

March 2009

Health Information Security and Privacy Collaboration

Guidance for Developing Educational Materials about Health IT and Consent for Consumers

Prepared for

RTI International

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Prepared by

Consumer Education and Engagement Collaborative
New York HISPC III Consumer Education and Engagement Team

Health Information Security & Privacy
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1. BACKGROUND

This report is the second of two by the State of New York, based on its experience as part of the Health Information Security and Privacy Collaboration (HISPC) initiative and its Consumer Education and Engagement Collaborative (CEE).

HISPC is a national initiative funded by the federal Office of the National Coordinator for Health IT (ONC) to address state-level privacy and security variations and challenges related to the electronic exchange of health information. CEE is made up of eight member states, each of which developed both materials for its own state and materials for use by other states.

Although each state is unique, New York believes that its experience will inform other states (and perhaps other kinds of entities) as they develop educational materials for their constituents.

New York's first HISPC report, "Guidance for Developing Consumer Consent Policies for Health IT," describes its experience in developing policy related to consumer choice about whether to have their own health information shared and accessed electronically via the Statewide Health Information Network for New York (SHIN-NY) enabled by regional health information organizations (RHIOs).¹

At the most basic level, "consent" in the health IT context refers to policies that give consumers choice about whether and how to make their personal health information available to others electronically. Consent for the electronic sharing of information builds on existing policies from a technologically simpler era. In New York, consumers provide consent for health care provider organizations to access their health information electronically for basic health care functions. They may also provide additional consent for other uses of their information, such as health research.

The first report addresses how the advent of health IT affects consumer consent, how consent fits within a larger policy picture and as part of a suite of security and privacy policies, key considerations for states in crafting consent policy, and the collaborative policy-making process used by New York. As it says, consumer education is an essential cornerstone of support for New York State's health IT policy.

This report builds on the first by focusing on the educational materials that New York developed to explain health IT to the public and equip individuals to make informed consent

¹ ONC uses the term health information organization or "HIO" rather than "RHIO." It defines an HIO as "an organization that oversees and governs the exchange of health-related information among organizations according to nationally recognized standards." See http://www.nahit.org/images/pdfs/HITTermsFinalReport_051508.pdf for more information.

decisions. It also includes a set of educational materials and tools that can be adapted and used by others.

2. STATEMENT OF THE PROBLEM

While consumer or patient education is important in any setting in which health information is shared electronically, systems that rely on consumer consent have an even greater responsibility to communicate effectively about what they are doing and why. Without an understanding of the general benefits and risks of health IT, as well as the specifics associated with consent in a particular context, consumers are not able to make truly informed decisions.

Even with strong educational materials and support, given the complexity of the topic and the importance of what is at stake—including the quality and convenience of health care services and the extent of privacy protection—it is essential to view consent as only one part of a comprehensive policy framework that protects consumers.

New York's first HISPC report describes the specific components of a comprehensive policy framework. Too much reliance on consent without complementary privacy and security policies is risky because it places a burden on individuals to make choices for which there is no "right answer" —the benefits and risks associated with health IT, which is quickly evolving, are difficult to assess with certainty, even for experts.

3. PROCESS

One unique aspect of health IT planning and implementation in New York is the Statewide Collaboration Process (SCP). Health care leaders from across the state, with leadership and support from the New York State Department of Health, established the New York eHealth Collaborative (NYeC). NYeC is a public-private partnership playing an integral role in the development of information policies through consensus-based governance. NYeC's key responsibilities include (1) convening, educating, and engaging key constituencies, including health care and health IT leaders, RHIOs, and Community Health Information Technology Adoption Collaboratives (CHITAs); (2) developing health information policies, standards, and technical approaches; and (3) evaluating and establishing accountability measures. Through NYeC, New York has brought hundreds of individuals into the SCP over the last year.

