New York eHealth Collaborative Policy Committee Meeting
June 9, 2015
10:00 a.m. – 3:00 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on June 9, 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
Dr. Glenn Martin, Queens Health Network
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.
Dan Tietz, AIDS Institute
Amanda Parsons, Montefiore
Geraldine Johnson, NYS DOH PH Informatics
Gus Birkhead, MD, NYS DOH Office of Public Health
Paul Schaeffer, New York City Department of Health and Mental Hygiene
Linda Adamson, New York City Department of Health and Mental Hygiene
Ted Kremer, Rochester RHIO
Tom Check, Healthix RHIO
John Rodat, Public Signals, LLC
Corinne Carey, NYCLU
Christie Allen, NYS DOH
Cindy Sutliff, NYeC
Vinay Chopra, NYeC
Carianne Borut, NYeC
Inez Sieben, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 10:00 a.m.

I. Welcome

Mr. Levin welcomed everyone to the meeting and introduced Mr. Kirkwood from the New York State Department of Health ("NYS DOH") to discuss the draft SHIN-NY regulation and changes to related documents.

II. NYS DOH Update

Mr. Kirkwood said that NYS DOH was making "tweaks" to the draft regulations. NYS DOH was not expanding the scope of the provision allowing medical facilities to obtain a waiver from the requirement to connect to the SHIN-NY due to technical or economic infeasibility. Mr. Kirkwood said that if a particular facility had concerns about connecting to the SHIN-NY due to the especially sensitive nature of the data it maintained, that facility could request a waiver on the ground that it lacked the technical capacity to properly segregate its sensitive data from other data.

Mr. Kirkwood said the department's goal was to publish the draft regulations in the August 6 state register. After it is published , there is a 45-day period for public comments as per SAPA. Mr. Levin noted that if there were sufficient comments leading to changes by DOH, the regulation would then likely go out for an additional 30-day comment period. Mr. Kirkwood agreed that this was a possibility, but he said NYS DOH's goal in consulting with stakeholders prior to publication was to avoid if possible substantial revisions to the draft that would necessitate the additional public comment opportunity, which could lead to a delay of a couple of months.

Mr. Kirkwood said that draft guidance relating to dial tone services and other issues will not be published in the state register. Instead, that guidance will be emailed to stakeholders and will be subject to an informal comment process.

III. Community Wide Consent Notice Requirements

Mr. Belfort introduced the issue of the required notice to patients related to community-wide consent. Mr. Belfort said that the draft SHIN-NY regulations allow for patients to agree to a community-wide consent but require patients to be notified whenever a new Participant joints a Qualified Entity ("QE"). Mr. Belfort noted that the regulations did not provide any detail on what that notice should look like, and he asked whether the Policy Committee should provide recommendations to NYS DOH on the form of notice. Mr. Kirkwood said that NYS DOH would find such a recommendation helpful.

Ms. Shatzkin said it was an issue of what the Policy Committee was trying to accomplish. If they viewed getting a patient's signature one time as the goal, then a notice is not important, but if they view the notice as a way to educate patients, it is extremely important. Mr. Check said they needed to think about what patients would consider a "fair" disclosure.

Dr. Martin said patients generally don't understand what they are signing. He said that the process needs to reflect the fact that some people read what is given them and many others do not, and that the consent needs to be informed. Mr. Belfort said that the Committee faced a more narrow question about the required *form* of any notification, rather than the integrity of informed consent in general.

Dr. Mahoney asked whether patients were given the option to consent to allow access to only one Participant under a community-wide consent model. Mr. Allen said that HealtheLink has implemented a community-wide consent giving patients such a choice, and that patients do not have to agree to allow their information to be shared with all Participants but instead could be

selective. Mr. Allen said that it was not always clear from the consent form what the patient wanted, so that sometimes the QE must engage the patient to better understand what that patient wanted.

