

New York eHealth Collaborative Policy Committee Meeting
July 20, 2021
2 p.m. – 3:30 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on July 20, 2021. Present via telephone or videoconference were:

Policy Committee Voting Members

Nance Shatzkin, Bronx RHIO
Steve Allen, HealthLink
Dr. Tom Mahoney, Common Ground Health
Dr. John-Paul Mead, Cayuga Medical Associates
Dr. Glenn Martin, Queens Health Network
Alan Cohen, JASA
Chuck Bell, Consumer Reports

Other Attendees

Karen Romano, HealthConnections
Taiymoor Naqi, Hixny
Jonathan Karmel, NYS DOH
James Kirkwood, NYS DOH
Deirdre Depew, NYS DOH
Chelsea Sack, NYS DOH
Dan Schiller, NYS DOH
Ken Wiczerza, NYS DOH
Kate Bliss, NYS DOH
Molly Finnerty, NYS OMH
Tammy Harris, OPWDD
Margaret Vijayan, OPWDD
Jennifer Freeman, OPWDD
Zeynep Sumer King, GNYHA
Puja Khare, GNYHA
Linda Adamson, NYSTEC
Jill Eisenstein, BOC Representative
Valerie Grey, NYeC
Cindy Sutliff, NYeC
Alison Bianchi, NYeC
Zoe Barber, NYeC
Alexandra Fitz Blais, NYeC
Nate Donnelly, NYeC
Sam Roods, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Ms. Sutliff at 2 p.m.

I. Welcome and Introductions

Ms. Sutliff welcomed the Committee members and provided an overview of the agenda and meeting materials. She noted the Committee members may submit corrections to the meeting minutes.

II. Federal and State Update

Ms. Grey explained that the federal government is seeking to build up a national HIE network through TEFCA and is hoping to go live with TEFCA sometime next year. She added that the ability of the SHIN-NY to participate in the national networks depends on changing the consent model, and there is ongoing work with the QEs to determine what that change might involve.

Ms. Grey said that the government has released the final USCDI version 2, and that NYeC was excited to see that some of their comments were addressed in that version. She said that the new version captured information on sexual orientation, gender identity, and social needs. She explained that this new version is not going to be required in the near future, but it is designed to signal to the industry what is coming next.

III. DOH Update

Mr. Kirkwood noted that NYeC had submitted revisions to the policies and procedures that are being reviewed by NYS DOH.

Mr. Kirkwood said that the governor's emergency orders regarding the pandemic have been rescinded, and the end of such orders impacts the disclosure of ECLRS laboratory data and telehealth information.

IV. Ad Hoc Workgroup Report: Secondary Use of Cross QE Data

Ms. Sutliff introduced the working session regarding cross QE disclosures for research purposes. Mr. Dworkowitz provided an overview of the proposed changes to the policy provisions governing research. He said under the proposal, a centralized research committee would be established to govern approvals of research projects involving data from multiple QEs.

Ms. Finnerty asked about the circumstances under which a QE could decline to participate in a research project. Ms. Eisenstein responded that it is typical for QEs to assess the costs of participating in a research project and ask the researcher to cover those costs. Mr. Allen agreed, adding that HEALTHeLINK's core mission is to be an HIE, and that any research support it provides is in addition to that core mission.

Ms. Shatzkin said that researchers were just beginning to understand that the SHIN-NY can be a valuable tool for research, and that the QEs may see more research requests in the future. Ms. Finnerty agreed, saying centralized review was an important first step.

Ms. Shatzkin asked if there are plans for selecting members of the centralized research committee. Ms. Sutliff answered that the Business and Operations Committee would need to address membership in 2022.

Ms. Sutliff asked if there was consensus to adopt the proposal. Committee members agreed that the proposal should be adopted.

V. Disclosure of De-Identified Data

Ms. Sutliff explained that Section 1.6.3(a) of the policies requires affirmative consent for the disclosure of de-identified data, subject to some exceptions. She said this was being re-evaluated in an effort to modernize the policies and bring them more in line with HIPAA, which does not require affirmative consent for the disclosure of de-identified data.

Mr. Dworkowitz outlined different policy options. He said one option was complete alignment with HIPAA, which would end all restrictions on the disclosure of de-identified data, assuming disclosure was permitted under the applicable business associate agreements. Another option was to provide more flexibility, but prohibit disclosures for certain purposes, such as disclosures involving the sale of de-identified data. A third approach was to continue the status quo, but allow for the disclosure of de-identified data for additional use cases as they arose.

In response to a question, Mr. Belfort noted that there had been state laws that had prohibited the sale of de-identified data to pharmaceutical companies, but one of those laws had been struck down by the Supreme Court, and he was not aware of any state restrictions on the disclosure of de-identified data. He said that people have had different perspectives on this issue: some think that if the data is de-identified, it can be used for any purpose, while others have concerns that there is a risk that the data could be re-identified. He added that another concern is that if providers are going to be compelled to contribute data their information should not be sold for commercial purposes.

Dr. Martin said even if a patient's identifiers are stripped from a data set, the patient may still object on the grounds that their data is being used for an objectional purpose. He counseled caution against changing the provision. Ms. Shatzkin said it was hard to understand why they needed this change, absent a specific use case. Mr. Belfort said a QE may need to raise money if their budget was cut. Dr. Mahoney said if that occurs, the Policy Committee can address that scenario at that time.

Ms. Sutliff said they would revisit the discussion at their next meeting.

VI. Patient Engagement: Requests from third-party applications

Ms. Sutliff observed that the Policy Committee had already addressed disclosures at the patient's request, but had not yet addressed the scenario where the requestor is a third-party app seeking

information on a patient's behalf. Mr. Dworkowitz noted that this now occurs under the interoperability rule, where apps can make requests directly to health plans.

Ms. Eisenstein said that Rochester RHIO works with the app Ciitizen, which participates in the Carin Alliance. She said they make disclosures in accordance with a HIPAA authorization from a patient. She said they are operating manually has of now, but they are planning to go live with a more automated version. In response to a question, she said this is a one-time exchange, but they could make repeated disclosures if needed.

Dr. Mahoney questioned whether there is a need to address this issue in policy, given that some QEs are already making disclosures to third-party apps.

Mr. Allen said that the QE is relying on the app to identity proof the individual, and it is not unreasonable to have a contract that obligates that entity to comply with certain rules. Ms. Shatzkin agreed.

Mr. Bell said the contract with the app could require the app to show warnings and provide education to patients. Mr. Naqi said there could be concerns about potential violations of the information blocking rule if they mandated that the app agree to certain requirements. Ms. Sumer King agreed. Mr. Belfort observed that the information blocking rule is a caveat emptor model.

Ms. Sutliff said the Policy Committee would continue to explore different options for policies regarding third-party apps at the next meeting.

VII. Closing

Ms. Sutliff thanked the Committee and adjourned the meeting.