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NEW YORK eHEALTH COLLABORATIVE

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Critical Data: Supporting Community-Based Organization Information Exchange Under New York's New Medicaid Waiver

About the New York eHealth Collaborative

The New York eHealth Collaborative (NYeC) is a nonprofit organization working to improve health care and patient outcomes by collaboratively leading, connecting and integrating health information exchange statewide. NYeC works with a diverse group of stakeholders to advance health information technology and information exchange in New York.

As an organization, NYeC develops policies, operates statewide technology, promotes standards and workflows, fosters innovation, and conducts analyses, including research, that support the value of technology and information exchange to improve the health of New Yorkers. This directly supports health care providers, public health departments, health plans, community-based organizations and others.

NYeC partners with the New York State Department of Health to lead the Statewide Health Information Network for New York (SHIN-NY), a network connecting health care professionals and regional health information exchanges across the state. NYeC serves as the state designated entity for the implementation and oversight of the SHIN-NY. For more information, visit https://www.nyehealth.org/.

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Executive Summary

As a key component of its new $13.52 billion Medicaid waiver, the New York State Department of Health (DOH) proposes the development of "a statewide data store [that] will provide the State with near real-time insights into waiver activities such as screenings and referrals" related to community-based organizations (CBOs). This database "will support health care providers' ability to make appropriate referrals, facilitate the exchange of SCN [social care needs] data, and ultimately ensure increased access to critical housing, food and other social support services."[1]

For the state, a critical component of improving the social determinants of health of Medicaid enrollees is the exchange of both health care data and social services data. A CBO providing medically tailored meals cannot provide the right nutrition without knowing the medical diagnoses of its clients. Likewise, a hospital discharging a patient lacking stable housing needs to know which CBOs are actively providing services to the patient in order to ensure continuity of care.

The state envisions that improved CBO data exchange will leverage the information already maintained in the Statewide Health Information Network for New York (SHIN-NY). The SHIN-NY is the state's publicly supported health information exchange comprised of six qualified entities (QEs), also known as regional health information organizations. Currently, the SHIN-NY connects every single hospital in New York State and over 100,000 health care professionals, and it contains information on millions of people living or receiving care in New York. The SHIN-NY also exchanges data with other types of organizations, including public health agencies, health plans and CBOs.

Given the importance of the exchange of data between CBOs and the health care sector under the new waiver, the New York eHealth Collaborative (NYeC), the state-designated entity that oversees the operation of the SHIN-NY, undertook a study of the challenges to such data exchange in collaboration with Manatt Health. NYeC sought the perspective of CBOs that are on the front lines of providing services to New York Medicaid enrollees and have years of experience with sharing information on their clients. A wide range of CBOs responded to NYeC's request and described their experiences with information exchange. Seventeen CBOs participated in an October 2022 roundtable related to CBO information sharing, the Medicaid waiver and the SHIN-NY. Other CBOs responded to two different surveys administered by NYeC. In addition, a smaller group of CBOs shared insights during interviews.

During the roundtable and interviews, CBOs repeatedly emphasized the importance of client-level data with regard to the services they provide. While many of the CBOs indicated that they rely on their own data platforms to collect social services data about their clients, they also recognized the value of protected health information (PHI) maintained in systems like the SHIN-NY. Many CBOs noted that the information available from the SHIN-NY—such as hospital admission and discharge alerts, laboratory test results, and analytics providing individual client profiles—can help CBOs both provide better care and demonstrate the value of their own services. The CBOs also noted that the information they collect can be a valuable tool to health care providers and health plans and will help better inform the services of such providers and plans.

However, the roundtable, surveys and interviews also revealed there are significant barriers to achieving the vision of allowing CBOs, health care providers, health plans and other organizations to easily share information about the individuals to whom they are jointly providing care. Many CBOs noted that they lack

security practices sufficient to keep secure the PHI that may be shared with them under such an exchange and also lack familiarity with applicable legal requirements and means of sharing information. The CBOs stressed that this is compounded by a dearth of funding available to CBOs to improve their data exchange. Further, very often CBOs use software that is not interoperable with software used by those in the health care delivery system, inhibiting the exchange of information. These barriers exist against a backdrop of laws that were written with the expectation that patient data is shared only among health care providers and health plans, not with CBOs, and therefore are unclear as to when disclosure to CBOs is permitted. Likewise, the SHIN-NY's policies as currently crafted may create interoperability barriers that should be resolved.

Nevertheless, there are means to address these challenges. NYeC proposes the following:

1. **Technical Assistance to CBOs**: CBOs recommended that a portion of the funding in the new Medicaid waiver be dedicated to improving CBOs' information technology and security practices. Technical assistance and grants for technology improvements to CBOs and the organizations that administer networks of CBOs could help these organizations substantially improve their exchange of data.
2. **Consent Standards**: Implementing reforms to the SHIN-NY consent requirements for disclosures of PHI to CBOs could better support the 1115 waiver. Aligning current Medicaid consent requirements with the reformed SHIN-NY consent framework could allow for the sharing of minimum necessary PHI as part of referrals with the verbal or implicit consent of individuals being served.
3. **Security Standards**: The establishment of consistent security standards for CBO platforms that receive referrals and PHI under the waiver would help ensure the security of information exchange under the 1115 waiver.
4. **Interoperability Standards**: CBOs cited the lack of interoperability between CBOs that utilize different systems as an inhibitor to data exchange. A partnership between New York State agencies to improve interoperability between different CBOs using different systems could help address this barrier. While doing so is not central to the new Medicaid waiver, it could help enhance CBO data exchange more generally.
5. **Screening Tool Standards**: DOH's proposal to develop and implement uniform screening tools is supported by many CBOs as a way to reduce burden. The state can explore steps to ensure that the screening data collected can be easily shared with other organizations, an activity with which the SHIN-NY can assist.
6. **Disclosure of Medicaid Claims Data**: Permitting the disclosure of Medicaid claims can help support certain waiver activities. The SHIN-NY can facilitate some of these uses, including by credentialing, validating and auditing such disclosures on DOH's behalf.
7. **Federal Advocacy**: Coordinated communication with the federal government by NYeC, QEs and CBOs could help with obtaining clarity on federal rules regarding the exchange of data with CBOs.
8. **Advisory Council**: The establishment of a CBO advisory council that is representative of DOH, NYeC and CBOs could help identify issues related to the implementation of waiver priority services and improve overall information exchange.

With these reforms, CBOs and their partners in the health care system will be better positioned to use data to improve the quality of care provided to Medicaid enrollees under the waiver amendment.

