

New York eHealth Collaborative Policy Committee
February 11, 2015
10:00 a.m.– 3:00 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on February 11, 2015. Present either in person or via telephone were:

Art Levin, Center for Medical Consumers, Co-Chair Policy Committee
Corinne Carey, NYCLU
David P. Martin, Consumer Health Care Advocate
Dr. Thomas Mahoney, Finger Lakes Health Systems Agency
Dr. Glenn Martin, Queens Health Network
Ronnie Pawelko, JD, Family Planning Advocates of NYS
Dr. John-Paul Mead, Cayuga Medical Associates, P.C.
Irene Koch, Healthix
Steve Allen, HealtheLink
John Rodat, Public Signals, LLC
James Kirkwood, NYS DOH
Linda Adamson, New York City Department of Health and Mental Hygiene
Paul Schaeffer, New York City Department of Health and Mental Hygiene
Dr. David Cohen, Maimonides Medical Center
Ted Kremer, Rochester RHIO
Dan Tietz, AIDS Institute
Amanda Parsons, MD, Montefiore
Geraldine Johnson, NYS DOH
Cindy Sutliff, NYeC
Inez Sieben, NYeC
Alie Cohen, NYeC
Bob Belfort, Manatt
Bill Bernstein, Manatt
Alex Dworkowitz, Manatt

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

I. Welcome and Introductions

Mr. Levin welcomed everyone to the meeting. Mr. Levin explained that there were several objectives for the meeting, including agreeing on the Policy Committee’s role and policy priorities for the upcoming year.

II. Review of Committee Charter and New Committee Members

Mr. Levin noted that an important issue for the charter was the Policy Committee’s interaction with the Transparency, Evaluation and HIT Workgroup (“HIT Workgroup”). The HIT Workgroup was scheduled to sunset at the end of the year, but it is being continued, and it will focus on coordinating efforts across many different health information technology issues including the SHIN-NY, the All Payer Database (APD), and the Delivery System Reform Incentive Payment (“DSRIP”) Program.

Mr. Levin said it was important for the Policy Committee to harmonize its work with the HIT Workgroup. Ms. Carey asked if more information on the HIT Workgroup was available. Ms. Sutliff said information on its membership was listed at the end of its report, and she would circulate the report when it is finalized.

Ms. Sutliff said the Policy Committee would continue to focus on the SHIN-NY privacy and security policies; larger policy issues that cannot be addressed by the Policy Committee should be brought to the attention of the HIT Workgroup for consideration.

In regards to new committee members, Ms. Sutliff said they were looking for additional consumer, health plan, behavioral health provider, pediatric provider, and security officer representation. Dr. Martin said it would be useful to have a list of current members with their backgrounds so that members could understand the committee's gaps in expertise; Ms. Sutliff said she would provide that information. Mr. Levin requested that the committee survey its members to get their perspective on these gaps.

Dr. Mahoney said the committee should consider adding someone from the Public Health Improvement Program as a member. Ms. Sutliff asked if they needed additional representation (other than Dr. Cohen) from Performing Provider Systems ("PPSs") under DSRIP. Dr. Mead and Dr. Mahoney said they both had relationships with PPSs.

III. Proposed 2015 Policy Agenda Framework

Ms. Sutliff outlined the committee's agenda framework for the upcoming year. She said that areas to focus on include a statewide consent model, minor consent, integration of behavioral health data sources, patient engagement and access, and whether some of the policies were unnecessarily burdensome and therefore present barriers to appropriate usage of the SHIN-NY data. Ms. Sutliff added that they (the Committee) should address ongoing policy needs as they emerge. Ms. Koch asked how this policy framework compared to the list prepared by the Business and Operations Committee ("BOC") and whether all items on that list were included here. Ms. Sutliff said that this framework was broader, and she would check to see if everything in the BOC list was accounted for here.

Dr. Martin said the framework seemed to be driven by people with their own agendas, and that other issues—such as robust education of consumers—were being ignored. Mr. Levin said the Policy Committee's job was somewhat different this year in that its priorities were being driven by the needs of other programs, and that the SHIN-NY shows its value by helping these programs succeed.

IV. BOC Subcommittees and SharePoint

Ms. Sieben explained that they (the BOC) had determined that it would be helpful to establish subcommittees to the BOC. With that in mind four subcommittees were established. The Strategic Planning Subcommittee will think strategically about what needs to be accomplished through the SHIN-NY and develop a 3-5 year strategic plan. The Technical Subcommittee will make sure that technical implementation is aligned across the Qualified Entities ("QEs") and will provide guidance on what technically needs to be done to implement policies. Other subcommittees are the

Implementation Subcommittee and Certification & Policy Adherence Subcommittee. Ms. Sieban noted that there is some overlap between the committees.

