

New York eHealth Collaborative Policy Committee Meeting
September 17, 2021
2 p.m. – 3:30 p.m.
Meeting Notes

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

Policy Committee Voting Members

Art Levin, Chair, Center for Medical Consumers
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, HealtheConnections
James Kirkwood, NYS DOH
Deirdre Depew, NYS DOH
Chelsea Sack, NYS DOH
Dan Schiller, NYS DOH
Molly Finnerty, NYS OMH
Tammy Harris, OPWDD
Jennifer Freeman, OPWDD
Marybeth Babcock, OPWDD
Jennifer Rosenbaum, Office of the Aging
Zeynep Sumer King, GNYHA
Puja Khare, GNYHA
Tom Hallisey, HANYS
Linda Adamson, NYSTEC
Valerie Grey, NYeC
Cindy Sutliff, NYeC
Alison Bianchi, NYeC
Elizabeth Amato, NYeC
Alexandra Fitz Blais, 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 that the most recent version of the SHIN-NY policies, version 3.8.1, had been approved by NYS DOH and was now publicly available. He said NYS DOH was shifting from approving a different version of the policies from once a year to once every six months.

Mr. Kirkwood said NYS DOH was ramping up its work on vaccine boosters given the latest federal recommendations, and the Department was also working with schools on back-to-school COVID-19 testing.

II. Federal and State Update

Ms. Grey said NYeC had submitted comments on the proposed Medicare rules related to inpatient hospitals and physician payment rates. She explained that NYeC was continuing to push for the same issues, such as the need to leverage existing HIE infrastructure, and the need to be practical on the readiness of FHIR.

Ms. Grey noted that there is a new governor and the Medicaid program has released a concept paper on the next iteration of DSRIP, which NYeC is reviewing carefully. She said NYeC was pleased that the Medicaid waiver recognizes a role for the SHIN-NY and NYeC is examining whether any policy changes may be needed to facilitate the SHIN-NY's role in DSRIP.

III. Working Session

Policies on De-Identified Data

Mr. Dworkowitz explained that the SHIN-NY policies were stricter than HIPAA regarding the disclosure of de-identified data. He outlined three different policy approaches: complete HIPAA alignment; allowing for uses and disclosures of de-identified data except for particular use cases of concern; and continuing the current approach of allowing use of de-identified data on a case-by-case basis and otherwise requiring consent.

Dr. Martin noted honest brokers are used for the de-identification of data for purposes of research, but honest brokers need to be regulated in what they do. He said he was comfortable with continuing the current approach but was open to hearing reasons for a policy change. He expressed concern about the use of de-identified data for competitive purposes.

Mr. Belfort said there are a broad range of commercial uses of data that do not relate to marketing. He said a pharmaceutical company can use de-identified data for marketing purposes

if it uses the data to target doctors with prescription drug promotions. But he noted other, non-marketing uses include using de-identified data to improve functioning of AI systems.

Dr. Mahoney said he was concerned that de-identified data could be used to learn about what types of services different hospitals are performing and having competitors use that information for their advantage. Dr. Martin said he was interested in knowing what the SPARCS policy is regarding the use of de-identified data.

Ms. Shatzkin asked what was motivating the proposed change in language. Mr. Allen responded that HealthLink is in discussions with a couple of entities regarding the use of de-identified data in support of life science companies, largely relating to clinical trial design and execution. Mr. Bell said he was concerned about SHIN-NY data being used to promote off-label marketing of drugs. Mr. Belfort said marketing a drug for off-label purposes would be illegal, but there is a range of legal commercial activity that could be bolstered with de-identified data.

Dr. Martin said much of this information was available elsewhere, since many forms of data can be purchased from organizations like Surescripts. Mr. Allen said Surescripts data will show what drugs are being prescribed, but SHIN-NY data will contain the denominator of how big a population meets the clinical criteria for a particular drug, and therefore provides value that is not available from Surescripts.

Ms. Shatzkin said she was not strongly in favor of modifying the policy, but it was worthwhile to explore other revenue opportunities for the QEs. She said this is not just a policy discussion, but also a discussion related to business operations and the overarching purpose of QEs.

Ms. Sutliff said the policies in question were created a long time ago and are stricter than HIPAA. She said at the next Policy Committee discussion could focus on the range of commercial activities that may help the Committee come up with a solution that is not such a rigid approach. Dr. Mahoney recommended that they reach out to other HIEs in the country to see how they handle this issue.

Mr. Bell said that some are concerned that the HIPAA de-identification standard is not protective enough, and de-identified data can be re-identified. Mr. Allen answered that data use agreements can prohibit the recipient from attempting to re-identify the data.

SHIN-NY Policy Advances Update

Mr. Levin told the Committee that the NYeC board had recently approved three recommendations from the Committee: a change in the password requirements, cross QE research disclosures, and disclosures to the Office of Mental Health as a public health agency. He said these proposed policies would now be submitted to NYS DOH.

Update from Health Plan Roundtable

Ms. Sutliff said a priority area in the 2021 policy agenda relates to increasing health plan participation in the SHIN-NY. She said a roundtable devoted to this topic would be held the following Monday, September 20th.

Ms. Sutliff provided an overview of the topics that would be addressed at the roundtable, which would include alerts, using data for HEDIS calculations, and consent. Mr. Levin said results from the roundtable would be reported to the Policy Committee.

IV. Closing

Mr. Levin thanked the Committee and adjourned the meeting. The October Policy Committee is scheduled for Friday, October 22nd from 12-3 pm.