I. Background

A. The New York Health Equity Reform Waiver Amendment

On September 2, 2022, DOH submitted to the Centers for Medicare & Medicaid Services (CMS) a proposed amendment to the state's 1115 waiver demonstration. Under New York Health Equity Reform (NYHER), DOH is seeking a $13.52 billion investment over five years to address "the inextricably linked health disparities and systemic health care delivery issues that have been highlighted and intensified by the COVID-19 pandemic."[2]

Improving health equity is central to the design of NYHER. DOH proposes the establishment of Health Equity Regional Organizations (HEROs), which would be responsible for developing regional plans for "a coordinated, holistic, clinically integrated, and value-driven approach to evaluating and addressing the needs of vulnerable populations in a financially stable and efficient manner through VBP [value based purchasing]." The HEROs would build off the work undertaken by Performing Provider Systems (PPSs) under the state's Delivery System Reform Incentive Payment (DSRIP) program, which concluded in 2019. DOH has indicated that some of the former PPSs may seek to become HEROs.

In accordance with the vision that addressing social care needs is essential to improving the health of many Medicaid enrollees, CBOs will play a central role in delivering care to Medicaid enrollees under NYHER. DOH seeks to establish Social Determinants of Health Networks (SDHNs), which would be coordinated networks of CBOs. The CBOs would provide services in four core areas: housing, food insecurity, transportation and interpersonal safety. SDHNs would receive $92.5 million in funding in the first year and $185 million in funding in each subsequent year. In addition, CBOs would be paid directly for their services. In its proposal, DOH acknowledges that the DSRIP program could have done more to support CBOs, and indicates that the NYHER will result in "more direct investment in services rendered by community based organizations."

Along with certain health care providers, CBOs would be responsible for administering to their clients a "uniform social needs assessment." CBOs would use a screening tool to ask their clients about needs related to housing, food, transportation and services, and CBOs could capture the results in this questionnaire. DOH indicates that the tool would be chosen by the state and standardized. Data from the tool would be used both to provide services and to help inform the development of targeted interventions.

An improved CBO data infrastructure is a component critical to the success of the state's Medicaid waiver. DOH notes that the exchange of data with CBOs has been "stymied by a lack of commonly used data sharing standards and many CBOs utilizing bespoke or 'closed loop' data systems that are not widely interoperable." Further, without efforts by the SHIN-NY, NYeC and SDHNs, "the interoperability problems that plagued the introduction of electronic medical records will similarly inhibit the integration of CBOs and SCN [social care needs] interventions into traditional health providers."

To address the concern about barriers to the exchange of data between CBOs and the health care system, DOH proposes the development of "an aggregated, interoperable, and comprehensive statewide resource repository of CBOs and services that will support health care providers' ability to make appropriate referrals, facilitate the exchange of SCN data, and ultimately ensure increased access to critical housing, food, and

other social support services." DOH envisions that information from this system will feed into a statewide data store that is supported by the existing SHIN-NY infrastructure. DOH has indicated that such data store is likely to include the history of referrals made to CBOs as well as screenings undertaken by CBOs and other organizations.

In short, CBOs would capitalize on the state's existing data infrastructure. While CBOs may not use the SHIN-NY as a platform for receiving referrals, DOH envisions that the SDHN platforms will share data with and collect data from the SHIN-NY, including analyses of data undertaken by QEs or NYeC. As a result, CBO networks will obtain needed data from the health care system and vice versa.

B. The Statewide Health Information Network for New York

For more than a decade, the SHIN-NY has fostered the secure exchange of clinical information among health care providers and other organizations throughout New York State. The SHIN-NY aims to improve health care through the exchange of health information whenever and wherever needed. The SHIN-NY is a publicly funded health information exchange, and New York State has invested in its creation and growth.

Health care providers and other organizations have come to rely on information in the SHIN-NY to improve the quality of their care. Every month, the SHIN-NY sends over 10 million alerts about emergency department or hospital visits to primary care providers and others responsible for managing the care of their patients. Treating providers share nearly 600,000 laboratory test results through the SHIN-NY each month.[3] And hospitals treating patients can "break the glass" and see a patient's medications and other information that is critical to providing care during an emergency. Research suggests that use of the SHIN-NY results in lower rates of hospital readmissions and reduces unnecessary health care spending by $160 million to $195 million per year.[4]

The SHIN-NY was initially designed to promote the exchange of information among health care providers. Its current mix of participants reflects this, with health care providers comprising the large majority of organizations that connect to the SHIN-NY. Providers can access information from the SHIN-NY even if the source of that information uses a different electronic health record (EHR) system.

Nevertheless, other types of organizations send and receive information through the SHIN-NY. These include health plans, public health agencies and organ procurement organizations. CBO participation in the SHIN-NY is small but growing, with larger CBOs more likely to connect to the SHIN-NY.

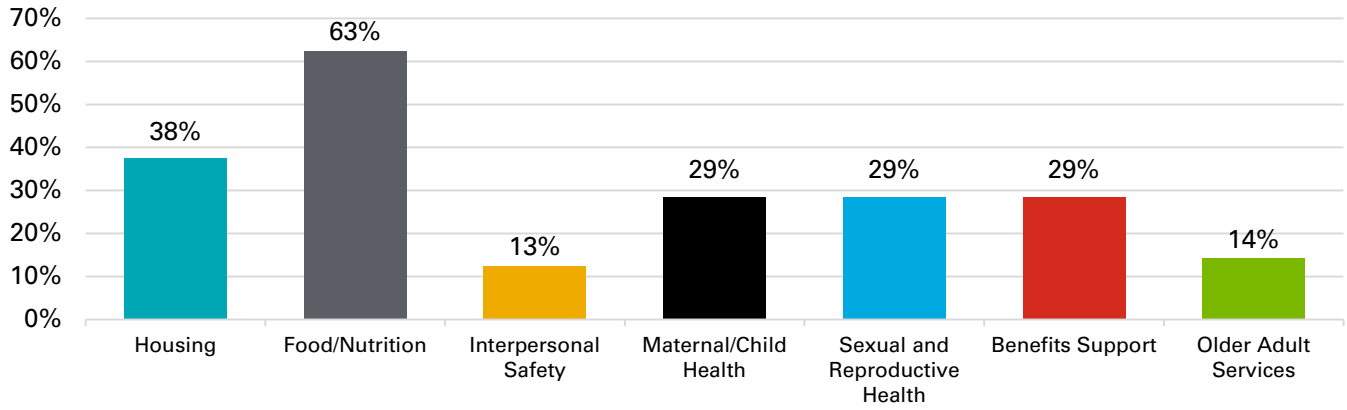
The SHIN-NY is not one organization but a coalition of organizations that share a mission of promoting health information exchange. The SHIN-NY consists of six QEs, also known as regional health information organizations: Bronx RHIO, HealtheConnections (based in Syracuse), Healthix (based in Manhattan), HEALTHeLINK (based in Buffalo), Hixny (based in Albany) and Rochester RHIO. NYeC operates under a contract with DOH and facilitates the exchange of information between QEs as well as the development of the policies that govern the SHIN-NY (SHIN-NY Policies), which are ultimately issued by DOH.

