

**New York eHealth Collaborative Policy Committee Meeting**  
**October 22, 2021**  
**12 p.m. – 3 p.m.**  
**Meeting Notes**

A meeting of the NYeC Policy Committee was held on October 22, 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. Glenn Martin, Queens Health Network  
Chuck Bell, Consumer Reports  
Dr. David Cohen, Maimonides Medical Center

*Other Attendees*

Judy Mendoza, Rochester RHIO  
Karen Romano, HealtheConnections  
Todd Rogow, Healthix  
James Kirkwood, NYS DOH  
Deirdre Depew, NYS DOH  
Chelsea Sack, NYS DOH  
Christie Hall, NYS DOH  
Geraldine Johnson, NYS DOH  
Ken Wiczerza, NYS DOH  
Molly Finnerty, NYS OMH  
Tammy Harris, OPWDD  
Jennifer Freeman, OPWDD  
Marybeth Babcock, OPWDD  
Jennifer Rosenbaum, Office of the Aging  
Puja Khare, GNYHA  
Tom Hallisey, HANYS  
Linda Adamson, NYSTEC  
Valerie Grey, NYeC  
Cindy Sutliff, NYeC  
Zoe Barber, 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**

Ms. Depew noted that there is new leadership in place throughout the Department of Health. She said new leadership will continue to be educated on the SHIN-NY during the next round of policy updates.

## **II. Health Plan Roundtable Report Out**

Mr. Levin described the attendees at the health plan roundtable. He provided an overview of the key insights from the roundtable, including the importance of diagnoses, timing of data, and the quality of data.

Dr. Mahoney noted there was great interest in using the SHIN-NY for HEDIS reporting in the Syracuse area, and he asked if QEs are accommodating this. Ms. Sutliff responded that some QEs have received certification from NCQA and therefore are providing data to health plans for HEDIS reporting. Ms. Shatzkin said QEs save plans significant funds by doing this since plans no longer need to send out large staffs to collect the data, and it is therefore a value-added service for which QEs can charge.

Mr. Levin said his impression was that the health plans found the session to be valuable. He added that a roundtable summary report would be provided at a later date.

## **III. SHIN-NY Policy Committee 2022 Membership**

Mr. Levin provided an overview of the different classes of the policy committee and explained when different members are scheduled to leave the committee. He explained that three new members were scheduled to join the committee in 2022: Dr. Ram Raju, Dr. Laurence Brown, and Louann Villani. Dr. Martin said he has worked with Dr. Brown, and that he was a wise selection.

Ms. Shatzkin noted that all three new members of the Committee will be clinicians. Ms. Sutliff responded that there still will be two QE representatives on the Policy Committee, as required under the charter.

Ms. Sutliff said the members who would be leaving the Committee in 2022 are still welcome to attend the meetings and provide their perspectives, although they would no longer have voting power. Mr. Levin said the participation of those members always will be valued.

#### **IV. Approaches to De-Identified Data**

In an effort to provide the Committee with different approaches regarding the treatment of de-identified data, Mr. Roods said he had examined the policies of NIST, SPARCS, and PSYCKES as well as other state HIEs, regarding de-identified data.

Mr. Roods explained that NIST guidance on de-identification, SP 800-188, sets forth data sharing models for de-identified data, which includes an enclave model, a data use agreement model, and a release and forget model (data is made publicly available). He noted that SPARCS does allow some de-identified data to be released publicly, and that such data has been de-identified both in accordance with the HIPAA safe harbor and expert determination method.

Mr. Roods said it was not easy to determine the approaches to de-identified data of other states, but that many state consumer privacy acts aligned with the HIPAA de-identification standard.

Dr. Martin said the SPARCS data appears to be curated. Mr. Wiczerza answered that the publicly available data is curated, and to get an uncurated data set the rules regarding identifiable data or a limited data set would apply.

#### **V. CARIN Alliance Presentation**

Ms. Sutliff introduced David Lee of Leavitt Partners to provide an overview of the CARIN Alliance and its significance to the SHIN-NY. Mr. Lee began to provide background on the CARIN Alliance and its code of conduct, but his presentation was interrupted due to technical issues. Ms. Sutliff told the Committee that a presentation from the CARIN Alliance would be rescheduled.

