

New York eHealth Collaborative Policy Committee Meeting
May 15, 2019
12 p.m. – 4 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on May 15, 2019. 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
Todd Rogow, Healthix RHIO
Amy Warner, Rochester RHIO
Jill Eisenstein, Rochester RHIO
Nick VanDuyne, NYCIG
James Kirkwood, NYS DOH
Jonathan Karmel, NYS DOH
Deirdre Depew, NYS DOH
Lynn Dicerbo, NYS OMH
David Nardolillo, NYS OPWDD
Dr. John-Paul Mead, Cayuga Medical Associates
Dr. Tom Mahoney, Common Ground Health
Dr. Glenn Martin, Queens Health Network
Dr. David Cohen, Maimonides Medical Center
Herb Glose, Barclay Damon
Laura Alfredo, GNYHA
Zeynep Sumer King, GNYHA
Evan Brooksby, HANYS
Tom Hallisey, HANYS
Valerie Grey, NYeC
Eric Boateng, NYeC
Cindy Sutliff, NYeC
Nathan Donnelly, NYeC
Alexandra Fitz Blais, NYeC
Gamble Heffernan, NYeC
Bob Belfort, Manatt
Alex Dworkowitz, Manatt

The meeting was called to order by Mr. Levin at 12 p.m.

I. Welcome and Introductions

Mr. Levin welcomed the Committee members and described the meeting agenda. Mr. Levin introduced Ms. Grey to provide an update.

II. NYeC Executive Director Update

Ms. Grey provided an overview of federal developments relevant to the SHIN-NY. She explained that the federal government was trying to develop a norm that information should be shared unless there is a reason not to share the data, as well as create a level playing field. She noted that both the CMS and ONC proposed rules are ambitious, and include provisions regarding information blocking and expanding the common core clinical data set.

Ms. Grey said that TEFCA was another important development, and that a revised proposal had recently been released. Ms. Shatzkin asked if NYeC would circulate draft comments in response to these rules and the TEFCA, and Ms. Grey answered yes. Dr. Mead asked if there would only be one recognized coordinating entity (RCE). Ms. Grey said that there would be only one, but that ONC was signaling more flexibility regarding the number of Qualified Health Information Networks (QHINs) participating in TEFCA.

III. Death Notification Policy Language

Ms. Sutliff explained that the Policy Committee had already reviewed a proposed policy on death notifications, but that changes had been made to the proposed language based on comments at the last meeting. Mr. Dworkowitz noted that two changes were made: death notifications could no longer include location of death, and deaths occurring in mental health facilities were no longer treated differently. Ms. Shatzkin asked about the timing of implementation. Ms. Sutliff said that if the Policy Committee approved the new language, it would be sent to the NYeC board and DOH for approval, and that an FAQ regarding implementation would be developed.

Hearing no objections to the proposed language, Ms. Sutliff said the language would be sent to the NYeC board and DOH for approval.

IV. Disclosures to Coroners and Medical Examiners

Ms. Sutliff noted that the issue of disclosures to coroners and medical examiners had been raised at the prior meeting, and that further research had been undertaken on the issue. Mr. Dworkowitz provided background information on coroners and medical examiners in New York State. He noted that under New York State law, medical examiners, but not coroners, must be physicians, and that only physicians are permitted to determine cause of death. He observed that under current policies, public health agencies may access SHIN-NY data for determining cause of death in some circumstances, but in other circumstances there is no exception that permits disclosures of SHIN-NY data for such purpose.

Ms. Shatzkin said she thinks allowing disclosures to death investigators makes sense, and that coroners should be allowed to access SHIN-NY data regardless of the structure used by a given county. Dr. Mead questioned the need to provide data to coroners who are not licensed physicians. Dr. Cohen asked what the downside is of providing access to unlicensed coroners. Mr. Belfort said that in some counties, a coroner may know a lot of people in town, and could have open access to everyone's medical records. Dr. Cohen said this was true of every practitioner that can access SHIN-NY records. Mr. Belfort said the idea is that doctors are

trusted more to respect privacy. Dr. Martin agreed, saying he did not like the idea of giving an elected official with no medical qualifications access to SHIN-NY data.

Ms. Warner questioned whether permitting access to death investigators would create a new auditing responsibility. Ms. Shatzkin said she did not think the proposal would create a requirement to audit all disclosures to death investigators.

Mr. Karmel noted that in many cases, a coroner acts more as a law enforcement officer than as a public health official, and that allowing law enforcement access to the SHIN-NY would be a new area for the SHIN-NY. Dr. Martin said there needs to be a minimum necessary standard, and that disclosures need to be controlled.

Mr. Levin said they were hearing consensus on the issue, and that proposed language would be provided at the next meeting.

