New York eHealth Collaborative Policy Committee Meeting
December 8, 2015
10:00 a.m. – 1:30 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on December 8, 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
Steve Allen, HealtheLink
James Kirkwood, NYS DOH
Jonathan Karmel, NYS DOH
Geraldine Johnson, NYS DOH
Paul Schaeffer, New York City Department of Health and Mental Hygiene
Dr. David Cohen, Maimonides Medical Center
Dr. Amanda Parsons, Montefiore
Dr. John-Paul Mead, Cayuga Medical Associates, P.C.
Dr. Glenn Martin, Queens Health Network
Dan Tietz, AIDS Institute
Tom Check, Healthix RHIO
Colleen Mooney, NYSTEC
Zeynep Sumer-King, GNYHA
Cindy Sutliff, NYeC
David Whitlinger, NYeC
Alie Cohen, NYeC
Vinay Chopra, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt
Jeannette Rossoff, NYeC
Susan Van Meter, HANYS
Victoria Choi, NYS DOH
Amy Warner, Rochester RHIO
Hershel Wolf, Parameds

The meeting was called to order by Mr. Levin at 10:00 a.m. Mr. Levin welcomed the committee members and walked the committee through the distributed materials.

I. NYS DOH Update

Mr. Levin introduced Mr. Kirkwood to discuss the draft SHIN-NY regulation. Mr. Kirkwood said the update to the regulations was being presented to the Codes Committee and the Public Health Planning Council on Thursday. He noted the comment period ends on December 21, and that they have not received any formal comments yet.

Mr. Kirkwood said that NYS DOH has proposed changes to Section 1.2.2 of the Policies in regards to the rights of public health agencies to access the SHIN-NY. Dr. Martin asked if there was anything that public health agencies would not have access to. Mr. Karmel replied that the purpose was to be as comprehensive as possible in order to state all possible ways public health agencies might want to use the information. Dr. Martin suggested that the section be changed to simply say that public health agencies can access the SHIN-NY for any purposes allowed by law. Mr. Levin replied that committee members had wanted specificity.

Mr. Check noted that paragraph (b) said that public health agencies can access information through the QE's clinical viewer or portal, but that there are other ways to access information through a QE. Mr. Levin said this raises the question as to whether the provision should be so specific.

Dr. Martin said the specificity allowed for tight auditing, but that might change if the public health agencies were given a data dump. Mr. Whitlinger suggested they instead refer to other mechanisms that might satisfy a need for an audit. Ms. Shatzkin said they should make sure this section is consistent with the audit section.

Mr. Allen asked what paragraph (a) allows that paragraph (b) does not. Mr. Levin said (a) provided a narrative context, and (b) provided the details. Mr. Allen noted that paragraph (c) only applied to paragraph (b) and is silent on whether it applies to paragraph (a). Ms. Sutliff said they would go back and make sure the section is structured correctly.

Dr. Martin asked if they were certain that patients never had a right to opt-out of access for public health purposes. Mr. Karmel said he was unaware of any law or regulation that gives patients the right to opt out. Dr. Martin said he would feel more comfortable if there was a comment at the end of paragraph (c) that indicated that a patient had a right to say no if authorized by law. Ms. Sutliff said this would be changed.

II. Comments on the SHIN-NY Regulation

Mr. Belfort discussed NYeC's comments to the proposed SHIN-NY regulation. He said the comments are not new. The first addresses the role of the state designated entity, in that the later version of the regulation is less expansive about the role of the state designated entity than the earlier version. The second addresses the notice requirement under the community-wide consent provision and the concern that it would be burdensome and not helpful to patients if they received a constant update of the list of participants.

Mr. Tietz observed that the comment refers to a reasonable time period for updates being monthly or quarterly. Ms. Shatzkin said it could be as frequently as new participants are approved by a QE's board. Mr. Check said the regulations should have a different role than operational guidance, and the idea is that the regulations should be fairly flexible.

Mr. Karmel said they are trying not to change the text of the regulation so they can finalize it, and said that instead there could be a well drafted response to the comment that satisfies what the commentor is looking for. Mr. Belfort said they were concerned not so much with NYS DOH enforcement but more that the present language could make some QEs think they would be violating the law if they did not affirmatively send written notice, so it would be important to have clarification on the record. Mr. Karmel said that NYeC could suggest a response to its comment that would address this issue.

Mr. Belfort noted that there is a reference in the letter that should be to the regulation and not the Policies, and this reference would be changed.

III. SAMHSA Strategy

Ms. Sutliff explained that cross QE exchange was causing problems in regards to Part 2 data, and the federal Part 2 regulations are becoming a huge barrier. This has been an issue in the exchange between the Hixny and Buffalo QEs. Based on a discussion arising out of the issue between Hixny and Buffalo, the participants decided that the best strategy may be to contact SAMHSA and attempt to influence SAMHSA's interpretation of the regulations.

