs
7 and to make claims data available to RHIO participants, and they want to
8 know that these investments will realize a benefit.

- 9 • **RHIO Executives:** RHIO executives want to ensure that new consent policies
10 and procedures give RHIOs operational flexibility and support an evolving
11 landscape as they embark on implementing their health information
12 exchange. They are concerned that new consent policies and procedures will
13 be difficult to implement, sustain and monitor, and that they will place burdens
14 on providers that may reduce their participation. RHIO executives also are
15 concerned about how to fund mandates that are different from the standards
16 they have begun to implement. With limited resources, extremely small
17 central staffs and with guidance coming on the eve of or even just after
18 information has begun to flow, RHIO executives want to know that they will
19 have the funding necessary to support implementation of new and evolving
20 standards.

- 21 • **Government:** Policymakers are charged with advancing health IT to support
22 improvements in health care quality, affordability and outcomes. Through a
23 statewide, multi-stakeholder process, health IT strategies are formulated in
24 the public's interest and facilitate a dynamic, bi-directional information
25 infrastructure to support quality improvement interventions, public health
26 reporting and biosurveillance activities. Protecting the privacy of individuals
27 and earning and maintaining their trust is a top priority of policymakers;
28 understanding that success will be not realized without broad-based support
29 from patients, clinicians, providers, payers and other stakeholders in the
30 healthcare system.

31 **IV. Recommendations**

32
33 The following policies and practices seek to provide specific guidance to RHIOs of
34 sound patient-centered public policy while at the same time being operationally and
35 financially feasible. Several areas, however, have been identified in which more
36 process and thought is necessary before more detailed recommendations can be put
37 forth. In those instances, the report recommends further action through a statewide
38 collaboration process facilitated by the New York's public private partnership convened
39 by the NY eHealth Collaborative (NYeC) (described further in Section VIII).

40 The recommendations are summarized in Figure 7 and described in more detail below:
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1 **Figure 7**

2
3 **Recommended Policies and Standards for Consumer Consent to Exchange**
4 **Information via SHIN-NY governed by RHIOs**

- 5
6
7 1) **Scope of Governed Activities:**
8 The new consent rules apply statewide to interoperable health information
9 exchange of patient identifiable health information via SHIN-NY governed by
10 RHIOs and their participants.
- 11 2) **Affirmative Consent:**
12 Each provider organization and payer organization participating in a RHIO must
13 obtain an affirmative consent from the consumer that specifically references the
14 RHIO prior to accessing her/his personal health information.
- 15 3) **Up-Loading Data:**
16 Health care providers may “upload” patient information to a RHIO without
17 patient consent.
- 18 4) **Uses of Health Information:**
19 Permissible uses of health information fall into two categories, each requiring
20 different types of consent.
- 21 5) **Sensitive Health Information:**
22 A single consent may be obtained to exchange all health information, including
23 all specially protected health information.
- 24 6) **Consent Form:**
25 RHIOs must use a State-approved consent form.
- 26 7) **Durability and Revocability:**
27 RHIO consents are both durable and revocable.
- 28 8) **Consumer Engagement and Access:**
29 RHIOs must comply with consumer education, engagement and access
30 standards.
- 31 9) **Audits and Transparency:**
32 RHIOs must conduct audits at least annually; inform consumers promptly of any
33 breaches and make audit trails available upon request. It is anticipated that on-
34 line tools and paper-based reports will be utilized.
- 35 10) **Benefits and Penalties:**
36 To be eligible for State funding through HEAL and other initiatives, and to
receive Medicaid data, RHIOs must adhere to consent policies.
- 11) **Enforcement:**
Consent standards initially will be enforced through contractual relationships
between RHIOs and New York State, and should migrate towards requirements
for an accreditation process.

1 **Scope of Governed Activities:** The new consent rules apply
2 statewide to health information exchange of personal health
3 information via the SHIN-NY governed by RHIOs and their
4 participants.

5 The scope of activities that the following policies seek to govern includes all
6 interoperable health information exchange conducted through SHIN-NY and governed
7 by RHIOs. RHIOs are important because the definition of interoperability includes much
8 more than technical interoperability of information systems; it is people and policies or
9 organizational interoperability, also.

10
11 Health information exchanges, like SHIN-NY, use the term liquidity to express the level
12 of interoperability or rate of flow of assets through the exchange. Exchanges are
13 characterized as very liquid when almost all uses succeed (e.g., finding clinical
14 information about a patient to inform medical decisions; receiving a drug-drug
15 interaction alert). Conversely, in an illiquid exchange a large number of uses may fail
16 (e. g. not finding current and/or complete medication profiles for patients).

