A meeting of the NYeC Policy Committee was held on March 8, 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
Dr. Thomas Mahoney, Finger Lakes Health Systems Agency
Nance Shatzkin, Bronx RHIO
Steve Allen, HealtheLink
Dan Porreca, HealtheLink
James Kirkwood, NYS DOH
Jonathan Karmel, NYS DOH
Geraldine Johnson, NYS DOH
Dr. David Cohen, Maimonides Medical Center
Dr. John-Paul Mead, Cayuga Medical Associates, P.C.
Dan Tietz, AIDS Institute
Tom Check, Healthix RHIO
Amy Warner, Rochester RHIO
Zeynep Sumer-King, GNYHA
Laura Alfredo, GNYHA
Cindy Sutliff, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 9:00 a.m.

1. **SAMHSA Comment Letter**

Mr. Levin introduced Mr. Belfort to discuss NYeC’s comment letter on SAMHSA’s proposed rule. Mr. Belfort explained that SAMHSA had proposed a rule to revise the Part 2 regulations. He said the biggest issue with the Part 2 rules is that in guidance SAMHSA has said that the patient consent form must identify all information recipients, and this is problematic for RHIOs that want to use a community wide consent. Mr. Belfort explained that the proposed rule loosens this requirement, although in convoluted language, and it permits a general designation to be used of treating providers. He noted that this general designation was only for providers, not for health plans, and that it possibly might not apply to care management.

Mr. Belfort said that SAMHSA was giving with one hand and taking away with the other, in that they were now requiring the consent form to list the name of the entities disclosing the information, and that this was particularly hard to implement in a consent-to-access system like the SHIN-NY. A third issue is that the regulations will require a description of the information being disclosed. Mr. Belfort said in the past the regulations have been interpreted to allow the
form to say that “all of my records about me” are being disclosed, but now that would not be allowed. Instead, there would have to be an overinclusive list to capture anything that might be disclosed now or in the future.

Mr. Belfort outlined other proposals in the proposed rule. He noted that the rule allows for electronic signatures, but this has always been the general interpretation, so this is just a helpful clarification and not a change. He said that the regulation imposes security standards, and the draft comment letter seeks clarification as to whether this is intended to go beyond HIPAA. He said that the regulation also will define Qualified Service Organizations (QSOs) to include entities that provide population health management to Part 2 programs, which NYeC never thought was in doubt, but that this is a helpful clarification.

Mr. Levin said they are looking to get comments from Committee members on the draft letter to SAMHSA, and they are also looking to get input in writing.

Mr. Karmel said that it was a great idea to comment on the proposed rule and try to get SAMHSA to approve the use of a community-wide consent so long as the consent itself describes what the person is consenting to. Mr. Karmel said that under the proposed rule if a Part 2 program obtained a consent to upload, it would allow access under a community-wide consent model. Mr. Belfort responded that this could potentially be an approach, but that it would require a two-step consent process. Mr. Belfort said there is skepticism as to whether providers will actually obtain a consent to upload, since a provider would have to get a consent for the purpose of benefiting another provider.

Mr. Porreca asked about the possibility of overriding the requirement to name the discloser on the consent form. Mr. Belfort said that perhaps listing the intermediary disclosing the information would be adequate.

Mr. Check said the written response to SAMHSA was very true regarding the advantage of a consent-to-access model, and that they should not advocate for a consent-to-disclose model. Mr. Check also noted that the treating provider limitation in the proposed rule was a concern, since health plans and care management organizations are increasingly taking on roles related to care management and quality improvement. Ms. Shatzkin said the general designation should apply to care managers wherever they may be situated, whether they work for an insurance plan or a treating organization. Mr. Allen said they want a rule that is written such that all of their Level 1 uses are permitted; anything else would require RHIOs to implement another level of controls that would tremendously complicate things.

Ms. Alfredo said that one of the proposed definitions would not include patients that are attributed but not yet engaged, and that this would be an issue for the Delivery System Reform Incentive Payment (DSRIP) program. Ms. Alfredo recommended that they give some thought to addressing the alternative approach in the proposed rule in which SAMHSA proposes to redefine the term “organization.”

Mr. Martin said once a disclosure is out there, the patient is not protected. Mr. Belfort said the purpose of the rule is to allow disclosures outside of Part 2 providers. Mr. Martin asked whether
patients understood that this information was being sent to other providers. Mr. Belfort said that
this was a good point and the language needs to be clear enough so that patients understand this.

