

New York eHealth Collaborative Policy Committee Meeting
February 17, 2016
10:00 a.m. – 12:00 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on February 17, 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, HealthLink
James Kirkwood, NYS DOH
Jonathan Karmel, NYS DOH
Victoria Choi, NYS DOH
Paul Schaeffer, New York City Department of Health and Mental Hygiene
Christine Julien, New York City Department of Health and Mental Hygiene
Dr. Glenn Martin, Queens Health Network
Tom Check, Healthix RHIO
Amy Warner, Rochester RHIO
Zeynep Sumer-King, GNYHA
Laura Alfredo, GNYHA
Susan Van Meter, HANYS
Cindy Sutliff, NYeC
Jeannette Rossoff, NYeC
Vinay Chopra, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 10:00 a.m. Mr. Levin welcomed the committee members and noted the calendar provided to committee members set out the meeting dates for the year.

I. NYS DOH Update

Mr. Levin introduced Mr. Kirkwood to discuss the SHIN-NY regulation. Mr. Kirkwood said that the regulation may appear in the state register on March 9. He noted that the final regulation says that the state “shall” establish a statewide collaboration process and policy guidance, compared to the previous version which used the word “may.”

Mr. Kirkwood said they had received questions regarding one-to-one exchanges, and that NYS DOH had decided to punt on answering those questions in favor of getting feedback from stakeholders. Mr. Karmel said questions about the breadth of the one-to-one exchange concept is a question for the Policy Committee going forward. Mr. Levin asked if the Policy Committee’s

role was to ask specific questions or look at the big picture. Mr. Kirkwood said it was the latter, and that they were valuing the Policy Committee's thinking on this higher level.

Ms. Alfredo asked how comments were being taken into account. Mr. Kirkwood said NYS DOH took into account all comments they received, but there were not huge changes, and that many of the responses to the comments involved cleanup. Mr. Kirkwood said they would summarize each comment in the state register and explain their response.

Mr. Allen asked if they could get a copy of the new version of the policies prior to March 9. Mr. Kirkwood said the guidance documents would be included in the state register as well, and they will be provided a little bit before March 9. Ms. Sutliff said those documents would be posted on the NYS DOH and NYeC websites.

II. 2016 SHIN-NY Policy Committee Framework

Mr. Levin reviewed the history of the NYeC Policy Committee, explaining that they had started to work on privacy issues in a vacuum. He said they were now moving to a value equation: what do we want out of this? Mr. Levin said they had worked from the bottom up, and now they should work from the top down.

Mr. Belfort said it was important to test policies to determine if they were working in the right way and to determine what is happening on the ground. Dr. Martin agreed that it was good to work on bigger picture items. Ms. Shatzkin said that second generation efforts are often better than the first generation, and that they are at the stage of looking at how implementation works.

Mr. Check said they are discovering over time new and more valuable ways for the data in the SHIN-NY to be used, with the DSRIP program an example of that. Dr. Mahoney said that the goals of these programs are often not in sync with privacy concerns, and Ms. Sutliff agreed they needed to strike a balance. Mr. Levin said it would be helpful if they could obtain a description of all of these new programs, since it would benefit the Committee to know what the horizon looks like. Ms. Sutliff noted that the HIT Transparency Workgroup had a rundown of IT programs; Mr. Kirkwood noted that it included some but not all care transformation programs. Mr. Belfort observed that there are also federal programs, such as Medicare ACOs, and commercial clinically integrated arrangements. Mr. Belfort said all of these programs aim to take a greater responsibility for care across the continuum, and all of them depend on data sharing, so the idea is that the SHIN-NY will be a utility to serve these programs so that providers do not need to invent new infrastructure for each new arrangement. Dr. Martin said it would be good to know how many lives the SHIN-NY has, and what is actually flowing. Ms. Sutliff said they could share that information.