V. Consent Workgroup Update

After a break, Ms. Sutliff described the process of the consent workgroup, which has been considering the issue of whether a consent form naming one QE can be recognized by a different QE. She said that it was a complex issue and that it was important to hear from QEs. She said on May 3, four QEs presented comments to the consent workgroup, and while there was not agreement on all areas there was general agreement that further clarification from DOH and modifications to the consent form are needed. Mr. Dworkowitz described several policy options that emerged from the discussion, including DOH guidance notifying QEs of their ability to recognize consents of other QEs and, on the opposite end of the spectrum, DOH guidance informing QEs that they should not recognize those consent forms.

Ms. Warner thanked NYeC for issuing a corrective notice that informed Committee members that Rochester RHIO's consent form had been approved by DOH as compliant with 42 C.F.R. Part 2. She expressed concern that allowing QEs to recognize consent forms obtained by other QEs would not comply with Part 2, and she suggested that DOH and NYeC obtain comments from patient advocacy groups as well as further clarification on Part 2 concerns before moving forward.

Ms. Warner said there are 22 references to Rochester RHIO on its consent form, and that patients understand that it is Rochester RHIO that is providing them with a service, not another QE. She explained that she gets phone calls on a weekly basis from patients asking for assistance, and that their 97% consent rate was a reflection of trust in the Rochester RHIO. She said that she views access under sPRL as different from the consent transferability issue.

Dr. Mead said it would be good to get the patient's perspective, but that his presumption is that patients care about which doctors can see their data through networks, not which network is used to access their data. Mr. Levin said there is no evidence that patients care about this issue. Ms. Warner said she receives calls every week asking about Rochester RHIO. Dr. Cohen said that when his hospital provides a consent form, the identification of Healthix does not enter into the discussion. Mr. Rogow said the QEs don't collect consents, providers do, and that if a provider

chooses to select a different QE the provider should be able to do so without losing the consents it has obtained.

Ms. Shatzkin said she did not want to create a situation where consents signed before a certain date are treated differently than consents signed after such date. Dr. Martin said the central flaw is that there is no centralized consent process, and that the discussion was about how to deal with this. He said he thought people need to be notified. Ms. Alfredo disagreed, saying that requiring notification is equivalent to requiring a second consent process.

Mr. Rogow said the Committee should not impose an additional burden on participants, who are the customers of the QEs. Ms. Warner said that patients have the right to be informed.

Mr. Karmel said the process aimed to achieve consensus among Committee members, but this may be an instance where there is no consensus, and they could move forward with a proposal where two QEs disagree with that proposal. Mr. Karmel said the new consent form should not name a particular QE at all, and that such form should be publicized for a while before transferability of consents is operationalized.

Mr. Allen said that when the QEs were formed, there were good reasons to use QE specific branding on consent forms. He added that he agreed that having different rules for different consent forms would be a logistical nightmare. Ms. Eisenstein observed that the form requires a phone number and website for patients to contact, and they needed to think through the complexity of how to address this.

Ms. Sumer King said at the federal level, QHINs would eventually operate under TEFCA, and that providers will want to connect to only a QHIN. She said the SHIN-NY's rules could be confusing, and that providers could gravitate toward a national QHIN instead.

Dr. Mead said he thought there was a plurality in favor of the transferability of consents. Ms. Sutliff agreed, saying that NYeC and DOH would collaborate to develop draft language on this issue as well as establish a process for redesign of the SHIN-NY consent form.

VI. Social Determinants of Health Legal Analysis Initiative

Mr. Levin introduced Ms. Warner to share learnings from the systems integration project. Ms. Warner explained that Rochester RHIO has been working to integrate various data systems to address care coordination. For example, a child may not appear in school, and a person working in child protective services would have access to that child's information. She said the project was a wonderful opportunity to help provide better care to children and adults in crisis mode. Ms. Eisenstein added that their plan is to build upon care coordination platforms existing in the community and extract data from such platforms to create a data hub.

Mr. Rogow applauded Rochester's work, and commented that it is worth exploring census data that has useful information regarding social determinants of health.

Ms. Shatzkin said there are a couple of different models, one of which where the HIE expands to manage many additional data sources. Ms. Eisenstein said there is a difference between social determinants of health – where health care providers do a better job by understanding their patients – and cross-sector exchange, which is where Rochester RHIO is trying to go.

Dr. Mead said there may be worries that the data could be used for other purposes, such as being used to track who is not paying their taxes or who is not documented. Ms. Warner said she understood that concern, but that they have not gotten into those issues.

VII. Closing

Mr. Levin thanked the Committee members for their time and adjourned the meeting.

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