A meeting of the NYeC Policy Committee was held on November 7, 2017. 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  
Nance Shatzkin, Bronx RHIO  
Steve Allen, HealtheLink  
Tom Check, Healthix RHIO  
Amy Warner, Rochester RHIO  
James Kirkwood, NYS DOH  
Christie Allen Hall, NYS DOH  
Deirdre Depew, NYS DOH  
Geraldine Johnson, NYS DOH  
Roslyn Windhol, NYS OMH  
Dr. Tom Mahoney, Common Ground Health  
Dan Tietz, AIDS Institute  
Laura Alfredo, GNYHA  
Zeynep Sumer-King, GNYHA  
Susan Van Meter, HANYS  
Will Pelgrin, CyberWA  
Valerie Grey, NYeC  
Cindy Sutliff, NYeC  
Jeannette Rossoff, NYeC  
Nathan Donnelly, NYeC  
Bob Belfort, Manatt  
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 10 a.m.

I. Welcome and Introductions

Mr. Levin welcomed the Committee members and outlined the meeting’s agenda. Mr. Levin introduced Ms. Sutliff to discuss the cybersecurity policies.

II. Proposed Cybersecurity Policies

Ms. Sutliff thanked the Committee members for participating in the comment period on the cybersecurity policies. She said NYeC had received comments on the definitions in the proposed cybersecurity policies, and she asked whether the Committee members preferred to create a separate definition of a “SHIN-NY Enterprise” or just revise the existing definition of “SHIN-NY.” Several Committee members voiced a preference for creating a separate definition
of “SHIN-NY Enterprise.” Ms. Shatzkin noted that there needed to be a definition of “SHIN-NY Hub.” Ms. Sutliff agreed a new definition was needed.

Ms. Sutliff explained that the draft cybersecurity policies do not give the statewide CISO responsibility for the day-to-day management of the QEs. Mr. Check observed that the draft said that the statewide CISO would have authority over the entire SHIN-NY Enterprise, which includes the QEs, and therefore the statewide CISO would have the authority to put forward security standards for both the hub and the QEs. Ms. Sutliff agreed. Ms. Warner asked if the statewide CISO could unilaterally make a change to a policy. Ms. Sutliff said that the statewide CISO could not, and that any proposed amendments to the cybersecurity policies would have to go through the Policy Committee.

Mr. Allen said he was concerned about the statewide CISO having authority over an individual QE’s security program, and that the certification requirements should take care of a QE’s activities inside its own walls. Mr. Kirkwood said the state was looking for someone to have responsibility over the whole system and as such there needs to be a coordinating entity focusing on the security of the SHIN-NY enterprise. Mr. Check said as the CEO of a QE he would like not to be answerable to anyone but that is not the reality, and security is only as good as its weakest link.

Ms. Sutliff introduced Mr. Pelgrin to discuss the cybersecurity policies. Mr. Pelgrin noted that several commentators questioned why the policies did not reference HITRUST. Mr. Pelgrin said that key principles in the draft cybersecurity policies were the basic principles of any cybersecurity policy, and that HITRUST relies on the NIST framework. Mr. Mahoney asked how much of these requirements were incorporated in HITRUST certification. Mr. Pelgrin said there was nothing in the proposed policies that are incompatible with the certification process.

Ms. Shatzkin asked about the process the state used to pick a certification body, and whether the state could change certification bodies unilaterally. Mr. Kirkwood said the state believed picking HITRUST this round was the appropriate thing to do given that HITRUST deals with health information exchanges, but that the state could decide to use a different certification body in the future.

Mr. Levin asked if there were any objections to forwarding the draft cybersecurity policies to the board for approval. Hearing no objections, Mr. Levin said the draft would be provided to the board at their November meeting as recommendations for forwarding to NYS DOH to incorporate into the SHIN-NY P&P's.

III. SHIN-NY Access vs. Disclosure

Mr. Dworkowitz described the draft policies that would allow QEs to make disclosures to non-participants. He said that in a previous discussion, Committee members had expressed a preference for a more conservative option under which such disclosures could only be made to a limited list of individuals and entities, and that disclosures should not be made to anyone in the world.
Mr. Allen asked why research entities within New York State would be allowed to receive disclosures. Mr. Dworkowitz noted that some researchers, such as universities, might not qualify as Participants and therefore this provision would allow such researchers to receive data.

Mr. Check suggested revising the provision on disclosures to life and disability insurers to allow disclosures to entities that receive a claim from a patient even if the patient has never filed an application, since under Social Security a person can file a claim without applying for benefits.

Mr. Allen and Ms. Shatzkin questioned the point of the provision that would require disability or life insurers to agree not to require a patient to provide access to his or her SHIN-NY records as a condition of receiving benefits. Mr. Allen said that in the case of Social Security, you sign a consent saying you have to give access to all your records. Mr. Dworkowitz suggested that this provision be limited to commercial insurers and not apply to governmental insurers. Ms. Shatzkin said she liked that approach better.

Mr. Tietz asked about the consent form that would be used. Ms. Sutliff said a Level 2 consent would be required. Mr. Martin asked if Part 2 data could be sent. Ms. Sutliff said it would be up to the patient to decide whether or not they wanted to share their Part 2 data.

Mr. Check suggested that the provision requiring the QE to provide a list of sources of data should be struck because it is redundant with the Level 2 consent form requirements. He also suggested adding VA facilities to the list even in cases where those facilities are located in New York State, since the local VA facilities often struggle to get clearance from Washington DC to become participants. Mr. Levin asked if there was any objection to including VA facilities on the list. Hearing none, he said the draft policies would be revised to include VA facilities.

Ms. Sutliff said they were not finalizing the draft disclosure policies now, and another draft would be provided for the December meeting.

IV. Number of patients for research

Mr. Levin asked if there were any objections to presenting to the NYeC board the proposal to allow researchers to obtain a count of the number of patients who meet research criteria. Hearing no objections, Mr. Levin said the proposal would be sent to the board.

V. Level 1 Use for Payment

Mr. Levin introduced the topic of health plan access to data for payment purposes under a Level 1 consent. Ms. Sumer-King asked that they not vote on this proposal at this time, since some members of GNYHA have concerns about the proposal. Ms. Sutliff agreed to hold a discussion on the issue in December.

VI. Closing

Ms. Sutliff thanked the Committee members for their active participation and said they were helping to make the SHIN-NY more valuable. Mr. Levin closed the meeting.