A meeting of the NYeC Policy Committee was held on November 20, 2020. Present via telephone or videoconference were:

Art Levin, Center for Medical Consumers, Chair of Policy Committee
Nance Shatzkin, Bronx RHIO
Steve Allen, HealtheLink
Amy Warner, Rochester RHIO
Karen Romano, HealtheConnections
Taiymoor Naqi, Hixny
James Kirkwood, NYS DOH
Deirdre Depew, NYS DOH
Dan Schiller, NYS DOH
Molly Finnerty, NYS OMH
Carmen Barber, NYS OMH
Tammy Harris, OPWDD
Laurie Pferr, Office for the Aging
Dr. Alicia Bell, University of Rochester Medical Center
Dr. Tom Mahoney, Common Ground Health
Dr. John-Paul Mead, Cayuga Medical Associates
Dr. Glenn Martin, Queens Health Network
Tom Hallisey, HANYS
Laura Alfredo, GNYHA
Jill Eisenstein, BOC Representative
Chuck Bell, Consumer Reports
Alan Cohen, JASA
Linda Adamson, NYSTEC
Val Grey, NYeC
Cindy Sutliff, NYeC
Zoe Barber, NYeC
Alexandra Fitz Blais, NYeC
Sam Roods, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 2 p.m.

I. Welcome and Introductions
Mr. Levin welcomed the Committee members and provided an overview of the meeting materials. Mr. Levin said if any Committee members had edits to the meeting minutes they should be communicated via email.

II. DOH Update

Mr. Kirkwood said the QEs had recently completed the certification process and all were certified. He noted all health departments in the state are busy with the COVID-19 response and vaccine planning.

Mr. Kirkwood explained that under the new federal interoperability rules, Medicaid must make its information available to Medicaid beneficiaries, and the state is in the process of implementing this requirement.

III. Executive Director Update

Ms. Grey explained the Senate Minority leader had reappointed her to the Health Information Technology Advisory Committee (HITAC). She said that in 2021, HITAC will review issues such as USCDI submissions, the use of electronic health information for providers and plans, telehealth, interoperability of laboratory data, and privacy issues regarding the secondary use of data.

Ms. Grey observed that the information blocking compliance deadline has been postponed to April 5, 2021, and that NYeC is continuing to work together to address changes that need to be accomplished for compliance.

IV. Proposed Patient Access Language

Mr. Dworkowitz provided an overview of the new proposed policy language regarding disclosures to patients and third parties on behalf of patients. He noted there were two separate provisions – Section 5.2 that addressed disclosures directly to patients and Section 5.3 that addressed disclosures to third parties, including patient apps, on behalf of patients.

Ms. Alfredo asked whether the information blocking rule permits a business associate like a QE to refer a patient back to a covered entity in order to obtain sought-after information. Mr. Belfort said theoretically this could be done, but QEs have their own obligations, and they cannot tell patients to submit requests to 20 different providers.

Mr. Allen said he was concerned about the lack of description regarding adequate identity proofing. Ms. Sutliff said the goal was to provide QEs with flexibility, and proper identity proofing would be discussed further among QEs as part of implementation.

Dr. Martin questioned whether the section on minors should say that QEs “may” not provide, but instead should be rewritten to say that QEs are prohibited from providing data in that scenario. Dr. Martin also asked if patients could be required to sign a document in the case where they
want data sent to a third-party app. Mr. Belfort said that requiring a patient to sign a warning that they agree to the risk of disclosure is risky.

Dr. Martin and Ms. Shatzkin asked if patients would need to be notified if the QE attempted to send their data to a third party but was unable to do so. Ms. Sutliff said this question could be addressed in an implementation FAQ.

Dr. Martin suggested that the policy include a provision that states how disclosures should be handled in the case where the request comes from the patient’s app rather than directly from the patient. Mr. Allen noted that there should be a means for patients to provide their permission just once, and from that point forward the QE would send all of the patients’ data to the app. Ms. Sutliff responded that they should focus on patient requests in this version of the policy, but it could be later revised to address requests originating from apps.

Ms. Finnerty said many hospitals use MyChart and suggested that hospitals could undertake the credentialing on behalf of QEs. Mr. Belfort said building on a connection that has already been validated is a smart approach, but QEs cannot force a patient to sign up for a patient portal. Mr. Allen agreed, but said theoretically the QEs could subcontract the identity proofing process to hospitals in some cases.

Mr. Levin asked if they could agree to move the proposed policy forward, understanding that there were a number of implementation issues that would need to be addressed at a later point. There were no objections to this approach, and Mr. Levin said the language would be provided to the NYeC board for their meeting on December 1st.

V. Policy Committee Rotation Process

Ms. Sutliff explained that the chart provided to the Committee was simply demonstrating when Committee members had joined the Committee, and no current action was being taken about ending a particular member’s service with the Committee.

Ms. Shatzkin asked who was responsible for making sure there is broad representation among the Committee? Mr. Levin answered that the Policy Committee is a Committee of the NYeC board, and therefore the NYeC board is responsible for ensuring broad representation.

VI. 2021 Policy Agenda

Mr. Levin solicited comments from the Committee members about possible topics for discussion in 2021.

Mr. Cohen suggested that the Committee focus on the roles that community-based organizations (CBOs) play in the SHIN-NY. He acknowledged that the SHIN-NY policies had recently been rewritten to permit CBOs that are non-covered entities to become participants, but he said CBOs that are covered entities are facing issues as well. For example, he noted there was still a barrier to such CBOs receiving alerts.
Dr. Mead suggested that they do what they can to make the entire information network appear in the background, as it needs to be experienced by patients and providers as being seamless, both in New York and across state lines.

Dr. Mahoney said the Committee should focus on social determinants of health and means to address disparities.

Mr. Allen said there were still issues that need to be addressed regarding research. For example, he wanted to understand whether QEs can mine data in response to a request from a researcher. Dr. Martin agreed, and he questioned whether the HIPAA de-identification standard was sufficient, and that the SHIN-NY policy needs to reflect the reality of the risk of re-identification of data.

Mr. Naqi said the critical issue was consent, which needs to be addressed given that the New York model is more restrictive than what occurs in other states and data is moving across state lines more often. He said they had to keep in mind the Epics of the world, and that they could quickly regulate themselves out of business.

Ms. Eisenstein said she had spoken with other QEs who raised four issues to address: (1) access of EMS providers via the break the glass functionality while they are on the way to an emergency; (2) the potential exclusion of data such as genetic test results in cases where a patient self-pays for health care and may not want such data to be shared with a health insurer; (3) the sharing of COVID-19 care alerts out of state; and (4) research and the potential of using data from other QEs.

Ms. Finnerty said the SHIN-NY policies could be improved to facilitate engagement of the behavioral health sector. She added that she is personally not against opt-out, but worried that if there is an opt-out system that providers will not bother to seek to get a consent to access needed for behavioral health information.

Ms. Alfredo suggested the Committee examine whether there is a role for the SHIN-NY regarding COVID-19 vaccine planning and tracking of patients, such as making sure patients receive both of their needed doses.

Ms. Pferr agreed with prior comments on the need to focus on social determinants of health and CBOs. Mr. Barber agreed that it was important to focus on consent.

**VII. Closing**

Ms. Sutliff said that in December there would be a meeting of the NYeC leadership, DOH, and Manatt to prioritize ideas for 2021. Mr. Levin thanked the Committee and adjourned the meeting.