A meeting of the NYeC Policy Committee was held on March 10, 2015. Present either in person or via telephone were:

Art Levin, Center for Medical Consumers, Co-Chair Policy Committee
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
Ronnie Pawelko, JD, Family Planning Advocates of NYS
Irene Koch, Healthix
Steve Allen, HealtheLink
James Kirkwood, NYS DOH
Paul Schaeffer, New York City Department of Health and Mental Hygiene
Dr. David Cohen, Maimonides Medical Center
Ted Kremer, Rochester RHIO
Dr. Amanda Parsons, Montefiore
Geraldine Johnson, NYS DOH
Cindy Sutliff, NYeC
Inez Sieben, NYeC
Vinay Chopra, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 9:00 a.m.

I. Edits to Privacy and Security Policies and Procedures (the “Policies”)

Definition of “Participant”

Mr. Belfort explained that the proposed revisions would add two different entities to the definition of Participant: a Performing Provider System (“PPS”) Partner and a PPS Centralized Entity. The vast majority of the entities participating in a PPS would already qualify as Participants because they are providers, but the amendments are designed to allow PPS Partners who are not traditional health care providers and management companies to fall within the definition of Participant.

Dr. Parsons said she was excited to see this change, and that this change would be critical to the Delivery System Reform Incentive Payment (“DSRIP”) program. Dr. Parsons asked whether non-provider organizations such as the Asthma Coalition would have full access to Qualified Entities (“QEs”) and asked about the relevancy of role-based access to this issue. Mr. Belfort said that there would be no restrictions beyond those applied to other Participants, and that the role-based access rules would apply equally to these non-provider organizations as they do to other Participants.
Mr. Martin asked if the changes would allow urgent care centers to become Participants. Mr. Belfort said that urgent care centers should be able to become Participants under the current version of the rules since urgent care centers are structured as Article 28 Diagnostic & Treatment Centers or professional corporations.

**Training of Authorized Users**

Mr. Belfort said that the language regarding training of authorized users differs in Section 4.7.4 than in the previous subsections, and it was unclear why there was a difference; the proposed revision therefore eliminated this difference. Dr. Parsons said the intent of the language was to give QEs the option of providing the training themselves or requiring the Participants to do this. Mr. Belfort agreed and said the revision was intended to standardize the language across the subsections; without such standardization, people are confused as to why the language differs.

**Termination of Authorized User Access**

Mr. Belfort explained that in some cases, the access of an authorized user should be changed not because the authorized user’s employment was terminated but because the authorized user's job function had changed, and that the revised language is designed to address this. Mr. Belfort noted that some of the language in this section was sloppy and had been revised to improve clarity.

Ms. Shatzkin said that in reality, it is difficult for a Participant to terminate an authorized user’s access within one day of the end of that user’s affiliation with the Participant. Ms. Sutliff agreed that there is usually a lag time. Dr. Parsons said that in her time at the Health Department, the Department was sure to terminate access as soon as an individual was terminated from his or her position. Dr. Cohen said that access should be terminated immediately if an individual was fired for a particular reason, but in the case of a role change there may be a reasonable lag time.

Ms. Shatzkin explained that for some organizations, their local systems control access to the QE, and for these organizations it may be easier to quickly end QE access. But other organizations may forget that their data feed connects to a QE, and that a 24-hour termination requirement is not realistic for these organizations. Dr. Martin said that the policies sometimes impose requirements that not all Participants meet, but that it should be a question of enforcement, not whether the underlying standard should change.

Mr. Levin asked whether there should be different time standards for cases where an authorized user was terminated versus a change in job function. Mr. Belfort asked whether the difficulty was terminating an authorized user’s access to a Participant’s internal system or translating that into an additional termination of access to the QE. Ms. Shatzkin said it was the latter. Mr. Belfort said a person who was terminated might have an interest in stealing data from his or her former employer, and that the Policy Committee should not have a policy that gives that person up to an additional 30 days of access. Dr. Parsons agreed that this is a high risk period in cases where a person is terminated, but that there can be a longer time period if someone is changing a job function, such as switching from a medical director to a vice president.

Mr. Belfort suggested a policy that requires termination of access within 24 hours in cases where the authorized user is terminated, and in cases where the authorized user changes job functions, termination of access can occur as soon as reasonably practical. Ms. Sutliff said there was a
consensus to adopt this change, and that Manatt should recraft the language. Ms. Sutliff said the Business and Operations Committee (“BOC”) Implementation Subcommittee should work to determine what “as soon as reasonably practical” means.

II. Cross QE Data Exchange

Mr. Belfort observed that there is nothing in the Policies or in the Qualified Entity Participation Agreement (“QEPA”) that prohibits QEs from exchanging data with one another. The issue for the Policy Committee is whether the Policies need to be more prescriptive in this area, or whether it is best to let sleeping dogs lie.

