

**New York eHealth Collaborative Policy Committee Meeting**  
**July 14, 2015**  
**9:00 a.m. – 11:00 a.m.**  
**Meeting Notes**

A meeting of the NYeC Policy Committee was held on July 14, 2015. Present either in person or via telephone were:

David P. Martin, Consumer Health Care Advocate  
Dr. Thomas Mahoney, Finger Lakes Health Systems Agency  
Dr. Glenn Martin, Queens Health Network  
Nance Shatzkin, Bronx RHIO  
Dr. Amanda Parsons, Montefiore  
Steve Allen, HealthLink  
James Kirkwood, NYS DOH  
Geraldine Johnson, NYS DOH PH Informatics  
Dr. John-Paul Mead, Cayuga Medical Associates, P.C.  
Dan Tietz, AIDS Institute  
Paul Schaeffer, New York City Department of Health and Mental Hygiene  
Linda Adamson, New York City Department of Health and Mental Hygiene  
Ted Kremer, Rochester RHIO  
Tom Check, Healthix RHIO  
John Rodat, Public Signals, LLC  
Christie Allen, NYS DOH  
Cindy Sutliff, NYeC  
Vinay Chopra, NYeC  
Inez Sieben, NYeC  
Bob Belfort, Manatt  
Alex Dworkowitz, Manatt

The meeting was called to order by Ms. Sutliff at 9:00 a.m.

**I. NYS DOH Update**

Ms. Sutliff introduced Mr. Kirkwood from the New York State Department of Health (“NYS DOH”) to discuss the draft SHIN-NY regulation. Mr. Kirkwood said that the updated regulations have been submitted, and that NYS DOH is hoping that the regulations will be released for public comment in August. He said the regulations will be subject to a 45-day comment period.

Ms. Sutliff asked about the relationship between the draft regulations and Performing Provider Systems (“PPSs”) participating in the Delivery System Reform Incentive Payment (“DSRIP”) program. Mr. Kirkwood said that there was more communication with PPSs and their partners about the consent requirements for accessing the SHIN-NY. He noted that NYS DOH will be sending an opt-out form to Medicaid beneficiaries over the next month which would allow them to opt-out of the sharing of their claims data. Mr. Kirkwood said it was important to align the

Health Home, DSRIP and SHIN-NY consent policies, particularly since claims data may be released through the Qualified Entities (“QEs”).

Mr. Allen asked if the SHIN-NY consent form allows for the disclosure of claims data. Mr. Kirkwood said he believed the form does allow such disclosure. Ms. Shatzkin said that on a recent call, NYS DOH said that QEs cannot access this claims data. Mr. Kirkwood responded that the way standing language is right now, the data can only be released to the PPS, but they are working on addressing that issue. Ms. Shatzkin observed that there is a fairly rigorous process for complying with the claims data security requirements, and she asked if there is a person at NYS DOH who the QEs could contact regarding this process. Mr. Kirkwood said he would look into finding the appropriate contact, and that NYS DOH was already in touch with some QEs about starting the process. Mr. Check said that Healthix already has some claims data from MCOs but that it would love to qualify to get data from NYS DOH.

Mr. Allen said that the various consent forms use different terms such as medical record, protected health information, and health record. He asked if claims data was meant to be encompassed by those terms, and whether the Policy Committee needs to settle on one term. Mr. Belfort said that the Policies use the term protected health information, and that term includes both medical records and claims records. Mr. Belfort said that the Policies were never meant to distinguish between provider’s medical records and payers’ claims records.

## **II. Level 2 Consent form for exchange of family member information**

Ms. Sutliff explained that one of the follow up items from the June meeting was the need for a consent form to address situations where a family member of a patient provides SHIN-NY access to that patient’s provider. Mr. Dworkowitz said that Manatt had drafted a form that was based on the Level 1 consent form that is typically used. He said that the form was meant to be filled out by the family member, not the patient who was being treated by the provider. Mr. Dworkowitz noted that the information being shared did not fall within the scope of the genetic privacy laws because the information involved standard medical records, not genetic tests.

Ms. Shatzkin said that she thought the wrong word (“you”) was used in paragraph 3. She also said that paragraph 7 of the form would be tough to implement.

Mr. Check said that this is not the type of form that would be used in high volume, and therefore if it took more dialogue in order to explain the form to patients that would be okay. Mr. Check said that allowing for use of the form would require the QEs to make some software changes, but that there is no way to implement this type of policy without such software changes, so therefore they should focus on getting the policy correct.