17
18 A high level of liquidity for the health information flowing through SHIN-NY is essential.
19 The key to generating liquidity in any exchange is the belief on the part of stakeholders
20 that uses of the exchange will succeed and be beneficial and that, in rare cases of
21 problems, the stakeholders will be protected and problems solved. This is as much a
22 function of trust as technology or clinical participation, and is achieved through policy
23 and governance, which is the main purpose of a RHIO. Thus, policies that govern the
24 SHIN-NY must be implemented through the RHIO, and the policy recommendations
25 outlined in this document are applicable to all RHIOs, or other similar entities governing
26 health information exchange.

27
28 RHIOs must ensure the health information service providers with whom they contract for
29 health information exchange software and services and the participants of the RHIO
30 comply with the minimum protocols, standards, and services of the new consent policies
31 and procedures. All statewide health information exchange enabled by a RHIO must
32 comply with RHIO protocols and standards related to consent, with limited exceptions
33 described below.

34
35 One exception relates to “one-to-one” electronic health information exchange. “One-to-
36 one” health information exchange taking place through a RHIO is not subject to new
37 consent policies. One-to-one exchange is best described as a request by a treating
38 clinician to receive information from or send information to an identified source (i.e.
39 either another clinician or an ancillary service provider.) Common examples include
40 physician referrals, a discharge summary being sent by a treating hospital to the
41 referring physician, or the delivery of lab results to the clinician who ordered the test.
42 One-to-one exchanges utilize technology to transfer information in a way that mirrors
43 paper-based exchange, in essence, simply replacing the facsimile machine with email.
44 Each one-to-one exchange is understood and predictable to the patient, and limited in
45 scope to the two exchanging providers.

1 RHIOs may include one-to-one exchange services among their offerings. So long as
2 the RHIO has the capacity to separate this exchange – including policies and tools that
3 enable the types of exchanges within the RHIO to be readily distinguishable – RHIOs
4 need not apply the new consent policies to one-to-one components of the exchange.
5 Obviously, consent requirements in existing law applicable to any one-to-one exchange
6 remain in force.

7
8 The “one-to-one” exception is important to avoid significant unintended consequences
9 that could impact a range of electronic health information exchange activities that are
10 adequately regulated and do not constitute community-wide or statewide health
11 information exchange. However, further guidance is required to clearly distinguish the
12 line between “one-to-one” and community-wide/statewide exchange. More deliberation
13 and guidance is necessary regarding the boundaries of “one-to-one” exchange to
14 ensure that it is enforceable and effective, and does not disrupt existing techniques for a
15 clinician and provider to access information he/she ordered for a patient.

16
17 It also is important to note that to the extent public health reporting does not require
18 consumer consent under New York law, consent requirements related to RHIOs do not
19 apply to information exchange related to such reporting. However, public health
20 reporting has been recognized as a high priority for RHIOs in New York and RHIOs are
21 encouraged to integrate public health reporting into consumer education efforts.

22
23 Furthermore, the new consent policies and procedures for RHIOs apply only to
24 identifiable data. According to HIPAA, “de-identified health information neither identifies
25 nor provides a reasonable basis to identify an individual.” While greater clarity is
26 required regarding consent policies and procedures for de-identified data exchanged
27 through a RHIO for quality and population health measurement and reporting, clinical
28 research, among other purposes, this requires further deliberation that is beyond the
29 scope of this initiative and should be further developed through the statewide
30 collaboration process and approved by the State.

31
32 Finally, minimum technical protocols, standards and services serve as the floor for
33 RHIO policies and practices. RHIOs may choose to implement policies and practices
34 that exceed the protocols, standards and services defined by the state.

35
36 **Affirmative Consent:** Each provider organization and payer
37 organization participating in a RHIO must obtain an affirmative
38 consent from the consumer that specifically references the RHIO
39 prior to accessing her/his personal health information.

40 Affirmative consent must be obtained by each provider and payer organization before
41 accessing health information via the SHIN-NY governed through the RHIO. Consent to
42 providers may be done at a provider or organizational level (e.g. medical practice,
43 hospital) and need not be at the individual clinician level. Once a provider obtains
44 patient consent, it may access the information of all other participating providers unless
45 the RHIO has voluntarily established additional restrictions on disclosures as indicated
46 below. It is required that providers and payers each obtain consent prior to accessing

1 information; a one time general consent which provides multiple organizations with
2 simultaneous consent will not be permissible for reasons discussed in Section VII.

3
4 Providers and payers may, at their discretion, also seek consent prior to *disclosure* of
5 personal health information, but are not required to do so. This option is likely to be of
6 special interest to providers of particularly sensitive health services (e.g. family planning
7 and abortion service providers) because it would limit the access of other health care
8 providers (who had obtained their own consents) to this sensitive information unless the
9 patient expressly authorized the provider of the sensitive services to make the
10 information available.

11
12 Consumers must be able to prevent any or all provider and payer organizations from
13 accessing their personal health information via SHIN-NY governed by a RHIO without
14 being refused treatment or coverage.