Ms. Sutliff said that the question of universal opt out—whether a patient can deny consent to all QEs at once—is one that needs to be considered. Ms. Shatzkin noted that the QEPA does state that a QE has no responsibility for users accessing the SHIN-NY through another QE. Mr. Belfort said the QEPA is focused on liability, not operations, and that all this is saying is that a QE is not liable for another QE’s actions.

Ms. Sutliff said these questions should be addressed by the BOC Implementation Subcommittee, which develop guidance to be reviewed by the BOC and shared with the Policy Committee.

III. Research Consent Form

Ms. Sutliff told the Policy Committee that a tiger team was working on developing the Level 2 Research Consent Form. Dr. Martin said that developing the form was not as easy as it looked, and that in some cases a form is needed for cases where an Institutional Review Board (“IRB”) consent is being signed and in other cases no IRB consent is being signed. Dr. Martin said the tiger team was working on the former scenario first. Under this scenario, a patient would be signing an IRB consent and a HIPAA authorization, and the SHIN-NY consent would be in addition to those other two consents.

Ms. Sutliff said that the research consent would be first implemented as a pilot. Mr. Allen said that the pilot would be along the lines that Dr. Martin outlined, and that they would report back in a few months on lessons learned.

IV. Patient Access to Lists of Authorized Users

Mr. Allen said that he was concerned that there is an obligation to provide the names of authorized users who access patient data to patients, and that is not required by HIPAA. Mr. Belfort agreed that this policy is not required by HIPAA, but that the Policy Committee made a conscious decision to adopt a rule that went beyond HIPAA.

Dr. Martin said it was a tradeoff: in exchange for a patient giving thousands of people access to the patient’s health records, that patient got the right to find out who accessed those records. Mr. Levin said he would hate to see a change to this provision because it was a critical right. Mr. Martin said it was important that a patient have access to the name of the person who accessed his or her record in order to meet the patient’s concerns.
Mr. Kremer said the policy was asking hospitals to do something beyond what they do today. He said there have been two recent incidents of violence on care providers by patients. Mr. Allen said that hospitals were fearful of retribution against their employees. Mr. Martin said he did not think retribution was a concern—if an authorized user accessed the patient’s data legally, then the patient would not be concerned.

Mr. Belfort said that under HIPAA, very few patients ask for an accounting, and of those that do, most are suspicious of the provider or have a dispute with the provider. Mr. Belfort said that if a patient was concerned that a neighbor who worked for a Participant wrongfully accessed the patient’s data, just providing the name of the Participant—particularly in the case of a large hospital system—would not be meaningful. Dr. Mahoney said that it would bring bad press if patients could not find out who accessed their records, and that this is a trust issue.

Mr. Allen said that patients cannot get the full picture from the QE. Patients will only learn of which individuals accessed their records through the QE, but they would not learn about which individuals accessed their records through the provider’s internal system. Mr. Allen questioned whether patients had any obligation to keep the list of authorized users secure. Mr. Belfort said he did not think that this was proprietary information, and that by law every staff member needs to wear a badge with his or her name on it. Mr. Levin said there was no better way of getting people to trust the system then to let them know who can look at their data and for what purpose, and that it is a fundamental principle that the public can act as an auditor. Ms. Pawelko noted that in the world of Planned Parenthood, they are protective of the names of individual providers.

Ms. Sutliff said that they could query the QEs on this issue. Mr. Allen said they receive these requests a couple of times per year. Mr. Kremer said they receive such requests about five times a month. Mr. Levin said the query should also seek comments on Participants’ experiences with these patient requests. Mr. Martin recommended that the query ask for information on the patient request process, including what information the patient must provide in order to make such requests.

V. Department of Health Update

Mr. Kirkwood said the draft SHIN-NY regulations were going to the DOH counsel office this week, and that the counsel's office will have two weeks to review. There is a significant amount of review from DOH, the Department of Budget, and the Governor’s Office.

Mr. Kirkwood said the Governor’s budget proposed $45 million in this year’s budget, to be reduced to $30 million in the following year, and that they were hoping to get additional funding from CMS. Ms. Sieben said they were making good progress with CMS.

VI. Next Steps

Ms. Sutliff and Mr. Levin outlined the following action items for the next meeting.

- Ms. Sutliff and Manatt will develop a questionnaire to be used to determine QE and Participant experiences with granting patients data on authorized users.
- Manatt will revise the Policies regarding terminating authorized user access.
- The tiger team will continue to develop the Level 2 research consent form.
Ms. Sutliff said the next meeting would be April 14th at 9 a.m. Hearing no other questions or comments, Mr. Levin closed the meeting.