

New York eHealth Collaborative Policy Committee Meeting
October 5, 2017
12 p.m. – 4 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on October 5, 2017. 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
David Cohen, MD Maimonides Medical Center
Nance Shatzkin, Bronx RHIO
Kathy Miller, Bronx RHIO
Steve Allen, HealthLink
Tom Check, Healthix RHIO
Amy Warner, Rochester RHIO
Jonathan Karmel, NYS DOH
James Kirkwood, NYS DOH
Christie Allen Hall, NYS DOH
Deirdre Depew, NYS DOH
Jessica Eber, NYS OMH
Christine Julien, New York City Department of Health and Mental Hygiene
Dr. John-Paul Mead, Cayuga Medical Associates, P.C.
Dr. Glenn Martin, Queens Health Network
Dr. Tom Mahoney, Common Ground Health
Dan Tietz, AIDS Institute
Maria Ayoob, NYSTEC
Laura Alfredo, GNYHA
Zeynep Sumer-King, GNYHA
Evan Brooksby, HANYS
Will Pelgrin, CyberWA
Valerie Grey, NYeC
Cindy Sutliff, NYeC
Nathan Donnelly, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at noon.

I. Welcome and Introductions

Mr. Levin welcomed the Committee members and outlined the meeting's agenda. Mr. Levin introduced Mr. Kirkwood to provide an update on DOH's work.

II. DOH Update

Mr. Kirkwood said the most recent version of the SHIN-NY Policies and Procedures, Version 3.4, had been approved and was now available on the NYS DOH website. Mr. Kirkwood explained that NYS DOH was in the process of working with QEs on security.

III. Proposed Cybersecurity Policies

Ms. Sutliff provided a history of security requirements imposed on the QEs and explained that NYeC was working with NYS DOH to strengthen the security posture for the SHIN-NY enterprise as a whole. She said following last year's cybersecurity assessment performed by KPMG, NYeC and NYS DOH determined it was important to develop specific policies and procedures related to cybersecurity, and to that end NYeC identified an outside expert, Will Pelgrin, to help with that process with NYS DOH support and approval.

Mr. Pelgrin said he was pleased to be helping NYeC move forward with cybersecurity, and that it was essential that they undertake this process in a collective way. Mr. Pelgrin said that the health sector is a primary target, and that the Equifax hack was a game changer because a company that is supposed to be protecting people's information was hacked affecting millions of individuals' personal information.

Mr. Pelgrin said the overarching structure of the proposed cybersecurity policies is to align with the NIST cybersecurity framework (CSF), a nationally recognized standard. He said that the cybersecurity policies will apply to the entire statewide infrastructure, including QEs, the SHIN-NY Hub, and any third party vendors that provide services to the QEs or to the SHIN-NY Hub. Mr. Pelgrin outline the five major areas of the proposed policies: identify, protect, detect, respond, and recover.

Mr. Allen asked how HITRUST compared to NIST. Mr. Pelgrin explained they both set concrete frameworks for implementation. He added that these cybersecurity policies were intended to represent a minimum baseline, and that the QEs would be able to figure out ways to implement these requirements.

Mr. Check said he was completely invested in the goals that Mr. Pelgrin described. Mr. Check added that he wanted to make sure that the applicable standards are the HITRUST standards and expressed concern that the QEs might not be able to meet the HITRUST certification requirements if they were forced to meet other certification standards. Ms. Sutliff said that this was the intent, and that the security elements were intended to be at a high level.

Ms. Sutliff said a draft of the proposed cybersecurity policies would be circulated to the Committee with the goal of providing a final document to the board at the end of November.

IV. SHIN-NY Roadmap

Mr. Levin introduced Ms. Grey to provide an overview of the SHIN-NY 2020 Roadmap. Ms. Grey said the roadmap was a result of many different conversations with stakeholders. Ms. Grey outlined the five key strategies under the roadmap: ensuring a strong HIE foundation, supporting

value-based care, enabling interoperability and innovation, promoting SHIN-NY efficiency and affordability, and advocating collectively.