Ms. Shatzkin said that in some instances the form may not be completed in the office of the provider; instead, the patient may give the form to the family member, and the family member would complete the form at home and mail it in. Mr. Check said that there needs to be a way to authenticate that the person who signs the form is actually the family member whose data is being accessed, and perhaps the form should be notarized. Mr. Allen agreed that this is important to do, and that since this is a low volume transaction it would not be too burdensome

to require the form to be notarized. Ms. Shatzkin suggested that if the form was signed in person in front of a provider it need not be notarized, but if it was mailed in it would have to be notarized.

Mr. Mahoney asked if consent forms are generally signed in person or whether there is also a use of notaries. Ms. Sutliff and Ms. Shatzkin said that notaries are not involved. Mr. Allen said that HealtheLink does require witnesses to sign a form if it is signed outside a provider's office, but that it does not require the form to be notarized.

Ms. Johnson asked if the family member's information would become part of the patient's record. Mr. Belfort said the information would be treated the same way as other records, and if it was downloaded it would be part of the provider's medical records. Dr. Parsons asked if that meant that the patient would therefore have access to the provider's medical records with information about the family member. Mr. Belfort said that in the paper world, the family member's medical record would be integrated into the patient's record, but there is a provision of the state Public Health Law that allows a provider to deny a request to access a record that was not created by the provider. Mr. Allen said that in the SHIN-NY this information would be associated with the family member's record, not the patient's record. Ms. Shatzkin said that this information would in fact be integrated into the patients file.

Dr. Parsons said she was concerned if the patient had access to this information. For example, if the provider treating a patient sought access to the patient's mother's medical history regarding breast cancer, the mother gave permission to the provider to access that information, but did not give permission to her daughter to access that information. Mr. Belfort said that this is the same issue as exists in the paper world, and since there is a provision in the Public Health Law that would allow the provider to deny the patient access to the medical record if it were created by another provider, the provider would not be required to provide this information to the patient in this scenario.

Dr. Martin said that in the paper world, the patient's provider is not given access to the family member's entire medical record; instead the provider only has access to information that is relevant to treatment of the patient. However, the form as currently written gives the provider access to the family member's entire medical record, and that access is ongoing. Dr. Martin said he thought that access should be turned off. Ms. Sutliff said she agreed that limited access might be appropriate, and that perhaps the access should be read only. Mr. Belfort said he agreed that limiting the data to relevant information made sense, but he wondered if the QEs have the technical capacity to do this.

Dr. Martin also questioned the utility of the family member information. In the case where a patient wanted to find out about her mother's treatment for breast cancer decades ago, this information would not be available in the QE.

Mr. Check said the family member would be willing to trust the provider to access only the information in the family member's record that is relevant to the patient's treatment. Dr. Martin said that he thought that a family member would not necessarily trust his brother's oncologist. Ms. Shatzkin said one of the challenges here is the issue of trust. Dr. Martin said the consent

form and the Policies should both limit the type of information that can be exchanged in this scenario. Ms. Shatzkin agreed.

Mr. Check noted that if there was a limitation on the type of information that participants could provide to the patient of the family member, then a QE might be required to audit the participants to make sure they follow that type of restriction. Ms. Shatzkin said she understood Mr. Check's point, and that she wasn't sure how this issue could be enforced with an audit. Mr. Allen said that QEs currently have an obligation to make sure all uses are appropriate.

Ms. Sutliff said that they should draft a policy statement, a recommendation to NYS DOH about what should be included in the Policies, regarding access to a family member's information where a Level 2 consent is granted. Ms. Sutliff said that the draft Level 2 form should be revised based on the discussion.

Mr. Allen suggested that the reference to "medical records" in the form should be changed to "personal health information." Mr. Belfort said they have used the term "medical records" because this is a term that patients understand, and that it was best to keep the Level 2 form consistent with the Level 1 form.

### **III. Community Wide Consent Notice Requirements**

Mr. Belfort said that under the draft SHIN-NY regulations community-wide consent option, a patient could provide consent to providers who join the QE after the date that the consent is signed if notice was provided to the patient. However, the nature and timing of that notice was not specified, so the Policy Committee was seeking more clarity of what notice means in this context. Mr. Belfort said the proposal put forward was intended to be a starting point for discussions. Under the proposal, the notice would be relatively easy to administer. Mr. Belfort said that the proposal would allow notice to be provided by updating the QE website on a regular basis, much as provider directories for health plans are updated. Any changes from the prior month would be updated for the next month. Patients could also request to receive an update by mail, and there could be an email update option that would supplement mail notification.