The core team of staff developing consumer education materials used the existing structure of the SCP and augmented it to assist in the strategy, refinement, and testing of consumer education materials. Because our subcontract as part of HISPC did not permit formal focus group testing, an informal panel of consumers was pulled together by our partner organizations on an in-kind basis to get direct consumer input.

Beginning with the conceptual stages of product development, draft materials were repeatedly shared with members of several groups and plans were adjusted based on their insights and input. We also worked closely with the New York State Department of Health's communications team, which helped in the design of the brochure and visual ads, and in finalizing radio scripts and the video. An outside firm was hired (through other resources) to help with website development.

The brochure and consent form were edited by professional literacy experts via the New York State Department of Health, and tested directly with consumers through the help of the department and members of the Consumer Advisory Council (CAC).

The CAC, led by the Legal Action Center and the Mailman School of Public Health at Columbia University, has played an especially important role as a steering committee or advisory body for New York's consumer engagement and education initiatives relating to ehealth. It was created expressly for this purpose, and to advocate for consumer-friendly ehealth policies. Members of the CAC include the following organizations:

- AARP
- AIDS Institute Division of HIV Healthcare
- Alcoholism and Substance Abuse Providers of New York
- Alzheimer's Association
- American Association of People with Disabilities

- Bazelon Center for Mental Health Law
- The Center for the Independence of the Disabled—New York
- Center for Medical Consumers
- Community Service Society
- Ferre Institute/New York State Genetic Counselors Group
- Guilderland Public Library
- National Breast Cancer Coalition Fund
- New York AIDS Coalition
- New York Association of Psychiatric Rehabilitative Services
- New York State Consumer Protection Board
- Planned Parenthood of New York City
- WE ACT for Environmental Justice, Inc.

In addition to input from the CAC, we worked closely with representatives of RHIOs, particularly those that have already invested in major public education campaigns. Educational materials developed by RHIOs were collected and analyzed. These materials helped inform the development of our statewide materials templates. Representatives of RHIOs (most of which are members of the SCP Connecting New Yorkers and Clinicians Work Group) that especially helped to review and shape our materials include the following:

- The Bronx RHIO
- Brooklyn Health Information Exchange (BHIX)
- Health Information Xchange New York (HIXNY)
- The Long Island Patient Information exchange (LIPIX)
- The Greater Rochester RHIO (GRRHIO)
- Southern Tier Health Link (STHL)

We also benefited from the input of members of the NYeC Education and Communications Committee, which consists of community leaders such as representatives of businesses, health plans, trade associations, and hospital and other provider communities. Members include

- AARP
- American College of Physicians, New York Chapter
- Brooklyn Health Information Exchange (BHIX)
- Business Council of New York State
- Center for Independence of Disabled, NY

- Center for Medical Consumers
- Community Health Care Association of New York State
- e-Health Network of Long Island
- Greater New York Hospital Association
- Healthcare Association of New York State
- HIMSS, New York Chapter
- Home Care Association of New York State
- Medical Society of the State of New York
- New York Association of Homes & Services for the Aging
- New York Health Plan Association
- New York State Department of Health
- Northeast Health
- Southern Tier HealthLink
- UnitedHealth Group
- Visiting Nurse Service of New York

4. PRODUCTS

Preparing consumers to make the most informed consent decisions possible was the ultimate goal of New York’s HISPC consumer education work. However, it was also identified that it was necessary to provide New Yorkers with more general information about ehealth. (After much debate the term “ehealth” was chosen rather than “health IT” for our materials because the group thought it was simpler and less technical sounding; it is also more intuitive because it puts an ‘e’ in front of a word to “computerize” it.)

Materials were developed in a variety of media that are appropriate for different kinds of contexts and audiences. Often, the medium shaped the message. For example, it is not possible to provide a lot of detail in a 30-second radio PSA, but radio can convey a single emotion or idea quite forcefully. Materials containing both general and detailed information are needed.

