A meeting of the NYeC Policy Committee was held on October 22, 2020. Present via telephone were:

Art Levin, Center for Medical Consumers, Chair of Policy Committee
Nance Shatzkin, Bronx RHIO
Steve Allen, HealtheLink
Amy Warner, Rochester RHIO
Taiymoor Naqi, Hixny
Todd Rogow, Healthix
James Kirkwood, NYS DOH
Jonathan Karmel, NYS DOH
Deirdre Depew, NYS DOH
Dan Schiller, NYS DOH
Molly Finnerty, NYS OMH
Carmen Barber, NYS OMH
Margaret Vijayan, OPWDD
Tammy Harris, OPWDD
Jen Freeman, OPWDD
Laurie Pferr, Office for the Aging
Dr. Tom Mahoney, Common Ground Health
Dr. Raul Vazquez, Urban Family Practice
Dr. John-Paul Mead, Cayuga Medical Associates
Dr. Glenn Martin, Queens Health Network
Puja Khare, GNYHA
Lorna Thorpe, NYU Langone
Jill Eisenstein, BOC Representative
Chuck Bell, Consumer Reports
Alan Cohen, JASA
Linda Adamson, NYSTEC
Bill Howard, Audacious Inquiry
Val Grey, NYeC
Cindy Sutliff, NYeC
Nate Donnelly, NYeC
Zoe Barber, NYeC
Alexandra Fitz Blais, NYeC
Sam Roods, Nye-
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 12 p.m.
I. Welcome and Introductions

Mr. Levin welcomed the Committee members and introduced Alan Cohen, the newest board member. Mr. Cohen described his role as chief program officer at JASA, which serves older adults as both a HIPAA covered entity and as a community-based organization. Mr. Levin asked for a motion to approve the prior meeting’s minutes, and the motion was approved with no objections.

II. DOH Update

Mr. Kirkwood said that in addition to its COVID-19 work, DOH was getting ready for the CMS interoperability rule by making additional data available in the FHIR format.

Ms. Finnerty asked for an update on the all payer database (APD). Mr. Kirkwood responded that APD work has been paused due to the COVID-19 focus. Dr. Vazquez commented that data from the APD could be useful for value-based agreements.

III. Updated Policy Committee Charter

Mr. Levin provided an overview of changes to the Policy Committee charter. He explained that membership classes and staggered terms have been established, so that certain classes would cycle off the Committee at given times. Ms. Grey added that the Committee would be clearer on expiration of terms going forward.

IV. Overview of SHIN-NY Consent Assessment

Ms. Sutliff explained that the Committee had previously approved a SHIN-NY wide consent approach, and that the Business and Operations Committee had requested that consent be examined on a broader basis. Audacious Inquiry (Ai) was awarded a contract through an RFP process to look at the bigger picture on issues related to SHIN-NY consent that will include topics such as opt-in vs. opt-out.

Mr. Howard described his background and Ai’s approach to the project. He explained that the first step was assessment of current needs, followed by a development of options examined on a scoring rubric.

Dr. Mead asked if the analysis assumed that Part 2 and other sensitive data could be segmented. Mr. Howard said that the QEs are separately analyzing what can be segmented. Mr. Karmel asked if the operational issues related to a change to an opt-out system would be examined. Mr. Howard responded that such issues would be included in the analysis.

V. Telehealth and SHIN-NY Policies

Mr. Levin introduced the subject of the proposed telehealth policies. He said that the Committee had already reached agreement on most of the proposed language, but had not yet agreed on the
durability issue. Mr. Dworkowitz described the new language on durability, intended to be a compromise between various options presented at the prior meeting.

Ms. Shatzkin asked if there would be any change to audit requirements related to the new policy. Ms. Sutliff said there was nothing related to audits in this particular policy, and the auditing issue would be addressed in implementation. Ms. Eisenstein noted that there would be a challenge in having a system for two forms of positive consent: one for a written consent and one for a verbal consent. Ms. Shatzkin agreed implementation would be a challenge.

Ms. Finnerty asked why substance use and mental health data were being treated differently, since verbal consent was currently being used for mental health data. Mr. Barber answered that OMH had agreed to verbal consent only during the public health emergency, and that they would not support verbal consent once the emergency expired. Mr. Barber also recommended a grammatical change to the clause regarding mental health data.

