A meeting of the NYeC Policy Committee was held on March 19, 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, HealtheLink  
Tom Check, Healthix RHIO  
Karen Romano, HealtheConnections  
Amy Warner, Rochester RHIO  
Taiymoor Naqi, HIXNY  
James Kirkwood, NYS DOH  
Jonathan Karmel, NYS DOH  
Christie Hall, NYS DOH  
Geraldine Johnson, NYS DOH  
Lynn Dicerbo, NYS OMH  
David Nardolillo, NYS OPWDD  
Dr. Virginia Scott-Adams, NYS OPWDD  
Margaret Vijayan, NYS OPWDD  
Dr. John-Paul Mead, Cayuga Medical Associates  
Dr. Tom Mahoney, Common Ground Health  
Dr. Glenn Martin, Queens Health Network  
Linda Adamson, NYSTEC  
Laura Alfredo, GNYHA  
Zeynep Sumer King, GNYHA  
Eric Boateng, NYeC  
Cindy Sutliff, NYeC  
Nathan Donnelly, NYeC  
Gamble Heffernan, 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 agenda. Mr. Levin introduced Mr. Kirkwood to provide an update.

II. DOH Update
Mr. Kirkwood announced that the revisions to the SHIN-NY policies and procedures had been approved and posted to DOH’s website. Ms. Sutliff said that NYeC would provide a document explaining where changes have been made and will introduce policy guidance. The revised version will also be available via the NYeC website.

III. NYeC Update: Policy Guidance Status

Mr. Levin introduced Ms. Sutliff to describe the policy guidance process.

Ms. Sutliff explained that NYeC has been working on revising the policy guidance process. As part of those changes, NYeC will introduce guidance documents on new policy provisions regarding research and transmittals. Ms. Sutliff said that the guidance would be presented to the implementation subcommittee of the Business and Operations Committee to make sure the guidance fits the needs of implementers. She said the guidance would then be adjusted based on commentary and distributed to key stakeholders as well as posted on the NYeC website.

IV. New Policy Proposal Approach

Ms. Sutliff explained that NYeC is looking to promote an evidence-based approach to policy proposals. Going forward, policy proposals should frame a use case and address various issues such as workflow, costs and revenues, and what success measures might be. She said the death notifications proposal followed this approach, and that this framework should be used in the decision-making process going forward.

Mr. Check said he thought this was a really good idea, and he suggested that those bringing forth proposals should describe potential downsides. Ms. Sutliff agreed. Mr. Allen said he thought it was appropriate to express this in the concept of risks.

V. Proposed Death Notification Policy Provision

Mr. Dworkowitz provided an overview of federal and state laws relevant to death notifications and the proposed policy language regarding death notification proposals. Mr. Allen described how HealtheLink implements such notifications. He noted that this information can be very helpful in regards to care management activities, and there is also a use case for payers. Mr. Allen added that he did not anticipate significant costs associated with this proposal.

Dr. Mead expressed concern about what may happen if a notification wrongly reported that a person had died, which could result in a person losing health care coverage. Mr. Allen said that based on HealtheLink’s review of the data, there are a few instances where that occurs, and they are trying to understand why that happens. Dr. Martin asked how frequently this occurs. Mr. Allen said it happened infrequently: of a file of 20,000 records, 123 had incorrect information, but in nearly all of those cases the error was in regards to the date of death, not the fact of death, but there was one instance where a person was incorrectly reported to have died.
Dr. Martin noted there are also false negatives, in that many people die but would not be included in this database. Mr. Allen agreed, and that based on 16,000 deaths in a region, it appears that about 12,000 would occur in a facility such that a notification would be sent.

Dr. Martin said it seemed silly that notifications could not be sent from a mental health facility. Mr. Belfort said this distinction was based on an interpretation of the mental hygiene law but noted that feedback from DOH or OMH would be welcome. Ms. Dicerbo said they could look at this issue. Mr. Allen said if the location of death was eliminated from the record then there would be no need to treat mental health facilities differently. Ms. Dicerbo said there would not be an issue if the zip code or town of death was included instead of the name of the facility. Ms. Shatzkin expressed concern that converting the name of a facility to a name of a town would place burden on QEs. Mr. Allen said all geographic location could be suppressed. Ms. Sutliff agreed, saying the option of location could be removed from the provision. Mr. Levin asked if there were any objections if geographic location and the mental health carve out were removed from the proposal. No one objected, and Mr. Levin said a revised proposal with the revised language either would be circulated via email or reviewed at the next Policy Committee meeting on May 15th.

VI. Disclosures to Non-Covered Entities

Ms. Sutliff said the Policy Committee was addressing disclosures to non-covered entities this year, and that the Committee would first address disclosures to coroners and medical examiners. She said NYeC was not putting forward any particular provisions, but instead opening up the topic for discussion. Mr. Dworkowitz provided an overview of HIPAA and New York State law regarding disclosures to coroners and medical examiners and asked the Committee about the level of interest in permitting disclosures to coroners.

Ms. Shatzkin asked if medical examiners are part of departments of health. Mr. Check said they sometimes can be part of a county department of health, but that is not always the case. Dr. Mead said a County can designate a physician to be a medical examiner. Mr. Allen said that if the medical examiner was part of a public health department then the public health provisions of the policies already permit disclosures to such medical examiner. Ms. Sutliff and Ms. Shatzkin agreed.

Ms. Sutliff said the concern was about those medical examiners who fall outside public health departments and therefore cannot access SHIN-NY data in the capacity of public health agencies. Mr. Allen said that medical examiners find it very useful to access SHIN-NY data, and Ms. Shatzkin agreed. Mr. Levin asked: why are some medical examiners part of a public health department and why are others not? Mr. Check said in New York City, the chief medical examiner reports to the health commissioner and therefore is part of the public health department, but in Suffolk County the medical examiner reports to the County Executive.

Mr. Check said he was comfortable with allowing medical examiners to become Participants, and Ms. Shatzkin agreed. Mr. Naqi said that under the public health law, medical examiners have to determine the cause of death within 72 hours, and that they are reluctant to ask family
members for relevant information. Therefore, allowing medical examiners to access data through the SHIN-NY could be a win-win.

Dr. Martin asked about the distinction between medical examiners and coroners. He noted that it makes sense to allow a medical examiner who is trying to determine cause of death to access SHIN-NY data, but questioned why a coroner would need SHIN-NY data if the coroner does not need to determine cause of death. Ms. Sutliff said they would undertake some research on this issue, and they would come back to the May meeting with use case proposals. Ms. Shatzkin said allowing funeral directors to access SHIN-NY data seemed like a step too far. Dr. Martin agreed.

VII. Closing

Ms. Sutliff said that in April, there would be a conference call meeting to discuss the diversity of consent forms and related consent issues, and that the April meeting would be of a small workgroup to discuss these issues rather than the full Committee. Recommendations from the workgroup will be presented to the full Policy Committee. She said the next face-to-face meeting would be in May.

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