

CBO Roundtable Summary Report of Key Findings

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NEW YORK eHEALTH
COLLABORATIVE

CBO ROUNDTABLE SUMMARY REPORT OF KEY FINDINGS

Executive Summary

In September, the New York State Department of Health submitted an amendment to the State's 1115 Medicaid demonstration waiver to the Centers for Medicare and Medicaid Services (CMS) entitled 'New York Health Equity Reform.' The waiver amendment aims to reduce health disparities exacerbated by the COVID 19 pandemic in good part through investment in social services including those provided by Community Based Organizations (CBOs). Critical to achieving the vision of the 1115 Waiver initiative is the ability to provide Medicaid enrollees with the social services they need through CBOs engaged in delivering such services. The Waiver requires certain data exchange functions and envisions the SHIN-NY as key to supporting CBOs in the delivery of cross network data exchange and reporting.

The SHIN-NY Privacy and Security Policies and Procedures (the SHIN-NY Policies) govern how data in the SHIN-NY may be used and disclosed. The SHIN-NY Policies address, among other things, who may participate in the SHIN-NY and how access to SHIN-NY data may be allowed. Current SHIN-NY Policies allow for both covered and non-covered entity CBOs to participate in the SHIN-NY with heightened rules that govern non-covered entities related to access to an individual's protected health information (PHI) and security requirements aimed at ensuring a person's health information is protected and private. Given the scope and expectations of the 1115 Waiver and the anticipated role of the SHIN-NY to support the waiver implementation, the SHIN-NY Policy Committee took under advisement several possible policy areas that may pose barriers to CBO participation and the exchange of social determinants of health (SDOH) data via the SHIN-NY.

To address the SHIN-NY policy concerns the SHIN-NY Policy Committee convened a CBO Roundtable on October 19, 2022. The purpose of the roundtable was to engage social services organizations across NY State in a discussion to identify key policy challenges and data needs for effective data exchange as envisioned by the 1115 Waiver and ways that SHIN-NY policy can support these efforts.

Seventeen (17) CBOs attended the roundtable. The organizations were representative of CBOs that currently participate in the SHIN-NY and/or have some knowledge of the SHIN-NY and reflect a geographic spread that included both upstate, downstate, and north country organizations. (See attached list of attendees.) A pre-roundtable survey of the attendees was conducted to get a better understanding of services and security practices and to help inform the guided discussion.

The following report summarizes the pre-roundtable survey results and key findings of the roundtable and outlines potential next step recommendations.

"I think that regulation or policy about the technology vendor requirements will also be important. They [the vendors] aren't incentivized to do what we hope they would do—such as process complex consents like we're talking about—so if there are minimum standards, they should be set at the state and federal level and not left to some other entity or to procurement alone. It's one of those market failures that only policy could address."

GILLY CANTOR

DIRECTOR OF EVALUATION & CAPACITY BUILDING
THE INSTITUTE FOR VETERANS AND MILITARY FAMILIES (IVMF)

Pre-Roundtable Survey Results

From October 7th–October 18th, NYeC administered a brief pre-roundtable survey via email to participants invited to attend the SHIN-NY Policy Committee CBO Roundtable discussion. The survey questions were developed by NYeC, SHIN-NY Policy Committee leadership, and Manatt Phelps & Phillips, LLC, to better understand each organizations familiarity with HIPAA, PHI, and general security practices. The survey included the opportunity to offer comment on significant challenges to CBO participation in the SHIN-NY and New York's Medicaid Section 1115 Waiver demonstration initiative.

Roundtable participants represented social service organization voices from across New York State. The majority provide direct services to the communities they serve, including housing support, food and nutrition services, Maternal/Child Health services, sexual and reproductive health services, case management services, among others. Others facilitate services in partnership with CBOs. If an organization did not identify as a CBO, they were redirected to a few free text questions that solicited recommendations for minimum security practices they believe CBOs should be required to follow to obtain PHI data via the SHIN-NY, including barriers to security compliance for CBOs. The full survey results and questions can be found attached.

Overall, the survey results revealed that roundtable participants are either HIPAA covered entities or have signed business associate agreements with covered entities that share PHI with their organization. If they are receiving PHI from covered entities, survey respondents noted that it is either through a QE, an Electronic Health Record (EHR), a Referral Network, or directly from a covered health entity. To provide services, respondents indicated needing an individual's diagnoses and list of

medications. A few reported requiring lab results, ER admission and discharge summaries. To protect information of individuals who receive CBO services, respondents indicated the most utilized security practices are; 1) requiring password requirements; 2) encryption of electronic data in transit; and 3) employee related trainings focused on security practices. None reported having any security certifications, but most reported having cyber liability insurance with varying amounts of coverage.

