New York eHealth Collaborative Policy Committee Meeting Sept. 25 2019 12 p.m. – 4 p.m. Meeting Notes

A meeting of the NYeC Policy Committee was held on Sept. 25, 2019. Present either in person or via telephone were:

Art Levin, Center for Medical Consumers, Chair of Policy Committee

Nance Shatzkin, Bronx RHIO

Steve Allen, HealtheLink

Dan Porreca, HealtheLink

Amy Warner, Rochester RHIO

Dr. Virginia Scott-Adams, NYS OPWDD

David Nardolillo, NYS OPWDD

Molly Finnerty, NYS OMH

James Kirkwood, NYS DOH

Jonathan Karmel, NYS DOH

Deirdre Depew, NYS DOH

Laurie Pferr, NYS Office for the Aging

Dr. John-Paul Mead, Cayuga Medical Associates

Dr. Tom Mahoney, Common Ground Health

Dr. Glenn Martin, Queens Health Network

Dr. David Cohen, Maimonides Medical Center

Zeynep Sumer King, GNYHA

Tom Hallisey, HANYS

Linda Adamson, NYSTEC

Cindy Sutliff, NYeC

Nate Donnelly, NYeC

Carianne Borut, NYeC

Hiral Patel, NYeC

Tijuana Summers, 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, provided an overview of the meeting materials, and described the meeting agenda.

II. DOH Update

Mr. Levin introduced Mr. Kirkwood to provide an update. Mr. Kirkwood said that the Qualified Entities (QEs) had gone through the certification process, and that no findings had been made,

although there were opportunities for process improvements. Ms. Sutliff explained that certification included a third-party assessor examining whether a QE adhered to SHIN-NY policies in addition to a separate HITRUST certification, also conducted by third party assessors, which focuses on security controls.

III. Participation of Community Based Organizations (CBOs) in the SHIN-NY

Mr. Donnelly explained that under the SHIN-NY 2020 Roadmap, different advisory groups have been started, one of which relates to CBOs. About half of the members of the CBO advisory group have connected to QEs. Mr. Donnelly described those CBO's experiences with participation in the SHIN-NY, and said that upcoming meetings of the advisory group would focus on food pantries and housing. Ms. Warner noted that CBOs have been participating in the Rochester RHIO, and that the use of direct secure messaging with such CBOs has worked well.

Mr. Kirkwood noted that CBOs do not need to receive all clinical data, but instead sometimes just need information for referrals. Mr. Kirkwood said it can be impractical to require CBOs, which are often not HIPAA covered entities, to comply with all of HIPAA. Mr. Donnelly agreed that CBOs often do not need the entire record, but that in some cases they seek clinical data, particularly when they are participating in a value-based payment arrangement.

Mr. Dworkowitz provided a background on CBOs and HIPAA, noting that CBOs may receive Protected Health Information (PHI) with patient authorization or in limited circumstances where their services may impact the health of a patient. He also said that the SHIN-NY Policies currently allow CBOs to become participants if they fall under the definition of a "Social Services Program." Mr. Levin asked if any CBOs might be outside such a definition, and Ms. Warner questioned whether exercise programs would meet this definition.

Mr. Belfort noted that the SHIN-NY Policies typically regulate only how information is provided to participants and do not address restrictions on re-disclosures under the assumption that the recipient is a HIPAA covered entity. But since many CBOs are not HIPAA covered entities, they may have to condition their participation on compliance with HIPAA.

Ms. Sutliff asked if the standard participation agreement could be used for CBOs. Ms. Warner said Rochester RHIO uses a participation agreement tailored for CBOs.

Dr. Martin said he has concerns about disclosures to CBOs since they are often not HIPAA trained, and therefore should be given a relatively small amount of information. He noted the minimum necessary standard does not apply where information is disclosed under an authorization.

Ms. Shatzkin said this raises the issue of participants making copies of SHIN-NY data and failing to properly update it. Mr. Levin said the issue of data integrity was a separate discussion. Mr. Belfort and Ms. Sutliff agreed that this issue was out of scope of the discussion. Mr. Belfort said the core issue is whether patients should be able to disclose all of their information to CBOs, or whether the SHIN-NY needs to play a more protective role since patients often do not understand what they agree to and CBOs do not have the same culture of privacy as HIPAA

covered entities. Dr. Cohen said if the organization is a Tier 2 or Tier 3 CBO (as such terms are used under Medicaid) then the same principles apply to disclosures to such CBO as disclosures to a hospital.