15
16 In an emergency situation in which the consumer is unconscious or otherwise unable to
17 give or withhold consent, and the treating clinician determines that information that may
18 be held by the RHIO may be material to treatment, and the consumer has not previously
19 withheld consent for the provider organization to access his/her information, the RHIO
20 may allow the physician to access the consumer's information through "break the glass"
21 capability. The physician must attest that all of these conditions apply, and the RHIO
22 software must maintain a record of this access.

23
24 As indicated above, the transfer of data to an "Owner CDR" model would require a
25 HIPAA authorization in addition to meeting state standards related to affirmative
26 consent.

27
28 **Up-Loading Data:** Health care providers may upload patient
29 information to the SHIN-NY governed by a RHIO without patient
30 consent.

31 Health care providers may upload patient information without patient consent to a CDR
32 maintained by a RHIO if the RHIO is serving as the provider's business associate and
33 the RHIO does not make the information accessible to other RHIO participants until
34 patient consent is obtained. Health care providers routinely enter into data storage and
35 management arrangements with electronic medical record hosting vendors, outsourced
36 data centers and other technology companies. Indeed, many facets of a provider's
37 routine operations may be carried out by independent contractors who have access to
38 identifiable patient information, and this occurs without patient consent.

39
40 To date, New York regulatory authorities have not interpreted the State's existing
41 medical privacy laws as requiring patient consent for the storage or management of
42 data by technology vendors acting on behalf of health care providers. If a vendor holds
43 patient data solely as a custodian of the provider and does not make the data available
44 to other entities, the storage arrangement is not treated as a "disclosure" to a third party
45 requiring consent under New York law. Accordingly, existing New York law does not
46 require providers to obtain patient consent to upload information to a RHIO as long as

1 the RHIO does not make the information accessible to other entities without patient
2 consent. No change in New York law is required in this area.

3
4 This approach regarding patient consent is appropriate for three primary reasons. First,
5 information uploaded to a RHIO will not be viewed by other entities, and therefore
6 patient privacy will not be compromised. Second, the information held by the RHIO will
7 be subject to the RHIO's obligations under its business associate agreements, which
8 track HIPAA requirements. Third, uploading information in this manner will expedite
9 providers' access once patient consent is obtained or in an emergency thereby making
10 important clinical information available at the point of care. .

11
12 It is worth noting that the concept of "up loading" data – where information is held on
13 behalf of a provider or payer by a business associate – is not possible where the RHIO
14 is acting as an Owner CDR. RHIOs operating under an Owner-CDR model would be
15 required to obtain a HIPAA authorization and affirmative consent before any transfer of
16 data would be permissible.

17
18 **Uses of Health Information:** Permissible uses of health information
19 fall into two categories, each requiring different standards of consent.

20 Consent policies will be determined and applied according to the use of the information.
21 There are two levels of permissible uses and therefore two different standards of
22 consent. Level 1 Uses include uses that are likely to be expected by the consumer and
23 bring the consumer direct personal benefit, including information exchange for the
24 purposes of treatment, quality improvement and care management. A description of
25 Level 1 Uses follows.

- 26
27
- 28 • **Treatment:** Treatment is defined as the provision, coordination, or management
29 of health care and related services among health care providers or by a health
30 care provider, and may include providers sharing information with a third party.
31 Consultation between health care providers regarding a patient; and the referral
32 of a patient from one health care provider to another also are included within the
33 definition of treatment.
 - 34 • **Quality Improvement and Disease Management:** These activities include
35 conducting quality measurement, assessment and improvement activities,
36 including outcomes evaluation and development of clinical guidelines,
37 population-based activities relating to improving health or reducing health care
38 costs, clinical decisions support and evidence-based clinical protocol
39 development, case management and care coordination, contacting of healthcare
40 providers and patients with information about treatment alternatives, and related
41 functions.

42
43 Any entity accessing information must have had a relationship with the individual who is
44 the subject of the information and the information must pertain to such relationship. In

1 addition, disclosure of information for quality improvement purposes must be restricted
2 to the “minimum necessary,” consistent with requirements under HIPAA.

3
4 Level 2 Uses are less likely to be anticipated by the consumer or to bring direct personal
5 benefit. Level 2 Uses include research, marketing and other uses that are not Level 1
6 or prohibited. Descriptions of Level 2 Uses include:

- 7
8 • **Research:** Research means a systematic investigation, including research
9 development, testing, and evaluation designed to develop or contribute to
10 generalizable knowledge, including clinical trials.
- 11
12 • **Marketing:** Marketing means any communication about a product or service that
13 encourages recipients to purchase or use the product or service; or an
14 arrangement whereby a RHIO participant discloses consumer health information
15 to another entity, in exchange for direct or indirect remuneration, for the other
16 entity to communicate about its own products or services encouraging the use or
17 purchase of those products or services.