It should be noted that the organizations invited to take the survey and participate in the roundtable discussion represent a small sample size of social service organizations in New York State. The SHIN-NY Policy committee will seek additional perspectives from social services organizations that may not be subject to HIPAA security rules to broaden its understanding of the impact SHIN-NY Policy may have to support New York's 1115 Medicaid Waiver demonstration initiative.

"We're hyper focused on diabetes... [T]he key measure with diabetes is the HbA1c, and we want to be able to know what an individual's HbA1c is as a baseline before they participate in a program, and then to be able to track that over time to see if the program could be contributing to ...better maintenance or management of that HbA1c."

ANN MORGAN
EXECUTIVE DIRECTOR
NORTH COUNTRY HEALTHY HEART NETWORK

CBO Roundtable Key Findings

During the roundtable, the participants addressed many important issues related to their exchange of data. Some of those comments related specifically to the SHIN-NY and the SHIN-NY policies. Other comments focused on broader issues that CBOs face regarding the exchange of information, including for example challenges related to too many requests for data from health plans. All participants agreed that the exchange of data was critical to the services that CBOs provide.

The key themes from the discussion were:

- ***The Need for Data:*** Participants noted that they have a need for many types of health care data, much of which is available in the SHIN-NY. Many participants described the value of alerts. Others noted that other forms of clinical data, such as lab tests results and diagnoses, can be important to the work of CBOs like medically tailored meal providers.
- ***The Need for Funding:*** Many participants said that interoperability and security require more funding. A CBO may receive alerts from hospitals, but it may lack the personnel to review and manage those alerts. A CBO may be interested in improving its security, but it may require substantial funds to do so.
- ***The Importance of Security:*** The CBOs recognized the importance of security, and none advocated the complete elimination of security requirements for CBOs. However, they stressed the need for security requirements to be reasonable. They noted that CBOs not subject to HIPAA should not be subject to the same security requirements for protected health information (PHI) and social data that covered entity CBOs are required to adhere to. Some stressed the need for software vendors to be subject to state security standards, while others also noted that CBOs should have responsibility for training their own staff on security policies and practices of their organization.
- ***Bidirectional Exchange:*** CBOs noted that it was not only important for CBOs to receive health care data, but for health care providers and health plans to receive information from CBOs. For example, a hospital discharge planner should have information on which CBOs are serving a hospital patient prior to discharge of that patient in order to enable more effective care coordination following discharge.
- ***Challenging Connections to the Health Care System:*** Several participants noted that it can be a challenge for CBOs to exchange data with health care providers and health plans. Providers each have their own electronic health record (EHR) system, and health plans have their own data systems as well. As a result, CBOs that provide services in conjunction with many different providers and plans face significant burdens in exchanging their data.

"We need to change our thinking that CBOs have just one [data/EHR/reporting] system. Some have dozens that they use for different services, processes, and reporting to New York State and Federal agencies."

LAURA GUSTIN
EXECUTIVE DIRECTOR
TOGETHERNOW

Potential Next Steps

The CBO roundtable was undertaken in part to address potential reforms to the SHIN-NY policies to promote CBO participation under the upcoming 1115 waiver demonstration. Several policy reforms could be undertaken based on comments made during the discussion. However, the roundtable participants also addressed issues that cannot be addressed through changes to the SHIN-NY policies alone, such as the need for more funding to improve CBO security practices.

Potential next steps include:

- **Consent Policies:** The SHIN-NY policies could be revised to permit disclosures to CBOs without written consent in certain circumstances. The "one-to-one" exception could be modified to recognize that patients may provide implicit consent for their information to be shared with CBOs. Similarly, the policies could permit alerts to be disclosed to CBOs in cases where such practice is permitted by HIPAA.
- **Security Policies:** The SHIN-NY security requirements could be modified to be more flexible for CBOs. Currently, CBOs that are not HIPAA covered entities must abide by HIPAA security rule requirements in the same manner that covered entities do. This rule could be modified to specify a more limited set of requirements for CBOs.
- **Interoperability:** NYeC and DOH should continue to focus on ways to make the SHIN-NY easy to access for CBOs, with integration into CBOs existing electronic record systems a key goal. This may help ensure that CBOs function not only as SHIN-NY participants but as data contributors.
- **Governance:** Reforms to promote exchange of information with CBOs will need to continue to occur. NYeC could work with a CBO Advisory Council to

engage in regular dialogue with the state to address key issues related to health information technology and the new Medicaid waiver demonstration.

- **Funding:** NYeC and the Advisory Council could work with the state to ensure that there is sufficient funding under the 1115 demonstration for investments in data infrastructure—and security—or CBOs participating in the demonstration.

An upcoming white paper on CBOs, the SHIN-NY, and the 1115 Waiver will address these next steps more in depth. The white paper will be informed not only by the roundtable discussion but also by an additional survey that is targeting smaller CBOs, many of whom have less experience sharing health care data compared to the roundtable participants.