#### **VI. De-Identified Data Policies**

Ms. Sutliff noted that Mr. Bell had provided an article on the risks of re-identification of de-identified data that was shared with the Committee.

Mr. Dworkowitz described the proposed policy options for treating de-identified data: allowing its use and disclosure in accordance with HIPAA, prohibiting certain uses but otherwise allowing disclosures of de-identified data, and continuing the status quo of only allowing de-identified data to be used for certain purposes. Mr. Dworkowitz noted that in the latter two options, the recipient of the data could be required to enter into a data use agreement that required the recipient to abide by certain protections intended to ensure the data was not re-identified.

Ms. Shatzkin said that if the policies were going to allow the disclosure of more de-identified data then there should be a data use agreement with the recipient. Dr. Martin said the requirements for data use agreements related to limited data sets should apply: for example, HIPAA rules on limited data sets permit the data to be used only for the purposes for which the data was given.

Mr. Rogow said that Healthix has more stringent requirements regarding use of de-identified data than those that are set forth in the policies, and that information about the different practices of QEs could be useful to the Committee. Ms. Sutliff noted that QEs can make their own determination as to whether to go above-and-beyond the requirements in the policies.

Mr. Allen said he was concerned about the provision regarding QEs auditing recipients of de-identified data. Mr. Dworkowitz responded that the provision gave QEs a right to engage in audits, but did not obligate a QE to conduct such audits.

Mr. Allen said he thought the middle ground approach – more flexibility but with prohibitions – was reasonable. Ms. Shatzkin agreed, adding she was not in favor of eliminating all restrictions and that the Committee needs to be careful on how far they progress on this issue. Dr. Martin said he could accept this approach as well.

Dr. Martin said a reporting requirement should be added to the policy proposal, so the Committee would have more information on how de-identified data was being disclosed. Ms. Shatzkin said this could be part of the quarterly filing requirement that QEs are already subject to.

Ms. Finnerty asked about the definition of selling data for marketing purposes. She said that many groups are developing predictive models that apply machine learning technologies and identify people at risk, which can be incredibly useful to clinicians and managers. She said that such groups may be willing to pay for the data and may even give the algorithm they develop back to the QE as compensation. Dr. Martin said he was frightened by this type of possibility, since AI and machine learning need a huge amount of data and more data means a greater re-identification risk. Dr. Martin added that AI can foster inequities and racial discrimination.

Mr. Bell said the list of use cases that would be prohibited might be quite extensive but it is challenging to think through all of the prohibitions, and he questioned whether the Committee could develop an effective list. Ms. Sutliff said the Committee does not need to develop a list of every use case that would be prohibited, and Mr. Allen said that QEs would still have local control as to whether they would permit disclosure of data.

Ms. Sutliff said that it appeared that the Committee was open to a middle ground approach and that new language would be provided to the Committee in the following meeting.

## **VII. Federal and State Update**

Ms. Grey provide an update on the work to develop an all-in consent model for the SHIN-NY. She noted that in 2019, the Committee had approved the concept of a single form of consent that would apply to the entire state, and the Committee recommended a two-year window for implementation. She noted that in 2020, NYeC engaged with Audacious Inquiry on the topic, and out of that work they developed a recommendation for a phased in approach. Under the initial phase, the current consent would co-exist with the all-in-consent option, and state agencies, health plans, and large health systems would use the new form of consent. Once

critical mass was reached, the state could have the technical readiness to adopt a more granular all-in-consent form.

Ms. Grey explained that the all-in-consent would apply to current and future treating providers as well as health plans, and it would also apply to providers outside of New York State.

Ms. Depew said NYS DOH agreed that this is the direction that the state needs to move in, and this is the direction that Medicaid is expected to move in as well.

Dr. Mahoney said that some patients do not want their information shared with particular providers, and that it was important patients understand what an all-in-consent means. Ms. Grey agreed and said there needs to be language in the form that people understand.

Dr. Martin said he was concerned about confusion over the rollout, given that patients may not understand why they are being asked to sign different forms. He said the SHIN-NY is never quite able to achieve the granularity and patient education that the Committee hopes will occur.

#### **VIII. Closing**

Mr. Levin said Committee members would be informed about a new scheduled date for the CARIN Alliance presentation. He thanked the Committee and adjourned the meeting.