18
19 Standards for obtaining consent for Level 1 and Level 2 Uses will differ, with a more
20 streamlined process for Level 1 Uses and higher restrictions for Level 2 Uses.

21
22 Certain uses of information exchanged by or received from RHIO participants will be
23 prohibited. Prohibited uses include underwriting, discrimination and other such uses as
24 may be designated by the statewide collaboration process and approved by the State.

25
26 Finally, RHIOs also must have limitations on re-use and disclosure that provide
27 protections identical to those provided under HIPAA.

28
29 **Sensitive Health Information:** A single consent may be obtained to
30 exchange all health information, including specially protected health
31 information.

32 A single consent may be obtained to exchange all health information, including HIV,
33 mental health and genetic information, which must specifically be referenced in the
34 consent form. An exception to this rule is information from designated substance abuse
35 providers that are subject to current Federal law. Further guidance related to consent to
36 exchange information from federally qualified substance abuse providers through a
37 RHIO currently is being sought through the national HISPC process. Pending that
38 guidance, standards on the exchange of substance abuse information is expected to
39 mirror other specially protected health information.³

40
41 RHIOs and their participants may, but are not required to, offer consumers the ability to
42 screen certain types of sensitive information from exchange through the RHIO.

³ The Substance Abuse and Mental Health Service Agency (SAMHSA) intends to provide clarification to federal law so that alcohol and substance abuse information can be included in health information exchange efforts with affirmative patient consent.

1 Clinicians must have the discretion, in consultation with their patients, to withhold
2 information from the health information exchange.

3
4 To ensure that consumers have knowledge of which providers are making the
5 consumer's health information available through the RHIO, consumers must be
6 informed of the RHIO participants at the time of consent. If the RHIO enters into
7 contractual arrangements to share data with other RHIOs, consumers must be informed
8 of which RHIOs they share such information. Consumers also must be informed that
9 RHIO participants change over time and be given instructions on how to learn about
10 changes in RHIO participants. RHIOs must make available to consumers real time
11 information on which entities are participating in the exchange.

12
13 **Consent Form:** RHIOs must use a State-approved consent form.

14 A standardized consent form will be developed through the statewide collaboration
15 process and approved by the State for use by RHIOs. The State Department of Health,
16 at its discretion, may approve customized forms created by a RHIO so long as the form
17 complies with the minimum standards incorporated in the State's form.

18
19 The standardized consent form required for Level 1 Uses must include the following:

- 20
21
- 22 • A description of the intended uses;
 - 23 • What information is being exchanged including specific reference to HIV, mental
24 health and genetic information;
 - 25 • The consumer's right to revoke consent; and
 - 26 • Information about who is participating in the exchange including through data
27 sharing relationships with other RHIOs and how to stay informed about
28 participants in real time.

29 The standardized consent form required for Level 2 Uses must include all of the above
30 plus information about:

- 31
32
- 33 • The specific entities with whom information will be disclosed;
 - 34 • For what specific purpose information is being exchanged;
 - 35 • Whether information is subject to re-disclosure;
 - 36 • Whether the RHIO or its participants will benefit financially from exchange of the
37 data; and
 - 38 • The expiration date of the consent.
- 39

40 Certain Level 2 Uses may require an authorization under HIPAA. As discussed above,
41 all exchange under the Owner CDR model also would require a HIPAA authorization. It
42 may be possible to combine the HIPAA authorization and the standardized state
43 consent form into a single document.

44

1 **Durability and Revocability:** RHIO consents are both durable and
2 revocable.

3 Consent for Level 1 uses are not time-limited but can be revoked at any time. Consent
4 for Level 2 Uses must be time-limited for a period specified in the notice. Revocation of
5 consent prevents a RHIO participant from accessing information through the RHIO in
6 the future. However, any data that has been accessed by the participant in the past will
7 remain part of the participants' records.

8
9 **Consumer Engagement and Access:** RHIOs must comply with
10 consumer education, engagement and access standards.

11 New York State will facilitate a consumer education initiative. New York is currently
12 working in partnership with NYeC and consumer representatives to craft a public
13 education and consumer engagement initiative. The initiative will include the
14 development of consumer-centric materials geared towards ensuring consumers
15 understand how SHIN-NY and RHIOs change the way their health care information is
16 accessed as well as the potential benefits and risks. In addition, the New York State
17 Department of Health is seeking to participate in a Multi-state Consumer Education
18 Collaborative in the next stage of the federal HISPC initiative, with a state specific
19 project on development of educational materials around the consent process.

20
21 Robust consumer education standards will be developed and approved by the State to
22 ensure that consumers are aware of what they are consenting to and to whom their
23 personal health information is available. RHIOs must conform to consumer education
24 program standards developed by a statewide collaboration process and approved by
25 the Department of Health.