Dr. Mead asked if there was a way to work to make sure that DSRIP groups used the SHIN-NY and not create a parallel infrastructure. Ms. Grey said some work needed to be done on this issue, but changes such as alerts without written consent and using QEs as repositories for claims data was helping to make the SHIN-NY more important to the DSRIP program.

Ms. Grey noted that their consent goal assumed an opt-out system and the goal may have to be modified if the model remained an opt-in approach. Mr. Allen asked whether a shift to opt-out was realistic. Ms. Grey said that 38 other states have opt-out and the temperature has changed a little bit in NY State towards such a change, but there were still barriers, such as 42 CFR Part 2. Mr. Karmel agreed and said that what the federal government did was not within their control and they should focus on issues within their control. Ms. Shatzkin said there was an effort to change Part 2 through H.R. 3545 and added there had been a 10-year investment in an opt-in system.

V. SHIN-NY Access vs. Disclosure

After a break, Ms. Sutliff introduced the topic of the difference between access to the SHIN-NY and disclosures from the SHIN-NY. She said that after the previous meeting they had gone back and developed more in depth questions.

Potential Recipients

Mr. Dworkowitz asked what types of entities should be allowed to receive a disclosure from a QE if the patient consented to disclosure. Mr. Dworkowitz set forth three different options: one in which disclosures could be made to any person or entity, a second in which disclosures could be made to any person or entity subject to limited exceptions, and a third in which disclosures could be made only to persons and entities specifically identified as trustworthy.

Ms. Eber asked if the consent form would need to be updated to allow for such disclosures. Mr. Belfort said the consent form was designed for a different purpose. Ms. Sutliff said it would have to be a Level 2 consent.

Dr. Martin said if there is consent, he did not care who the information is sent to. Mr. Belfort said that this was one point of view, but it was important to think about the implications. He said if the Policies allow for such disclosure, life insurers could require an applicant for life insurance to consent to a QE's sharing of health information with that life insurer.

Mr. Karmel said that under the third option, they needed to think carefully about how to define a patient's representative, since if a patient could make anyone their representative, it would quickly become the same as the first option.

Mr. Check said that easing into this with the third option would probably gain the most acceptance from providers, who are the originators of the data. Mr. Allen said he agreed with the

sentiment, but added that if a patient comes to a QE and asks for all the data, the QE is obligated to give the patient such data. Mr. Check said in that scenario, at least the patient would see his or her data first before further disclosing to the ultimate recipient.

Dr. Mead said they could envision patients being able to log in and build their own Level 2 consent form for such disclosures.

Mr. Karmel said they should also be thinking about employers, since employers could require disclosures as a condition of offering a job.

Ms. Shatzkin said her immediate reaction was to be in favor of the first option. Mr. Belfort said there is a difference between consenting freely to sharing information with a summer camp and signing a consent while under pressure from a life insurer. Mr. Belfort said he agreed with Mr. Check that it made sense to start with an option with more controls on it.

Safeguards

Mr. Levin asked what safeguards are needed in the context of disclosures. Ms. Warner said the issue is whether it's technologically possible to implement the suggested safeguards.

Mr. Check said he liked the proposed safeguards and it was not a bad idea to provide the patient with specific information on the data sources that were being disclosed.

Mr. Allen suggested some sort of contractual arrangement with the recipient. Mr. Belfort asked what a QE would do if the agreement was violated, since the QE would not be harmed, just the patient. Mr. Belfort worried that a QE would be opening itself up to a claim that it was acting as a negligent steward. Mr. Check said he would like to see an agreement between the QE and the recipient. Mr. Belfort said that one way to achieve this would be to make a patient a third party beneficiary under the agreement, so that a patient has a right to enforce if the agreement if it is violated.