Conceptually, the group thought about reaching people in a “generic” environment that may have nothing to do with health—for example at a bus stop or subway or in a government building, as well as in a “point-of-care” setting, which could be a clinic, doctor’s office, pharmacy, or anywhere else that is health related. When we developed the materials, it was assumed that people would be more receptive to shorter, simpler messages in a generic environment, and to greater detail in a point of care setting, especially if they were being asked to take action by reading and filling out a consent form. Some materials are inherently more flexible than others—a poster, for example, could be effective either in a generic or point-of care-setting.

Another consideration in the development of materials is making sure they are flexible enough to meet the needs of diverse populations. It is impractical to create a single brochure or other communications vehicle that meets everyone’s needs, in part because of differences in literacy levels, primary language spoken, cultural norms, and special considerations to enhance usability for populations with disabilities.

Rather than attempting to develop a full array of materials to meet every population’s needs, we designed a suite of items that are appropriate for the general population in a range of settings. These items are considered to be templates that can be adapted by various entities for specific purposes and populations. They will be translated into at least 10 languages by the New York State Department of Health, and it is expected that RHIOs will further customize them to include information particular to local needs. (See more about templates in the “lessons learned” section.)

The following primary materials developed by the NY team are included as attachments to this report:

Brochure. The brochure includes basic information about ehealth in New York, including what it is and its primary benefits (see Appendix A). It also has a section about privacy and answers basic questions about consent and accessing your own information through ehealth. The brochure went through numerous iterations, including debates among our advisory groups about how much content to include, the appropriate tone, and what literacy level to aim for. There was also a lot of discussion of images. In the end the group chose several photos portraying positive interactions between consumers and providers that include technology, such as laptops. Subjects include a range of ages and ethnicities. Images for the brochure, visual ads, and website were purchased from online stock photo sites. The design and layout were developed in partnership with the New York State Department of Health’s Office of Public Affairs.

Visual advertisements. These can be used as posters, print ads, or online. There are two versions, one emphasizing the value of ehealth in an emergency and the other the convenience it can bring every day (see Appendix B and Appendix C). The emergency version—with an image of a person falling off a ladder, was adapted from research done by the Markle Foundation in its report “Connecting Americans to their Healthcare” in 2004. That report found that a version of this particular image and the emergency message associated with it tested higher than any others in terms of persuasiveness in a public poll.² In addition, the figure is not specific with regard to the age, gender, or ethnicity of the subject—it could be almost anyone.

Radio PSAs. There are two 30-second radio spots, again emphasizing the emergency and convenience messages (see Appendix D). The group debated trying to make the visual ads and radio ads line up more exactly in their details, so that one would be a more literal translation of the other. Eventually, however, we decided that an exact match was less important than making sure each was effective on its own. The core team of staff working on consumer education wrote and refined the radio scripts, and worked with the New York State Department of Health to identify a local recording studio to record them.

Video. An adaptation of the video produced by members of the HISPC Consumer Education and Engagement Collaborative from Oregon was produced in NY by adding additional footage: an introduction and concluding comments by Dr. Richard Daines, the New York State Health Commissioner. See [better_information_means_better_care.wmv](#).

Website. The website <http://www.ehealth4ny.org/> is hosted by the Legal Action Center, which also organizes the CAC described in the previous section. The website incorporates the materials described above and also provides more in-depth information such as updates about upcoming events, more detailed questions and answers about ehealth, and information about the CAC and specific RHIOs in New York. Also, using the website the

² “Connecting Americans to their Healthcare” can be found at http://www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf.

Legal Action Center is establishing a statewide Consumer Network for ehealth to reach out to a wide range of groups and individuals in New York. The goal is to provide education on ehealth, and spur engagement and participation in local and regional ehealth efforts. A listserv of thousands of advocacy groups, service providers, patient organizations, and others is ready to launch.