C. Types of CBOs That May Provide Services Under the Waiver Amendment

There is tremendous variation in the types of CBOs that may participate in NYHER.[5] CBOs include, for example, organizations that connect individuals with public benefits, medically tailored meal providers, housing providers that help people find a place to stay, and asthma remediation providers that help eliminate from individuals' homes mold and other toxins that may exacerbate asthma attacks. Some CBOs are large organizations that operate with significant staff across a wide geographic area; others have only a few employees. Some have adopted policies to comply with rules under the Health Insurance Portability and Accountability Act (HIPAA) and receive PHI from the SHIN-NY and/or other sources; others have no experience with HIPAA compliance and do not exchange any PHI.

The results of NYeC's CBO surveys demonstrate this diversity. The CBOs reported providing many different types of services, including housing, nutrition, interpersonal safety, benefits connections/service navigation, health coaching, case management and maternal/child health services. CBOs that reported handling PHI typically used security requirements that are similar to those used by health care providers, such as requiring encryption of the data in transit and at rest, utilizing two-factor authentication and specifying password requirements. However, most respondents did not provide a detailed description of their security practices.

Exhibit 1. Types of Services Provided by CBO Roundtable Participants



Cataloging the full variety of CBOs that may provide services under NYHER is beyond the scope of this white paper. However, the following provides an overview of four CBOs that are providing different categories of services and exploring ways to exchange data with the health care sector.

Food Pantries for the Capital District

The Food Pantries for the Capital District (FPCD) is a coalition of approximately 70 organizations providing nutrition services in Albany, Rensselaer, Saratoga and Schenectady counties. The majority of FPCD members are food pantries. However, some of the coalition partners are food-as-medicine providers, providing medically tailored meals and medically tailored groceries.

FPCD operates the client management software Oasis Insight on behalf of its coalition partners. Food pantries are able to access basic demographic information in Oasis Insight and information about the number of units of services provided to clients, that is, how often they have obtained food from the pantries. Food-as-medicine providers have access to more detailed information, such as whether individuals need low-sodium meals. Oasis Insight does not include any PHI, and FPCD and its partners do not include diagnosis information, such as whether a person has diabetes, in the system.

FPCD acts as a business associate to a limited number of health care providers and health plans and receives PHI in accordance with that relationship. FPCD receives information such as blood sugar levels as measured by an A1C test; the data is intended to help FPCD measure the extent to which the nutrition services are impacting the health of clients. Because FPCD does not have direct access to hospitals' EHR systems, hospitals share this data with FPCD on an intermittent basis. The PHI is stored in a drive separate and apart from Oasis Insight and to which only a limited number of employees have access. FPCD is not currently a participant in the SHIN-NY.

Public Health Solutions

Public Health Solutions (PHS) operates sexual and reproductive health care centers and a nurse-family partnership, which are health care providers and subject to HIPAA. Its CBO side also provides a variety of services. Through its health care community partnerships, PHS navigators at a PHS coordination center located in a hospital assess hospital patients for social needs. The assessment includes whether an individual should be connected to benefits programs such as Medicaid, the Supplemental Nutrition Assistance Program (SNAP), or the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), as well as whether the individual may benefit from certain services such as those offered by a food pantry or medically tailored meal provider. If the navigator determines the individual may qualify for enrollment in SNAP or WIC, the individual is referred to PHS' SNAP and WIC program, under which a PHS enroller helps the individual apply for one or both of those programs.

PHS navigators working for the PHS coordination center receive PHI from their hospital partners and operate under a business associate agreement with those partners. When the navigators make referrals to the SNAP and WIC program, they include only demographics, not any health information, as part of the referral, and the SNAP and WIC program never receives PHI. Although not all of PHS is subject to HIPAA, the entire workforce receives annual HIPAA training.

Selfhelp

Selfhelp provides a broad set of services to more than 25,000 older and vulnerable New Yorkers each year. The organization offers a network of home care and community-based services in New York City and on Long Island. As a health care provider, Selfhelp's licensed home care agency employs more than 1,000 home health aides providing more than 2 million hours of care each year. As a CBO, Selfhelp operates a variety of programs supporting older adults in the community, including older adult centers, affordable senior housing, case management and naturally occurring retirement communities. In these programs, Selfhelp social workers connect older adults with benefits and entitlements, health and wellness workshops, and other needed services.

Although only its licensed home care agency is subject to HIPAA, Selfhelp trains its entire staff on HIPAA compliance. Selfhelp uses PeerPlace and Social Solutions' Efforts-to-Outcomes, two cloud-based data management systems, to capture information from its social workers providing case management services. PHI obtained by its licensed home care agency employees is excluded from these systems and is maintained in a separate cloud-based solution. As a participant in Healthix, Selfhelp receives relevant Healthix alerts for its clients.

Catholic Charities Family and Community Services

Catholic Charities Family and Community Services (CCFCS) provides a wide array of services—including housing, employment and care coordination—to individuals in the nine counties of the Diocese of Rochester. Housing support is one of CCFCS' core services. Such support includes emergency shelters, permanent supportive housing (inclusive of case management services and on-site drug and alcohol education), housing for individuals with developmental disabilities, and assistance with security deposits, emergency rent and emergency utilities. CCFCS also operates a behavioral health clinic and a health home. Although only some of the data collected by CCFCS is PHI, CCFCS treats all the personal information it holds as if it were subject to HIPAA, and all of its staff and contractors who touch such information receive HIPAA training.

The lack of interoperability among different information technology platforms is a significant challenge for CCFCS, which uses a dozen IT systems to maintain its data, including Unite Us, Netsmart for its health homes and TenEleven ECR for its behavioral health clinic. CCFCS noted that in many cases, the platform used for a particular program is dictated by the organization that funds that program. The platforms are generally unable to share data with one another, causing significant inefficiencies for CCFCS staff. For example, staff at an emergency shelter may fill out a detailed intake form for a client in the Homeless Management Information System, and that client may be referred to an emergency security deposit program. But because the shelter and security deposit programs are required to use different platforms that cannot exchange data with each other, staff at the security deposit program need to start the intake from scratch, collecting much of the same information from the client that the shelter may have collected just days before.