David P Martin observed that, due to the limited time available for patient education and/or the lack of adequate training of staff distributing the consent form, patients often were not that well informed about the purpose and scope of the form. He said also that patients who are in a crisis mode usually don't stop to think about the implications of signing the form. Dr. Mead said his office does a pretty good job at training the front desk staff to explaining the consent process to patients, although it is not perfect.

Mr. Belfort suggested that since some people may feel that a community-wide consent is inherently risky, a possible approach is to modify the draft regulations to require providers to give patients the option of choosing between a community-wide consent or simply granting consent to a limited number of providers. Mr. Check said he did not think the regulations need to specify this, since QEs are likely to do it anyway given the likely discomfort that some patients may feel with community-wide consent.

Mr. Tietz said he was curious to know, perhaps through surveys, whether people understand the consent process. Dr. Martin cited an informal study showing that people don't read forms and unknowingly agreed to sign away their first born child in exchange for free Wi-fi. Mr. Allen noted that while his RHIO's consent forms were originally at a sixth grade reading level, but that after lawyers reviewed and edited the forms, they were now at grade 14.

Ms. Shatzkin said there are two different reasons why PPS's, health homes and individual providers are pushing for community-wide consent. One is that providers view collecting consent as an administrative burden. The other is a question of timing—they want information to develop a plan for treating a patient before they are able to interact with the patient and obtain consent. Ms. Shatzkin said she was not sympathetic to the first issue, but she was more sensitive to the timing issue.

Mr. Rodat said that if too many patients get caught by surprise thinking that they didn't sign up for a community-wide consent, but in fact did there is a risk of a system backlash. Mr. Belfort said he nevertheless had concerns about abuses of community-wide consent, and that people will break the law and snoop. To address those concerns, Mr. Belfort suggested that patients be given a choice—they must have an option to choose between a single consent and a community-wide consent. Ms. Sutliff said she agreed with Mr. Belfort's suggestion, and others said they agreed with it in principle.

Ms. Adamson said that conversation was focusing on how to get informed consent at the front end, but maybe they should instead focus on the back end; that is, let patients know who accessed their data. Mr. Levin agreed that this is an important issue to patients.

Mr. Levin finally noted that the committee had not reached agreement on the type of notice that should be sent to patients regarding new participants in a QE, and that they might need to get a smaller group together to discuss the issue. Mr. Levin said that however, there appeared to be

agreement on the principle that patients should be given a choice between a single provider consent and a community-wide consent.

IV. Patient Accounting

Mr. Belfort explained that the SHIN-NY Policies currently require QEs to provide patients with an accounting of authorized users who accessed the patients' data. Mr. Belfort said that this requirement goes beyond what HIPAA requires.

Mr. Levin asked how often QEs get this type of request, and representatives of QEs in the room responded that there were very few requests, with some getting none at all. Mr. Levin asked how then this could be a burden to QEs if they were getting so few requests. Mr. Allen said it was not a burden to QEs, but they were concerned about it conceptually. Mr. Allen said that since hospital personnel typically accessed a patient's information through the hospital's own system it is not that helpful to patients to get an accounting of access through the QE. Ms. Shatzkin questioned why the Policies were setting the bar higher than what the law requires when it is not necessarily helpful to patients. Mr. Allen added that the fact that the number of patient accounting requests is low now does not mean it will continue to be so in the future.

Ms. Pawelko said she was torn on the issue. She said she could understand why patients might want this information, but in the Planned Parenthood world providers do not like to release the names of their staff. Dr. Martin said the Committee was being more protective of provider confidentiality than patient confidentiality, and that Planned Parenthood and similar providers could ask for the exception from the patient accounting requirement. Mr. Belfort said he did not understand the argument for provider confidentiality, since by law providers need to wear name tags identifying themselves.

David P Martin asked what recourse a patient has if the patient finds out there has been a breach of confidentiality. Mr. Belfort said the patient could file a complaint with the provider, and through this indirect and burdensome path the patient could find out the name of the individual who accessed the record. But there is no direct right to access those records from a provider.

