New York eHealth Collaborative Policy Committee Meeting
May 15, 2018
2 p.m. – 4 p.m.
Meeting Notes

A meeting of the NYeC Policy Committee was held on May 15, 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, HealtheLink
Tom Check, Healthix RHIO
Amy Warner, Rochester RHIO
Deirdre Depew, NYS DOH
Geraldine Johnson, NYS DOH
Jonathan Karmel, NYS DOH
David Nardolillo, OPWDD
Megan Jay, OPWDD
Virginia Scott-Adams, OPWDD
Dan Tietz, AIDS Institute
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
Linda Adamson, NYSTEC
Laura Alfredo, GNYHA
Evan Brooksby, HANYS
Val Grey, NYeC
Eric Boateng, NYeC
Cindy Sutliff, NYeC
Nathan Donnelly, 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 a summary of the topics to be covered by the meeting and the materials to be discussed.

II. Executive Director Update

Ms. Gray explained that NYeC was continuing to focus on the SHIN-NY 2020 roadmap, developing performance-based contracts with QE partners, and working with the new advisory groups. On the national level, she said ONC is taking its time to review the comments on the

TEFCA, and is still processing and absorbing the points of commentators. She said work was ongoing on the information blocking regulation and the new proposed rule on meaningful use was being reviewed.

III. SHIN-NY Modernization Roadmap

Mr. Levin outlined the driving forces behind the need for modernization of the SHIN-NY policies. He discussed potential issues for modernization, including consent, research, access, and standardization. Mr. Levin compared the roadmap goals to possible 2018 Policy Committee activities in support of those goals.

Ms. Sutliff explained that the goal was to begin with low hanging fruit, such as changes regarding research, and to lift some restrictions for the sake of modernization. In contrast, there are longer term priorities that can at least be framed in the interim.

IV. Transmittals to Non-Participants

Mr. Levin said the policy regarding transmittals to non-participants will be proposed at the NYeC Board meeting on May 22. Mr. Levin said that in response to a concern from Dr. Martin, QEs would be required to give enrollees 72 hours to respond to notification of a potential transmittal to a life insurer, instead of 24 hours as had been initially proposed.

Ms. Sutliff said implementation of the life insurance policy would not occur until members of the Business and Operations Committee have discussed an approach with which they feel comfortable. Ms. Shatzkin asked if actions would be taken to make insurers and patients more aware of the policy change. Ms. Grey said there were no formal plans for broadcasting the new policy, but there are variety of levers that can be used for education, including using the new consumer advisory group to spread the word.

Dr. Mahoney asked if a provision could be adopted by state insurance authorities to ensure that life insurers followed this policy. Mr. Belfort said the New York State Department of Financial Services could not enforce this policy because there is nothing in state insurance law that requires life insurers to follow this policy. Mr. Belfort said the remedy for patients who believed life insurers were acting inappropriately would be to file a complaint, and a QE could cut off a life insurer's access to data if a patient complained. Dr. Martin questioned whether consumers would know to file a complaint.

V. Research

Mr. Levin introduced the next item on the agenda, potential reform of the research policies. Mr. Dworkowitz described the research provisions in the policies for protected health information, limited data sets, and de-identified information, and he explained how the rules for all three categories were stricter than what HIPAA mandated.

Dr. Mahoney suggested they consider the SPARCS' experience with data sharing. Mr. Levin and Dr. Martin agreed.

Ms. Sutliff asked how the Committee Members felt about the current research policies and whether they are overly restrictive. Mr. Levin asked how the research authorization requirements compared to the HIPAA authorization requirements. Mr. Belfort said the core issue was not what is in the authorization, but whether authorization should always be required in the first place. Mr. Belfort said that getting authorization for clinical research is not highly burdensome, but it is if retrospective research is being conducted, since the researcher has no contact with patients. Mr. Belfort said that in regards to de-identified data, the heart of the issue is whether you believe de-identified data is really de-identified.

Mr. Karmel said if data cannot be used to identify a person, then there is no need to go to an IRB. Dr. Martin said that in practice, a QE will want an exemption letter from an IRB.

Mr. Levin asked if there was a standard for saying what data is de-identified. Mr. Belfort said he was not aware of a standard other than the HIPAA standard. Mr. Karmel said he would share a policy regarding a standard for de-identification of data.

Mr. Check said the QEs had discussed this issue recently, and they concluded that the current policies are not too burdensome, since they allow participants to conduct appropriate research. He said the QEs did not see a reason to make any changes. Mr. Levin said that stricter policy provisions need to be justified. Ms. Grey said this was part of an overarching review of the Policies, and it goes to a sustainability question.

Mr. Belfort said there was a huge chasm between the Policies and what HIPAA allows for research on identifiable data, and that the Policies make it very difficult to do retrospective research on identifiable data that is unconnected to treatment.

Mr. Levin said this issue would be taken back to a tiger team. Ms. Shatzkin recommend that they would benefit from hearing from representatives in the research world about this issue. Dr. Martin agreed.

SAMHSA Guidance

Mr. Dworkowitz noted that SAMHSA had recently released two fact sheets on 42 C.F.R. Part 2. He said the guidance did not contain any surprises and that the Policies were consistent with the new facts sheets.

VI. Closing

After Ms. Sutliff asked if anyone else had any further business, Mr. Levin thanked the Committee members and adjourned the meeting.

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