New York eHealth Collaborative Policy Committee Meeting
September 26, 2016
10:00 a.m. – 2 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on September 26, 2016. 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
Dan Porreca, HealtheLink
Rob Hack, HealtheConnections
Karen Romano, HealtheConnections
Tom Check, Healthix RHIO
Amy Warner, Rochester RHIO
James Kirkwood, NYS DOH
Jonathan Karmel, NYS DOH
Geraldine Johnson, NYS DOH
Deirdre Depew, NYS DOH
Dr. Thomas Mahoney, Finger Lakes Health Systems Agency
Dr. David Cohen, Maimonides Medical Center
Dr. Glenn Martin, Queens Health Network
Dan Tietz, AIDS Institute
Christina Galanis, HealthLink NY
Zeynep Sumer-King, GNYHA
Laura Alfredo, GNYHA
Evan Brooksby, HANYS
Valerie Grey, NYeC
Cindy Sutliff, NYeC
Jeannette Rossoff, NYeC
Elizabeth Amato, NYeC
Erica Haskin, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 10:00 a.m.

I. Welcome and Introductions

Mr. Levin introduced Valerie Grey, the new executive director of NYeC. Ms. Grey described her background, noting she had worked in state service, for a large national health plan, and most recently for HANYS. She said she was going on a listening tour across the state to hear from those in the field about what in the SHIN-NY works and what can be made better.

II. NYS DOH Update

Mr. Levin introduced Mr. Kirkwood to provide an update. Mr. Kirkwood said there is a push to ensure that the SHIN-NY is aligned with health information broadly in programs such as the Delivery System Reform Incentive Payment (DSRIP) program and State Innovation Models (SIM). Mr. Kirkwood highlighted an article in the New York Law Journal written by Mr. Karmel that discussed how the SHIN-NY can be used to support DSRIP going forward.

III. SHIN-NY Consent White Paper Review and Discussion

Mr. Levin began the discussion on the consent white paper, which had been presented to the Committee. Mr. Levin said it was an evidence-based paper that is pretty well baked but that it is important to hear from the Committee about places where clarification is needed. Mr. Levin said this is a two-phase process and they are now moving on to phase two where the Consent Workgroup will seek additional input from several stakeholder groups, look at the evidence gathered and make recommendations.

Mr. Belfort said the report was intended to take a step back from day-to-day tinkering and take a broad look on how the current consent model is working. Mr. Belfort explained that they had administered a survey relating to consent followed by a series of focused interviews. They had also undertaken a limited analysis of consent models in other states and a legal roundtable to focus on how state consent laws had been interpreted.

Mr. Dworkowitz presented an overview of the survey findings. He noted that this was not a survey of patients but instead focused on SHIN-NY participants. He explained that the findings suggested there is a lack of patient education, that consent can be an issue with care coordination, and that there is support for a switch to an opt-out model, although it was by no means universal.

Mr. Belfort said that when they had originally written the policies they had a particular model in mind in which providers would search the system in order to treat patients, but they had learned that this is not typically how the SHIN-NY is used. Instead, it is used for disclosures of laboratory tests which typically do not require consent because the 1-to-1 exchange exception is used. Providers are also interested in getting alerts and undertaking population health activities, which are impaired given the need to obtain consent for thousands of patients. Mr. Belfort suggested they tie consent to the nature and breadth of information being accessed. Mr. Belfort said the paper did not make recommendations since there was an insufficient foundation for recommendations, but instead it articulated options and a process for evaluating those options. He presented an overview of the three models: a SHIN-NY model aimed at preventing consent overload, an opt-out model, and a flexible consent model which would allow changes to the consent form.

Mr. Levin asked if there were any questions or requests for clarification. Dr. Martin suggested they add percentages to the chart on page 38. Dr. Martin also said that in discussing the history of the consent model, the intention was that participants be able to use their own consent form and there was never an intent that they had to use a specific form. Dr. Mahoney referred to a statement from NYS DOH in the report that an exception applies to care management and not

quality improvement, and that the expectation of what is considered generally acceptable practice has changed dramatically since the policies were first written.

Mr. Levin said that in phase two, they should consider nine measures to develop a recommendation. Mr. Levin described the measures set out in the report and the various options set out in the next steps. Mr. Levin said that the paper would be presented to the governor's office, and they aimed to have recommendations developed by December.