Audit Log

Mr. Dworkowitz asked what types of disclosures should be included in the audit log and outlined several potential approaches. Mr. Allen said that in a standing batch query order where the recipient gives a QE certain criteria, a QE is not making a decision, and therefore this may not be appropriate to include in the audit log, but otherwise everything else should be in the log.

Ms. Shatzkin said they were splitting hairs between access and disclosures, and a patient has a right to this information. Mr. Belfort said he agreed that from a consumer standpoint, the distinction between access and disclosure was meaningless, but the question is whether there are technical challenges to tracking these disclosures; if not, there is no compelling reason to exclude this information.

Mr. Check suggested a straw person policy be outlined that could include aspects of the various options presented. Mr. Levin said they would come back to the Committee with a draft for further feedback at the next meeting.

VI. Sensitive Health Information Paper

Ms. Sutliff said they have had lots of conversations about sharing of sensitive health information, and NYeC thought it would be helpful to put information on current laws and best practices in one document. Mr. Dworkowitz said that as part of this process NYeC would look to speak with QEs about their practices.

Mr. Check said this would be very useful. He suggested adding rules related to social service agency access to the analysis. Ms. Warner said what is technically possible will be a big factor in the discussion. Mr. Karmel suggested including rules about claims data in the analysis.

Mr. Allen asked which QEs currently have Part 2 data. Ms. Miller said the Bronx RHIO has some Part 2 data. Others noted additional QEs that have some Part 2 data.

Some additional refinement of the paper contents will be done and shared with the Committee.

VII. Number of patients for research

Mr. Check proposed that one sentence should be added to the Policies to clarify that affirmative consent is not required when a researcher obtains information on the number of patients who meet a study criteria. Mr. Check said this involved de-identified data and was pretty harmless, but did not fit under the current de-identified data exception because this occurs prior to IRB approval.

Mr. Levin asked if anyone objected to this proposal. Dr. Martin said if the number included the number of people with rare disease in a zip code, it could be considered PHI. Dr. Martin said if they do not include date of birth, zip code, or any of the other 18 identifiers the proposal would be acceptable.

Ms. Grey asked if this would be a value-added service that QEs could charge for. Mr. Check said it would.

Dr. Martin questioned whether this data could be used for marketing purposes, inquiring about a reference to qualified researchers.

Ms. Sutliff said that based on the lack of objection, the proposal would be presented to the NYeC board.

VIII. Level 1 Use for Payment

Ms. Sutliff explained that under the Policies, a health plan can only access data for payment purposes if the health plan obtains a Level 2 consent. She asked whether this should be changed to allow access using a Level 1 consent.

Mr. Belfort said that HIPAA would permit this sharing without any patient authorization at all. Dr. Mead said he could see both sides. Mr. Kirkwood said HEDIS measures get incorporated into payment schemes, so there was a desire on the part of plans and providers to make this type of exchange more efficient.

Mr. Belfort said this issue had been discussed 10 years ago, and at the time it was felt that everything in a Level 1 consent should be used to support a patient.

Mr. Levin asked if the group was okay with this change. Dr. Martin said it is very hard for consumers to believe that a health insurance company is working for them. Mr. Levin said there were fights over utilization review years ago, and things are in a different place today.

Ms. Miller said providers ask to give plans access for prior authorization purposes all the time, and it is a huge waste of staff time.

Dr. Mead said plans already have access to data through other means. However, if a provider answers four questions, often times a plan will come back with 16 follow up questions. Mr. Belfort said that in contrast to a life insurance scenario, where patients often will be harmed by disclosures, here the patient typically will benefit from the information being disclosed. Mr. Belfort noted there are certain exceptions, however, such as in the case where the disclosure reveals the patient received an MRI three months earlier and is not entitled to another MRI. Dr. Mead said that a prior authorization that used to take 48 hours now takes two weeks, and that patients often give up.

Ms. Sutliff said they would put forward a policy on this issue.

IX. Closing

Mr. Levin thanked the group for their time and said they had made some real progress. Mr. Levin said the next meeting would be a conference call in November. Date TBD.