Mr. Check said that the QE should update the website with the name of the new participants on a daily basis, not a monthly basis, since daily updates would not be an implementation problem. Mr. Allen said that HealthLink currently does daily updates, and it was not technically difficult. Ms. Shatzkin and Mr. Kremer agreed.

Mr. Check said he agreed that there should be an email option or a snail mail option. He said that this could be burdensome to the QE, but that it is a reasonable requirement. Ms. Shatzkin said the new consent form could include the option for notification.

Mr. Allen said that HealthLink gives patients the option to request a hard copy of the list in case they do not have internet access, but that ongoing notification seems problematic. He said he was concerned about the difficulty of setting up a listserv.

Mr. Belfort said the interest on whether people wanted a regular update would depend in part on whether the option was included on the consent form. If it was on the form, more people would exercise the option. Mr. Belfort said he was not sure that the notice would be meaningful to patients, so that it might be best to try to avoid an administrative burden.

Mr. Martin said giving notice would not be silly. If a patient had an adverse experience with a provider, they may want to track this issue. Mr. Martin said that he thinks that everyone should get a notice annually that is physically presented, and that there should be an option for physically disabled patients to request the notice by phone. Mr. Belfort said that if a patient is dissatisfied with a particular provider, that patient won't seek treatment from that provider, so that provider won't have a right to access that patients' records anyway. Mr. Belfort said patients would get a lot of information about providers they never heard of, and that perhaps it would be better to provide an annual notice of rights to patients which indicates that patients can always request a hard copy of a list.

Dr. Martin said if a patient is angry with a doctor, the patient just disappears and never signs a piece of paper terminating the patient's relationship with the doctor. Dr. Martin said that the fact that people are confused is a good reason to remind people of what they signed. He said that email reminders should be sent out, and that people should have the option of getting the information in written form. He said at the very least there needs to be an annual reminder.

Mr. Kremer said it would be awe inspiring if the QEs managed to collect patients' email addresses. Mr. Allen agreed, saying it is difficult enough to get the email addresses of their authorized users. Ms. Shatzkin said their energy was better spent on getting truly informed consent up front than on bells and whistles that are difficult to implement. Mr. Mahoney said it might be helpful if they spent more time explaining to patients what their rights are.

Dr. Mead said that patients don't want to receive an email every month of lists of providers. Dr. Martin agreed that most people do not want this information, but the people who want this information in paper form cannot be ignored. Dr. Martin said this information should be available on the portal too. Mr. Allen said that HealthLink makes sure that the list is available to all patients. Dr. Martin said that it would be a challenge to make the list available to the people of Queens who speak 170 different languages.

Ms. Shatzkin asked whether the community-wide consent form would allow for the exchange of Part 2 data. Mr. Belfort said it would not. Ms. Shatzkin said that community-wide consent would then be a disaster. The PPSs are dealing with high cost utilizers who have high substance abuse costs, so substance abuse information is needed in order to provide effective case management. Ms. Shatzkin said that the PPSs don't understand this issue, and that they do not understand that community-wide consent is not the panacea to all of their problems.

Mr. Check said that he could not imagine Healthix adopting a community-wide consent model that includes future participants, since it is important to disclose Part 2 data. Mr. Belfort said that this is the world that they live in so long as SAMHSA does not revise its position on privacy protections for Part 2 information. Dr. Martin said there is a bit of an opportunity here, since

Congressman Tim Murphy is working to overhaul the mental health system and might be receptive to revising the Part 2 consent requirements in his bill.

Mr. Kremer asked if the adoption of the community-wide consent form meant that QEs would have to obtain new consents from patients. Mr. Check said that it would.

Mr. Martin asked if patients would be notified that the community-wide consent form is an option. Ms. Shatzkin said that it would depend on the QE, and that some might be quick to roll out those forms and others might be slow to do so. Mr. Martin said it would be good for patients to know this, since some might be eager to grant such consent.

Dr. Parsons said that everyone is clamoring for community-wide consent, and that it is important to document the difficulty of adopting this model and the Part 2 limitation. Ms. Sutliff said they would put together a document on the Part 2 limitation and community-wide consent, and that she and Mr. Kirkwood would speak with SAMHSA about this issue. Ms. Sutliff said they would also revise the proposal regarding whether periodic notification of patients is required.