Mr. Martin observed that patient input has been absent, and that it would be a stronger paper if there was feedback from patients. Ms. Sutliff said that in the next phase, patient groups would be one set of stakeholder groups to interview. Dr. Martin asked if there ever been a study of patients regarding the SHIN-NY consent; he imagined that such a study would show that most patients would have no recollection of having signed such a consent.

Ms. Shatzkin said they should take one step back and identify their goals, something like a mission statement. Dr. Cohen said that practically speaking, the workgroup would need to develop such goals.

Ms. Galanis noted that EHR records do have a field where a consent choice can be indicated, but the problem is that if a patient has an online consent management tool and decides a particular provider should no longer be able to access that patient's records there is an issue with communicating that to the provider's EHR. Ms. Shatzkin noted that they are still dealing with challenges regarding patient identity.

Mr. Check said that it was really important in the next phase to learn from the experiences of QEs trying different consent models. Mr. Allen agreed, noting that since HealtheLink had implemented a community-wide consent model it has not experienced some of the problems of other QEs, and that therefore one of the recommendations could simply be to do what is already allowed. Mr. Allen said they do not currently include substance use disorder information subject to 42 CFR Part 2 in their QE but they are planning to change that. Ms. Sutliff noted that a proposed rule from SAMHSA would change the requirements for substance use disorder information. Mr. Allen noted that they would not invest in a new model until that rule was finalized. Mr. Karmel said that assuming the SAMHSA regulation gets finalized as proposed, Part 2 providers would have to get a consent to disclose and everyone else could operate under a community-wide consent.

Mr. Levin said that the paper would be presented at the NYeC board meeting on Wednesday, with the plan that recommendations would be developed in the second phase. Mr. Levin asked if there were any objections to this approach. None of the Committee members objected.

IV. SHIN-NY Security Framework Update

Mr. Levin noted that health information has become the most sought after information in the black market, not for the health information itself, but for the demographic data associated with it. Ms. Sutliff noted that a decision was made to work with an outside entity to conduct a cybersecurity vulnerability assessment of the SHIN-NY as this type of assessment was out of

scope for Policy Committee members. While the activity is considered a Policy Committee activity DOH determined that the assessment would be best conducted by a consultant group specializing in cybersecurity and cybersecurity assessments. KPMG was selected as the vendor through an RFP process. Ms. Sutliff said the vendor would perform vulnerability testing for all of the QEs but would not undertake penetration testing. In addition, the assessment will include an analysis of the current SHIN-NY Privacy and Security Policies and Procedures for QEs and their Participants V 3.3 to determine gaps in security policies/procedures and make recommendations for consideration by the Policy Committee and DOH. The full assessment will be completed by end of Q1 2017.

V. Patient Portal Meaningful Use Delay Standard

Mr. Kirkwood explained NYS DOH had selected 36 hours as the appropriate delay in displaying lab results on the patient portal. This was based on the 36-hour delay for hospitals under the meaningful use standard; under meaningful use, it is 96 hours for eligible physicians.

Dr. Martin expressed concern that there may be situations where test results would not be available from a hospital but they would be available from a patient portal. Mr. Check noted that the meaningful use standard was 36 hours from discharge, but the standard promulgated by NYS DOH was 36 hours from the test result.

Mr. Kirkwood noted some QEs push lab test results to their patient portals as soon as they are available. Ms. Shatzkin said they should keep this issue in perspective, and that the state of Kansas has pushed lab results to the patient portal immediately. Mr. Levin said there may be more valuable aspects of the patient portal. Ms. Sumer-King said getting lab tests in real time is not that helpful to patients and questioned whether it was valuable to dump a lot of laboratory results to patients through the portal. Dr. Martin said the 36-hour mandate was problematic and did not have a clear benefit.

VI. P&P Topic Areas for Discussion

After a lunch breach, Ms. Sutliff said there were issues regarding the policies that needed to be brought back to the Policy Committee for discussion.

Clarification of 1-to-1 Exchange

Ms. Sutliff said that as part of the March 2015 regulation, the 1-to-1 exception allows a health plan that has a relationship with a provider to share information for quality improvement and care management purposes without obtaining written consent. Ms. Sutliff said that QEs are wondering about other uses cases. Mr. Allen said they were interested in knowing about other use cases, such as whether information can be exchanged for utilization management purposes without written consent. Mr. Check said that whatever the outcome is, the instructions need to be clear about what the allowed uses are going to be. Mr. Allen said information was automatically exchanged based on the terms of the agreement between the provider and the

applicable payer. Ms. Alfredo said that if the payer and provider have an agreement to exchange data and have determined the legality of it, then they can exchange without written consent.