26
27 RHIOs must appoint at least one consumer representative to its Board. A consumer
28 representative is defined as a person whose interest in the RHIO is as a patient or
29 representative of patients and who does not otherwise participate in or have a financial
30 interest in the operation of a RHIO.

31
32 RHIOs must have policies in place related to consumers' access to their own health
33 information through the RHIO and must inform consumers of those policies through
34 their education efforts. Both the federal privacy regulation and state law mandate that
35 certain covered entities and health care providers provide people with access to their
36 own health data. However, the law does not require the information be disclosed in
37 electronic form, even if such capacity exists. People often experience cost and
38 bureaucratic hurdles in getting copies of their health information, particularly if an acute
39 or chronic illness is involved, or if there are multiple providers. Thus, RHIOs pose an
40 opportunity for consumers to have one-stop-shopping, requesting their dispersed
41 information through a single electronic portal. At this early stage of development,
42 RHIOs should set their own policies as to the form, time period and cost for responding
43 to such requests. However, in the future, guidelines as to consumer access should be
44 developed as part of the statewide collaboration process.

1 It is worth noting that as the market for consumer-driven health information products
2 grows, RHIOs will have increasing opportunities to work with third parties to facilitate
3 consumer access to their personal health information. A number of companies are
4 planning to offer software applications and services that will give consumers the ability
5 to organize and keep their personal health information in electronic form as a Personal
6 Health Record. Under current law, it is permissible for RHIOs to provide information to
7 such companies, provided such information is obtained through a valid state law
8 consent and, where necessary, HIPAA authorization. However, there is currently no
9 state regulatory framework for regulating third parties who gain access to information
10 through a HIPAA authorization and state law consent representing a gap in current law.
11 Use of such information therefore would be governed by (i) the terms of the consent; (ii)
12 the RHIO's contract with the third party and (iii) the privacy policies of the third parties.
13 While beyond the scope of this paper, it is crucial that further consideration be given
14 and policy guidance developed to help RHIOs ensure protection of consumer interests
15 while facilitating consumer access to and control of their personal health information
16 through such third party arrangements. In the interim, the policies in this paper can be
17 looked to for guidance. Until such policy guidance is developed, proposals involving
18 state funds will be reviewed on a case-by-case basis to ensure adequate protection of
19 consumer interest.

20

21 **Audits and Transparency:** RHIOs must conduct audits at least
22 annually, inform consumers promptly of any breach and make audit
23 trails available upon request.

24 RHIOs (or a third party designated by the RHIO) must conduct periodic audits no less
25 than annually. Audit reports, including identification of breaches, must be submitted
26 regularly to the Board, but also no less than annually. RHIO participants are required to
27 inform the consumer of breach (the consumer's identifiable information is reasonably
28 believed to have been acquired by an unauthorized person) of the consumer's health
29 information promptly upon detection. RHIOs and participants must make available to
30 the consumer upon request an audit trail of the consumer's health information accessed
31 through the RHIO.

32

33 **Benefits and Penalties:** To be eligible for State funding through
34 HEAL and other initiatives, and to receive Medicaid data, RHIOs
35 must adhere to minimum consent policies and standards.

36 Recognizing the complexity and effort on the part of RHIOs and their participants in
37 implementing a standardized consent process, compliance with new consent policies
38 and procedures will be tied to significant and meaningful benefits for RHIOs. In the
39 immediate term, compliance with standardized consent policies will be a condition of
40 eligibility for access to Medicaid data and HEAL funds. Penalties of not complying with
41 consent policies will include loss of benefits described above.

42

43 **Enforcement:** Consent standards initially will be enforced through
44 contractual relationships between RHIOs and New York State, and
45 should migrate towards accreditation.

1 It is well understood that RHIOs are in the early stages of building their organizational
2 infrastructures and that much will be learned in the next several years with respect to
3 different models for ensuring consumer participation in health information exchange. In
4 the short term, RHIOs will be expected to implement the consent provisions adopted by
5 the State as part of their contractual agreements with the State. Such provisions will be
6 considered in light of the specific needs of each project allowing adequate time to
7 implement the consent procedures and, if necessary, transition from other models
8 deployed. Contractual agreements with the State will also take into account that
9 consent policies and procedures can be expected to evolve over the next few years
10 through a statewide collaboration process.

11
12 In the longer term, it can be expected that RHIOs will be subject to a broader State
13 regulatory framework which may include accreditation of RHIO governance, privacy and
14 security policies and other policies viewed as critical to the RHIO's role in establishing
15 public trust as to the collection, storage and use of personal health information,
16 protection from liability under certain circumstances and defined penalties for breach of
17 RHIO obligations.