Mr. Tietz said that one premise behind the SHIN-NY is that electronic records are more secure than paper-based records—there is an authentication process to access electronic records so there is a record of who accessed them. Mr. Tietz asked why not set the bar higher than HIPAA. Ms. Adamson said they were trying to make this a more informed process, acknowledging that patients are not as informed as they should be at the start.

Ms. Shatzkin observed that somebody is going to have to respond to queries from patients about who accessed their records. She said hopefully this would not be the QEs, unless they are funded for it.

Ms. Carey said that there are very few patient accounting requests, and that generally they occur because a patient is suspicious of wrongdoing.

Mr. Levin said that there was no consensus on this issue, and suggested that next step should be development of a white paper that analyzes the pros and cons of the various approaches.

V. Family Members Genetic Information

Mr. Belfort said that in some cases, providers have an interest in learning about the medical history of their patients' family members in order to better understand their patients' genetics. Mr. Belfort said that a Level 1 consent form would not be appropriate because such a form is designed to allow a patient to access their own information for treatment. However, a Level 2 form might be appropriate and a Level 2 form could be drafted.

Ms. Sutliff suggested that a Level 2 consent form should be drafted for this purpose. Dr. Martin said that specific language related to genetic information would need to be in the consent in order to satisfy New York law, and that it would be a service to come up with such a form.

VI. Implementation Sub-Committee Update

Ms. Shatzkin explained that the Implementation Sub-Committee has been working on developing clear guidance to the QEs on redisclosure warnings, and she presented draft guidance on those warnings. Ms. Shatzkin said under a SAMHSA requirement, redisclosure warnings cannot appear at the log in page, but instead must appear after the particular patient has been selected. In contrast, warnings related to HIV and mental health information that are required by New York law can be given at the log in page.

Ms. Shatzkin said that the Implementation Sub-Committee was also working on guidance related to the Master Patient Index ("MPI"). Each QE has its own patient index, and the MPI is an index of indexes that is designed to link records from different QEs to one patient. Ms. Shatzkin said that the MPI workgroup has gone through a lot of material and has had three meetings in the last three weeks. She said the workgroup is looking to ensure that there is a high level of confidence in the matching algorithm that is being implemented at the statewide level.

Ms. Carey said the demographic information in the MPI could be a problem for domestic violence victims and others who want to keep their whereabouts confidential. Mr. Check said that this information is not disclosed until it is established that the user has the patient's consent to view the data. Ms. Shatzkin said that this gets addressed at the treatment location, and that patients can provide a fake address to protect their confidentiality.

Ms. Shatzkin said the patient matching algorithm was being developed by consultants who are experts. It is designed to identify potential mismatches, such as the fact that "Jim" can be the nickname for "James." Mr. Check said that the initial algorithm had been developed by Healthix, which used Audacious Inquiry as consultants. Mr. Check said the consensus is that it is better to not match records of the same patient than to accidentally provide to one patient the medical record of another patient. Ms. Shatzkin said that there was some discussion related to the use of Social Security Numbers by QEs in their local patient index and based on discussion outcomes they may be dropped from the matching algorithm as well.

Mr. Tietz asked whether the consent form granted consent to a QE to QE exchange. Ms. Shatzkin said that the patient is giving a participant consent to access, and that the consent covers all available data.

Ms. Carey noted the warnings related to HIV and mental health information did not describe the New York law that participants must follow. Ms. Shatzkin said that it had been hard to get clarity on what that language should say, but that she is open to recommendations. Ms. Carey said she would provide some suggestions.

Mr. Allen observed that if QEs choose to do the more limited implementation and include the redisclosure warnings with the data, it would raise other challenges.

VII. Patient Portal Presentation and Discussion

After a lunch break during which Dr. Mead gave a presentation about his experience treating patients with Ebola in West Africa, Ms. Sutliff introduced Ms. Borut to provide a presentation on the patient portal.