Model Consent Form. This form is the mechanism through which consumers choose to participate in ehealth in New York (see Appendix E). In the short term, it will be available in paper, although it may be available in electronic form or a statewide consent management service may be implemented in the future. It is designed for provider organizations participating in RHIOs to use—other versions based on this general language and layout are being developed for use by other participants in RHIOs, including health insurance providers. See further discussion of this form in the lessons learned section.

5. LESSONS LEARNED: ABOUT CONSUMER EHEALTH EDUCATION IN GENERAL

Inclusive Process. A very inclusive process like the one New York used requires extensive time and patience. The more people who are involved, the harder it is to achieve consensus, in part because it takes a lot of time educating people to get them up to speed, and in part because there are inevitably differences of opinion. The core team believes it is important to get input from a diverse array of stakeholders, and we hope their involvement will pay off in the long run, not just through better educational materials, but also because we have begun to develop a cadre of strong ambassadors of the messages. Nevertheless, it is important to realize that seeking and incorporating a significant amount of input requires a major investment of time.

Branding. Developing a brand image took a lot of effort and many visual design iterations. For example, many versions of a logo were tried before the group agreed on one we all liked. We did not want anything too technical, or anything too doctor focused. In the end, the image chosen was one that is both abstract and positive, using green to symbolize health and growth. Visual images carry a lot of weight; for the brochure emphasis was placed on positive images of people, consumers and providers together. Another branding challenge was that some people saw an association of our ehealth efforts with the New York State Department of Health as positive and even essential, while others feared that such an association with government would heighten privacy concerns.

Messaging. The group decided to focus on messages about safety in an emergency and about convenience; these two themes have had great traction with consumers in other initiatives, and our experience in New York seems to confirm those preferences. These themes were used for the generic ambient advertising (e.g., radio spots) which cannot provide a lot of detail, along with the basic statement “Better Information Means Better Care.” On the more in-depth materials (website, brochure) our messages were less pointed, more nuanced—in images as well as text.

Templates. No one educational item can meet the needs of all populations in all contexts. Our idea was to develop materials that could be used as-is by RHIOs or consumer groups, but also could be modified by them to fit specific needs. For example, one RHIO took our brochure language and extracted a portion of it for a one-page flier. In designing our templates the plan was to reach as broad an audience as possible, with the understanding that tailoring or adapting the template will be necessary to reach certain populations or communities. These templates were also intended to be customized for use by other states and organizations.

6. LESSONS LEARNED: ABOUT CONSENT EDUCATION

Consent in context. The policy and practice of consent in the health care setting and health IT context raise very difficult issues, posing both policy choices and implementation challenges. On its face, consent is usually posited as a “patient right,” something people are entitled to as they make their way through the health care system. The right to consent is often perceived as giving people the ability to make choices about whether to share their health information with providers, payers, and others outside of the core health care arena, and allowing them to choose how much of their information is viewed by which providers. However, as we have seen in practice, patient empowerment is much more complicated.

As a number of experts and advocates have stated in recent months, for consent to be meaningful, people must be able to make choices freely and after being fully informed. In addition, meaningful consent must be coupled with enforceable limits on the collection, use, and disclosure of identifiable patient data, so that the burden of these choices is not fully on the patient. In the health IT context, this is critical given that, even when people are offered choices about the collection and use of their information, it is virtually impossible to anticipate the myriad organizations and entities outside of health care with whom their information might be shared, and under what circumstances. In fact, meaningful consent coupled with enforceable privacy and security policies is appearing to gain support at the national level as the most balanced health privacy approach.³

As we approached the issue of consent with a wide variety of stakeholders and constituencies in New York, we quickly appreciated the challenges inherent in communicating the value of this comprehensive approach to consent. Further, we confronted the real-world difficulty of building privacy policy into systems—many that are already far into the development and implementation phases.

Tone. One challenge the group faced was how to talk about consent in a way that encourages participation by consumers by engendering trust and confidence, but not overburdening them with unrealistic or complicated choices. Confidentiality needs to be built into health IT, while still giving people the ability to make decisions free of coercion. How do we strike the right tone in communicating the benefits of participation in health IT as well as the potential risks to privacy and security?