CCFCS currently uses SHIN-NY data for its health care programs, not its community-based programs. Its behavioral health clinic examines data in Rochester RHIO to determine whether a patient has allergies or potential medication interactions before issuing a prescription; its health home also receives alerts. Although the housing programs do not currently exchange data with the SHIN-NY, CCFCS said there could be benefits of such an exchange. For example, a shelter may seek to refer a client to a behavioral health specialist, and if the shelter could learn the name of the clinician who treated the client previously, the shelter could refer the client to that clinician (assuming the client had a positive experience with that clinician).

II. Legal Requirements Relevant to CBO Data Exchange

The exchange of data between CBOs and the health care sector is governed by both federal and state laws and regulations. These laws, however, were not written with CBO information exchange in mind. CBOs therefore can struggle to determine which privacy requirements actually apply to their sharing of information.

A. HIPAA and Other Federal Laws

The primary federal privacy regulation, HIPAA, focuses on the exchange of information by health care providers and health plans, not CBOs. HIPAA applies to covered entities and their contractors, known as business associates. There are only three categories of covered entities: health care providers that transmit information in electronic form under HIPAA covered transactions,[6] health plans, and health care clearinghouses.[7] Hospitals, clinics, pharmacies, nursing homes and health care practitioners such as doctors, dentists, nurses and psychologists are all health care providers under HIPAA. CBOs can fall within the definition of "health care providers" if they provide health care services. For example, a CBO that operates a primary care clinic will be a health care provider under HIPAA. But services provided by individuals who are not licensed by state health care regulators—such as housing placement providers, food banks and asthma remediation providers—historically have not been considered to fall within the HIPAA definition of a health care provider even if their services may impact an individual's health.

> "There's a huge variance in what HIPAA compliance means and the level of risk that each organization is willing to tolerate."
>
> —Nutrition Network CBO

HIPAA imposes security requirements that can be difficult for some CBOs, particularly small organizations, to meet. Under the HIPAA security rule, covered entities must protect PHI in electronic form by employing various administrative, physical and technical safeguards. These include undertaking an analysis of security risks to the organization's electronic PHI, training workforce members on security practices, having data backup and disaster recovery plans, having policies to ensure that media containing electronic PHI are safely disposed of, and assigning unique user IDs to individuals who are able to access electronic PHI.[8] HIPAA covered entities face other obligations as well. Under the breach notification rule, covered entities must report breaches of PHI to the impacted individuals, the federal government and, in some cases, the media.[9] Under the privacy rule, covered entities must make available a notice of privacy practices, must provide individuals with a right to access and amend PHI they hold, and must limit their use and disclosures of PHI to certain permitted purposes.[10] HIPAA generally permits covered entities to use and disclose PHI for treatment, payment and "health care operations" purposes.[11]

Nevertheless, HIPAA does not prohibit the disclosure of PHI to CBOs that are not HIPAA covered entities (Non-Covered CBOs). Individuals may sign an authorization that permits a covered entity to disclose the individual's PHI to a Non-Covered CBO. Even if an individual has not consented to sharing of PHI with a Non-

Covered CBO, HIPAA permits the disclosure to such a CBO in some cases. If a Non-Covered CBO is providing services to a covered entity, the Non-Covered CBO may act as a business associate of such a covered entity and may receive PHI under the terms of the business associate agreement.

Federal guidance also indicates that health care providers may share PHI with Non-Covered CBOs that are not business associates. The federal Office of Civil Rights of the Department of Health and Human Services (OCR) has explained: "Health care providers who believe that disclosures to certain social service entities are a necessary component of, or may help further, the individual's health or mental health care may disclose the minimum necessary PHI to such entities without the individual's authorization. For example, a provider may disclose PHI about a patient needing mental health care supportive housing to a service agency that arranges such services for individuals."[12] The guidance, however, does not address the issue of whether a similar exchange can be automated and not patient specific. For example, if a hospital determines that a particular CBO's services often have a positive impact on the health of the hospital's patients, it is unclear whether the hospital may send admission and discharge alerts to such CBO for all of its patients who receive services from such CBO.[13]

While many CBOs are subject to HIPAA, CBOs typically are not subject to the federal substance use disorder (SUD) confidentiality regulation, 42 C.F.R. Part 2. However, the regulation impacts how Part 2 providers may share information with CBOs with respect to common clients. Unlike HIPAA, 42 C.F.R. Part 2 generally requires a Part 2 provider to obtain patient consent prior to sharing information about an individual with a third party, even if that third party is providing treatment or social services to the individual. Part 2 has strict rules about what the consent form must include. In particular, under current rules, a consent form may include a general designation of recipients—that is, one that describes the class of potential recipients but does not list them all by name—only if the recipients all have "a treating provider relationship" with the patient.[14] If CBOs are generally not treating providers, authorization forms will need to list each potential CBO recipient by name in order for CBOs to receive Part 2 data under the form.[15]

B. The SHIN-NY Regulation and SHIN-NY Policies

The SHIN-NY rules impose requirements that extend beyond HIPAA. The SHIN-NY regulation establishes the SHIN-NY as an "opt-in" health information exchange. With an opt-in exchange, individuals generally must consent to the disclosure of their PHI; this is in contrast to an "opt-out" health information exchange, where an individual's PHI typically may be exchanged for treatment, payment and health care operations purposes unless the individual has signed a form indicating the desire to opt out of such exchange. There are exceptions when consent is not required, but they are narrower than those under HIPAA. For example, while HIPAA permits the disclosure of PHI for treatment purposes, the SHIN-NY regulation permits disclosures for treatment purposes in cases of a medical emergency or when prior consent for the disclosure has already been obtained under state law and no other law requires written consent (that is, if the individual has verbally consented or implicitly consented).[16]

The SHIN-NY Policies elaborate on the rules set forth under the SHIN-NY regulation and describe specific rules regarding CBOs. The SHIN-NY Policies define a CBO as "an organization, which may be a not-for-profit entity or government agency, which has the primary purpose of providing social services such as housing assistance, nutrition assistance, employment assistance, or benefits coordination."[17] Under the SHIN-NY

Policies, Non-Covered CBOs have obligations beyond those imposed under applicable law. Like other SHIN-NY participants that are not subject to HIPAA, Non-Covered CBOs must adopt or address all applicable safeguards under the HIPAA security rule. In addition, Non-Covered CBOs may only receive PHI with written consent. This means that a health care provider making a referral to a Non-Covered CBO cannot use the SHIN-NY to send relevant information to such Non-Covered CBO if that individual has not signed a form that allows for such information sharing, even in cases where HIPAA would permit such disclosure.

