A meeting of the NYeC Policy Committee was held on January 13, 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
Jonathan Karmel, NYS DOH
Geraldine Johnson, NYS DOH
Deirdre Depew, NYS DOH
Jessica Eber, NYS OMH
Dr. Thomas Mahoney, Finger Lakes Health Systems Agency
Dr. David Cohen, Maimonides Medical Center
Dr. Glenn Martin, Queens Health Network
Dr. John-Paul Mead, Cayuga Medical Associates, P.C.
Zeynep Sumer-King, GNYHA
Susan Van Meter, HANYS
Valerie Grey, NYeC
Cindy Sutliff, NYeC
Jeannette Rossoff, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 1:00 p.m.

I. Welcome and Introductions

Mr. Levin welcomed the Committee members and wished them a happy new year. Mr. Levin said the job of the Committee was to reach agreement on recommendations on revising the consent framework.

II. Overview of Value Based Payment (VBP) Workgroup Confidentiality Recommendations

Mr. Levin introduced Mr. Kirkwood to provide an update on the VBP Workgroup’s confidentiality work. Mr. Kirkwood explained that the VBP Workgroup had a number of sub-groups, one of which works on patient confidentiality issues, and that sub-group’s work was similar to the work being undertaken by the Policy Committee in examining the SHIN-NY
Mr. Kirkwood noted that one of the recommendations was to allow for an opt-out model. Mr. Belfort noted that the VBP Workgroup document suggested that there may not be a need to change state law to allow for opt-out, and asked if this was true. Mr. Karmel said that NYS DOH has not reached such a conclusion, but that the VBP Workgroup was hoping that a change may not be necessary. Ms. Warner said that there should be public hearings as part of a lengthy process prior to a switch to opt-out. Ms. Sutliff said that there would be either public hearings or a public comment period.

III. Consent Framework Recommendations

Mr. Levin said it was the Committee’s job to reach agreement on the recommendations that would be presented to the NYeC Board and which would then be submitted as recommendations to the Department of Health. Mr. Belfort explained that the proposed recommendations came from further deliberations following the release of the consent white paper. He said the document was divided into short-term recommendations which enjoyed broader support and longer-term recommendations that need further discussion from a policy standpoint. Mr. Dworkowitz outlined the three short-term proposals for consideration: the sharing of alerts without consent, the use of alternative consent forms, and the allowing for access following a referral or a scheduling of an appointment.

Alerts Without Consent

Ms. Eber said the footnote relating to exclusion from alerts from mental hospitals correctly reflected OMH’s interpretation on the need for a statutory change to implement the proposal. Dr. Mahoney asked about the form of opt-out under the proposal. Mr. Belfort said he thought there could be a narrowly tailored opt-out.

Ms. Warner said there was discomfort regarding the possibility that alerts could be shared with community groups such as the YMCA. Mr. Belfort said they had initially written the proposal to apply to a few categories of providers such as primary care practitioners (PCPs) and health homes, but that approach was too narrow, so the language was broadened. However, it is unlikely that a YMCA would be able to obtain alerts since it typically would not have a treatment or care management relationship with patients.

Dr. Martin said he was struggling to understand why there was a need to provide alerts without consent, since if a patient joined an organization that provides certain services, then presumably the patient could sign consent. Dr. Mead said there was multi-level complexity involved here, and that a physician group might hire another organization to provide care management to its patients, but that other organization may not have direct access to patients. Mr. Check said there were two scenarios at issue: one in which the party, such as a care manager, does not have direct contact with the patient, and the other in which a provider, such as an emergency room, does
have direct contact but it is difficult for them to get their front desk staff to ask every patient for consent.

Mr. Levin said the issue is whether the benefits outweigh the risks. Dr. Martin said that the care management organization scenario seemed like a problem, since information would be exchanged with an organization that the patient does not know exists. Mr. Check said this is already occurring with performing provider systems (PPSs) under the Delivery System Reform Incentive Payment (DSRIP) program.

Ms. Shatzkin said she concurred that alerts are important but questioned whether the proposal was necessary given that the alternative consent proposal would allow more data sharing under Medicaid, including the sharing of alerts. She also noted that patients are often auto assigned to a PCP and that as a result many PCPs often do not see their patients, meaning that the proposal would result in many alerts being sent to PCPs who did not need such information.

Dr. Martin said that patients cannot opt-out of a system that they do not know exists. He proposed that if an alert was sent in regards to a non-consented patient that the Qualified Entity (QE) inform the patient of the sending of the alert, similar to what occurs under the break the glass policy. He said this would increase patient understanding of which doctors were taking care of them. Ms. Warner said this would be a heavy lift.