Dr. Martin asked if the subcommittee's reports would be available to the Policy Committee. Ms. Sutliff said that they would, and that they would report both to the BOC and the Policy Committee.

Ms. Sutliff said committee members would be able to use SharePoint to share meeting materials. Members may need Microsoft access to use SharePoint, but members who used Macs could still access the materials. However, Ms. Sutliff said she would continue to email the materials for people who might have trouble accessing SharePoint. Mr. Levin asked if SharePoint could be used to host meetings. Ms. Sutliff said it could not, but that members could comment on documents through SharePoint.

V. Department of Health Update

Mr. Kirkwood noted that the state budget is being reduced for the SHIN-NY: \$52 was allocated for 2014. \$45 million is allocated for 2015; \$30 million for the following year and then zero funding in Year 4.

Mr. Kirkwood explained that the Department of Health ("DOH") was in the process of revising its SHIN-NY regulations. The provisions addressing patient consent and patient rights were not being changed at this time. DOH determined that it could not agree to a statewide consent model at this point, so it was sending out a new version of the regulations without that model included. However, the regulations were being simplified: some provisions that were in the prior version of the regulations would now be removed from the regulations.

Dr. Mead asked what the QEs would need to do to remain alive after the state funding runs out. Ms. Sieben said they need to think strategically about how to make the SHIN-NY sustainable and coming up with other funding sources. Ms. Sieben noted that the numbers Mr. Kirkwood cited were only state figures and did not include the federal match, but that if there is no state funding, there will be no federal match.

Mr. Kirkwood said that the new draft of the regulations were being reviewed by DOH's legal team and would likely be sent out for comment in mid to late March. This will be a 45 day comment period as there are substantive changes to what was originally released for public comment.

Mr. Kirkwood said that DOH had made minor consent issues a priority. DOH had four possible models for minor consent: the Rochester model, a let-the-data-flow model, a hybrid model, and a fourth model relating to acting independently. DOH was looking to evaluate the technical feasibility of the let-the-data-flow model.

Mr. Kirkwood said that the HIT Workgroup had a meeting scheduled for Friday, February 13th and that the consent process under DSRIP would be discussed at that meeting. Mr. Kirkwood said that DOH may be considering a different consent model for DSRIP than under the SHIN-NY, but he did not know the details.

Dr. Martin questioned whether the minor consent models were in compliance with the law. Mr. Belfort said that data subject to the Part 2 regulations would need to be separated out from other

minor consent data. Otherwise, state law is ambiguous as to whether the sharing of data about minors without minor consent is prohibited. If the regulations clarified that sharing of such data is allowed, that would bring extra comfort to QEs who are nervous about that ambiguity, Mr. Belfort said.

VI. **Community-Wide Consent Model**

Mr. Belfort observed that the current version of SHIN-NY regulations and SHIN-NY policies preclude a community-wide consent model. Current policies allow patients to grant consent to multiple providers with one form, but the policies require that that form reference all providers who are being granted consent.

Mr. Belfort said that it would be helpful if the Committee could develop use cases regarding the value of the community-wide consent model; defining the need with more precision would help give people more confidence that a new model was needed. Mr. Belfort said feedback from the QEs on the cost of implementing a community-wide consent model would also be helpful. In addition, it would be helpful if state agencies would clarify whether this model could be used for various types of sensitive health data.

Mr. Kirkwood said that greater specificity would help tremendously; DOH wants to know what it is that the model is trying to solve.

Ms. Pawelko said that implementing a community-wide consent model could be logistically easier for QEs—they would no longer be required to keep track of which providers were in a QE on the date that a patient signs the consent form.

Mr. Tietz noted the community-wide consent model does not address data sharing between QEs. Mr. Belfort said that the model could address that—it's a policy decision as to whether the Policy Committee wants to start with sharing only within a QE or whether it wants to push to allow data sharing statewide.

Mr. Belfort commented that the SHIN-NY consent policies were not written with universal access in mind. Dr. Cohen said that was a different time—now people are more aware that it takes a village to provide care. Ms. Carey said patients' privacy interest still has not changed, and that patients are still not aware that their data is being uploaded to the SHIN-NY.

Mr. Martin said it was important to have accountability. Mr. Martin said that there is heightened concern about privacy with universal access, and that there should be ongoing reporting to patients about which providers have accessed their records. Mr. Belfort said that providers still would only be able to access the data for limited purposes, such as for treatment, and that patients would still have the option to grant more limited access to their information or no access at all.

Mr. Bernstein said that patients sign consents all the time, and they do not realize what they are signing. He said that there is a business reason for providers keeping patient information within their four walls, but this is terrible for patients. Mr. Bernstein said that leadership on this issue needs to come from the Policy Committee.