Ms. Sutliff said they would address this issue further at the October meeting, where policy options regarding CBOs will be presented.

IV. PSYCHES and the SHIN-NY Connections: Proposed Pilot

Mr. Levin welcomed Ms. Finnerty to present on Psychiatric Services and Clinical Knowledge Enhancement System (PSYCKES) for Medicaid.

Ms. Finnerty explained that PSYCKES is a web-based platform developed by OMH that is designed to share Medicaid data to support quality improvement and clinical decision support. She said 8 million current and former Medicaid enrollees have their data in PSYCKES, and that PSYCKES focuses on the behavioral health population. She said that OMH has tried to condense the data to make it as useful as possible.

Ms. Finnerty said that, similar to the SHIN-NY, any provider of clinical services is eligible to join PSYCKES. PSYCKES also allows consumers to see their own records. She said that PSYCKES currently has 10,000 active users and had under 100,000 logins in the last quarter, and that health homes are big users of the system.

Ms. Finnerty said that OMH is working with QEs to see if it is possible to integrate some PSYCKES information into the QEs, and that Healthix and OMH were working on such a pilot. She said the goal is to increase the penetration of QEs into the behavioral health world, where use of the QEs is fairly low but PSYCKES penetration is relatively high. She explained that under Phase 1, there would be a single sign on so that a user could log on to PSYCKES and a QE by entering the same information. Under Phase 2, upon obtaining consent a user of either of the systems could access the patient's information through an integrated view that incorporates both PSYCKES and QE data.

V. Consent Recognition Policies

After a break, Ms. Sutliff introduced a discussion on the recognition of consents across QEs. She explained that the Policy Committee's consent workgroup had been addressing this issue for a number of months, and that the workgroup has produced recommendations regarding a new policy provision to allow recognition of consents across QEs as well as the development of a new form of consent.

Mr. Dworkowitz described the proposed new section of the SHIN-NY Policies regarding naming of QEs and recognition of consents. He said that the new provision would indicate that consents forms are not required to include names of QEs. He explained that this provision would permit a QE to accept a consent form that names another QE if (1) the form was signed by the patient, (2) the form names the participant that is seeking the patient's information, and (3) the participant

has informed its patients that it may access their information through one QE on the basis of a form that names another QE.

Ms. Warner asked what would happen if a patient objected to disclosures based on a form naming another QE. Ms. Sutliff responded that if a patient objected, the patient could deny consent to the disclosure. Ms. Warner also asked how the audit process would work and how patients would be able to change their consent choice. Ms. Sutliff said that processes would occur in the same way as the do currently.

Mr. Levin said branding is the antithesis of a shared system, and that allowing for interoperability is an important step to promoting a statewide network.

Mr. Allen questioned the need for notice to patients under the proposed policy. Mr. Belfort explained that there are a couple of QEs that felt discomfort with recognizing the consent forms of other QEs, and that the new policy was designed to give them a policy provision they could point to that would give them assurances that doing so was permitted.

Ms. Sumer King said that SHIN-NY participants are being subject to federal policies that envision a single consent form, such as the Trusted Exchange Framework and Common Agreement (TEFCA) proposal. She said that this was an important step toward aligning the SHIN-NY Policies with national health information exchanges, and if this didn't occur then hospitals may choose to participate in TEFCA through their electronic health record systems instead of the SHIN-NY in order to avoid having to use seven different forms.

Ms. Warner asked how this would impact the goal of moving to opt-out. Mr. Levin said they didn't know what would happen with opt out, and therefore they need to make this change now.

Ms. Shatzkin said she had no problem with recognizing consents of other QEs, and that this would not be hard to implement. She added she had concerns regarding the proposed consent form. Mr. Allen said he thought the same data would be accessed under this proposal as currently occurs under statewide patient record lookup (sPRL), and that the only difference is the method of access.

Dr. Martin said that although he likes as much transparency as possible, people who received a notice about a consent recognition policy would throw such notice away, and therefore notice provided through posters in the office or a provider website may be sufficient.

VI. SHIN-NY Wide Form of Consent

A. Discussion of Form

Mr. Levin introduced the discussion of the proposed SHIN-NY wide consent form. Mr. Dworkowitz provided an overview of the form, discussing the key elements and how it differs from the current forms in use. Mr. Belfort noted that the option to provide consent only in the case of an emergency is no longer listed on the form.

