# New York eHealth Collaborative Policy Committee Meeting September 17, 2015 9:00 a.m. – 11:00 a.m. Meeting Notes

A meeting of the NYeC Policy Committee was held on September 17, 2015. 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 Dr. Thomas Mahoney, Finger Lakes Health Systems Agency Nance Shatzkin, Bronx RHIO Ronnie Pawelko, JD, Family Planning Advocates of NYS Steve Allen, HealtheLink James Kirkwood, NYS DOH Dr. John-Paul Mead, Cayuga Medical Associates, P.C. Dr. Glenn Martin, Queens Health Network Christie Allen, NYS DOH Paul Schaeffer, NYCDOHMH Tom Check, Healthix RHIO Colleen Mooney, NYSTEC Cindy Sutliff, NYeC Inez Sieben, NYeC Bob Belfort, Manatt Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 9:00 a.m. Mr. Levin encouraged Committee members to submit any corrections or comments to the meeting notes that they may have. Ms. Sutliff told the Committee that meeting agendas and meeting notes were now being posted on the NYeC website.

## I. NYS DOH Update

Ms. Sutliff introduced Mr. Kirkwood from the New York State Department of Health ("NYS DOH") to discuss the draft SHIN-NY regulation. Mr. Kirkwood said the regulations were still going through the approval process. He said he hoped the regulations would be released for public comment within two months, but it was difficult to give an estimate of timing. He said that the regulations were similar to the previous version but contained some grammatical changes.

Mr. Check asked which version of the Policies were currently controlling. Mr. Kirkwood said Version 3.2, which has been out for public comment since June or July, should be controlling. Ms. Shatzkin said she had assumed the prior Version 3.1 was still controlling, and Mr. Check agreed. Mr. Levin said this issue needs to be clarified. Ms. Sutliff said it would make sense if the new version was operative once the regulation is codified. Mr. Kirkwood agreed.

Ms. Sutliff asked about the upcoming meeting of the HIT Transparency and Evaluation Workgroup. Mr. Kirkwood said the workgroup was meeting on Friday, and that they planned to discuss the SHIN-NY regulations, statewide patient lookup, coordination with Performance Provider Systems ("PPSs") in the Delivery System Reform and Incentive Payment ("DSRIP") program, and the All Payer Database.

#### II. Level 2 Consent form for exchange of family member information

Mr. Levin turned to follow up items from the previous meeting. Mr. Dworkowitz explained that the draft Level 2 consent form for the exchange of family member information had been revised since the prior meeting: the form would be in effect for a period of 90 days after signing, although the individual signing the form would have the option of choosing a different time period.

Ms. Shatzkin said this form looked very similar to the standard consent form used more frequently, and that it was possible that participants and patients might be confused. Mr. Belfort said the form could be printed on different color paper to avoid confusion.

Dr. Martin asked how the deny box would be used. Mr. Belfort said the deny box was not intended to be used for denying consent, but instead would be for withdrawing consent. Dr. Martin said if a person wanted to withdraw consent, they could do so on a separate form, and that including this box here was needlessly confusing.

Mr. Levin said he thought the title of the form did not indicate what it is being used for, and he recommended the word "Your" be inserted into the title.

#### III. Comments to NYS DOH on Policies

Mr. Belfort explained that NYeC had submitted three comments to NYS DOH regarding possible revisions to Version 3.2 of the Policies. He said these comments reflected the discussions of the Policy Committee in recent months.

Comments on Community-Wide Consent

Mr. Belfort said that the first comment related to community-wide consent. He said the proposed revision was designed to better track what the new SHIN-NY regulations say, in particular the proposed regulatory provision on patient notice. He said the proposed language would include more specificity on the notice requirement, and it clarifies that a consent that is inclusive of future participants would not apply to information governed by 42 C.F.R. Part 2. Ms. Sutliff noted that QEs would need to list the Part 2 provider and the QE Participants who might access data of the provider via the QE. Future Participants would not be allowed to access the Part 2 data until the patient signed a consent that listed the new Participant as well. Mr. Belfort agreed this was cumbersome, but that they could not change what federal law requires.