18
19 For public trust to develop there must be an open and transparent process for
20 establishing and monitoring RHIOs or similar entities charged with ensuring the privacy
21 and security of health information. Accreditation is the best vehicle for ensuring
22 accountability. An independent accreditation entity would include public and private
23 representation, ensuring input from consumers and other industry stakeholders. Ideally,
24 the accrediting entity would function as a public-private partnership, so that compliance
25 with accreditation criteria would confer benefits and penalties by State and Federal
26 officials. Additionally accreditation criteria would evolve as the health information
27 exchange movement matures allowing state and federal governments to recognize the
28 process accordingly instead of dictating one that is subject to continuous evolution for
29 the next several years. An accreditation process for RHIOs as entities governing health
30 information exchange would also mitigate state-by-state health information exchange
31 regulation perpetuating and exacerbating the current patch work of state laws severely
32 limiting multi-state and nationwide health information exchange.

33
34

35 **V. Discussion of Policy Considerations**

36

37 **Enables consumers to make informed decisions regarding their personal health** 38 **information and promotes trust.**

39 While national surveys reveal that consumers generally support electronic collection,
40 storage and exchange of health information, concerns about the privacy and security of
41 their health information remain pervasive.⁴ An affirmative consent prior to accessing
42 personal health information is critical to earn consumer trust in RHIOs and to preserve

⁴ California Health Care Foundation. National Consumer Health Privacy Survey. 2005; Markle Foundation. Americans Want Benefits of Personal Health Records. June 2003.

1 consumer trust in their healthcare providers. The policies advanced in this document
2 seek to balance the need to encourage providers and payers to build the technical
3 infrastructure and capacity to promote greater information sharing, while at the same
4 time maintaining the consumers' ultimate rights to determine who has access to their
5 personal health information.

6 **Promotes provider access to complete patient records for clinical effectiveness**
7 **and tools to support quality improvements and cost reduction.**
8

9 Providers who have a full understanding of the patient's relevant medical history are
10 best equipped to provide high quality, cost effective care. Throughout the HISPC
11 process, stakeholders have struggled with how best to ensure clinicians have the best
12 available information to consistently and comprehensively treat their patients, without
13 encouraging "self-protective" behaviors among patients concerned about the exchange
14 of particularly sensitive health information. Patients who are concerned that information
15 related to their healthcare could subject them to discrimination or embarrassment may
16 avoid treatment or attempt to mask information in the care relationship. This has led
17 some to suggest that certain types of information should be excluded from the
18 exchange, or subject to higher standards of consent. Others have noted that to exclude
19 sensitive health information would undermine the benefits of health information
20 exchange for the very populations who need it most.

21 Ultimately, the recommendations created a high standard for all health information.
22 First, the consent form specifies consent to exchange all information, including HIV,
23 mental health and genetic information. Second, by requiring that each provider
24 organization and payer organization obtain consent to access the patients' health care
25 information, consumers are given the ability to exclude certain providers from accessing
26 health information through the exchange. Thus, patients can ensure that only trusted
27 entities have access to their information. Third, providers retain the discretion to
28 withhold information from the exchange. Some types of specialized providers in
29 particularly sensitive areas of practice, such as a genetics clinic, may choose to not
30 disclose any patient information from their practice and instead use the exchange only
31 to access data. In addition, clinicians will be given the discretion to consult with their
32 patients and make the best decisions for their care. Some providers may choose to
33 obtain consumer consent prior to uploading the consumer's data to the RHIO. Finally,
34 the recommendations prohibit participants from conditioning payment or treatment on
35 execution of the consent, ensuring that consents are voluntary, not coerced.

36 At the same time, the policy helps ensure that clinicians have access to a complete
37 medical record to treat patients in their care, and does not require RHIOs to facilitate
38 filtering of patient data.

39 **Supports payer access for the purposes of care management**

40 The recommendations seek to facilitate broad use of health information for uses that
41 promote good medical care and treatment, whether such uses are part of provider or
42 payer directed initiatives. Consumer always have the right to limit access of any

1 organization to their personal health information, but with their consent, information is
2 freely transferable to support better medical decision making and a broad range of care
3 management and quality programs.

4 There are differing views as to whether third-party payers should have the same level of
5 access to information exchanged through RHIOs as health care providers. Advocates
6 of payer access argue that payers perform important case management and quality
7 improvement functions, and that payer participation in the RHIO will improve patient
8 care. It is also noted that payers are actual or potential financial supporters of many
9 RHIOs, but are unlikely to lend such support if they are subject to onerous access
10 limitations. Critics of payer access argue, in turn, that it is not within the reasonable
11 expectation of patients that a consent they sign at a health care provider site will
12 facilitate their insurer's access to information. There is a concern that many patients will
13 feel misled when they learn their insurer has gained access to their information, without
14 regard to the actual language contained in the consent form. There is also suspicion
15 that payers may use information obtained through RHIOs against patients for
16 underwriting and other purposes unrelated to the delivery of medical care.