Within our group of advocates, providers, disability rights groups, and others, we worked hard to strike a balance between “selling” ehealth and being honest about its privacy risks and unknowns. An area for future work is developing more materials or tools that help individuals navigate consent choices that are right for them. The decision about whether to

³ Statement of Deven McGraw, Director of the Health Privacy Project at the Center for Democracy and Technology, before the Senate Judiciary Committee, January 27, 2009. Available at http://www.cdt.org/testimony/20090127_mcgraw.pdf.

consent may vary over time even for a single individual depending on his or her health status, employment status, and other factors. We are continuing to learn how to best illustrate both the benefits and risks. Our goal, again, is to ensure that the public understands the benefits of health IT for quality, safety, convenience, and access to health services, but not jeopardize their sense of security and trust in the system.

Level of detail. It is hard to decide how much the public needs to know to be “informed” about consent. On many of the materials, including the consent form, the group struggled between providing more detailed/accurate information, and more general statements. For example, does the public need to know the meanings of the terms SHIN-NY, RHIO, PHR, Health IT, etc. as well as names of local RHIOs? We recognize there is a “branding” issue with a number of these acronyms, but are also wary of rolling out too many new terms at once at this nascent stage of public education and exposure. The plan is to gradually saturate PSAs and other public education materials with relevant terms as people at the local and state levels are more able to absorb and understand them.

Literacy level. New York is committed to reaching as wide a population as possible, but the goal is easier set than reached. Although many New Yorkers read below a 10th-grade level, the group chose to peg our ehealth brochure and consent form at the 10th-grade level (at times to 8th grade) because at lower levels some of the actual meaning is lost, and we wanted to ensure that we were not misleading. The consent form is a legal document, so there are restrictions on the extent to which we can simplify it. Particular (and often very complex) terms must be included in it. Individuals who may require materials at lower literacy levels may need more support from providers, consumer groups, and others with whom they have direct contact to fully understand their consent choices. Those who cannot read at a 10th-grade level should be able to absorb information through the video or through the simpler “ambient” media (radio, posters), and augment that basic understanding with direct and more nuanced input from people they trust.

About the consent form itself. It is important to consider the consent form itself as part of the consumer education and outreach strategy. The group is dedicated to making the form consistent with our other materials, such as the ehealth brochure, PSAs, and the ehealth4NY website. For a number of reasons, it was decided that the consent form should be a standalone document that might be delivered to patients on its own, or coupled with supporting material and conversation with providers and others directly interacting with patients.

In New York, we needed to include in the consent form several legal requirements, including condition-specific limits for alcohol and drug abuse problems, birth control and abortion (family planning), genetic (inherited) diseases or tests for HIV/AIDS, mental health, and sexually transmitted diseases, while still communicating at an easy-to-understand level. On a more general level, it was essential that we build in fair information practices such as

informing people of practices and policies, how information will be used, for what purposes, what rights they have to access their information, and what enforcement mechanisms exist, including any remedies that may be available.

A key goal was to keep the messages and the material appealing, conveying certain ideas with images instead of verbiage. The group strove to translate legalese into simple English, which involves making word choices that continue to convey the legal requirements and patient rights, but in an approachable style. We tried to communicate directly to the consumer by using the second person (e.g. “How Your Information Will Be Used”).

One of the more challenging debates was whether to include in the consent forms three choices for consent, or two. The first two choices are whether to allow access to ehealth records always, or never. The third potential choice would have involved consent for health care providers to access health information in an emergency only. It was important to communicate potential options clearly and honestly to readers, but did not want to make the choices too confusing. In the end, we chose to include only two choices, and to add information about the two basic choices up-front, and below with the actual consent boxes. We have learned from survey data and experience that such choices need to be clear, in plain language, and reiterated in materials.

