A meeting of the NYeC Policy Committee was held on June 25, 2020. Present via telephone were:

Art Levin, Center for Medical Consumers, Chair of Policy Committee
Nance Shatzkin, Bronx RHIO
Steve Allen, HealtheLink
Drew McNichol, HealtheLink
Amy Warner, Rochester RHIO
Karen Romano, HealtheConnections
Taiymoor Naqi, Hixny
Todd Rogow, Healthix
James Kirkwood, NYS DOH
Jonathan Karmel, NYS DOH
Molly Finnerty, NYS OMH
Carmen Barber, NYS OMH
Tammy Harris, OPWDD
Margaret Vijayan, OPWDD
Laurie Pferr, Office for the Aging
Dr. John-Paul Mead, Cayuga Health System
Dr. Tom Mahoney, Common Ground Health
Dr. Raul Vazquez, Urban Family Practice
Dr. Glenn Martin, Queens Health Network
Lorna Thorpe, NYU Langone
Puja Khare, GNYHA
Tom Hallisey, HANYS
Jill Eisenstein, BOC Representative
Chuck Bell, Consumer Reports
Val Grey, NYeC
Cindy Sutliff, NYeC
Nate Donnelly, NYeC
Elizabeth Amato, NYeC
Zoe Barber, NYeC
Sam Roods, NYeC
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 provided an overview of the meeting agenda. He introduced Mr. Kirkwood to provide an update.

II. DOH Update

Mr. Kirkwood said DOH and the New York City Department of Health and Mental Hygiene have been working on implementing contact tracing apps. Under the state’s app, contact tracers receive information from the state’s Electronic Clinical Laboratory Reporting System (ECLRS), which contains information on positive COVID-19 test results. Mr. Kirkwood said the app will eventually have different functionalities, such as allowing DOH to exchange text messages with individuals while in isolation. He said the apps would not use Bluetooth technology.

Mr. Kirkwood noted that delays can occur if labs do not submit data to ECLRS in a timely manner. He also noted that the electronic laboratory system was not built for multiple lab test results for a single individual, as is the case with COVID-19 results. Mr. Kirkwood observed that a lack of information such as addresses and dates of birth can lead to difficulties in matching patients.

III. Executive Director Update

Ms. Grey said there are projections showing New York State could have a 14% budget shortfall, and that more detailed reports would come out at the end of July. She noted there were two bills in the state legislature regarding contact tracing, including issues related to when written consent is required and prohibitions on disclosures to law enforcement or immigration authorities.

At the federal level, Ms. Grey said they were exploring the viability of joining a national network like the TEFCA and evaluating whether NYeC should become a QHIN. She said information blocking issues will repeatedly come up as NYeC evaluates its policies going forward. With respect to the CMS interoperability rule, Ms. Grey said NYeC was working on a project aimed at ensuring that the SHIN-NY can be used to meet the hospital event notification requirement.

IV. Telehealth and SHIN-NY Policies

Dr. Vazquez presented on his practice’s telehealth work since the COVID-19 crisis began. He described the different types of telehealth services being provided. He noted that his practice had provided more than 500 telehealth visits per week, meaning they were seeing more people via telehealth in 2020 than they had seen in-person in 2019. Dr. Vazquez said that their system allows the practice to know how long a practitioner is seeing a particular patient. He added that the system also allows for connections to community-based organizations (CBOs), and such connections allowed for CBOs to distribute food to patients.

Dr. Martin asked if the practice had problems reaching older patients who did not have video capabilities on their phones. Dr. Vazquez responded that this was an issue, and the practice was trying to figure out a way to give phones to patients. In response to another question, Dr.
Vazquez said that their system allows for a video to record whether an individual provided verbal consent, so that the practice can go back and check to make sure consent was provided.

Dr. Mead discussed his practice’s implementation of telehealth during the COVID-19 pandemic. He said telehealth was critical to maintaining the financial solvency of the practice, and they used Medent and Zoom. Dr. Mead said there are issues with the digital divide, as many behavioral health patients do not have enough minutes on their phones to participate. He added that telemedicine had reduced the frequency of patient no shows.

Dr. Mead also described his experience with telemedicine while working at New York Presbyterian Hospital in New York City. He explained that telemedicine was used as a way of reducing the number of people who had contact with COVID-19 positive patients, since when he entered a room with such a patient he often had a virtual hospitalist who was listening to the conversation. He said these practices require a lot of resources, since patients need to be able to use iPads while in their rooms and need training on how to use them.

In response to a question, Dr. Mead said that verbal consents would be documented in notes, but would not be recorded.

Following Dr. Vazquez’s and Dr. Mead’s presentations, Ms. Sutliff introduced the subject of allowing verbal consents to be used after the end of the COVID-19 emergency. Mr. Dworkowitz described the proposed principles for verbal consent and telehealth, which include the proposal that such consents should persist after the initial encounter.

Ms. Shatzkin said she was absolutely in favor of allowing for verbal consents, but that she was opposed to such consents persisting. She said if a practitioner needs to access a patient’s record 10 different times, the practitioner should get verbal consent every time. Dr. Martin asked whether this rule would apply even in cases where a provider sees a patient regularly. Ms. Shatzkin responded that the requirement to obtain a new consent should still apply, since a QE does not have a means of differentiating a continuing episode of care from other situations.

Ms. Finnerty said the crisis had catapulted the system 10 years into the future. She said they should ask: how do we imagine the consent of the future? She questioned whether consent needs to be on a piece of paper and why a patient should be asked for consent multiple times. Mr. Barber said it was important that there is a record of consent, which could be in the provider’s notes. Mr. Belfort said there are two options: voice signatures that meet the standards of an electronic signature or having the provider note in the record that consent was provided.