17 Imposing substantial restrictions on payer access to RHIO information is likely to
18 impede needed financial support for certain RHIOs and undermine legitimate payer-
19 based quality improvement activities. However, permitting payers to access information
20 pursuant to patient consent obtained by providers poses an unacceptable risk of
21 consumer confusion and dissatisfaction.

22 To address these competing concerns, it is recommended that payers be permitted to
23 access RHIO information only if the payer has obtained its own consent from the patient
24 that specifically references the RHIO. A payer should not be able to rely on a RHIO
25 consent obtained by a provider or a general consent obtained by the payer that does
26 not reference the RHIO. In addition, the payer's consent should permit use of the
27 information only for care management and quality improvement intended to benefit the
28 patient, not medical underwriting and similar practices. Finally, to ensure that the
29 patient's consent is voluntary, payers should not be permitted to condition enrollment or
30 benefits on the patient's willingness to sign the consent.

31 **Promotes uniformity in privacy policies to be adopted and implemented by RHIOs** 32 **across New York State to achieve interoperability via SHIN-NY**

33
34 One of the main goals of the policies advanced in this document is to promote uniform
35 adoption of privacy policies across RHIOs in New York State; thereby ensuring patient
36 information is truly portable through chain of trust agreements among multiple RHIO
37 networks comprising the SHIN-NY so that patient care improvements can be realized.
38 Uniform privacy policy adoption is critical to interoperability of information via the SHIN-
39 NY and ensuring that consumers gain a common understanding of what it means to
40 consent to their information being accessed through a RHIO.

41 In building consensus around a uniform policy, it was necessary to make some hard
42 choices as well as choices that are inconsistent with some current practices of emerging

1 RHIO organizations. For example, the recommendations do not permit a one time,
2 multiple organization consent policy, but instead requires each provider organization
3 and payer organization to obtain consent to access information. Having the accessing
4 clinician or organization obtain consent will engage the organization in educating
5 consumers about the consent process. It also will allow consumers to connect the
6 consent decision to the specific entity to which the consumer is granting access -
7 whether it is at the office of their primary care physician, their local hospital, a specialty
8 care provider or at the point in time when they elect to select their health insurance
9 carrier.

10 **Recognizes early state of development of RHIO business models and permits**
11 **flexibility in how market develops**
12

13 The recommendations take into account the early stage of many RHIO technical and
14 business models and takes great care to promote uniform adoption of consent policies,
15 without limiting or specifying the manner in which the policies are adopted by RHIOs.
16 The policies are technology neutral, so that they are adaptable to multiple technology
17 approaches, and will allow RHIOs to adapt to changes in the healthcare industry such
18 as evolving models of care, the emergence of new clinical practice models; increasing
19 emphasis on home care and community-based services, new payment models, quality
20 interventions and increasing consumerism and technological advances.

21 It is understood that some RHIOs in New York are currently implementing privacy and
22 patient consent policies that do not align with the state's strategy regarding the SHIN-
23 NY and corresponding policy framework. These RHIOs therefore may need to modify
24 or adapt their privacy and consent policies based on the conclusion of this project and
25 policy guidance issued by the Department of Health. If applicable, the Department of
26 Health will work with individual projects to develop reasonable timelines and
27 approaches for implementing these changes.

28 **Streamlines and clarifies process for obtaining patient consent to access and**
29 **disclose health information**
30

31 The recommended policies make clear that RHIOs may upload data without patient
32 consent to a CDR (central or distributed distribution model), thereby clearing the way for
33 RHIOs and their payer and provider partners to build a technical infrastructure that can
34 support real time data exchange. One of the main reasons for providing consumers
35 with protection and control over the health information through a consent to access
36 requirement, rather than a consent to disclose requirement, is because it is believed
37 that the latter would impose very real obstacles in the ability to build a system that
38 supports real time data exchange. Further, the policies abandon the "opt-in" versus
39 "opt-out" framework for a more holistic approach.

40 **Limits additional requirements on provider organizations**
41

42 Understandably, there is significant concern among physicians and hospitals that new
43 rules not place burdensome obligations or unfunded mandates on clinicians whose

1 main focus is on providing treatment based on the best available information about the
2 patient. By requiring a simple access consent on a State approved form that covers all
3 types of health information, the recommended policies adopt a straightforward and
4 easily implementable solution for provider organizations that mirrors the process already
5 in place.