Ms. Sutliff noted that there have recently been changes at SAMHSA: the head of the agency has resigned and there have been other staff changes. SAMHSA has proposed changes to the Part 2 rules, and there is a provision in the draft regulation related to HIEs, although the substance of the change is not known. Ms. Sutliff said that they have decided to wait until January to see if the new regulation is released, but if it is not released in January they would attempt to meet with SAMHSA to affect change.

Mr. Levin asked if SAMHSA had a history of running pilots projects. Ms. Sutliff said there is such a history.

Mr. Check said he loved the idea of approaching SAMHSA now instead of waiting. He said that there are three different issues that should not be conflated: (1) the logistical burden of having to provide a consent form that includes a list of hundreds of providers; (2) the need to provide a new consent form every time a new participant joins a QE; and (3) the difficulty of responding to a request from another QE involving Part 2 data. Ms. Shatzkin said that this is not a problem for a QE that uses a participant-only consent, but there is a reason to be concerned under a community-wide consent model. Mr. Karmel said that there is a fourth issue that is similar to the third issue: exchange of information between states. Mr. Karmel noted that Vermont is seeking to access information from Hixny, and they want a system that works for other states. He added there are bills in Congress to address this issue: HR 2646 would solve the problem, and S1945 would help but would still require an annual consent. Ms. Shatzkin said that the proposals they are considering address only the local problem, and it would not resolve the issue of exchange with other states that use an opt-out process for consent.

Mr. Dworkowitz noted that the substance abuse statute requires consent, but it does not have any specifics on the form of consent, so that SAMHSA does have the flexibility to adopt more lenient rules. Mr. Karmel said that HR 2646 is the bill sponsored by Congressman Murphy. Dr.

Martin said that Democrats are opposed to certain provisions in the bill, and it has become increasingly politicized and tough to move.

Mr. Levin said that he had not heard any reason as to why the Policy Committee should not pursue contact with SAMHSA.

IV. Patient Portal

Ms. Sutliff introduced Ms. Cohen to discuss the patient portal. Ms. Cohen said that two issues have come up in regards to the patient portal, and for both issues there is the question as to whether there should be a statewide policy governing the issue. The first issue is data availability, whether there are specific things that a patient should not be able to access. The second issue is whether there needs to be delay in when information is available via the portal. CLIA requires laboratories to make information available within 30 days of when the result is issued, and Stage 2 of the meaningful use rules requiring information to be available within 36 or 48 hours depending on whether it is an eligible professional or eligible hospital.

Ms. Sumer-King said there had been a lot of discussion at the provider level about this issue. She noted that hospitals will hold genetic testing and HIV results until they have had a conversation with the patient.

Dr. Cohen said whatever they decide to do should be comprehensive statewide, and a minimum standard is appropriate. He said there is a lot of literature about how to break bad news to patients, and this shouldn't be done over the internet, which is why most clinicians want a reasonable delay in uploading the information in order to give time to discuss the result.

Dr. Mead observed that not all doctors are trying to achieve meaningful use. He suggested that there could be one version for meaningful users that would require the information to be uploaded within 36 hours, and another version for others that would give a longer time period such as 5 days, since a reasonable doctor would want more time than 36 hours.

Ms. Cohen said the state portal would not allow this to be done at the provider level, and if a provider wants their own version, that would be a delay in records coming to them, not a delay in records being sent out.

Dr. Martin said the worst thing that could happen is if a patient gets to see the laboratory results before the patient's doctor sees them. Radiology reports are also a problem because the doctor needs to be given an opportunity to explain what they mean. In addition, doctors need to review their notes before they are provided to their patients: sometimes those notes may indicate that a mother called the police on her son the patient, and you don't want the patient finding that out.

Mr. Tietz said in the context of the HIV population, there is a need to know the current medication list and lab values, and the issue of delay is important. He said he was torn on the issue of total transparency and whether people are going to understand the results.

Ms. Sumer-King explained that in the case of hospitals, there is a summary of care document that includes lab results. Under the current workflow, there is a determination of when that document can be added to the portal—it is a provider controlled delay.

Mr. Martin said in the case of those diagnosed with HIV, he was concerned about a delay. Some people do not see doctors frequently, and there is the possibility of someone having unprotected sex before they get their results. Dr. Mead said that if he had a potentially bad HIV result, he would schedule an appointment with the patient as soon as possible.

Mr. Whitlinger said they cannot be the first group to address this question, and there must be some guidance from the medical societies on this issue. Dr. Cohen said there is not much guidance on specific timeframes, but it should be pretty immediate, which is where the meaningful use standard comes from. Mr. Whitlinger asked if there had been lawsuits. Dr. Mahoney said there are a lot more lawsuits about failing to provide results, not about providing results too soon.

