

New York eHealth Collaborative Policy Committee Meeting
October 23, 2018
2 p.m. – 4 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on October 23, 2018. Present either in person or via telephone were:

Art Levin, Center for Medical Consumers, Co-Chair Policy Committee
Nance Shatzkin, Bronx RHIO
Steve Allen, HealthLink
Tom Check, Healthix RHIO
Amy Warner, Rochester RHIO
Deirdre Depew, NYS DOH
Christie Hall, NYS DOH
Jonathan Karmel, NYS DOH
James Kirkwood, NYS DOH
Jessica Eber, NYS OMH
Lynn Dicerbo, NYS OMH
Dan Tietz, AIDS Institute
Charles Gonzalez, AIDS Institute
Dr. John-Paul Mead, Cayuga Medical Associates
Dr. Tom Mahoney, Common Ground Health
Dr. David Cohen, Maimonides Medical Center
Linda Adamson, NYSTEC
Zeynep Sumer King, GNYHA
Evan Brooksby, HANYS
Val Grey, NYeC
Eric Boateng, NYeC
Cindy Sutliff, NYeC
Nathan Donnelly, NYeC
Alison Birzon, NYeC
Toby Lewis, 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 described the meeting objectives. He introduced Ms. Grey to provide the executive director update.

II. Executive Director Update

Ms. Grey introduced Ms. Birzon, the new Director of Federal Policy at NYeC, and said Ms. Birzon will help support federal level policy work.

Ms. Grey noted that it was expected that the Office of the National Coordinator (ONC) would provide a rule on information blocking in the very near future. As far as the Trusted Exchange Framework and Common Agreement (TEFCA), there were no real developments, although ONC does plan to release a revised version of the framework. Ms. Birzon noted that there is also an ONC regulation intended to clarify the rules regarding providing information to family members of a person with an addiction.

Ms. Grey observed that changes to 42 CFR Part 2 were not incorporated into the federal opioid bill. Mr. Levin asked who had objected to the change, and Ms. Grey said patient advocates had weighed in.

III. DOH Update

Mr. Levin introduced Mr. Kirkwood to provide an update. Mr. Kirkwood said that NYS DOH was going through the process of having Qualified Entities (QEs) work with medical record reviewers that are contracted with NYS DOH. He said it was an interesting use case, in that the SHIN-NY was being used to support a NYS DOH program. Dr. Mead asked if the QEs were supposed to be charging on a cost basis, saying that as public utilities QEs should not overcharge for their services. Mr. Kirkwood said it was based on costs in many cases. Ms. Grey said it was a balancing act, and it was a good conversation to continue. Ms. Shatzkin said she did not think of the QEs as monopolies, since some other organizations choose to build their own data pipes.

IV. Review of Revised Research Provisions

Mr. Belfort said that proposed revisions to the research policy provisions were discussed at a previous meeting, and based on that meeting and further discussions with the research tiger team there have been further edits to the proposals. He said the structure of the proposed provisions remains the same, with one section about de-identified data, another on limited data sets, and a third for protected health information for patient recruitment and retrospective research. Mr. Dworkowitz described the specific provisions related to de-identified data and limited data sets.

Mr. Allen said he thought the provision for accounting of disclosures for de-identified data and limited data sets seemed unnecessary. Mr. Check agreed. Mr. Belfort said the language was based on a recommendation from the previous meeting. Ms. Sumer King said she did not recall pushing for an accounting of disclosures, but wanted a more transparent process and an opportunity for participants to be more engaged. Mr. Belfort suggested that they remove the accounting of disclosures provision. Mr. Levin asked if there were any objections to approving the de-identified and limited data set provisions subject to such change. No objections were voiced.

Mr. Dworkowitz then described the specific rules regarding disclosure of protected health information under the proposed provision. Ms. Eber asked for clarification about what

disclosure is being made under the provision. Mr. Belfort said that the disclosure is the QE informing a provider that some of the provider's patients qualify for a research study.

Ms. Shatzkin asked if the researcher would need to get IRB approval prior to the QE searching for eligible patients. Mr. Allen said IRB approval should not be required for the QE to review the data, since this is already done without IRB approval. Mr. Allen said that Section 1.6.1(e) of the current policies already allow this without IRB approval. Mr. Check agreed.

Ms. Eber noted that the mental health law only allows for disclosure of mental health information for research purposes to a qualified researcher, not to a provider that is not conducting the research. She recommended that the provision be revised to reflect this. Ms. Sutliff asked Ms. Eber to send proposed language on this issue.

Mr. Allen asked about the provision that required the data supplier's agreement. He said he assumed that the data supplier does not need to approve each specific research project, but could instead agree to such disclosures by signing the participation agreement. Mr. Belfort agreed that this was the intention of the proposal. Ms. Sumer King expressed concern that this would allow a research project to be undertaken without the participation of the provider that is the source of the data. She asked: if a participant does not want their data to be used for research, what recourse do they have? Mr. Check responded that it depends on what the participant has agreed to in the participation agreement, and that some QE participation agreements give participants a right to refuse to participate in research, but this is not necessarily the case across the state. Ms. Sumer King suggested adding language saying that a participant does not violate the participation agreement if they do not allow their data to be used for research. Ms. Sutliff said this should not be put in policy, but instead should be a negotiation point between the QE and the participant.

V. Proposed Section 1.2.2(a)

Mr. Dworkowitz described the revisions to the proposed Section 1.2.2(a), which allows for the disclosure of HIV laboratory results for purposes of linkage and retention to care. Ms. Shatzkin asked how QEs were meant to implement the clause that allows disclosure to those with a clinical, diagnostic, or public health interest in the patient, since it was difficult to know who that is. Mr. Check said that Healthix would only use this exception to provide information to providers who are linked to a patient's care. Ms. Sutliff suggested they revise to include some examples. Mr. Karmel said it would be someone who is charged with coordinating a person's care, and it could include a managed care organization, a performing provider system, or a health home. Mr. Belfort said QEs can perform their own risk analysis as to whether they are willing to disclose to certain categories of providers, and some FAQs may make the QEs more comfortable.

Mr. Karmel said another option was to have NYS DOH approve projects on a case-by-case basis. Ms. Grey said she was concerned about tracking project approvals. Ms. Sutliff said they could have a targeted discussion on this point.

VI. Disclosures to Medicaid

Mr. Dworkowitz outlined a proposed policy that would allow QEs to make disclosures to NYS DOH and its contractors for purposes of administering the state Medicaid program.

Mr. Kirkwood said this is already done as part of the Medicaid program to calculate quality measures based on medical records.

Ms. Shatzkin asked if the proposal was based on the idea that Medicaid beneficiaries have already signed consent. Mr. Kirkwood said this was correct.

Mr. Levin asked if there was approval. No member voiced any objections.

VII. Closing

Mr. Levin asked if everyone agreed to the proposed changes regarding research. No one objected.

Mr. Levin thanked the Committee members and adjourned the meeting.

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