

**New York eHealth Collaborative Policy Committee Meeting**  
**April 22, 2020**  
**2 p.m. – 4 p.m.**  
**Meeting Notes**

A meeting of the NYeC Policy Committee was held on April 22, 2020. Present via telephone were:

Art Levin, Center for Medical Consumers, Chair of Policy Committee  
Nance Shatzkin, Bronx RHIO  
Steve Allen, HealtheLink  
Dan Porecca, HealtheLink  
Amy Warner, Rochester RHIO  
Karen Romano, HealtheConnections  
Taiymoor Naqi, Hixny  
Todd Rogow, Healthix  
James Kirkwood, NYS DOH  
Jonathan Karmel, NYS DOH  
Dan Schiller, NYS DOH  
Molly Finnerty, NYS OMH  
David Nardolillo, OPWDD  
Dr. John-Paul Mead, Cayuga Medical Associates  
Dr. Tom Mahoney, Common Ground Health  
Dr. David Cohen, Maimonides Medical Center  
Dr. Glenn Martin, Queens Health Network  
Lorna Thorpe, NYU Langone  
Chuck Bell, Consumer Reports  
David Lee, New York City Department of Health and Mental Hygiene  
Puja Khare, GNYHA  
Tom Hallisey, HANYS  
Linda Adamson, NYSTEC  
Jill Eisenstein, BOC Representative  
Val Grey, NYeC  
Cindy Sutliff, NYeC  
Elizabeth Amato, NYeC  
Alexandra Fitz Blais, NYeC  
Toby Lewis, NYeC  
Zoe Barber, 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 introduced Mr. Kirkwood to provide an update.

## **II. DOH Update**

Mr. Kirkwood described NYS DOH's efforts to support a response to the COVID-19 pandemic, including waivers related to telehealth and the SHIN-NY, making available to the SHIN-NY electronic lab information through the Electronic Clinical Laboratory Reporting System (ECLRS), and working with Qualified Entities (QEs) on research questions.

Ms. Thorpe asked if there was any discussion of using the SHIN-NY for contact tracing. Mr. Kirkwood responded that such discussions have not occurred yet.

## **III. Executive Director Update**

Ms. Grey said that the COVID-19 crisis has slowed legislative activity related to privacy, but that such issues should become front and center once the legislature returns.

Ms. Grey said that if the state receives no additional assistance, it is looking at a 20 percent cut to healthcare, education and local government services, and there are a lot of financial pressures on the state at the moment.

On the federal side, Ms. Grey described some of the delays in the application of the interoperability rules. She also noted that the CARES Act provision on substance use disorder confidentiality could impact the future of the SHIN-NY.

## **IV. SHIN-NY COVID-19 Policies**

Ms. Sutliff noted that the prior meeting had focused on NYS DOH's waivers to support the state's COVID-19 response. She said that the SHIN-NY should revise its policies to reflect these changes, including by establishing a policy that allows for waivers during a public health emergency.

Mr. Dworkowitz outlined the proposed policy, which states that NYS DOH has the authority to waive provisions of the SHIN-NY policies during public health emergencies and also permits an organization to contribute data to the SHIN-NY even if it is not a business associate of a QE. Mr. Karmel explained that NYS DOH already has the authority to change the policies at any time, but this provision indicates that NYS DOH can do so at a moment's notice without having to consult with the Policy Committee and other stakeholders. Ms. Grey said that the Governor already has the authority to waive laws through executive orders. Mr. Karmel agreed, but noted that such authority applied to orders from the Governor itself, not to changes in policies adopted by NYS DOH staff.

Mr. Dworkowitz said the policy change would put stakeholders on notice that changes could be made through waivers. Ms. Shatzkin said such an approach made sense. Mr. Levin said he did not see any reason not to make these changes.