Ms. Shatzkin said that by doing this, the Committee is encouraging people to believe that community-wide consent is a big help to them. Mr. Check said this would be very beneficial,

that by doing this they could have one consent cover their 160 participants, and that he was not too concerned if it did not cover an additional 5 participants who joined the following week. Mr. Belfort noted the proposed language would not require QEs to offer community-wide consent, it was just an option, and that some QEs might find it beneficial while others might find it burdensome.

Mr. Check said that participants in his QE are considering providing a current list of participants to patients by showing that list to the patient on a computer and mailing it to the patient afterwards, and that doing so would avoid the need for participants to print out the list. Mr. Belfort said that this was an issue dictated by 42 CFR Part 2 and the incredibly rigid guidance issued by the Substance Abuse and Mental Health Services Administration ("SAMHSA"). In that guidance SAMHSA said that a list of the providers need to be on or attached to the consent form, and that posting a list on a website was insufficient. Ms. Sutliff said she thought Mr. Check's approach complied with this guidance since that approach allowed for immediate access to the list of participants at the time the patient signs the form.

Mr. Allen asked if there should be an "or" between the second and first sentences in the draft language. Dr. Martin said that information subject to Part 2 would be flowing around, so he questioned whether QEs would always have to act in compliance with Part 2.

Mr. Allen said there could be issues where a local QE does not include Part 2 information but Part 2 data is available statewide. Mr. Belfort said this was a problem for Part 2 providers. Dr. Martin said this was a problem for the Committee since by extension the Committee was acting as an agent of the Part 2 providers.

Ms. Shatzkin said she thought the community-wide consent model would make sense in a couple of years when 90 percent of providers are participants, but for now it is an extraordinary burden. She said because the state proposed this as a solution in DSRIP, the PPSs are focused on this as a solution.

Mr. Allen said his QE was planning to bring in data on Part 2 facilities, but their data will have to be stored in a different place. Mr. Check said Healthix knows which facilities are subject to the SAMHSA rules, so it would be feasible to exclude Part 2 data from queries. Mr. Check noted, however, that not all QEs know this information.

Mr. Belfort said there was no evidence that SAMHSA was going to change its opinion, and that SAMHSA had a listening session a year and a half ago but issued no new guidance since then. Ms. Shatzkin suggested that they encourage the treatment community to pursue a letter writing campaign with SAMHSA to encourage them to change their opinion.

Dr. Mead said since Part 2 only required the name of an entity to appear on the consent form, it is possible that they could just define an entity as all providers within a PPS. Mr. Belfort said he did not think this would work, and in the case of a hospital system the clinicians are all part of one legal entity, but here those participating in a PPS are not the same legal entity. Mr. Belfort said there would be no harm in asking SAMHSA for its view, but he would be extremely surprised if they permitted this.

Ms. Sutliff said the goal of the Policies was to give QEs the option of implementing a community-wide consent model. Mr. Kirkwood said that NYS DOH is educating PPSs about the community-wide consent model, and that the NYS DOH staff are fully aware of the difficulties of implementing this model. Mr. Check said he hoped that they could encourage PPSs to work with their local QE rather than having the PPSs build their own network. Mr. Kirkwood said that PPSs had a performance requirement that encourages them to work with the QEs, so this would not be an issue. Mr. Allen observed that PPSs would face some of the same legal challenges if they decided to rely on their own networks.

Mr. Belfort said he did not concede that it was impossible to implement a community-wide consent model, and that the large providers would be willing to do such a consent. Ms. Shatzkin questioned whether the model really can be implemented.

#### Other comments

Mr. Belfort explained that a second comment to NYS DOH was to implement a policy on family member consents along the lines discussed by the Committee. He said that the final comment was just a technical correction to the Policies.