Ms. Borut said that they had just wrapped up a proof of concept with HealtheLink that gave them access to the portal. They were currently working on issues related to identity proofing. The next step would be a pilot for HealtheLink, with the goal of full functionality for the pilot in the fourth quarter.

Ms. Borut walked the Committee through the portal, demonstrating the log in process, the dashboard, and patient data. Ms. Borut said that the data on lab results did not show whether the results are in the normal range because the portal does not give medical advice. Dr. Martin said that patients are unlikely to understand the lab results. Dr. Mahoney and Dr. Mead noted that Medicaid and Medicare patients often fill out assessments and questionnaires, and that this would be useful information to include on the portal.

VIII. Life Insurance Intermediary Groups

Mr. Levin explained that there was a proposal for a pilot program under which a life insurance intermediary group would have access to the SHIN-NY. Ms. Sutliff said that Hixny made a proposal with Parameds, the life insurance intermediary, to allow Parameds the opportunity to access the SHIN-NY to verify an individual's eligibility to obtain life insurance. She explained that typically, a patient would have to request medical records from his or her providers, and those medical records would then be sent to the life insurer. This proposal would allow the intermediary to access records within a QE to determine insurance eligibility.

Dr. Mahoney said that the information in a QE may not be of high enough quality to be of value to insurers, so this could result in more work. He said that an independent party should do an evaluation of the effectiveness of the pilot, rather than letting an interested party evaluate it. Dr. Mahoney said there are some possible advantages, such as decreased workload for physician offices, but he did not see anything in the proposal as to whether physicians would have a lower workload. Dr. Mahoney recommended that the impact on workload be part of the evaluation.

Ms. Shatzkin said that this proposal could dramatically change the life insurance business. Mr. Belfort said the difference is not what information is being received from an individual provider, but what information providers actually provide. Currently, life insurers only have access to information from the providers that applicants include on their forms, but under the proposal life insurers would be able to access information from all providers that a patient sees. Mr. Belfort said that this could be scary for some patients, but others might say that this is part of the process of applying for life insurance.

Dr. Martin said it would be curious to see if underwriting would change as a result. He said that insurers may believe the data is accurate, and that people may be turned down. Mr. Levin said that the data can be highly prejudicial falsely to an applicant.

Dr. Mead said that patients may be concerned that if they fail to disclose everything, they might be removed from coverage. Mr. Belfort said that typically, a life insurer can only take away coverage based on fraud, so that if an applicant forgets to include a doctor it is usually less of a problem. Mr. Belfort said that if the Committee ultimately permits this, it could become the standard for insurers and applicants may be unable to get life insurance unless they consent to allowing access.

Mr. Rodat said an independent evaluation of the pilot is missing from the proposal as written. He suggested that NYS DOH talk to their counterparts at the Department of Financial Services about the proposal to see if they have any comments. Mr. Rodat said the proposal was not just relevant to life insurance: there are private long-term care policies that are also individually underwritten. Mr. Kirkwood agreed to raise the issue with the Department of Financial Services.

Ms. Sutliff said that this proposal could potentially be a source of income for the QEs. A suggestion was made that the pilot should not be operationalized until patients are able to access their data through the patient portal. Ms. Sutliff and others agreed.

Mr. Kremer said there might be value in initiating the pilot, since it would help answer questions such as whether this might lead to revenue for QEs and time savings for physicians. Mr. Levin said there were two different types of questions that need to be answered. One type are the questions that should be addressed by the pilot. But the other questions relate to whether the pilot should proceed or not. Mr. Rodat suggested that they needed to document what needs to be done to start the pilot, and what needs to come out of that pilot. Mr. Levin agreed, and Mr. Rodat volunteered to develop a document on those points.

IX. NYS DOH Changes to Policies

Mr. Belfort explained that NYS DOH had drafted revisions to the Policies. He said that in terms of the privacy rules themselves, there were few changes of significance. Mr. Belfort said that the biggest change was giving NYS DOH direct control over the Policies instead of NYeC.