6 Some have argued that a better approach would be not to require any affirmative
7 consent at all, but to allow patients to “opt-out” of the system if they so choose. But this
8 approach is not workable under current New York State laws which require affirmative
9 consent. It also is inconsistent with New York’s longstanding protection of consumer’s
10 right to control who has access to their health information. Significantly, the policy
11 recommendations are careful to avoid unintended consequences. This is done by
12 focusing the consent rules to health information exchange via SHIN-NY governed by
13 RHIOs, and by making it clear that the rules do not apply to one-to-one exchanges.
14 While the RHIO might use technology to facilitate the delivery of the physician ordered
15 results, the nature of that exchange is no different than transmission by a facsimile
16 machine. It is predictable and foreseeable to the patient, and does not expose the
17 patient to any greater risk of disclosure.

18

19 **VI. Next Steps**

20

21 After review of comments submitted in response to this document, the State
22 Department of Health will issue final policy guidance and take action to include its
23 recommendations in all future contracts with RHIOs in New York State and inform future
24 legislative and regulatory proposals. The contract provisions will require RHIOs to:

25

- 26 • Adopt privacy policies and procedures consistent with State recommendations;
- 27 • Use the standardized RHIO consent form approved by New York State to access
28 identifiable health information via the SHIN-NY governed by a RHIO; and
- 29 • Participate in a consumer education program initiative launched through the
30 statewide collaboration process to support the Privacy Policies and Procedures.

31

32 It is also recognized that further work and ongoing guidance is necessary to ensure the
33 successful implementation of these standards. The recommended standards seek to
34 provide specific, implementable policy guidance to RHIOs. Several areas have been
35 identified in which more process and thought is necessary before specific
36 recommendations can be put forth. In those instances, further action through a
37 statewide collaboration process is recommended.

38

39 New York State is implementing a statewide collaboration process to advance a
40 governance and policy framework for health information technology initiatives across
41 the State. The purpose of the statewide collaboration process is to:

42

- 1 • Providing a convening vehicle for the State and the health care community to
2 collaborate on key areas of New York’s health information technology agenda,
3 starting with HEAL NY Health IT projects;
- 4 • Providing a forum to discuss and collaborate on health IT policy priorities; and
- 5 • Coordinating and harmonizing the implementation of regional HIE and quality
6 and population health IT tools.

7
8 The New York eHealth Collaborative (NYeC), a NYS not-for-profit corporation is
9 facilitating the state level collaboration process and providing technical assistance to
10 HEAL grantees. The Department of Health is participating in the collaboration process
11 as a public-private partnership. NYeC’s mission is to improve health care quality and
12 efficiency through health IT and is comprised of health care leaders across the State,
13 including physicians, hospitals, health plans, public health officials, safety net providers,
14 employers, consumer and health care advocates, quality and regional health
15 information organizations, and includes participation by health information service
16 providers (vendors) and health care associations.

17
18 Among the issues that will require attention through a statewide collaboration process
19 are:

- 20
21 • Further definition of “one-to-one” health information exchange;
- 22 • Development of consumer education materials and campaign;
- 23 • Develop policy guidance to help ensure protection of consumer interests while
24 facilitating consumer access to and control of their personal health information;
- 25 • Consent policies and procedures for use of de-identified data exchanged through
26 RHIOs, focusing on ensuring adequate protections against reidentification;
- 27 • Consent policies and procedures relating to minors; and
- 28 • Consent policies and procedures relating to information obtained from federally
29 qualified alcohol and substance abuse facilities.

32 **VII. Acknowledgements**

33
34
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36 Transformation, New York State Department of Health. It is a result of a 2 year
37 statewide public process comprised of many contributors, including a Steering
38 Committee, a Legal Committee and multi-stakeholder workgroups.

39
40 In the last six months, NY HISPC, as part of Phase II, held three stakeholder meetings
41 to build consensus around a patient consent solution. The meetings were well attended
42 with participation from diverse stakeholders across the state, including providers,
43 payers, employers, business leaders, health IT leaders, public health, consumer and
44 health advocacy representatives, and government, among others.

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5

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Bronx RHIO	NYC Health Plan
Brownsville	NYC Health/Hospitals Corporation
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Cayuga Medical Center	NYHQ
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Childrens Health Fund	NYS Association of Health Systems
Community Care Physicians	NYS Clinical Lab
Community Health Center	NYS DOH AIDS Institute
Crystal Run Healthcare	NYSHFA
Department of Corrections	OMH
Excellus Health Plan	Prime Care
Genesee Region Home Care & Hospice	PSSNY
Glens Falls Hospital	Queens Health Network
GNHYA	Revival Healthcare
Greater Rochester RHIO	Rochester Business Alliance
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Greene County Public Health	Seton Health Systems
Harrison Center Outpatient	St. Ann's Community
Health Care Providers	St. Peter's Hospital
Health First	St. Vincent's Manhattan
Hill Haven Nursing Home	St. Vincent's Medical Center
Hometown Health Center	Staten Island University Hospital
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IBM	Strong Memorial Hospital
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Interim Health Care	Syracuse Chamber
IPRO	UB Associates
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Kodak	Unlimited Care
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