Mr. Allen noted that HealtheLink does not provide access to Part 2 data, and that such data is not uploaded to their system. Ms. Shatzkin said that Bronx RHIO does not do that either, but that they are preparing to do that.

#### **IV. Life Insurance Pilot**

Ms. Sutliff noted that at the last meeting they had discussed the possibility of a pilot under which a life insurance company would gain access to the SHIN-NY data, and that Mr. Rodat had volunteered to put forward an analysis on this issue. She said that Mr. Rodat will put something together for the following meeting, and that there is no rush on this issue. Mr. Rodat agreed.

#### **V. Patient Accounting**

Ms. Sutliff said that they needed to reach some level of consensus on the issue of what information patients are entitled to under a patient accounting.

Mr. Belfort said the HIPAA accounting rule is designed for a very different world than what is addressed in the Policies. The HIPAA rule excludes from the accounting requirements everyday disclosures relating to treatment, payment, or health care operations, and that the rule is focused on unusual uses such as disclosures related to litigation or public health.

Mr. Belfort said that the current rule requires that a QE disclose to the patient the name of all authorized users that accessed the patient's information through the QE when the patient requests an accounting. He said that on one hand, if patients received only the names of participants and not the names of authorized users, then this would not be that meaningful to patients, particularly in areas where there are only a couple of health systems. On the other hand, there may be a burden on the QEs in responding to requests for authorized users names; the burden may not be in generating the list of names, but in providing staff to address those inquiries.

Mr. Allen said that the list of authorized users was of limited benefit to patients. He said that a patient who is concerned about wrongful access to his or her information would be given a false sense of security by receiving this information. Ms. Adamson said that providing the name and role of the authorized user was another opportunity for transparency. However, she said that on the public health side, there may be concerns about disclosing the authorized user's role. For example, if the role indicates that the user is a doctor on an HIV team, that could lead to a disclosure of sensitive data. Dr. Martin responded that even if the role identified a doctor as an HIV specialist, this is not a concern because it is about information that is going to a patient. Ms. Adamson noted that case investigations may not only involve the patient who was being investigated, but contacts of that patient.

Ms. Shatzkin said that this issue is a mind bender. She said the issue has gotten a lot of attention given that the Bronx RHIO has only received one request for an accounting in eight years of operation. Mr. Allen noted that there eventually will be a space on the portal where a patient will be able to get a full accounting. Ms. Sutliff suggested that QEs only need to provide the name of the authorized user where feasible. Ms. Shatzkin said that if the information is displayed on the portal, then there would be more concern about displaying people's names, so perhaps there should be more of a limitation regarding online access.

Mr. Allen said one possible solution is to allow an individual to request an audit of access, and under that audit a QE would be required to confirm that access is legitimate. Ms. Shatzkin asked why the QE should be put in the middle of this, and the QE should provide what it can provide and then direct the patient to the participant for follow up. She said the middle ground could be if the QE is required to provide contact information of the participant and the QE is obligated to cooperate with the patient seeking information from the participant.

Dr. Martin said that they were setting up a system to promote care for patients and other things, and that at the very least they should facilitate the patient's ability to get information. He said that in regards to the privacy concerns of employees, patients generally know the nurses who treated them, and that it generally should not be a big secret. He said that in some cases they could create a loophole to protect provider privacy.

## **VI. Upcoming Meeting**

Ms. Sutliff said that the Committee would set up an August meeting to address unresolved issues and to provide comments on the guidance documents that NYS DOH would release with the draft SHIN-NY regulations. She said that the Committee would submit comments on the documents to NYS DOH. Dr. Martin asked if the Committee might submit comments without reaching a consensus. Ms. Sutliff said she hoped they could reach a consensus, but that submitting comments without a consensus was a possibility.

## **VII. Next Steps**

- Manatt to revise Level 2 consent form for sharing of family member information.
- NYeC to draft recommendation to NYS DOH about what should be included in the Policies regarding access to a patient's family member information.

- NYeC to revise proposal for community-wide consent notice.
- NYeC to draft paper on Part 2 limitations on community-wide consent.
- Mr. Rodat to develop an outline of the various issues for consideration by the Committee to inform recommendations on the proposal for a life insurance intermediary pilot.

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