The SHIN-NY Regulation and the SHIN-NY Policies only govern information exchanged through QEs. Data exchanges that occur entirely through other mediums, such as other health information exchanges operating in the state or EHRs, are not subject to the SHIN-NY requirements. It is important to note that, in some cases, organizations have established new data exchange methods with CBOs specifically to avoid the requirements in the SHIN-NY rules.

C. State Laws and CBOs

New York State privacy laws sometimes apply to the operations of CBOs. The state's HIV confidentiality law applies not only to health care providers but to any person who obtains confidential HIV information in the course of providing a social service.[18] Therefore, Non-Covered CBOs that obtain a client's HIV status must keep that status confidential, even though they are not subject to HIPAA. The confidentiality obligations, however, do not mean that CBOs can never disclose HIV information. For example, the law authorizes CBOs to disclose HIV information without consent to a "health care provider or health facility when knowledge of the HIV related information is necessary to provide appropriate care or treatment to the protected individual, a child of the individual, a contact of the protected individual or a person authorized to consent to health care for such a contact."[19]

Some CBOs may also be subject to the state's mental health privacy law, which applies to any organization that provides services to individuals with a mental illness or developmental disability and receives funding from the New York State Office of Mental Health or Office for People With Developmental Disabilities.[20] That law generally requires client information to be kept confidential and disclosed only with client consent, but allows disclosure without consent to certain organizations such as health homes that are responsible for coordinating an individual's care.[21]

III. Findings: CBO Perspective on the Benefits of and Barriers to Data Exchange

In developing this report, NYeC engaged in a series of conversations with CBOs. At a roundtable held in October 2022, 17 CBOs that currently participate in the SHIN-NY provided insights to the SHIN-NY Policy Committee related to their potential participation in NYHER and their data-sharing practices. This was accompanied by a survey of the roundtable participants on the same topics. A second survey was sent to smaller CBOs that did not participate in the roundtable. In addition, several CBOs were interviewed on these issues, and QEs provided their own input related to CBO participation in the SHIN-NY.

A. Potential Benefits of Exchanging PHI

Both in the roundtable and in interviews, CBOs repeatedly expressed that the exchange of health information helps foster their delivery of services. CBOs noted that in many cases, obtaining PHI from the SHIN-NY or other sources would help improve the quality of services they provide. The CBOs also recognized the value of their own data and saw potential benefit in sharing their information with the SHIN-NY so that other organizations can use such data to inform the services that they provide.

In the discussions, CBOs highlighted the following as valuable categories of data to CBOs:

- **Alerts**: QEs that comprise the SHIN-NY regularly send out alerts to their participants to indicate that an individual has been admitted to an emergency room (ER), admitted to an inpatient unit or discharged from the hospital. Like health care providers, CBOs indicated that alerts can be an important resource to them. For example, one CBO noted that its social workers providing case management would benefit from knowing when one of their clients has been admitted to the hospital so they can arrange for services as soon as that client is discharged.

> "It's helpful to know if a member of the community was hospitalized or had an ER visit, because the CBO may want to act on that."
>
> —Elderly Services CBO

- **Laboratory Values**: Several CBOs noted that lab results can provide important information. Blood sugar levels as measured by an A1C test were noted to be valuable to nutrition providers as well as providers of other types of services, such as tobacco cessation. These values are useful for determining the effectiveness of services provided to an individual; if laboratory values improve following the CBO's provision of services, this suggests the services are in fact having a positive impact on the person's health. These results not only can show the effectiveness of services provided to a particular person, but also can help demonstrate the benefit of the CBO's work at a population level, thereby helping the CBO make the case for continued investment in its services.

- **Analytics**: CBOs often lack the capability to conduct detailed analytics of data and noted that QEs, which have more expertise on analytics, can provide important assistance. One CBO noted that they often need to know which individuals to target with care coordination services, and therefore rely on other organizations to provide them with lists of individuals who should be prioritized for outreach.
- **Diagnoses**: CBOs observed that in some cases, an individual's diagnosis impacts the nature of services provided by the CBO. Medically tailored meal providers, for example, modify their meals in cases where an individual has hypertension or diabetes. Similarly, in some cases, a mental health or SUD diagnosis will impact housing placement offered by a housing provider.
- **Referral Tracking**: While some CBOs are already part of platforms that track referrals, they noted that the information they receive sometimes is inadequate. For example, a CBO explained that they often identify an individual as potentially eligible for SNAP, and they will refer such individual to another organization to help that person enroll in SNAP. The CBO noted that their referral platform informs them that the referral was made but does not indicate the outcome, that is, whether the person was actually enrolled in SNAP.

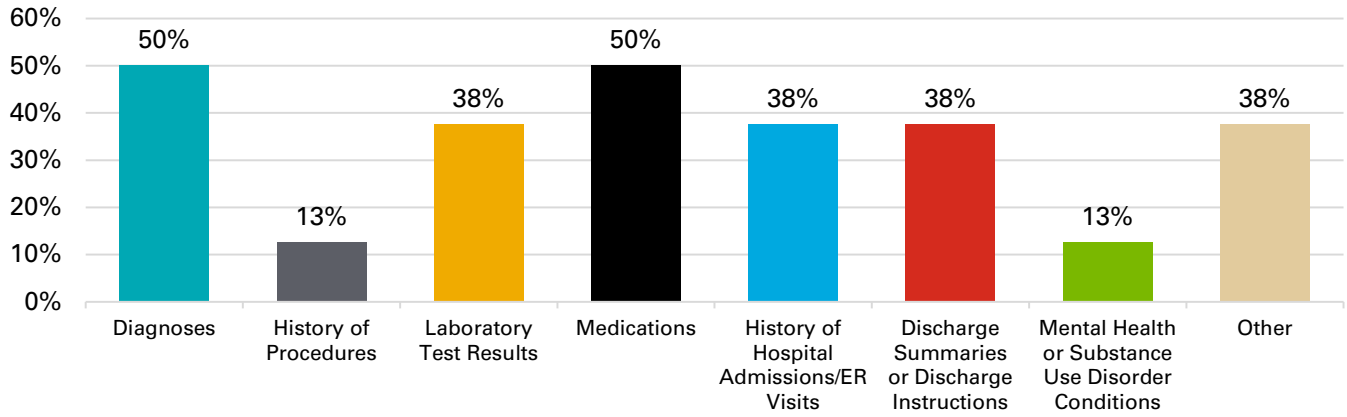
> "Some CBOs are trying to connect clients to a PCP to better their health, and it would be great to know if that was followed through. They currently don't know this, but it's part of what they are asked to do in a value-based contracting world."
>
> —Federally Qualified Health Center (FQHC) Network

- **Medications**: In both survey responses, CBOs cited an individual's medication list as an important data element. One CBO noted that its social workers providing care to elderly clients often find dozens of medications in the client's home, and by having a current medication list, the social worker can assist the client in organizing needed drugs and discarding unneeded pills.