Ms. Sumer-King said it would be helpful to better understand how this information is being uploaded, since if it is being uploaded as part of a summary of care document there may already be a delay built in. Ms. Shatzkin said most QEs get the majority of their data, including lab results, from direct feeds, not summary of care documents. Ms. Shatzkin added that she agreed with the notion of sharing data so that patients can be engaged in their treatment, but that it is not their role to be way ahead of the provider community and they needed to be in touch with their constituency.

Mr. Whitlinger suggested that they look a public comments on the meaningful use regulation to get a better sense of the issue.

Ms. Sutliff said she would convene a tiger team to address the patient portal issue.

V. Minor Consent Update

Ms. Shatzkin described the history of their work on the minor consent issue. Two subcommittees had been formed to work on the Let-the-Data-Flow (LDF) and Rochester models, which resulted in a template that describes how each model works. It was a tough process that came to a positive conclusion. Both approaches were well vetted by a large group of people.

Ms. Shatzkin said that the Business and Operations Committee (BOC) had a very particular agenda: they wanted to know if both models could be used in a statewide exchange. In answering that question, they identified a problem with the Rochester model in regards to statewide exchange. Rochester is solving that problem, and as a result others are now aware of that problem and will avoid falling into that trap.

Dr. Martin asked if these two models are the only models allowed. Mr. Kirkwood said it was restricted more by practically. Ms. Shatzkin said it goes back to the certification process: the certification teams need to have an understanding as to what it means to implement these models.

Ms. Sutliff said these two interim models have been approved as they work toward a technical solution. Dr. Martin said it sounded like the state had blessed these models, but a QE was free to try something else. Mr. Levin said they could try a different model, but they would have to raise their hand to go through the process.

Mr. Whitlinger asked if the draft regulation addressed these models. Ms. Sutliff replied that the regulation is silent on these models but requires that minor health information be shared via the SHIN-NY.

Mr. Tietz said that the governor's task force had proposed changes to minor consent for HIV information, and he asked whether the regulatory change addresses this. Ms. Sutliff asked if he knew the specific change that was recommended, and Mr. Tietz said he did not.

Ms. Shatzkin said that with the exception of Part 2, the laws in New York are not at all clear as to how minor consent information may be shared with other clinicians. The laws, however, are explicit about keeping this information away from the minor's parent, which is the operating concern of the LDF model.

VI. Life Insurance Proposal

During a lunch break, Mr. Levin explained that they had received a proposal from Parameds and Hixny regarding a life insurance pilot. Mr. Levin walked the Committee through various documents related to the proposal and introduced Hershel Wolf, CIO of Parameds, to address the proposal.

Mr. Wolf provided background on Parameds. The organization provides medical records retrieval for insurers; they primarily work with life insurers but they also work for disability and long-term care insurers. It is their job to retrieve medical records from providers, and it is currently done in a paper-based system through telephone calls and faxes. It is not the top priority of providers to respond to their requests, so they often make repeated inquiries. Parameds is the fastest in the industry, but turnaround time is generally measured in weeks.

Mr. Wolf explained that Parameds' strategy is to make the current retrieval process more effective and efficient by connecting to data aggregators instead of connecting to individual providers. Their goal is to retrieve all information that is not protected by statute. Parameds does not store data. For example, if a patient is denied a policy and applies to another insurer, Parameds has to contact the medical providers again and ask for the medical information previously provided. Parameds follows HIPAA security requirements: they only transmit encrypted data and the data is encrypted at rest.

Mr. Wolf said that the proposal is to demonstrate the effectiveness of the retrieval process through the SHIN-NY and achieve decreased turnaround time. The proposal should not be a huge burden on providers or RHIOs—it will be a win-win in terms of cost and burden. Parameds wants to make sure the proposal works for them in that the data is rich and full and sufficient for life insurance underwriters. If the proposal works, there will be a revenue stream

for the RHIOs and New York State. Applicants will benefit from lower turnaround times, and this will reduce administrative burdens on provider practices.

Mr. Whitlinger said the Policy Committee's role is to focus on whether to consent to Parameds access, and that the evaluation of the usefulness of this if for the BOC.

Mr. Wolf said they hoped to have a system of patient-centered requests, rather than provider-specific requests. Mr. Wolf said that Mark McKinney of Hixny had indicated that Hixny had other projects going on and was not ready to start the proposal tomorrow, but that he is committed to the proposal.

Ms. Sumer-King asked what portion of medical records is provided to Parameds. Mr. Wolf responded that Parameds gets everything, including progress notes, and they are not restricted by the minimum necessary standard.

Ms. Sutliff said the issue on the table was whether there should be a Level 2 consent to allow Parameds access to the SHIN-NY. Mr. Wolf said that other states have modified their participation agreements and data use agreements to give companies like Parameds access to information for non-treatment purposes.