## IV. Patient Accounting

Mr. Allen described a proposal to address the patient accounting issue, and that the proposal was designed to address concerns about the disclosure of names of health care workers. He said there were two use cases of interest. The first is one where a patient has a general interest about which entities accessed his or her records, and the second is where the patient has a concern about a particular person wrongly accessing his or her records.

Mr. Allen said the proposed language for Section 6.4.1 was designed to preserve the first use case. In addition, 6.4.1.1 was added so that a patient with a concern about a specific person can request an audit. Mr. Allen said the QE would be obligated to perform an audit. If there was no improper access, the QE would inform the patient. If there was improper access, the breach response process would be initiated which could lead to notification to the patient.

Ms. Sutliff said she thought this was a fair compromise, and that this could be inserted in the comments to NYS DOH. Ms. Shatzkin asked whether it was too late to submit comments, and Ms. Sutliff said she thought NYS DOH would still consider this comment.

Mr. Belfort said that from a legal standpoint, this issue is unhinged from HIPAA. He said the current language in the Policies is not required by HIPAA, and that the proposed language is not required by HIPAA either. Mr. Belfort said that this proposed language only allows a patient to ask about a specific authorized user, and it does not allow a patient to request the name of every person who accessed his or her records.

Dr. Martin said the change eviscerates a patient right previously given under the Policies, and that he opposed the change. He said that people in hospitals often look at patients' charts when

they shouldn't, and this happens every time a person of interest goes into a hospital. Ms. Shatzkin said the flip side of this problem is that patients could request the names of people who work for an institution and use that list to harass staff inappropriately. Dr. Martin said that any person who sees a patient should be wearing an ID badge, so their identity should not be a secret.

Ms. Sutliff said that they had received comments from hospitals requesting this change because it is a burden to implement the patient accounting of authorized users. Ms. Shatzkin said it was not a burden. Mr. Belfort said the burden was not in running the report, but in the follow up in going over the list of names with the patient on the phone.

Mr. Belfort said he did not think the proposal gave the patients much. Mr. Levin said he agreed. Mr. Levin said consumer advocates have argued that patients should have this right, since it gives patients a watchful eye over the process. Mr. Belfort suggested an alternative: if a patient requests information about which authorized user accessed his or her data, the QE must forward the inquiry to the participant, and the participant would be required to conduct an investigation and report back to the patient. If there was unauthorized access, the QE would be required to identify the person who wrongly accessed the information. Dr. Martin said he would like to see this proposed alternative language. Mr. Levin said this alternative was better than the current proposal. Dr. Martin said the current proposal was unacceptable and a major step backwards.

Dr. Martin agreed that under the current approach the risk to a participant's employee is not zero, but that is a risk that all employees face. He said the theoretical possibility that a records clerk might be stalked in a parking lot was not a sufficient reason to adopt this proposal.

Mr. Martin asked whether this would be a limited right regarding access only through the SHIN-NY as opposed to access for all hospital records. Dr. Martin said that this is a limited right.

Ms. Sutliff said the Committee would need to look at the revised language of Mr. Belfort's proposal in order to reach agreement.

# V. Life Insurance Proposal

Ms. Sutliff said that John Rodat has met with Mark McKinney of Hixny to discuss the life insurance proposal and also had a discussion with Parameds. She said that Mr. Rodat has additional calls set up for the following week and that he is working with those behind the life insurance proposal to develop an approach to evaluating the proposal.

### VI. Stakeholder Comments on SHIN-NY Policy Guidance Documents

Ms. Sutliff said the Committee had received about 30 comments from stakeholders. She said that NYeC is reviewing those comments and putting together responses to NYS DOH, and that there will be further discussion on these issues.

### VII. Closing and Next Meeting

Mr. Levin told the Committee that the next meeting would take place on October 13 from 9 to 11am, and he closed the meeting.

# VIII. Next Steps

- Manatt to revise Level 2 consent form for sharing of family member information.
- Manatt to revise recommended policy language on community-wide consent notice.
- Manatt to draft alternative proposal for patient accounting.

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