It is important to explain privacy in straightforward terms without being unnecessarily alarming, or raising unlikely scenarios. The ehealth4ny website will be able to provide people with more detail and links to other resources. To keep the form short and digestible, we culled out any unnecessary material or information. We were able to keep the form to one two-sided page. We are prepared to tailor the form as needed to incorporate changes in policy and practice, or to reflect lessons we learn from consumers once the form is in the field.

7. AREAS FOR ADDITIONAL WORK/STUDY

We have identified a number of challenges in New York State that we will need to tackle in the coming months and years:

Broad dissemination of materials—and funding to support it. Our goal of broad dissemination of materials will be tough to reach given limited resources; however, we are especially dedicated to reaching certain target populations, such as the chronically ill, those with acute illness, vulnerable, disadvantaged communities, communities of color, and others whom we know are most likely to distrust electronic health information systems. It is critical to the success of ehealth that we foster trust and confidence within the communities that are most likely to benefit, as well as those most likely to suffer stigma and discrimination from misuse. We strongly recommend that additional federal dollars be invested in the dissemination of consumer education materials already developed, as well as the development of additional ones.

Coordination across stakeholder groups. Ongoing coordination with education efforts designed to reach other stakeholders (providers, policymakers, health plans, members of the business community, etc.) is essential to maintain momentum of our early successes.

Translation into multiple languages. We plan to translate our materials into a number of languages, including Spanish, Mandarin, Russian, Italian, French and other languages spoken in New York, being mindful to match the multilanguage materials with particular regions and/or services and organizations that serve those populations.

Translation into multiple formats. We must also translate our materials into formats that are usable by populations with disabilities. Additional resources are needed for closed captioning of the video and the development of print or online versions of materials that are easier for people with impaired vision (including the elderly) to read.

Personalized support for consent decisions. More needs to be done to develop consumer materials related to consent, making clear the real choices people have and giving them the information needed to make choices appropriate to their unique circumstances. Further, it is important that providers and health care organizations also be educated so that they do not attempt to condition the delivery of health services or benefits upon obtaining a patient's consent.

Maximizing Internet use. Developing materials that take advantage of the Internet is critical to the widespread outreach we seek, including through other groups' websites, listservs, and free ads on certain sites run by health-related groups that serve New Yorkers. We may also be able to incorporate social networking sites and viral marketing.

Measuring impact. We are committed to measuring the successes (and weaknesses) of our outreach and education efforts over the next months and years as RHIOs become

operational, consent forms are disseminated, advocacy and health groups begin to incorporate ehealth into their missions, and ehealth is made real in the delivery of health care and other health-services in New York. Further, it is important to be able to measure the impact of consent choices on RHIOs, particularly within certain populations, so that we may assess who withholds consent and why, what impact that has on care, and whether there are policy and/or practice steps that can be taken to address the public's ongoing concerns.

8. CONCLUSION

Creating a policy and practice environment that enables the public to be truly informed about consent is a tall order, one that requires significant education and outreach. Further, a robust set of supporting policies is required to couple consent with enforceable, meaningful rules.

Consumer education is a process, not a product. New York is only at the beginning of this process, and we foresee that many more chapters will need to be written and reviewed as we go forward. Our hope is that the materials we developed for New York, and the lessons we learned here, will be of use to others around the country at the state and national levels.

9. ACKNOWLEDGEMENTS

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The consumer education materials were developed by a core consumer education team with support from the New York State Department of Health's Office of Public Affairs and significant input from the Consumer Advisory Council, the Education and Communications Committee of the New York eHealth Collaborative (NYeC), and several RHIOs in New York State.

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**APPENDIX A:
eHEALTH BROCHURE**

**APPENDIX B:
POSTER 1**

**APPENDIX C:
POSTER 2**

**APPENDIX D:
RADIO PSA SCRIPTS**

RADIO: 60 (163 words, 12/15/08)
“eHealth/ER”

[SFX: Sirens/gurney bursting through doors/ER chatter]

DOCTOR: We have an unconscious female. So you're her son?

