

New York eHealth Collaborative Policy Committee Meeting
November 17, 2021
2 p.m. – 4 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on November 17, 2021. Present via telephone or videoconference were:

Policy Committee Voting Members

Art Levin, Chair, Center for Medical Consumers
Nance Shatzkin, Bronx RHIO
Taiymoor Naqi, Hixny
Steve Allen, HealthLink
Dr. Tom Mahoney, Common Ground Health
Dr. Glenn Martin, Queens Health Network
Dr. John-Paul Mead, Cayuga Health System
Alan Cohen, JASA
Dr. David Cohen, Maimonides Medical Center

Other Attendees

Judy Mendoza, Rochester RHIO
Karen Romano, HealthConnections
Amy Warner, Healthix
James Kirkwood, NYS DOH
Deirdre Depew, NYS DOH
Chelsea Sack, NYS DOH
Geraldine Johnson, NYS DOH
Dan Schiller, NYS DOH
Molly Finnerty, NYS OMH
Carmen Barber, NYS OMH
Tammy Harris, OPWDD
Jennifer Freeman, OPWDD
Jennifer Rosenbaum, Office of the Aging
Tom Hallisey, HANYS
Linda Adamson, NYSTEC
Sheena Patel, NYSTEC
Valerie Grey, NYeC
Cindy Sutliff, NYeC
Alison Bianchi, NYeC
Elizabeth Amato, NYeC
Sam Roods, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 2 p.m.

I. Welcome and Introductions

Mr. Levin welcomed the Committee members and provided an overview of the agenda and meeting materials.

I. DOH Update

Mr. Kirkwood noted many activities regarding COVID-19 were still occurring, including the push for more vaccinations and booster shots. He observed that COVID-19 hospitalizations were starting to increase again.

II. De-Identified Data Working Session

Mr. Dworkowitz provided an overview of the proposed provisions on the use and disclosure of de-identified data. He said the new policy would allow disclosures of de-identified data if such disclosures were in the best interest of patients, if the disclosure was consistent with the terms of the QEs' business associate agreement, and if the QE entered into a data use agreement with the recipient that had provisions intended to prevent the re-identification of such data.

Dr. Martin said the proposal raised the question of whether QEs are permitted to do things that are not in the best interest of patients. Ms. Shatzkin agreed, saying she was a little uncomfortable with such language. Dr. Martin also questioned why patient consent could be allowed to override a QE's determination that a disclosure was not in the best interest of patients. Mr. Belfort responded that the best-interest-of-patients standard calls for an opinion, and if a patient disagreed with the QE's assessment the patient has a right to have such data disclosed.

Mr. Naqi said QEs are not in the business of determining what is in the best interest of patients. Ms. Shatzkin said that QEs are familiar with the mission of the SHIN-NY, and that the language should refer to the SHIN-NY's mission instead. Mr. Naqi agreed, saying QEs are in a far better position to determine whether a disclosure is consistent with the mission of the SHIN-NY than whether a disclosure is in the best interest of patients.

Mr. Allen said he had some concern about language in Section 1.6.1 that suggested that QEs have an obligation to disclose de-identified data and suggested that the language be clarified to indicate that disclosure is optional.

Mr. Allen asked about proposed section 1.6.3(d), which requires the recipient of de-identified data to notify the QE if there was an unsuccessful attempt to re-identify data. He questioned whether notification is necessary where no re-identification actually has occurred. Mr. Levin asked if the Committee agreed to modify the language accordingly. Ms. Shatzkin said she agreed with the change.

Ms. Sutliff said revised language would be provided to the Policy Committee members via email for their review and approval.

III. 2022 Policy Areas of Focus

Ms. Sutliff noted that NYeC had solicited proposals from the Committee members regarding policy areas of focus for 2022. Ms. Sutliff reviewed an initial list of areas of focus, including the all-in consent framework, third-party applications, and payer utilization.

Mr. Allen suggested that the all-in consent effort be harmonized with a behavioral health consent form being developed.

Dr. Mahoney said that efforts were ongoing to include social determinants of health data, such as school-level data and enforcement data, and the Policy Committee should remain engaged in this area. Mr. Cohen said it was important to create the expectation of participation and input from community-based organizations. Ms. Rosenbaum said some SDOH data is subject to the Older Americans Act, and it is important to consider the consent requirements under that act.

Dr. Mead said the Committee should continue to focus on third-party apps. He added that many users still need to separately log onto a QE, and efforts need to be undertaken to make the SHIN-NY more usable. Ms. Shatzkin said there could be a policy that encourages the adoption of a single sign-on.

Dr. Martin said a patient portal should be developed so patients can modify their consent, control their consent, and learn how their data has been used. Mr. Levin agreed, saying patient understanding of how their data is used is critical.

Ms. Finnerty recommended the Committee develop additional policies regarding Medicaid data, saying it is a good source of information regarding homelessness and poverty.

IV. Policy Committee Member Recognitions

Mr. Levin provided recognition to the longest serving members of the Policy Committee who were stepping down from the Committee. Mr. Levin thanked Ms. Shatzkin for being a dedicated, consistent, and energetic member of the Committee. Mr. Levin said Dr. Martin had been an extremely valuable member of the Committee who was not afraid to insist on answers to important questions. Mr. Levin added that Dr. Mead had also been very dedicated to the Committee, and he thanked Dr. Mead for bringing a needed perspective to the Committee.

Ms. Shatzkin, Dr. Martin, and Dr. Mead thanked Mr. Levin for the recognition.

V. Closing

Mr. Levin said it was the last Committee meeting of the year since no meeting was scheduled for December. He thanked the Committee and adjourned the meeting.