Ms. Shatzkin said they have a big problem here. She said the changes were bad for RHIOs
regardless of whether they are doing a participant-specific consent or a community-wide consent.
Mr. Belfort said this was a good point, and under the current framework a provider-specific
consent is workable. Mr. Check said if an entity was performing analytics, there is no way to
unscramble this information and not expose it to the one provider that did not get consent.

Mr. Belfort added that there was a potentially challenging transition issue, since SAMHSA could
take the position that any disclosure made after the effective date would need to conform to the
new rules.

Ms. Sutliff said April 11 was the deadline to provide comments to SAMHSA, and that they
should have a small group discussion on revising the letter. Mr. Levin noted that the Business
and Operations Committee was having a meeting on March 15, and that it might be helpful for
that committee to hear a presentation on the proposed rule. Ms. Sutliff said Mr. Belfort could
join that meeting. Ms. Sutliff asked for comments back from the Policy Committee members by
the following week.

II. NYS DOH Update

Mr. Levin introduced Mr. Kirkwood to provide an update. Mr. Kirkwood said the SHIN-NY
regulations would come out in the State Register the following day, and the only changes from
the previous version involve replacing the word “may” in regards to establishing a statewide
collaboration process. Mr. Kirkwood said the policy documents themselves would be on their
website.

Mr. Karmel said the newest version of the policies and procedures open up access for public
health activities and also clarifies that the New York City Department of Health and Mental
Hygiene is a public health authority.

III. SHIN-NY Policy Proposed White Paper Topic Areas

Mr. Levin introduced the subject of development of white paper topic areas. Ms. Sutliff said
they are in a good place for the Committee to take a step back and conduct some high level
thinking. She explained that various topic areas had been presented, and that once people are on
board with these areas they will be taken to the Board on March 30th, and the Board will review
and weigh in. She said their goal was to produce three white papers this year and not explore
every single topic listed.

Mr. Levin said the first three topic areas had already been discussed. The first is the consent
framework and the need to evaluate the SHIN-NY consent model. The second is the security
framework, being more attuned to governance than to technical issues of security, but they hope
to get an understanding from security experts. The third issue is about access and use of the
SHIN-NY; they have had their toe in the water with the life insurance discussion, but this is only the tip of the iceberg. The fourth area is in regards to patient engagement: how do we envision the portal actually engaging patients, and what is missing regarding patient education? Last, they will examine what is needed in regards to the 42 C.F.R Part 2 rules.

Ms. Sutliff said it would be helpful if the Committee could come to an agreement on these priorities. Once they identify the top three priorities, they will work on mapping out activities required to meet the goal.

Mr. Tietz asked if there were plans from NYS DOH to allocate resources to address these priorities. Ms. Sutliff said NYS DOH was on board with the development of white papers, and that they will enable the department to determine what might be required in terms of statutory changes or implementation changes that might need resources behind them. Mr. Kirkwood said if there are policy changes recommended by the Policy Committee, NYS DOH will examine whether the state or the federal government can fund it and how feasible such changes are given resources.

Ms. Shatzkin said that with security issues, it needs to be recognized that these issues cross over to other areas of expertise. Ms. Sutliff said she agreed, and that they would bring in subject matter experts who are not currently on the Committee to present the landscape and options.

Mr. Allen said that the last area has a lot of overlap with the first one, and that they should consider doing them together. Ms. Sutliff said the last item was funded under a grant and is more of a technical perspective—what are the technical abilities to segregate and tag Part 2 data.

Dr. Mead said the third topic area would need to address issues related to DSRIP and care management, since there are other companies coming into the health care arena that would be looking to interact with the SHIN-NY. Ms. Warner concurred.

Mr. Levin asked which of the topic areas is the most important from the perspective of the committee areas. Mr. Tietz suggested they conduct a doodle poll on the subject. Mr. Levin said they would do that, and there would be room for a narrative, so it would be helpful if Committee members could explain their rankings.

Mr. Levin noted that they may provide background papers, and Ms. Sutliff said they would draft some assessment and background papers.

IV. Closing and Next Meeting

Mr. Levin asked if there were any other questions. Hearing none, Mr. Levin thanked the group for an efficient meeting.

V. Next Steps

- Committee members to provide comments on draft SAMHSA letter.
- NYeC to conduct small group meeting on SAMHSA letter.
• NYeC/Manatt to revise SAMHSA comment letter.
• NYeC to conduct poll of white paper topic area priorities.