Mr. Belfort said the 1-to-1 exception is not written to say that no consent is needed. Instead, it says that the special SHIN-NY consent is not needed. If under the applicable law there is implicit consent for sharing information for utilization management purposes, then it can be shared under a 1-to-1 exchange. He said that the examples in the policies are illustrative and not exhaustive.

Ms. Sutliff pointed out that the policies specifically call out certain exchanges with health plans. Mr. Belfort responded that if Participant A wants to share with Participant B and the patient has not done anything to implicitly authorize the sharing, then the 1-to-1 exception should not apply. He added that the exception was written to impose an obligation on the participants to obtain consent and that there is not an obligation on the QE. Mr. Check said there is an audit obligation on the QEs to ensure that the 1-to-1 exception is being used for legitimate purposes.

Mr. Belfort said he saw the HIPAA minimum necessary standard as a challenge to 1-to-1 exchanges. If a patient is going in for a hip replacement, then that should not entitle the individual to 25 years of medical records without consent. Mr. Belfort said that if the current language in the policies was creating the impression that the examples are limited, then the language should be clarified, but that the discussion suggested that there may be some cases where the 1-to-1 exception was being used in violation of HIPAA. Ms. Sutliff said she would work with Ms. Alfredo, Mr. Allen, and Ms. Shatzkin to clarify the language.

Right to Names of Health Care Personnel Through Audits (Section 6.4.2)

Ms. Sutliff said the Committee had had a lot of discussion about this provision, and that they had reached a compromise. Ms. Alfredo said she appreciated the compromise, but that GNYHA had not participated in those discussions and that a member was concerned about the compromise. She said there was a concern about employee safety when employee names were disclosed to patients, even in cases where there is a finding of inappropriate access. She said 9 times out of 10 the issue is moot anyway because if the employee had done something inappropriate they would be terminated.

Mr. Allen observed that if there was inappropriate access, this could result in the breach response process in which case the patient would be informed of the incident anyway. Mr. Belfort said under HIPAA, the requirement was to do everything reasonably necessary to remedy the breach, which sometimes includes disclosure of an employee's name but that is not required in every case.

Dr. Martin said that a hospital system may have 10,000 employees and there needs to be granularity in order to allow for self-policing. He said he did not buy the concern that this was an employee safety issue, and suggested that a possible compromise would be to disclose the name unless the employer asserts that doing so would put the employee in jeopardy. Ms. Alfredo said it should be flipped and that the name should be supplied only if the name is

necessary to protect the patient or help the patient defend himself or herself. Ms. Sutliff asked Ms. Alfredo to draft language along these lines.

Analytics and Audit Requirements

Ms. Shatzkin noted on some occasions an analyst runs a query and gets back half a million records the first time, and the analyst then modifies the query and eventually gets the results down to the 250 patients the analyst is interested in. The reality is that the analyst did not look at the half a million records, but there is a question of whether an audit request from a patient in that half a million records must result in the QE disclosing to the patient that his or her name turned up in that initial query. Ms. Shatzkin said currently it is QE staff who are running this report, but there is pressure under DSRIP to allow users at other organizations to run similar analytics.

Mr. Check said he viewed this as an administrative function and that this should be allowed. Mr. Belfort agreed saying that this would be an incidental use under HIPAA. Ms. Shatzkin clarified that the policies say that there must be accounting of disclosures made "through the QE" and that it wasn't clear that if a patient's name turned up in the query of half a million records that this would count as a use that needed to be disclosed to the patient. Mr. Belfort said that this issue would need to be clarified in the policies.

Cross Border Alerts

Mr. Porreca explained there were three pilots to share HIE information across state lines, but those pilots all occur in opt-out states. He said they would need to examine whether there are policies in New York that would prohibit data sharing across state lines. He gave the example of a western New York patient who is admitted to an emergency room in western Pennsylvania, and that western Pennsylvania hospital notifying the New York QE about the admission. Mr. Belfort said that whether this is permissible depends on the law of the state in which the disclosing hospital is located, and he noted that informing a clinician that a patient has been admitted to a hospital is different than giving the clinician a key to the patient's medical records for their entire life.

VII. Closing and Next Meeting

Ms. Sutliff said the Policy Committee will be kept informed about the activities of the consent workgroup as they develop the white paper recommendations. Mr. Levin thanked the group for a productive day.