SON: Yes.

DOCTOR: Can you tell me what happened?

SON: She was changing a light bulb and hit her head...

DOCTOR: Any major illnesses or injuries?

SON: Yeah, I think she might have high blood pressure...

DOCTOR: Is she on any medications?

SON: A lot of pills, but I'm not sure exactly what...

DOCTOR: Any allergies?

SON: Um, I don't really know.

DOCTOR: Who is her regular doctor?

SON: Uh, sorry, I dunno. Is it a Dr. ... Miller?

ANNOUNCER: Don't let this happen to you or the people you love. Access to information about your health could save your life.

The New York State Health Department is working with doctors, patients, and medical experts to support ehealth—the use of secure computer networks instead of paper files to store and manage your medical records. With ehealth, the doctors you choose can see your records when it matters most—like in an emergency.

Better information means better care. So ask your health care provider about ehealth—or visit www.ehealth4ny.org.

RADIO: 60 (167 words)
“eHealth/No More Paper Bag”

[SFX: Hospital waiting room]

PATIENT: Hi. I have an appointment with Dr Smith. I'm a new patient. Here are some of my files and prescriptions.

[SFX: Patient drops a big pile of papers on the counter, followed by a paper bag with medicines falling out and bouncing on the floor.]

RECEPTIONIST: OK, I can check you in, but what's all this?

PATIENT: When I called to set up the appointment, they told me to bring my medical records so Dr Smith can give me the best care possible. So—*that's* the X-ray from my broken ankle, and *these* are the pills I take for headaches, and this *other* pill I used to take but don't anymore, and—

RECEPTIONIST: [Interrupting] Do you know about eHealth?

PATIENT: No. What's that?

RECEPTIONIST: The New York State Health Department is working with doctors, patients, and medical experts to support ehealth—the use of private and secure computer networks, instead of paper, to store and manage your medical records. You choose who can see your records. When your records follow you, you don't have to carry them around or worry that they'll get lost.

ANNOUNCER: Better information means better care. So ask your health care provider about ehealth—or visit www.ehealth4ny.org.

**APPENDIX E:
CONSENT FORM**

MODEL RHIO CONSENT FORM
[NAME OF PROVIDER ORGANIZATION]

In this Consent Form, you can choose whether to allow [Name of Provider Organization] to obtain access to your medical records through a computer network operated by [Name of RHIO], which is part of a statewide computer network. This can help collect the medical records you have in different places where you get health care, and make them available electronically to our office.

You may use this Consent Form to decide whether or not to allow [Name of Provider Organization] to see and obtain access to your electronic health records in this way. You can give consent or deny consent, and this form may be filled out now or at a later date. **Your choice will not affect your ability to get medical care or health insurance coverage. Your choice to give or to deny consent may not be the basis for denial of health services.**

If you check the **"I GIVE CONSENT"** box below, you are saying "Yes, [Name of Provider Organization]'s staff involved in my care may see and get access to all of my medical records through [Name of RHIO]."

If you check the **"I DENY CONSENT"** box below, you are saying "No, [Name of Provider Organization] may not be given access to my medical records through [Name of RHIO] for any purpose."

[Name of RHIO] is a not-for-profit organization. It shares information about people's health electronically and securely to improve the quality of health care services. This kind of sharing is called ehealth or health information technology (health IT). To learn more about ehealth in New York State, read the brochure, "Better Information Means Better Care." You can ask [Name of Provider] for it, or go to the website www.ehealth4ny.org.

Please carefully read the information on the back of this form before making your decision.

Your Consent Choices. You can fill out this form now or in the future. You have two choices.