Dr. Mead said they are going through a painful transition period, but that providers would get used to such a system. Ms. Shatzkin asked if this was something that they cared about for the non-Medicaid population. Mr. Check said that commercial payers would be supportive of this proposal, and Mr. Belfort said there are Medicare patients who have not granted consent to their PCP. Ms. Shatzkin said the Committee has to be pretty careful about what they do, and that once they open the door it is hard to close it again. Ms. Warner said that she did not believe the proposed changes solve the problems that they are trying to fix.

Ms. Sutliff noted that they have been discussing these proposals over a long time period, and that the proposals reflect the feedback they have received. Mr. Levin said that he found statements in support of the alert proposal from clinicians to be compelling, and that this would be a big improvement.

Ms. Shatzkin said that alerts would be sent without patients having enough knowledge of their right to opt-out. One Committee member suggested that emergency rooms discuss the sending of alerts with their patients. Mr. Belfort said that it was not realistic that such discussions would occur.

Mr. Levin asked the Committee if there was a general consensus to put the proposal forward to the NYeC board, noting the presence of some disagreement and the opportunity for further public comment. No Committee member objected.
**Alternative consent forms**

Mr. Levin asked the Committee for its comments on the alternative consent form proposal. Mr. Check said it was an excellent recommendation but suggested that a person should be given a choice to withhold consent. Mr. Belfort said every insurance policy form contains some confidentiality waiver which is often narrowly focused, and as an enrollee in that plan you do not have a right to cross out that provision. Instead, patients have rights under HIPAA to restrict a disclosure that is permitted. Mr. Belfort said a big challenge is that this would require a new interface between payers and QEs with monthly uploads of membership information. Mr. Check said such a process is already in place.

Mr. Allen asked what would happen in the scenario where a provider covered by an insurer’s consent form leaves the insurer’s provider network after the signing of the consent. He added that from the perspective of his QE, he was not sure what they gained from the proposal given that they already had a community-wide consent model. Mr. Check said the advantage is that under this proposal they would get consent up front.

Ms. Warner expressed concern that the proposal should not force a QE to switch to a community-wide consent model. Mr. Belfort said the recommendation does not mandate a QE to use an alternative consent form; it simply permits a QE to do so.

Mr. Allen said he heard statistics that 30% had opted-out DSRIP data sharing. Mr. Karmel said he did not know the exact number, but the Medicaid program had made a decision that if a piece of mail came back due to a wrong address, that would be treated as an opt-out. Mr. Allen said if the percentage of opt-out really was near 30%, he would not want to get near implementing this proposal.

Mr. Levin asked the group if they could agree to put forward this recommendation. No Committee member objected.

**Access following referral or appointment**

Mr. Levin asked to get a sense from the group on the third proposal. Dr. Mead said it was a good idea from the perspective of a practicing physician. He said that sometimes his practice gets a crazy result from a pathologist and needs to talk to the pathologist, but there are problems with the ability to exchange information with pathologists. Mr. Check said his QE was supportive, but suggested that a referral is not sufficient, and that in addition there should be some action taken by the patient to accept that referral.

Mr. Belfort said the challenge with this conceptually is that under the proposal, a provider could view a patient’s information one day before an office visit but during the office visit the provider would have to get consent. Dr. Martin said there was a difference between point-to-point communications and full access to the chart. Dr. Mead said in some cases patients are irritated with him if they get a sense that he did not look at their records prior to the appointment. Dr. Mahoney said there are some cases where this would be clearly beneficial.
Ms. Shatzkin said there is a parallel between this proposal and break the glass, and asked if they could develop language that would set limitations on this proposal. Mr. Levin said that there were three buckets at issue with this proposal: situations that the one-to-one exchange exception already covers, situations involving pathologists who never see the patient, and a third bucket of other scenarios.

Dr. Martin said that the proposal may not be particularly helpful, since a doctor who has not been paid yet is unlikely to go through the records of a new patient. Mr. Levin acknowledged that the 1-to-1 exception already took care of a certain percentage of cases addressed by this proposal. Mr. Belfort agreed that 1-to-1 covered most aspects of the proposal, and that the rest was not fully fleshed out. Ms. Eber said the proposal was too broad and she was not comfortable with it. Mr. Levin concluded the proposal was not fully baked enough and therefore would not be put forward as a recommendation.

Next steps

Ms. Sutliff said they would revise the recommendations document, and distribute to the Committee members. Mr. Levin said there would be further discussion on moderate and long-term proposals going forward.

IV. Closing

Mr. Levin thanked the group for their time and closed the meeting. The next meeting will be scheduled for February with a date and time TBD.