

New York eHealth Collaborative Policy Committee Meeting
September 15, 2022
2 p.m. – 3:30 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on September 15, 2022. Present via telephone or videoconference were:

Policy Committee Voting Members

Art Levin, Chair, Center for Medical Consumers
Dr. Ram Raju, Health Disparities Consultant
Dr. David Cohen, Maimonides Medical Center
Louann Villani, Ontrak
Taiymoor Naqi, Hixny
Steve Allen, HealtheLink
Alan Cohen, JASA

Other Attendees

Nance Shatzkin, Bronx RHIO
Liana Prosonic, HealtheConnections
Patricia Burandt, HealtheLink
Todd Rogow, Healthix
James Kirkwood, NYS DOH
Deirdre Depew, NYS DOH
Ken Wiczerza, NYS DOH
Chelsea Sack, NYS DOH
Meredith Locke, NYS DOH
C.J. Barber, NYS OMH
Tammy Harris, OPWDD
Meg Vijayan, OPWDD
Jen Freeman, OPWDD
Amy Hsi, Planned Parenthood of Central and Western New York
Colleen Schiffhauer, Planned Parenthood of Central and Western New York
Dawn McClary, Planned Parenthood of Greater New York
Lori Trzop, Planned Parenthood of Greater New York
Chelly Hegan, Upper Hudson Planned Parenthood
Megan Sherman, Planned Parenthood Empire State Acts
Puja Khare, GNYHA
Tom Hallisey, HANYS
Leilani Prusky, NYSTEC
David Horrocks, NYeC
Cindy Sutliff, NYeC
Alison Bianchi, NYeC
Kathryn Lucia, NYeC
Sam Roods, NYeC
Bob Belfort, Manatt

Alex Dworkowitz, Manatt
Julian Polaris, 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, the meeting materials, and the meeting objectives.

II. Federal and State Updates

Ms. Bianchi noted that the applications for Qualified Health Information Networks (QHINs) under the Trusted Exchange Framework and Common Agreement (TEFCA) were scheduled to open on October 3. She said that the Maryland network, CRISP, is the first state health information exchange that stated it plans to participate in TEFCA under eHealthExchange.

Ms. Bianchi said that the American Data Privacy and Protection act has stalled in Congress. She added that the Cures Act rule is scheduled to be released in October and the HIPAA modification scheduled for release in March 2023.

III. DOH Update

Mr. Kirkwood said the state's Medicaid waiver application had been made public earlier in the week and has been submitted to CMS. He said the SHIN-NY regulation is up for consideration by the Public Health and Planning Council, and that it was possible the regulation would be released in October.

IV. Working Session on Reproductive Health Data

Ms. Sutliff explained that NYeC had met with key stakeholder groups regarding potential revisions to SHIN-NY policies regarding reproductive health information following the decision in *Dobbs v. Jackson Women's Health Organization*. She expressed hope the Policy Committee could come to an agreement on a policy going forward.

Mr. Dworkowitz summarized the key takeaways from meetings with QEs, Greater New York Hospital Association, and Planned Parenthood affiliates regarding different approaches to abortion data in the SHIN-NY. He noted that Committee members had an out-of-cycle meeting where they discussed potential options, and during that meeting Committee members expressed reluctance to exclude abortion data from the SHIN-NY but considered revising Section 1.4.2, regarding patient rights to withhold data. Mr. Dworkowitz presented two potential modifications to Section 1.4.2: one which would require Participants and QEs to give patients the right to

withhold their sensitive health information, including reproductive health information, from the SHIN-NY, and the other requiring more education to patients on their rights to withhold data.

Mr. Allen said the QEs were concerned about the technical ability to reliably identify sensitive health information and abortion information. He asked about the specific risks being addressed. Mr. Alan Cohen said there are concerns both about out-of-state patients and about religious providers discriminating against in-state patients who have had abortions. Ms. Hegan said she has had patients who go to Catholic hospitals for miscarriage management and have been turned away out of the belief that such patients received an abortion.

Dr. Cohen said there is always the potential for misuse of data, that such discrimination is improper use of data, and that such discrimination can be based on data from any source, not just the SHIN-NY. Mr. Naqi said abortion data can be found in many different types of data, including laboratory results and physician notes, and it is not possible to know that abortion data was properly tagged. He said that SHIN-NY policies do not permit prosecutors to obtain patient data without consent, and that if the adopted a policy of allowing patients to withhold sensitive information, then all records from that patient from a particular provider may need to be withheld.

Dr. Cohen said that if the concern is about out-of-state patients restricting access to their data, such patients probably will not have much data in the SHIN-NY, so restricting their information may not be that impactful.

Ms. Trzop said that Planned Parenthood of Greater New York's providers have concerns, particularly in the scenario where an out-of-state patient comes to New York and receives a medication abortion and therefore may receive follow-up treatment in their home state.

Mr. Cohen said if the Committee truly believes it is important to give patients control of sensitive health data, the policies should reflect that principle.

Ms. Shatzkin said she agreed with Mr. Naqi's prior comments, and that the SHIN-NY already has controls in place that work well. She said providers, not QEs, were best positioned to filter the data. Ms. Villani echoed concerns about the difficulty of segmenting abortion data, and said it is key that people are educated about their ability to share and withhold data. Mr. Levin questioned how effective education would be.

Several Committee members said they were comfortable with the status quo under which providers can seek a waiver to prevent their patient data from being disclosed to the SHIN-NY as well as rely on the provision in 1.4.2 that allows but does not require Participants and QEs to give patients the right to withhold their sensitive health information including abortion information from being uploaded to the SHIN-NY. Hearing no objection to such position, Mr. Levin said there was consensus not to amend the policies on this issue at this time.

V. Community-Based Organization Roundtable

Ms. Sutliff explained that a community-based organization (CBO) roundtable would be convened during the next Policy Committee on October 19. She said that with the release of the new 1115 Medicaid waiver, the state is seeking to have CBOs play a more prominent role in providing care to patients and receiving patient information. She said there are both real and perceived barriers to CBO participation in the SHIN-NY, and that the roundtable would address these questions.

VI. Closing

Mr. Levin thanked the Committee and adjourned the meeting.