Dr. Mead said that it is not possible to achieve the Triple Aim without allowing for multiparty consent. Mr. Levin said the Policy Committee would need to wait to see what DOH says about consent in the revised SHIN-NY regulations.

VII. Work Session

After a lunch break, Ms. Sutliff began the work session.

Definition of “Participant”

Mr. Belfort explained that SHIN-NY policies initially limited QE access to providers, since they were viewed as the most trustworthy. Since then, the definition has been expanded to include Health Homes, Accountable Care Organizations, and Independent Practice Associations—organizations involved in managing care but not licensed providers. Under DSRIP, some PPSs will form centralized organizations. Some of these will become ACOs or IPAs, but others will not. These new organizations will not fit within the current definition of “Participant.” Mr. Belfort said that the Policy Committee needs to determine whether to amend the definition only to include PPSs or whether a broader change to the definition of Participant was needed.

Ms. Sieben said that in three years, PPSs could be operating under a different name, so the Policy Committee might have to revisit this issue and that therefore perhaps a broader definition might be best. Dr. Mead said he supported a broader definition of Participant to include organizations that provide health care or quality improvement, so long as there are physicians on the board. Mr. Belfort said that thousands of organizations are involved in care management, and that they need to carefully consider where to draw the line. Dr. Martin said the Committee should add PPSs to the definition of Participant immediately, and explore a more encompassing definition later; he said that allowing all business associates to be Participants would be too broad.

Mr. Rodat asked whether social welfare organizations participating in DSRIP should have access to the SHIN-NY. He noted that granting them access was consistent with DSRIP policy, but there are serious concerns about their capabilities to properly secure data. Mr. Belfort said that it is expected that all SHIN-NY Participants comply with HIPAA’s Security Rule, but he does not know whether the QEs are actually vetting Participants to determine whether this is the case.

Dr. Mahoney said that food cupboards and housing services can be part of DSRIP, and the desire is not to give them the same level of access as physicians. Mr. Kremer said DOH guidance was needed on this issue, but noted that DOH had said that all PPS participants need to be interoperable. Ms. Koch said in the case of Health Homes, the theory was that if an organization was part of a Health Home, it had been vetted, and the same cut needs to apply to PPS participants.

Ms. Koch said that the policies limited patient alerts to Participants, citing Section 1.10.1 of the policies. Mr. Belfort said the intent was to allow care alerts to be sent to non-Participants, and Dr. Martin agreed.

Mr. Belfort suggested that both PPSs and PPS participants be included in the definition of Participant, and defer broadening the definition for later discussion. Ms. Sutliff asked whether this change would be considered a “minor edit” to the policies. Mr. Kirkwood said it should be included in the policies for public comment.

Level Two Form for Research

Mr. Belfort noted that at the last meeting, the Policy Committee had agreed to convene a small group to discuss the specifics of how the Level Two Consent Form could be used for research, but that group had never met. Ms. Sutliff said the group consists of Dr. Martin, Ms. Koch, Dr. Mead and Mr. Allen.

Cross QE Data Exchange

Mr. Belfort said there is nothing in the policies that prevents exchange among QEs, and some provisions reference that type of exchange. Nevertheless, the assumption was that exchange would typically occur within a QE, and the summary provided to the Policy Committee consisted of examples of such provisions. Mr. Belfort said the Policy Committee should consider whether to modify these provisions.

Ms. Koch said that this issue may be addressed in the Qualified Entity Participation Agreement (“QEPA”). Mr. Belfort said that if this is the case, there are some advantages to leaving this in the contract, although it could create potential confusion if the contract and the policies are at odds. Mr. Belfort suggested creating a crosswalk between the QEPA and the policies to see how they address this issue. Ms. Sutliff said she would be more comfortable if the breach, sanctions and audit policies were in the policies and not just the contract.

Patient Portal

Ms. Cohen explained that NYeC was initiating a pilot test of its patient portal in March. The portal will not allow access to data on minors during this initial phase, and minors will not be able to log in. In Phase 2, however, parents would be able to view immunization data on their children. Phase 2 is expected to begin in the summer. Ms. Cohen said the reason that minor data was generally not included was that they did not have a good way of linking a parent to a minor, but this is not a concern with immunization registries given the verification they undertake.

In response to a question about whether HPV immunizations were included in the registries, Mr. Schaeffer said the immunization registry does include data on HPV vaccinations. Ms. Pawelko said minors cannot consent to the HPV vaccine—only parents can consent—although she would like to see this changed. Ms. Carey said she had a different take, and that court decisions had advanced the position that providers can administer the HPV vaccine without the parents’ consent. Mr. Schaeffer noted that there is a proposed change to the law such that the HPV vaccine would be an exception to parental consent but that that law has not been passed and is still under the comment period. Ms. Carey added that some providers are giving these immunizations without parental consent.