> "Folks delivering specific interventions don't need the entire medical chart."
>
> —FQHC Network

While many types of PHI can be valuable, CBOs that participated in the roundtable stressed that they do not need to know everything about their clients. The CBOs noted that often targeted health care information was needed to provide services, and therefore there is typically not a need to have access to an individual's entire health care record. In addition, certain categories of CBOs may not need access to PHI at all. For example, while medically tailored meal providers need to know diagnoses in order to provide services to their patients, some interview participants observed that food banks generally do not need to know medical information about their clients, and some organizations want to avoid obtaining PHI entirely so as not to be subject to HIPAA obligations. Some organizations explained that it is the networks that organize CBOs—such as independent practice associations (IPAs) and former PPSs—that are likely to have the greatest need for PHI since they will have the means of developing client profiles using analytics, and these are the organizations that are most likely to directly connect to the SHIN-NY. These organizations may operate as SDHNs under the waiver amendment.

Exhibit 2. Types of PHI Needed by CBO Roundtable Participants



CBOs similarly noted that some of the data they collect will be valuable to health care providers and other organizations in the health care system, and there can be important benefits to the CBOs making such data available through the SHIN-NY. For example, NYHER envisions CBOs undertaking screenings for social care needs using a standard tool, and the information from that tool could inform the care plans of others, such as primary care providers.

Similarly, sharing information about the services they provide can improve the care provided by both health care providers and CBOs. One CBO noted that hospital discharge planners often seek to connect a patient in the community with services to be provided after discharge. If that discharge planner knew which CBOs were already providing services to that patient, the hospital could connect the patient with those CBOs, rather than providing a referral to an organization that had no history with that individual. Information on existing client relationships need not come directly from CBOs, but also could come from SDHNs, QEs or health plans that had paid for CBO services.

B. Barriers

While the roundtable and interviews showed that there are clear opportunities to improve CBOs' exchange of data under the NYHER waiver amendment, the conversations also revealed there are significant barriers to the effective exchange of information. Some of those barriers relate to legal and policy requirements, while others reflect operational challenges.

Lack of Funding for Health Information Technology and Security

The CBOs that spoke at the roundtable and participated in interviews typically were well aware that obtaining PHI often requires a CBO to develop a HIPAA compliance program and enhance its security practices. Some CBOs have already done so and are capable of handling PHI in compliance with HIPAA. Others, however, have noted that it is difficult to obtain HIPAA compliance without additional sources of funds. One CBO, for example, said it spent three years revising its privacy policies and security practices in order to provide sufficient comfort to health care providers and health plans that PHI could be shared with the CBO. Such efforts represented an "exorbitant expense."

> "Take a small food pantry that is run by retirees and serves 20 people. It would be very hard to HIPAA train every single agency like that."
>
> —Nutrition Network CBO

Other CBOs noted that they avoid seeking out PHI given the costs of HIPAA compliance. These CBOs said that although PHI may be useful to their organizations, they cannot afford to develop HIPAA compliance without external funding dedicated to supporting such efforts.

Lack of Familiarity With Data Exchange and HIPAA

As noted earlier, there is a tremendous diversity of CBOs in New York State. Many larger CBOs have full-time information technology staff who are familiar with potential data platforms, including the SHIN-NY, as well as privacy experts who can provide necessary HIPAA guidance.

> "We have talked about becoming a participant in the SHIN-NY. We don't know what it takes."
>
> —Nutrition Network CBO

But some CBOs indicated that data exchange infrastructure and HIPAA obligations remain a mystery to them. Some CBOs were unaware of how the SHIN-NY operates. One CBO, though interested in potentially joining a QE, questioned what becoming a participant in a QE actually entails. Many CBOs do not have experience with HIPAA security requirements and have difficulty distinguishing between mandatory and optional standards.

Lack of Interoperability

For years, health care providers have struggled to exchange data with other providers using different EHR systems. But as NYHER observes, interoperability problems also impact CBOs seeking to engage in the exchange of data.

One CBO noted that alerts from its local QE were valuable, but it struggled to make use of the data because it could not incorporate alerts into its standard client management software. As a result, a new workflow needed to be developed, with an employee being responsible for logging into the QE and viewing the alert data. The CBO said that given time pressures, it did not examine the alert data as often as it would like.

> "We don't have control over most systems we use. Most systems are controlled by HUD or the state or a partnership. We have about 12 different data platforms, and none of them are interoperable with the others."
>
> —Family Services CBO

Interoperability issues are not specific to the SHIN-NY; they also apply to the CBOs' own software platforms. One CBO explained that it was hoping to exchange data between its platform and another platform used by an IPA and many other CBOs affiliated with the IPA. But the CBO and the IPA were unable to develop a means of data exchange, and therefore the CBO cannot easily exchange data with the IPA and many other CBOs operating in the same region. A roundtable participant noted that unlike providers, which tend to keep most of their PHI in one EHR, CBOs that provide many different types of services often have different software platforms for each category of service. Unless those different software platforms have been designed to interoperate, the ability to effectively share service information is challenging at best. This can even be a challenge for organizations internally, as CBOs that operate many different programs may struggle to coordinate care among their own staff as a result of funder requirements to use different software platforms for each program.

Lack of Screening Tool Standardization

Several CBOs reported being overburdened by screenings. CBO partners—including health systems and health plans—often turn to CBOs to administer social needs assessments. But CBOs reported that different partners require the use of different tools, so they often are using multiple questionnaires to assess the needs of the same individual. While CBOs agreed that a standardized screening tool under NYHER could be useful, some expressed concern that they would still be obligated to perform other types of screenings, and therefore the standardized tool would not meaningfully reduce burden.

CBOs also face challenges in receiving screening data from others. One CBO noted that it does receive assessments from a partnered health plan, but such assessments are in pdf and cannot be integrated into their own platform.

Lack of Contribution of Data

Unlike many health care providers that are required to participate in the SHIN-NY, there is no requirement that CBOs contribute data to the SHIN-NY (unless they also qualify as a "health care facility" subject to the SHIN-NY participation requirement).[22] As a result, many CBOs do not contribute data to the SHIN-NY or otherwise share their information with health care providers and health plans. The majority of organizations that responded to NYeC's CBO surveys indicated that they do not contribute data to the SHIN-NY. This means that many other organizations that are interested in CBO data, such as primary care practices and hospitals serving the same individuals, often cannot obtain information on the social services delivered to their patients.