After asking if there were any additional concerns related to the policy and hearing none, Mr. Levin said they had come to agreement on the durability issue. Ms. Shatzkin said the Committee had done well to develop a policy on a thorny issue and thanked the Committee. Mr. Levin agreed.

VI. Executive Director Update and Information Blocking

Ms. Grey shared reflections on the information blocking rule. She noted that the rule originated from reports to Congress that HIT vendors were not sharing data, and that arguably HIEs were developed to address the lack of interoperability among HIT vendors. Nevertheless, under the rule, HIEs are considered actors in the same way that HIT vendors are.

Ms. Grey said that the regulation is really complex, and that the challenge of implementing it is similar to the challenge of understanding HIPAA in its early days. She noted that the regulation is not always clear. She said the regulation presented an opportunity to review the SHIN-NY’s framework and policies, and that the Committee was starting in the right place by addressing disclosures to third-party apps.

Ms. Eisenstein said that each QE had the responsibility to ensure its compliance with the information blocking rule. Ms. Grey agreed, and said the SHIN-NY policies did not prevent the QEs from doing so.

VII. Consumer Education on Third-Party Apps

Mr. Bell provided a presentation on the risks of third-party apps and how to approach consumer education related to such apps. He said it was hard for consumers to understand these apps because they do not understand the risks. He added that consumers also do not understand what they are agreeing to because it is rare for consumers to read user agreements on their phones.
Mr. Bell spoke in favor of a certification like the one issued by the Carin Alliance, but the issue is whether consumers could even know about such certification. He said that any education provided should be in multiple formats, translated into different languages, and provided at the right literacy level.

Mr. Belfort said that the challenge is that apps are in the business of commercializing data, and that patients are not the customers for the apps but the raw material whose data is being sold.

Ms. Shatzkin said they may want to obtain input from QEs that have firsthand experience in making disclosures to third-party apps. Ms. Sutliff responded that two QEs who had implemented patient access pilot programs had presented their lessons learned to the Policy Committee. Mr. Belfort noted that the organizations with the most experience in this area are hospitals, which have been required to transmit to third-party apps under the meaningful use requirements.

Ms. Shatzkin observed that QEs historically have not communicated with patients, and that this would be a whole new system for some QEs that does not exist today.

VIII. Proposed Patient App Policies

After a break, Mr. Dworkowitz described the proposed policy language on disclosures to patients and patient apps. He noted there were two separate sections: one for disclosures directly to patients, and a second for disclosures to third parties upon the request of patients, including third-party apps.

Mr. Allen asked what was meant by “adequate” identity proofing, and asked if the same standard would apply to patients as applies to authorized users. Ms. Sutliff said patients were in a different position than authorized users, and therefore the same standard would not necessarily apply. Mr. Allen noted that under pilots, they require a notary to authenticate the patient. Mr. Naqi said Hixny also uses notaries. Mr. Levin said requiring a notary seemed like going back to the dark ages. Ms. Finnerty said using a notary would be an onerous burden on patients. Ms. Eisenstein responded that while the requirement may seem onerous, QEs have the responsibility for identifying people.

Dr. Mahoney asked if they were better off having one statewide warning to patients instead of having each QE write their own disclaimer. Mr. Allen agreed one statewide message is important. Mr. Dworkowitz said one disclaimer may be the best approach, but that does not necessarily mean that the language for such disclaimer should appear in the policies.

Ms. Eisenstein said Rochester RHIO had a long discussion internally on what fees may be permitted. Ms. Grey said they may want to include examples of what types of fees are permissible and which are not.

IX. Section 1.2.10 Recommendations
Ms. Sutliff said the Committee had already agreed to a change to this provision, and that the proposed language was being provided for discussion. Mr. Dworkowitz described the proposed language.

Mr. Allen asked if it made sense to limit the provision to HEDIS and QARR metrics. Dr. Vazquez said these seemed liked the right measures.

Ms. Finnerty asked why it was DOH that was being specified and not other agencies like OMH. Mr. Kirkwood responded that DOH is a payer, but OMH is not. Ms. Finnerty questioned if it made sense to draw a line in that manner.

Hearing no objections from Committee members, Ms. Sutliff said there was general consensus on the language and the amended policy will be presented to the NYeC Board at their December meeting.

X. Closing

Ms. Sutliff said they would continue discussions on the patient access language at the November meeting. Mr. Levin thanked the Committee and adjourned the meeting.