Ms. Cohen said that in the pilot phase, they were doing a proof of concept—whether it works to pull data from the statewide connection. She said that an important issue was identity proofing. In the pilot, a person would be able to access data only through a provider. But in later releases, they would have online ID proofing which would consist of two phases. First would be a certified financial ID proofing, where questions will be asked about the person’s financial history. Second would be clinical ID proofing, where questions will be asked about the person’s medical history.

Ms. Cohen said in some cases, patients will likely be concerned that there is either too much or too little information available, and they need to develop some sort of help desk or other system for people to call with concerns. She said the hope is that if a parent sees an immunization is missing from the record, it could lead to that parent raising the issue with the pediatrician and better information in the immunization registries. Mr. Schaeffer observed that because of the meaningful use requirements, the quality of information in the immunization registries had already improved.

Mr. Tietz asked whether those who did not have access to a computer would be able to view the portal, and suggested that individuals be able to access the portal through their phone. Ms. Cohen said the portal would be mobile compatible. Dr. Martin asked for a demonstration of how the portal would work, and Ms. Cohen said that a demonstration could be arranged.

Mr. Schaeffer said there is a form that children need to fill out when they go to school, camp or day care, and that if this form would be incorporated into the portal that would be a tremendous benefit.

Ms. Koch said that they would need to keep an eye out for false negatives, and that patients are going to see that data is missing. She noted that this could lead to wrong answers in the Clinical ID proofing. Ms. Cohen said that there would initially be a phone number to call at the SHIN-NY level; eventually QEs could have this number.

Dr. Mahoney asked if birth or pregnancy related information was being excluded. Ms. Cohen said it was not. She said that it was important to figure out which questions are acceptable in regards to ID proofing; patients may not want to receive questions about abortions, for example. She said that it would be helpful to receive guidance from the Policy Committee on this issue.

Dr. Martin said he was worried that recent immigrants might struggle to access the portal since they may not have a financial history. Ms. Cohen said for this reason they thought it was important to use clinical ID proofing as well. Ms. Adamson said that city agencies had data sources that could be of use. Ms. Cohen agreed.

Other Recommendations for Policy Changes

Mr. Allen noted that there was an inconsistency in the phrasing of the training requirements in the policies. Section 4.7.4. says that “QEs shall ensure” but the preceding subsections says a “QEs shall, or shall require their Participants to.” Mr. Belfort said that this may have been intentional, and that he recalled a debate about not wanting to delegate responsibility. Ms. Sutliff said that the Committee should review prior minutes to determine the rationale for the policy.

Mr. Allen noted that Section 4.8.1(b) requires termination of access when an authorized user ends employment or affiliation with a Participant. Mr. Allen said access also needs to end when the authorized user takes on a different role with the Participant that does not qualify them for access. Ms. Sutliff agreed and said the policies should be changed.

Mr. Allen questioned why Section 6.4.1(a) gave each patient the right to know the name of each Authorized User who accessed the patient’s information. Mr. Allen said he was concerned about giving out names of workforce members to patients. Mr. Belfort said the Policy Committee was aware this policy went beyond HIPAA requirements when it adopted the policy, but the feeling was that this would be meaningful to patients. Dr. Mahoney observed that there were differences

between accessing data through the SHIN-NY and accessing data through a provider's own private system.

VIII. **Concluding Remarks**

Mr. Levin said he would appreciate input about candidates for new committee members. He thanked the group for a productive meeting.

Hearing no other questions or comments, Mr. Levin closed the meeting.

Action Items

- Ms. Sutliff will send out list of HIT Workgroup members.
- Ms. Sutliff will circulate a list of Policy Committee members and their backgrounds; Policy Committee members to suggest candidates for membership.
- Ms. Sutliff will examine Business and Operations Committee policy framework to ensure its key items are represented in the Policy Committee's policy framework.
- Regarding the community-wide consent model, the Policy Committee will develop use cases regarding the value of such a model and obtain feedback from QEs on the cost of implementing such a model.
- Manatt will draft revisions to the Policies to redefine "Participant" and to Section 4.8.1(b) on terminating authorized user access.
- Manatt to create crosswalk between QEPA and Policies to determine how they address the issue of cross QE data exchange.
- Manatt to review past meeting materials to determine rationale for language of Section 4.7.4 in the Policies.
- Dr. Martin, Ms. Koch, Dr. Mead and Mr. Allen to meet to discuss specific uses of level two form for research.
- Ms. Cohen to arrange for a demonstration to the Policy Committee on the patient portal.