Dr. Mead said that the data that Parameds would receive from Hixny would not be as rich as they want—they would got a lot of threads and they would need to obtain more consents to obtain more information.

Mr. Whitlinger said these expanded uses will make the SHIN-NY better over time. Ms. Sumer-King said they should pursue their primary goal first and there is a risk of becoming too diffuse and scattered. Mr. Levin said there should be a time limit on the pilot.

Dr. Martin said they needed to make sure users were comfortable with the sharing of their data. Dr. Martin said that he has never given all his records in response to a life insurance request; he only gives a summary. He said that he also never responds to a request without confirming with the patient that the patient knew what they were signing. Mr. Wolf said if there is a specific class of data that they are not entitled to, they do not want to receive that data—they only want to access the same information that they have access to today. Dr. Martin responded that under the proposed model there is no way for providers to know that their patients' information is being accessed by Parameds.

Dr. Mead said that in his office, if there is HIV or mental health information in the record, they will flag that information in the record and review the consent form to make sure the life insurer is entitled to access that information. But in the SHIN-NY, there is no data segmentation, which is the whole problem. Ms. Shatzkin agreed, saying that sensitive information is not automatically flagged as sensitive. She said that some providers stay off the grid, but those that give data tend to give all the data.

Dr. Mahoney said they need to make sure this works before they have a policy, and they need a way to make sure this is more efficient. Dr. Mahoney said he is worried that a lot of nuance will

be missed if information is gotten through the health exchange. He said that his disability was held up because someone saw an MRI result but never saw the rotator cuff repair that went well, and that he wanted to be sure that they were not creating more work. Mr. Wolf said that the idea is that the burden would be removed entirely from the provider.

Mr. Whitlinger said that in the practical world, physicians do their own filtering and don't provide all information. The challenge is that not all information can be filtered under the current process. Mr. Levin said they need to be comfortable with having a pilot. Ms. Sumer-King said they need some assurance that Hixny would be aware that providers understand that this is happening. Mr. Wolf said it was intended that there be a human being on the Hixny side, and that it might be possible for Hixny to review the information being sent. Ms. Sumer-King said the pilot should be limited to data from Hixny and not other RHIOs.

Mr. Martin said he was concerned about whether the life insurers were being given access to more than enough information—whether they would be able to see things they should not be able to see. Mr. Wolf said that what is delivered electronically now is much weaker than what is supplied by paper, and that they are only looking to access what can be accessed by paper. Dr. Cohen questioned whether they would need IRB approval given that the pilot involved human subjects. Dr. Martin asked if it made sense to have a limited pilot with de-identified data in order to get some sense of the risks involved.

Mr. Whitlinger observed that providers may say that they will not join a QE because they know that insurers might review the information they provide. Mr. Wolf responded that providers already have to deliver the information if they receive a request. Mr. Whitlinger said that is true, but under the current system providers can manage the process. Mr. Wolf said that in working with two states, their biggest problem is not having too much data but insufficient data. Mr. Levin asked: if Parameds has to go back to providers to get more information 90 percent of the time, why is it worth it to pursue information from the SHIN-NY? Mr. Wolf said that over time the data will get more complete.

Mr. Whitlinger asked why Hixny was not participating in the presentation of the pilot, since their members might be upset about the proposal. Ms. Shatzkin said they had to flesh out the evaluation criteria, since it does not include a number of issues.

VII. 2016 Policy Agenda

Mr. Levin asked the group for comments on the proposed policy agenda for 2016. Ms. Shatzkin said they need to address audits on analytics. Ms. Shatzkin said in working with DSRIP partners they can run a query that totals a million patients, and she questioned whether the audit requirement is the same, i.e., whether the QE is required to tell a patient about which query they are returned in. Dr. Martin said this is a very good idea. He said there is a growing trend of providers joining multiple QEs and this could lead to the exact same visit being reported to multiple QEs. Mr. Whitlinger said there are a lot of reasons why there will be duplicative data, and redundancy of data is a problem but not a policy problem.

Mr. Allen said that within the subject of security requirements, they need to look at the concept of certified applications and develop more specificity.

Ms. Sutliff said that as they reconvene they can build out this list for the next cycle.

VIII. Closing and Next Meeting

Ms. Sutliff thanked the committee for all of its work during the year's cycle. Mr. Levin wished everyone a great holiday and closed the meeting.

IX. Next Steps

- Manatt to draft suggested changes to Section 1.2.2 of the Policies.
- Manatt to revise SHIN-NY regulation comment letter.
- NYeC to reach out to SAMHSA if new Part 2 regulations are not issued by the end of January.
- Tiger team to address patient portal policy questions.

203314898.1