Dr. Martin said he did not want to deal with a piece of paper again. Mr. Naqi said it was not the responsibility of the SHIN-NY to babysit patients, and that the fundamental issue was whether verbal consent is a new type of consent entirely or simply a different method of collecting consent? Mr. Naqi advocated that it should be latter. Mr. Barber said it was important that the patient be informed of the right to revoke consent. Mr. Allen said he agreed with Mr. Naqi, and that the participant could be required to sign an attestation saying the participant provided certain information to the patient, such as the patient’s right to obtain a copy of the form.
Mr. Levin asked if there was any evidence that obtaining consent virtually was worse than in person. Dr. Mahoney responded that some patients do read consent forms and want to talk to their clinicians about the forms, and he doesn’t want that to disappear.

Ms. Sutliff thanked Dr. Vazquez and Dr. Mead for sharing their experiences. She expressed agreement with Ms. Finnerty’s comments and said that they should think about how the current crisis is creating opportunities to think about consent differently.

V. Patient Mediated Exchange

After a break, Mr. Levin introduced Mr. Naqi to discuss Hixny’s experiences with providing data to patients. Mr. Naqi described Hixny’s efforts to provide data to patients through the Apple Health app. He noted that Apple does not directly contract with health information exchanges (HIEs), but Hixny nevertheless was able to work to provide data to the app. Mr. Naqi noted the advantage of such a system is that patients can get all of their data in one place, rather than logging on to different patient portals from different providers. He added that the program is still in the testing phase.

Mr. McNichol described HealtheLink’s activities to share data with patients. He explained that HealtheLink had received a grant to develop its portal, and they had worked with a patient advocate to understand the patient’s viewpoint. He noted there are data usability issues for patients, and the data needed to be displayed in an understandable and consumable way. As a result, Mr. McNichol said there is a need to develop a help desk function as the portal is expanded beyond a pilot. He added that HealtheLink chose to work with Health Wizz because it supported the FHIR standard and the OAuth security model.

Ms. Eisenstein discussed Rochester RHIO’s experiences regarding patient data sharing. She said the RHIO was looking for a low cost and easy approach for providing patients with their data. She also noted that the information blocking rule requirements mean RHIOs must share data with third party apps. Ms. Eisenstein said Rochester had chosen to work with the Ciitizen app, which is a member of the Carin Alliance. She said that today, the SHIN-NY Policies are silent on disclosures to such apps, and that the Committee should develop rules to address disclosures to these apps.

Mr. Bell expressed concern with third party apps, noting that their business model still is being developed and it’s not clear how they plan to monetize the information they obtain. He noted that in the case of fertility tracking apps, the consumer may be unaware that the app will sell their data to marketers, and may be surprised to receive pregnancy related coupons. Ms. Eisenstein said the patient consent paradigm does not work well for third-party apps, and that under the information blocking rule patients have a right to their data and have it sent where they want it to go.

Mr. Belfort said the issue is not so much the patient’s consent to the app, but what happens once the information is in the app, since HIPAA doesn’t apply any more and the information only is subject to general rules in the FTC Act about not engaging in false and misleading practices. He
added while the Committee may prefer that disclosures only be made to apps that adopt certain safeguards, there is a question about whether they have the legal flexibility to do that.

Mr. Dworkowitz described how the new information blocking rule may impact policies regarding disclosures to patients through apps. He noted that the information blocking exceptions protect certain activities, such as engaging in identity proofing and patient education regarding the risks of certain apps. He added that the rule was intended to allow patients to choose what to do with their data, and certain practices – such as limiting which apps can receive disclosures – may violate the rule.

Ms. Grey asked if the feasibility exception may allow QEs to limit which apps they engage with. Mr. Belfort responded that if certain standards like FHIR become widely adopted, it may be harder to deny disclosures to apps based on the technical challenges of connecting to those apps.

Dr. Mahoney said it would be ideal if they could tie disclosures to apps approved by an organization like the Carin Alliance. Mr. Belfort said if the state adopted a law prohibiting QEs from disclosing data to apps that did not follow certain safeguards, QEs may be in compliance with the information blocking rules by declining to make disclosures to such apps, but there is a risk that such a law could be preempted.

Dr. Mead said the SHIN-NY needs to view itself as a steward of patients’ data, and they should be conservative as to how they disclose such information to apps. Mr. Bell said it is difficult for consumers to interpret what the app’s agreements actually say, and better consumer education is needed.

Dr. Mahoney asked if each QE could have their own specific approach to this issue. Ms. Grey said from a legal perspective, the risk to the SHIN-NY enterprise would go up if one QE says a particular app is fine and another prohibits disclosure to that app. Mr. Belfort agreed, saying that many of the exceptions depend on not engaging in discrimination, and if QEs take different positions it would make it harder to justify a position as non-discriminatory.

Ms. Grey noted that the information blocking requirements also apply to data contributors like hospitals, and it behooves the SHIN-NY to work with partners on the rule. Mr. Naqi said QE participants have already seen the writing on the wall, and that the federal government is trying to empower the patient.

VI. Life Insurance Policies

Mr. Levin introduced the last item on the agenda, regarding revisions to life insurance policies. Ms. Sutliff reviewed the proposed language, explaining this was an attempted compromise on the patient notification issue.

Dr. Martin asked if there would be implementation guidance regarding how to count two business days. Ms. Sutliff said there would be. Dr. Martin said in that case, he supported the proposal. Mr. Rogow noted it can be challenging to identify days vs. number of hours.
Mr. Levin asked if there were any objections to the proposal. Hearing none, he said there was consensus on the change.

VII. Closing

Mr. Levin thanked the Committee and adjourned the meeting.