- I GIVE CONSENT for [Name of Provider Organization] to access ALL of my electronic health information through [Name of RHIO] in connection with providing me any health care services, including emergency care.**

- I DENY CONSENT for [Name of Provider Organization] to access my electronic health information through [Name of RHIO] for any purpose, *even in a medical emergency.***

NOTE: UNLESS YOU CHECK THIS BOX, New York State law allows the people treating you in an emergency to get access to your medical records, including records that are available through [Name of RHIO].

Print Name of Patient

Patient Date of Birth

Signature of Patient or Patient's Legal Representative

Date

Print Name of Legal Representative (if applicable)

Relationship of Legal Representative to Patient (if applicable)

Details about patient information in [Name of RHIO] and the consent process:

- 1. How Your Information will be Used.** Your electronic health information will be used by [Name of Provider Organization] **only** to:
- Provide you with medical treatment and related services
 - Check whether you have health insurance and what it covers
 - Evaluate and improve the quality of medical care provided to all patients.

NOTE: The choice you make in this Consent Form does NOT allow health insurers to have access to your information for the purpose of deciding whether to give you health insurance or pay your bills. You can make that choice in a separate Consent Form that health insurers must use.

- 2. What Types of Information about You are Included.** If you give consent, [Name of Provider Organization] may access ALL of your electronic health information available through the RHIO. This includes information created before and after the date of this Consent Form. Your health records may include a history of illnesses or injuries you have had (like diabetes or a broken bone), test results (like X-rays or blood tests), and lists of medicines you have taken. This information may relate to sensitive health conditions, including but not limited to:
- Alcohol or drug use problems
 - Birth control and abortion (family planning)
 - Genetic (inherited) diseases or tests
 - HIV/AIDS
 - Mental health conditions
 - Sexually transmitted diseases
- 3. Where Health Information About You Comes From.** Information about you comes from places that have provided you with medical care or health insurance (“Information Sources”). These may include hospitals, physicians, pharmacies, clinical laboratories, health insurers, the Medicaid program, and other ehealth organizations that exchange health information electronically. A complete list of current Information Sources is available from [*Provider Organization OR RHIO, as applicable*]. You can obtain an updated list of Information Sources at any time by checking the [Name of RHIO]’s website at _____ or by calling _____.
- 4. Who May Access Information About You, if You Give Consent.** Only these people may access information about you: doctors and other health care providers who serve on [Name of Provider Organization]’s medical staff who are involved in your medical care; health care providers who are covering or on call for [Name of Provider Organization]’s doctors; and staff members who carry out activities permitted by this Consent Form as described above in paragraph one.
- 5. Penalties for Improper Access to or Use of Your Information.** There are penalties for inappropriate access to or use of your electronic health information. If at any time you suspect that someone who should not have seen or gotten access to information about you has done so, call [Name of Provider Organization] at: _____; or visit [Name of RHIO]’s website: _____; or call the NYS Department of Health at 877-690-2211.
- 6. Re-disclosure of Information.** Any electronic health information about you may be re-disclosed by [Name of Provider Organization] to others only to the extent permitted by state and federal laws and regulations. This is also true for health information about you that exists in a paper form. Some state and federal laws provide special protections for some kinds of sensitive health information, including HIV/AIDS and drug and alcohol treatment. Their special requirements must be followed whenever people receive these kinds of sensitive health information. [Name of RHIO] and persons who access this information through the [Name of RHIO] must comply with these requirements.

7. **Effective Period.** This Consent Form will remain in effect until the day you withdraw your consent.
8. **Withdrawing Your Consent.** You can withdraw your consent at any time by signing a Withdrawal of Consent Form and giving it to *[Provider Organization or RHIO, as applicable]*. You can also change your consent choices by signing a new Consent Form at any time. You can get these forms on [Name of RHIO]'s website at _____, or by calling _____. **Note: Organizations that access your health information through [Name of RHIO] while your consent is in effect may copy or include your information in their own medical records. Even if you later decide to withdraw your consent, they are not required to return it or remove it from their records.**
9. **Copy of Form.** You are entitled to get a copy of this Consent Form after you sign it.