Mr. Kirkwood said that there was one substantive change related to one-to-one exchanges. That new provision states a health plan accessing clinical information for quality improvement or care

management activities may constitute a one-to-one exchange. Mr. Belfort said that this could be a great efficiency for health plans, but he questioned whether this falls within the definition of a one-to-one exchange since the patient does not expect that his or her information is being used for quality improvement activities. Mr. Belfort also questioned why plans were being singled out as not needing consent for this purpose, since arguably Performing Provider Systems ("PPSs") are performing similar activities and have to get consent.

Mr. Allen said that his QE is using a one-to-one exchange in implementing HEDIS reporting. Mr. Allen said this felt like a one-to-one exchange since a package of information is being sent to a particular payor. Ms. Shatzkin agreed that this was consistent with current policy.

Mr. Allen said the notion is that a payor would not be issuing queries to the exchange. Instead, one provider would be choosing to share the data with a particular health plan. Mr. Kirkwood agreed that this rule would not allow queries to the exchanges.

Mr. Levin asked who has the responsibility for informing patients that this is occurring. Mr. Belfort noted that the Medicaid enrollment form requires beneficiaries to consent to plan access to their data for quality improvement purposes, and this was done because plans were having trouble accessing that data without such consent. Mr. Belfort said that under this model, the provider was disclosing information to a plan without patient consent, and providers need assurances that doing so complies with Section 27F and other aspects of New York law.

Ms. Sutliff said that the Committee should develop comments on the NYS DOH revisions.

X. Other Policy Issues

Mr. Levin noted that the Committee's earlier discussion had focused on what informed consent really means and what people understand that they are signing. Ms. Sutliff said that a patient education program has never been put in place, and that there ought to be such a program. Mr. Levin said many problems could be solved with more out-of-the-box and innovative thinking, and that in some ways they were still thinking about a paper-based model. Mr. Kremer agreed that it was important not to forget that the broader landscape was changing so dramatically.

Ms. Shatzkin said that the Committee needs to create an environment where QEs can figure out what participants in the Delivery System Reform Incentive Payment ("DSRIP") Program really need, and that it was important to foster discussions about this. Mr. Kirkwood said that in some ways, the PPSs do not know what they need, and that one of the goals of the PPS CIO steering committee is trying to address this issue and give examples of how different QEs are dealing with data exchange. Mr. Belfort said it would be a terrible missed opportunity if QEs did not become the central infrastructure for DSRIP, since DSRIP is what the SHIN-NY was built for.

Mr. Kirkwood explained that DSRIP had its own consent process under which the PPS lead could get claims data from beneficiaries unless they opted out from such exchange. Ms. Shatzkin asked if the PPS lead could then transfer that claims data to a QE. Mr. Kirkwood said that NYS DOH was working on this issue, and that they were working on changing the policies that suggest that only the recipient of the claims data is allowed to see that data. Dr. Mead asked

if QEs had the capability to take claims data. Ms. Shatzkin responded that some QEs do, others do not. Ms. Sutliff said the moral was that if QEs want to facilitate DSRIP, they need to communicate with NYS DOH about that.

Mr. Belfort said that two-factor authentication is a big issue. Dr. Martin responded that all doctors will have two-factor authentication in the next year, but he is not sure about administrators.

XI. Upcoming Meeting

Mr. Levin informed the Committee that their next meeting would be July 14, 2015 from 9 am-11am as a conference call meeting. He thanked everyone for attending and closed the meeting.

XII. Next Steps

- NYeC to form small group to develop a proposal for the type of notice that must accompany community-wide consent.
- NYeC to draft a white paper focused on patient accounting.
- Manatt to draft a Level 2 consent form for access to a family members' genetic information.
- Mr. Rodat to develop an outline of the various issues for consideration by the committee to inform recommendations on the proposal for a life insurance intermediary pilot.
- NYeC to develop comments on NYS DOH's revisions to the Policies.

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