## **V. Life Insurance Policies**

Ms. Sutliff said that Healthix and HealtheLink had submitted documentation reflecting the viewpoint that the life insurance provisions in the SHIN-NY policies are too onerous. Mr. Rogow said Healthix had received two pieces of feedback from life insurers. The first is giving patients a 72-hour period to retract their consent is unnecessary. The second, larger concern is the requirement that a consent to disclose to life insurers take the form of a level 2 consent. Mr. Rogow explained that this requirement forces life insurers to use a second authorization form in addition to their standard authorization form. Mr. Porecca said that HealtheLink would like to be able to disclose data to life insurers without the life insurer having to get a second signed consent from the same patient.

Mr. Allen observed that there are two requirements of a Level 2 consent that are problematic for life insurers: the notice regarding the QE benefiting financially and the reference to data suppliers in the form.

Ms. Shatzkin said the Policy Committee had stopped managing the consent forms at this level of detail and asked why would they require such detail here. Mr. Belfort noted that from a HIPAA standpoint, the information about remuneration is only needed if the form is used for marketing purposes, and this disclosure was not for purposes of marketing.

Ms. Sutliff asked for comments on the 72-hour requirement. Mr. Belfort inquired whether patients were responding to the opportunity to revoke their consent. Mr. Rogow said there is no information on this, since Healthix only has had two transactions where the life insurer was willing to obtain a second consent. He said there was some urgency to this request given the higher demand for life insurance during the COVID-19 crisis.

Dr. Martin said patients would be signing a consent form that would give life insurers access to a system that the patients didn't know existed in the first place. He said this upset him, and he did not have great faith in the consenting process undertaken by life insurers. Mr. Porecca responded that this change would benefit patients, since they will more quickly receive a response to their life insurance request.

Ms. Shatzkin said she was inclined to support a change to the life insurance policies, but wanted to understand whether there was an agreement between the QE and the life insurer. Mr. Rogow said there are signed contracts between these organizations, and life insurers are restricted in terms of how they use the data they receive.

Mr. Levin inquired whether they had agreement to remove the 72-hour piece. Dr. Martin said the 72-hour requirement was reasonable and noted that some of his patients have rescinded their consent to life insurers. Ms. Shatzkin suggested that life insurance agents could be trained on how to explain the meaning of consent. Mr. Belfort said he did not think such training would

resolve Dr. Martin's concern, but added if a patient did rescind consent, the patient could face a penalty in the inability to obtain life insurance.

Mr. Levin said language would be drafted regarding proposed life insurer changes and would be provided back to the Committee for written comment prior to the next Policy Committee meeting.

## **VI. CARES Act Changes**

Mr. Dworkowitz explained that a provision of the CARES Act changed the substance use disorder (SUD) confidentiality statute that underlies 42 C.F.R. Part 2. He described the changes regarding patient consent and enforcement.

Ms. Warner asked if QEs would still be required to follow the consent form requirements set forth at 42 CFR 2.31. Mr. Dworkowitz responded that those requirements may be revised as a result of the new statute.

## **VII. Patient Mediated Exchange**

Mr. Belfort explained that certain provisions of the new interoperability rules recently released by the Office of the National Coordinator (ONC) and the Centers for Medicare & Medicaid Services (CMS) could foster patient mediated exchange. He said that under this model, protected health information (PHI) will be disclosed to apps, which often will not be business associates of a provider or health plan. The apps therefore will not be subject to HIPAA but would be subject to other laws such as the Federal Trade Commission Act.

Mr. Belfort said that these apps may view commercialization of data as a major business opportunity, and this could be an area where the SHIN-NY can help guide consumers.

Mr. Naqi noted that Apple will not connect directly with health information exchanges. Instead, the exchange will send data to a partner organization that sends the patient's data to Apple Health through an API. This allows the patient to own their data and populate Apple Health with their data.

Ms. Grey asked if the SHIN-NY came up with a set of reasonable criteria for apps to connect to the SHIN-NY and applied those criteria consistently, it seems like such activity would not be considered information blocking. Mr. Belfort responded that such an approach needs to be taken carefully, since every restriction needs to fit within a particular information blocking exception.

## **VIII. Closing**

Mr. Levin adjourned the meeting and wished everyone good health. The next meeting is scheduled for May 20<sup>th</sup> from 2-4 pm via zoom video conference call.