# New York eHealth Collaborative Policy Committee Meeting July 20, 2022 2 p.m. – 3:30 p.m. Meeting Notes

A meeting of the NYeC Policy Committee was held on July 20, 2022. Present via telephone or videoconference were:

Policy Committee Voting Members
Art Levin, Chair, Center for Medical Consumers
Dr. Ram Raju, Health Disparities Consultant
Taiymoor Naqi, Hixny
Steve Allen, HealtheLink
Alan Cohen, JASA
Chuck Bell, Consumer Reports

### Other Attendees

Nance Shatzkin, Bronx RHIO

Liana Prosonic, HealtheConnections

Elizabeth Amato, HealtheConnections

Patricia Burandt, HealtheLink

Dan Porreca, HealtheLink

Todd Rogow, Healthix

James Kirkwood, NYS DOH

Jonathan Karmel, NYS DOH

Deirdre Depew, NYS DOH

Chelsea Sack, NYS DOH

Michelle Warner, NYS DOH

C.J. Barber, NYS OMH

Tammy Harris, OPWDD

Meg Vijayan, OPWDD

Jen Freeman, OPWDD

Dr. John-Paul Mead, Cayuga Medical Associates

Michelle Casey, Planned Parenthood of Central and Western New York

Zeynep Sumer King, GNYHA

Puja Khare, GNYHA

Tom Hallisey, HANYS

Leilani Prusky, NYSTEC

Michael Golden, NYeC Board

David Liss, NYeC Board

David Horrocks, NYeC

Cindy Sutliff, NYeC

Alison Bianchi, NYeC

Don Juron, NYeC

Kayana Cobb, NYeC

Kathryn Lucia, NYeC

Julia Sisti, NYeC Sam Roods, NYeC Bob Belfort, Manatt Alex Dworkowitz, Manatt Julian Polaris, 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 an overview of the agenda, the meeting materials, and the meeting objectives. The June meeting summary notes were approved by the Committee members.

# II. Federal and State Updates

Ms. Bianchi noted both the federal and state governments have been busy following the Dobbs decision overturning Roe v. Wade. She said that the federal government had issued privacy guidance regarding reproductive health services, and that Governor Hochul had introduced a legislative package to protect providers of reproductive health services and their patients.

Ms. Bianchi noted that the roll out of TEFCA continues, with Epic announcing that they plan to become a QHIN.

Ms. Bianchi explained that the HHS spring 2022 regulatory agenda had been released, with the HIPAA rule release date scheduled for March 2023 and the information blocking enforcement rule scheduled for September 2022.

# III. DOH Update

Mr. Kirkwood said revisions to the SHIN-NY regulation hopefully would be scheduled for an upcoming state PHHPC (Public Health and Health Planning Council) agenda. He noted that the regulatory changes would include the all-in consent model, as well as expanding the number of providers that would connect to the SHIN-NY.

### IV. Alternative Consent Forms

Ms. Sutliff said that the Policy Committee had approved in principle changes to the alternative consent policy and now needed to approve specific policy language. Mr. Dworkowitz described the proposed language. He explained that under current policies, QEs are free to recognize many different alternative consent forms, but under the policy revisions QEs could only recognize

alternative consent forms in limited circumstances once the all-in consent form was in widespread use.

Mr. Allen said he assumed that the term "state approved AIC" meant a Level 1 consent form that has no other purpose. Ms. Sutliff said this could be clarified. Mr. Allen asked if the policy would apply to life and disability insurers; Mr. Dworkowitz responded that the restrictions would not apply to life and disability insurers since they do not use protected health information for Level 1 purposes.

Mr. Naqi asked: what is the problem we are trying to solve by limiting the use of alternative consents? He said QEs currently try to push individuals to use the model form, but have the discretion to permit alternatives. Ms. Sutliff answered that the intent with all-in consent is to move away from having multiple consent forms in the state. Ms. Depew agreed, saying DOH wants to get to a singular form of consent so that when a patient signs a form the patient knows what the patient is agreeing to.

Mr. Raju said the all-in consent form needed to be translated. Mr. Karmel said the state already has a process for translating its forms. Mr. Cohen said he agreed with the policy but recommended removing the reference to "grandfathering" in the policy summary given the term's racist history. (In the United States, 'Grandfather Clause' originally referred to provisions adopted by seven Southern states after the Civil War in an effort to disenfranchise Black voters by requiring voters to pass literacy tests or meet other significant qualifications, while exempting from such requirements those who were descendants of men who were eligible to vote before 1867. This type of law ensured that illiterate white Americans were able to vote while preventing Black Americans from voting. The practice of grandfather clauses ended in 1965 when the Voting Rights Act was implemented.)