Mr. Allen said if an individual does not grant consent, then the individual effectively is preventing access even in the case of an emergency. Ms. Sumer King suggested that this point be clarified.

Ms. Shatzkin asked what is being accomplished by the change in the consent form. Ms. Sutliff said the change reduces the burden on providers, helps make the SHIN-NY a true statewide network, and helps put the SHIN-NY in a position to play in a national arena. Ms. Shatzkin said the form would force all QEs to become community-wide consent collectors.

Dr. Martin recommended several changes to the form. He said the language on the consequence of a consent denial was unclear, and that the form should clarify what happens in case of emergencies. He said there was no indication how someone could implement a change in their consent choice, and that individuals may not want to provide a form to their provider indicating they no longer give that provider consent. He said the phrase "study and make the care of all patients better" was unclear, and he thought it should apply only to quality improvement and not research.

Ms. Finnerty said that the denial of consent is not the same thing as a withdrawal of consent.

Mr. Levin said these comments on the form are valuable, and that members should provide additional comments via email.

B. HealtheLink Experience with Community-Wide Consent

Mr. Levin introduced Mr. Porreca to describe HealtheLink's experience with a community-wide consent model. Mr. Porreca said when a consent requirement was first adopted, HealtheLink decided to develop one consent for the community. He said it was more cost and more work up front, but the overall value realized has justified the cost. He cited the ability of pathologists, who do not meet with patients face to face, to access data as an example of the benefit of community-wide consent. Mr. Porreca said they did not receive pushback from providers or patients on this model, but the difficulty was more in the logistics of operationalizing.

Ms. Sumer King said community-wide consent was a good approach. Mr. Allen observed that they receive between 20,000 to 30,000 consent forms a month, half of which are duplicates, but HealtheLink is making efforts to reduce the rate of duplicate consents. He said the rate of consent varies depending on who asks for consent, with individuals much more likely to give consent when asked by a provider as opposed to a health plan or an employer. Mr. Allen said that only one tenth of 1% cherry pick, that is, provide consent but only select a limited number of providers. He added that HealtheLink audits 100% of providers who deny consent.

Mr. Allen said Dent Neurologic Institute was the poster child for community-wide consent, in that it never collects consent but instead relies on the consent obtained by others.

Mr. Allen said they audit nearly all the consent forms obtained in the community. Ms. Shatzkin asked how other QEs could implement that. Ms. Sutliff said not all QEs need to implement community-wide consent in the same way. Mr. Allen agreed.

C. Advisory Group's Reaction to SHIN-NY Wide Proposal

Mr. Donnelly noted that the proposed SHIN-NY wide consent form had been shared with the provider advisory group, and that the feedback was overwhelmingly supportive. Mr. Donnelly noted the providers felt that such a form would make participation in the SHIN-NY easier. Ms. Sumer King said some providers she has been meeting with had some clarifying questions but they were all on board with the proposed change.

D. SHIN-NY Wide Consent Form and 42 C.F.R. Part 2

Mr. Dworkowitz described how the SHIN-NY wide consent form was intended to comply with 42 C.F.R. Part 2. He provided an overview of the key Part 2 requirements and explained how the form addressed such requirements. For example, Part 2 rules allow for a general designation of information recipients to apply to only to organizations with a "treating provider relationship" with a patient, and the form therefore does not apply the general designation to health plans.

Mr. Allen asked if a provider with a treating provider relationship may access Part 2 data for all Level 1 uses. Mr. Belfort said that if a provider really is treating the patient, then such activities are ancillary to treatment.

Dr. Cohen asked if a health home could be considered to have a "treating provider relationship" with a patient. Mr. Belfort said this was a gray area, and that the rule was based on the antiquated idea that only treating providers are involved in managing medical care. Ms. Sutliff said the latest proposed rule from the Substance Abuse and Mental Health Services Administration (SAMHSA) did not change this requirement, and that NYeC is preparing comments to SAMHSA on this issue.

VII. Closing

Mr. Levin said the Committee had reached consensus on the new policy provision regarding consent recognition, subject to a modification regarding the notice provision. He said the draft SHIN-NY wide consent form would be revised based on the discussion at the meeting, and that Committee members should submit any additional comments on the form to Ms. Sutliff.

Ms. Sutliff said the next Committee meeting was scheduled for October 22, and it would be an in-person meeting.

Mr. Levin thanked the Committee members for their time and adjourned the meeting.