Lack of Consent Processes

Some CBOs reported that the requirement to obtain written client consent can also prevent the exchange of information. One CBO that leads a coalition of diabetes self-management, pain self-management and other chronic disease prevention services noted that many of its partner organizations provide services virtually or over the phone and therefore do not meet face-to-face with their clients. As a result, it is very difficult for these organizations to obtain signed written consent for the disclosure of information from their clients. Due to a lack of written consent, PHI often cannot be shared to help benefit the clients of these organizations, even in cases where their clients have provided verbal consent for disclosure of their information.

IV. Proposals

DOH has already taken important steps to improve data exchange between the health care sector and CBOs. NYHER recognizes the importance of a sound information-sharing infrastructure, and it also seeks to capitalize on the SHIN-NY, one of the most widely used health information networks in the country. However, there is more the state and other stakeholders—including NYeC itself—can do collaboratively to ensure that CBOs, health care providers and others participating in NYHER have the information they need in order to provide a higher level of care to Medicaid enrollees.

A. Technical Assistance to CBOs

NYHER envisions that substantial funding would be provided to CBOs for the delivery of services under the Medicaid demonstration. Given CBOs' desire for assistance with improvements to their data-sharing infrastructure, the development of a technical assistance program supporting such infrastructure could help these organizations substantially improve their exchange of data.

Non-Covered CBOs do not have the same familiarity with HIPAA that health care providers do, and many lack understanding of issues related to data exchange. Technical assistance can help CBOs understand HIPAA, what it requires, what platforms are available and how such software can help CBOs better deliver services. Further, technical assistance on security practices is essential, even if a CBO will not act as a HIPAA covered entity. Such assistance can help CBOs translate difficult-to-understand regulations into everyday practices that can help keep information on their clients secure—practices that are valuable even for non-covered entities. In some cases, direct grants to CBOs for technology improvements may also be appropriate.

> "We need technical assistance. Someone needs to write up what is the bare minimum versus what HIPAA requires. We have been spinning our wheels on this for a few years."
>
> —Nutrition Network CBO

In many cases, this infrastructure may be developed at the SDHN level, with SDHNs maintaining software platforms that can be used by their CBO networks. Any technical assistance that is provided should be targeted to have a positive impact on the practices of the organizations that need to exchange information under NYHER.

B. Consent Standards

Standards for consent requirements for Non-Covered CBOs' access to PHI, modeled on reformed SHIN-NY rules, could help further align consent across the state.

As noted above, HIPAA imposes limits on how PHI may be shared with Non-Covered CBOs without consent. Nevertheless, HIPAA permits PHI to be disclosed to Non-Covered CBOs without an individual's authorization in certain circumstances. In particular, a health care provider that refers patients to a Non-Covered CBO is permitted to share minimum necessary PHI with such CBO to the extent such PHI would assist the CBO in its provision of services.

DOH and NYeC have already begun to address the divergence between HIPAA rules and SHIN-NY Policies related to referrals. In January, NYeC recommended a revision to the SHIN-NY Policies to permit the disclosure of limited PHI to Non-Covered CBOs in conjunction with a referral based on an individual's verbal or implicit consent. For example, if a primary care provider referred a patient to a diabetes self-management program and the patient verbally agreed to participate in that program and the exchange of information related to such program, that primary care provider would be permitted to share relevant portions of the patient's record with that program.[23]

> "A big part of this is how to get patient consent to get access. Getting a signed consent on paper is complicated since many of our programs are delivering care virtually."
>
> —Cardiac Services CBO

This reform only applies to data exchanged via the SHIN-NY and will not directly apply to the sharing of information through other platforms. Nevertheless, this framework offers a useful model for consent that should be considered for SDHN referral platforms. That is, SDHNs and their CBOs would be permitted to receive limited PHI included in referrals based on verbal or implicit consent of their patients, regardless of whether the CBOs received such information via the SHIN-NY or another platform. But if the SDHN or CBO sought access to an individual's full medical record[24]—whether through the SHIN-NY or another platform—the organization would need the individual's written consent to do so. The alignment of consent requirements across platforms would help ensure that the same privacy rules apply regardless of the means by which PHI is shared.

C. Security Standards

In order to properly protect data exchanged under NYHER, the referral platforms used by CBOs should be required to meet recognized security standards.

SDHNs will procure or otherwise influence the platforms that are used by their CBO networks. While SDHNs and CBOs likely will have the freedom to select their own platforms, minimum security standards nevertheless may be established for those platforms. Those standards should reflect the nature of the information that is accessible to the CBO. CBOs that have access to a client's full medical record should be subject to more stringent requirements than CBOs that only receive limited PHI via a referral.

> "It's a fledgling industry in terms of technology; the data vendors are all niche, and the regulatory framework is immature. Their way of dealing with data and security is very different. If you can publish some sort of standards that all these systems have to adhere to, that would go a long way to bringing clarity."
>
> —Elderly Services CBO

Any security standards imposed should be consistent with SHIN-NY security rules, and NYeC and QEs can play a key role in helping further develop security specifications. SDHNs and CBOs should face the same security requirements regardless of whether the PHI they obtain comes from the SHIN-NY or another source. The establishment of minimum security standards will help ensure that information exchanged under the waiver amendment will remain secure while also promoting a level playing field among different platforms; vendors will know they will not be able to offer cheaper products by circumventing necessary security.

D. Interoperability Standards

In its proposed waiver amendment, DOH indicates that "[e]xisting and future referral platforms/data systems supporting screening and referral processes will be qualified to ensure interoperability" and that "[a]ll systems and data will connect to existing state systems including the SHIN-NY." Therefore, the state has already committed to ensuring that the referral platforms selected by SDHNs will be capable of exchanging data with the SHIN-NY, a vital step toward promoting the sharing of social services data under NYHER.

However, there are other steps that can be taken to promote interoperability. A collaboration among New York State agencies can help promote interoperability of CBO data platforms. Many CBOs use certain software because they are required to do so under their state contracts, but often those state contracts do not require the platforms to be interoperable with other systems. State agencies should consider working together by exercising their procurement authority to require interoperability between commonly used platforms, not just the SHIN-NY.

While these efforts will not have a direct impact on the new referral and screening database created under NYHER, they will assist CBOs more generally in their efforts to share information to coordinate and improve client services.

E. Screening Tool Standards

DOH has already indicated that the screening tool to be used by CBOs and others under NYHER will be uniform. The decision to standardize this tool will increase the utility of the screenings to those sharing information under NYHER.

Given the critical importance of screening data to NYHER, the state can explore additional steps to ensure that such data can be easily shared with other organizations via the SHIN-NY. Even if all CBOs are using the same tool, if they have different approaches to recording answers to the same questions, the data will lose significant value. Therefore, CBOs, SDHNs and QEs should work together to ensure that the screening information is being consistently collected and standardized.