Ms. Shatzkin asked for clarification on when the AIC date would occur. Ms. Sutliff said it was not tied to roll out of using the all-in consent form under the New York State of Health.

Mr. Levin asked for a vote. Attending members agreed to the changes, absent Mr. Naqi who abstained.

## V. De-Identified Data Policy

Mr. Dworkowitz explained that the de-identification policies had recently been changed to require data use agreements for the disclosure of de-identified data. However, the policies had previously permitted the disclosure of the count of the number of patients that met proposed clinical trial criteria without such an agreement, so long as the count could not be used to identify any patients. Mr. Dworkowitz noted that a Committee member had proposed to re-insert the prior policy language regarding disclosure of clinical trial counts, as well as to align the definition of de-identified data to the HIPAA definition.

Mr. Levin asked if there were any objections to the proposed policy change. No objections were voiced, and Committee members indicated they supported the revision.

# VI. Open Forum: SHIN-NY Implications of the Overturning of Roe v. Wade

Mr. Levin explained that the Committee needed to be aware of the implications of the Dobbs Supreme Court decision, which overturned Roe v. Wade. He introduced Michelle Casey, president and chief executive officer of Planned Parenthood of Central and Western New York.

Ms. Casey said her organization was seeing an influx of patients from other states, mostly from nearby states such as Ohio and Pennsylvania but also some from Texas. She explained that in the case of medication abortion, Planned Parenthood provides the initial dose of Mifepristone in the clinic, but that the second dose of misoprostol needs to be taken 24-48 hours later, and that the patient could be back in the patient's home state when taking the second dose. She noted that the process of medication abortion is generally the same as the process for miscarriage management, and that people are worried that documentation will be used against them.

Ms. Casey said that Planned Parenthood of Central and Western New York receives patient information form other systems, but avoids sharing abortion related information. She noted that the New York affiliates do not currently use Epic but plan to do so, in which case they would aim to prevent the sharing of abortion related information via Epic. Ms. Casey said she does not think abortion related information should be included in the SHIN-NY for now, although she does not like such an outcome from a public health perspective.

Ms. Shatzkin asked for guidance on the definition of data that should be protected by the SHIN-NY by either not storing it in the SHIN-NY or tagging it for extra protections. Ms. Casey responded that it could include anything related to pregnancy, and that even the fact that someone had a positive pregnancy test and did not end up with a child could be used against a person. She also noted that in-vitro fertilization could be illegal in some states.

Mr. Polaris described legal issues that have emerged following the Dobbs decision. He noted one important issue is the possibility of cross-state liability, with states trying to make it more difficult for individuals to cross state lines to receive abortions out of state. He noted that most states have laws on the books that state the presumption is that their laws do not reach out-of-state conduct, but now some states are trying to pass laws that indicate that such laws do touch out-of-state conduct. He said in-person services delivered in New York could remain low risk, but services delivered via telehealth would be higher risk, since telehealth services are deemed to apply where the patient is located.

Mr. Polaris noted that conflicts regarding EMTALA had also emerged, with CMS putting out guidance informing hospitals that they must provide stabilizing treatment which includes life-saving abortions even if state law makes such abortions illegal.

In response to a question, Mr. Polaris noted that state courts were in the best position to determine the scope of their state laws, but that if there were an irreconcilable conflict between state laws, the case may need to be decided by the United States Supreme Court.

Mr. Levin thanked Ms. Casey and Mr. Polaris for participating and their insights.

Ms. Sutliff noted that next steps on this issue would be to convene an out-of-cycle Policy Committee meeting following the hosting of several key stakeholder discussions to gather further input and insights related to the issues of abortion data in the SHIN-NY and related policies. Ms. Sutliff indicated that more information on when those meetings would be held would be sent out to the members of the Committee and that the out-of-cycle meeting would be held prior to the September 15<sup>th</sup> full Policy Committee meeting.

# VII. Closing

Ms. Sutliff reminded Committee members that no meeting would take place in August, and they would reconvene on September 15<sup>th</sup>. Mr. Levin thanked the Committee and adjourned the meeting.