Mr. Levin said they should put security back in the discussion, given the major breaches that have recently occurred. Ms. Shatzkin said she had a mixed reaction. She said security issues have become more threatening, and that this needs to be on the agenda, but on the other hand, security is a completely different world made up of people who have different knowledge and interest than the Committee, and that the Committee might not be the right place for such

discussions. Mr. Allen agreed, and said that some attention to security policies would be a good idea. Ms. Sutliff suggested that they bring in a group of subject matter experts, and perhaps they would be charged with drafting the first level of the security policies. Mr. Belfort said that hackers had grown very sophisticated and go far beyond what the typical HIPAA security professional is capable of dealing with, and that the SHIN-NY would become an attractive target for these hackers. Mr. Belfort said they needed to bring a small group of outside consultants, and the Committee also had a responsibility for determining where the responsibility for security lies, that is, whose job it is to ensure that someone has done a complete evaluation of vulnerabilities. Ms. Shatzkin agreed that it was important to identify the role of the Committee.

Mr. Check said it would be helpful to hear from NYS DOH about the set of topics that NYS DOH would like the Committee to focus on. He said that NYS DOH would like to publish security standards for QEs holding Medicaid claims data, and that this would likely become the de facto standard for security, in which case the Committee may not need to worry about setting a security standard.

Mr. Levin said another area for discussion for 2016 is the consent model. They would take a high level look at whether the consent model has helped or hindered the Committee's objectives.

Mr. Levin said a third topic area is the use of data and who controls access. Mr. Belfort said this came out of questions presented to the Committee in the past, in which case organizations questioned who can be users of the system. Ms. Julien asked about the New York City Department of Health and Mental Hygiene being able to access the SHIN-NY data for public health purposes. Mr. Belfort said it is well settled that public health agencies can access the SHIN-NY, but there are questions as to whether other governmental users should be able to access the SHIN-NY, such as whether the Medicaid inspector general should be able to go into the system. Ms. Shatzkin said there were not only use cases of what people wanted to accomplish, but also use cases of what people can do but should not do.

III. SAMHSA Proposed Rule

Mr. Levin introduced the subject of SAMHSA's recently issued proposed rule. Mr. Belfort explained that a couple of years ago, SAMHSA began soliciting input on modernizing the Part 2 rules. Mr. Belfort said that some were hoping for a fundamental reconfiguration of the rules, but the proposal issued shows they were just nibbling around the edges. He said that for the purposes of the SHIN-NY, the most significant changes relate to the rules regarding the consent form.

Mr. Dworkowitz outlined three proposed changes to the consent form. He said that the proposed change to the recipient of information arguably would make it easier for QEs to share Part 2 information, but the proposals regarding identifying the information source and the "amount and kind" of information to be disclosed would likely make information sharing more difficult. In regards to other changes, Mr. Belfort said there is already a general consensus that the consent form can include electronic signatures, the change regarding medical practices is consistent with informal guidance issued in the past, and the proposed change regarding redisclosure is also consistent with his previous understanding of how the rule has worked.

Mr. Allen said he was floored by the proposal to require a list of the names of information sources on the consent form, and that SAMHSA is creating the same sort of problem all over again. Mr. Belfort said SAMHSA expressed in the preamble that they are concerned that the whole thing would become too general, but if they wanted to be more privacy protective, they should have kept the form the way it is. Ms. Alfredo said the proposed rule is taking away with one hand and giving with the other, and that they needed to submit robust comments to SAMHSA, since SAMHSA might not be aware of what the net effect of the proposal is.

Mr. Belfort said that if you are die hard traditionalist, the proposal just made life more complicated, since now even a single provider consent form needs to have a long list. Mr. Check said the proposal is really based on a consent-to-disclose model, but this would be really onerous in a consent-to-access model like the SHIN-NY. Mr. Belfort said that in their comments, they should explain why the consent-to-access model has a lot of benefits. Ms. Sutliff said they would draft comments to SAMHSA. Mr. Belfort said they would welcome feedback on drafting the comments.

Mr. Levin asked if there are any other states with health information exchanges that play by the same rules. Mr. Check said he was pretty sure Florida also had a consent-to-access model. Dr. Martin said they would have allies in the substance abuse world, and these are people that SAMHSA would want to hear from. Mr. Check said there are other provider groups and behavioral health agencies that they might want to reach out to.

IV. Closing and Next Meeting

Ms. Sutliff said they had wanted to do a face-to-face meeting, but they are not yet at the point where a full process has been established in order to hold such a meeting. She said they would honor the dates on the calendar. Mr. Levin thanked the group for a productive meeting.

V. Next Steps

- NYeC/Manatt to draft SAMHSA comment letter.
- NYeC/Manatt to 2016 work plan.