F. Disclosure of Medicaid Claims Data

Medicaid claims data can help support NYHER, providing important insights on Medicaid enrollee utilization of services at both the individual and aggregate levels. During the roundtable and interviews, CBOs emphasized the value of such information, noting that these types of analyses can help them both target their services and measure the impact of their work. SDHNs in particular are likely to find Medicaid claims data a useful resource, as SDHNs are responsible for coordinating CBO services based in part on data analyses.

SDHNs, if permitted, could use Medicaid claims data to provide and coordinate services under NYHER. Any revised policies could allow the SHIN-NY to help facilitate SDHN uses of claims data. For example, QEs could engage in audits of SDHNs on behalf of DOH to determine that SDHNs meet necessary security requirements and are only accessing data for individuals they actively serve, and QEs could perform analytics on behalf of SDHNs.[25]

G. Federal Advocacy

While NYeC, QEs and CBOs based in New York have the ability to address many of the barriers to the exchange of data between the health care system and CBOs, some changes must occur at the federal level. Therefore, these organizations should collectively advocate for necessary federal changes.

One important federal ask is clarifying guidance on HIPAA and the permissibility of disclosures of PHI to CBOs. As noted above, prior guidance is ambiguous as to whether disclosure without consent may only occur when a health care practitioner makes an assessment that a particular patient's data can be sent to a Non-Covered CBO, or whether automated alerts may be sent as well. There are many different circumstances under which PHI may be shared with Non-Covered CBOs; communication with the federal government on the rules that apply under each such scenario will help both CBOs and their provider and health plan partners exchange information appropriately. Similarly, guidance from the federal government on the interaction of 42 C.F.R. Part 2 and CBOs could be valuable.[26]

H. Advisory Council

As NYHER is implemented, additional issues regarding the exchange of data to and from CBOs will emerge. Implementing changes will not be easy and will require continuing effort.

Therefore a CBO advisory council, established by DOH, NYeC and CBOs, could help inform DOH on its efforts to better utilize CBOs under the state Medicaid Program. The council would provide ongoing feedback on the implementation of the waiver amendment on all issues important to CBOs, with a particular focus on the exchange of data. The council should be representative of the diversity of CBOs in the state in terms of size, geographic region and type of service. NYeC could play the role of convenor of the council.

V. Conclusion

NYHER is an important and ambitious proposal to improve the quality of care delivered to Medicaid enrollees throughout New York State. Both CBOs and the SHIN-NY are central to the proposal, with CBOs providing critical services and the SHIN-NY providing much-needed technical infrastructure to facilitate the exchange of information to CBOs and others assisting enrollees under the waiver amendment.

DOH has a tremendous opportunity to use NYHER as a means to improve the system of care provided by CBOs as well as the data infrastructure supporting such system. As this white paper indicates, there are significant challenges to enhancing the CBO delivery system and data exchange. But there are also practical solutions to many of these challenges. By prioritizing such solutions, DOH can help to achieve the laudable goals of NYHER.

[1] New York State Department of Health, New York State Medicaid Redesign Team (MRT) Waiver Amendment, https://www.health.ny.gov/health_care/medicaid/redesign/med_waiver_1115/docs/2022-09-02_final_amend_request.pdf.

[2] New York State Department of Health, New York State Medicaid Redesign Team (MRT) Waiver Amendment, https://www.health.ny.gov/health_care/medicaid/redesign/med_waiver_1115/docs/2022-09-02_final_amend_request.pdf.

[3] New York eHealth Collaborative, SHIN-NY Impact and Value, https://www.nyehealth.org/shin-ny/impact-and-value/.

[4] New York eHealth Collaborative, SHIN-NY Impact and Value, https://www.nyehealth.org/shin-ny/impact-and-value/.

[5] For purposes of this white paper, a CBO is a nonprofit or government organization that provides, directly to individuals, services that aim to improve the social determinants of health of those individuals, but that does not fall within the traditional definition of a health care provider or health plan.

[6] 45 C.F.R. § 160.103. HIPAA covered transactions generally consist of exchange of information between health care providers and health plans for payment purposes; therefore, some health care providers that do not bill health plans fall outside of HIPAA. A "health care provider" includes any "person or organization who furnishes, bills, or is paid for health care in the normal course of business." "Health care" means "care, services, or supplies related to the health of an individual."

[7] A "health care clearinghouse" is an intermediary between covered entities that either "[p]rocesses or facilitates the processing of health information received from another entity in a nonstandard format or containing nonstandard data content into standard data elements or a standard transaction" or "[r]eceives a standard transaction from another entity and processes or facilitates the processing of health information into nonstandard format or nonstandard data content for the receiving entity." 45 C.F.R. § 160.103.

[8] 45 C.F.R. § 164.302 et al.

[9] 45 C.F.R. § 164.400 et al.

[10] 45 C.F.R. § 164.500 et al.

[11] Health care operations include a variety of activities, such as quality assessment and improvement activities, case management and care coordination, reviewing the competence and qualifications of health care professionals, customer service, and resolution of internal grievances. 45 C.F.R. § 164.501.

[12] United States Department of Health and Human Services, Does HIPAA permit health care providers to share PHI about an individual with mental illness with a third party that is not a health care provider for continuity of care purposes?, https://www.hhs.gov/hipaa/for-professionals/faq/3008/does-hipaa-permit-health-care-providers-share-phi-individual-mental-illness-third-party-not-health-care-provider-continuity-care-purposes/index.html.

[13] In a 2021 proposed rule, the federal government proposes to codify the ability of providers to share PHI with CBOs without written consent, but so far has not addressed this question. 86 Fed. Reg. 6446 (Jan. 21, 2021). The proposed rule would add the following provision to the HIPAA privacy rule: "A covered entity may disclose an individual's protected health information to a social services agency, community-based organization, home and community based services provider, or similar third party that provides health or human services to specific individuals for individual-level care coordination and case management activities (whether such activities constitute treatment or health care operations as those terms are defined in § 164.501) with respect to that individual."

[14] 42 C.F.R. § 2.31(a)(4)(ii). A "[t]reating provider relationship means that, regardless of whether there has been an actual in-person encounter: (1) A patient is, agrees to, or is legally required to be diagnosed, evaluated, and/or treated, or agrees to accept consultation, for any condition by an individual or entity, and; (2) The individual or entity undertakes or agrees to undertake diagnosis, evaluation, and/or treatment of the patient, or consultation with the patient, for any condition." 42 C.F.R. § 2.11.

[15] The federal government recently proposed to amend the Part 2 consent requirements. The proposed rule provides more flexibility for consent forms but continues to limit disclosures made through an intermediary (defined to include health information exchanges) to recipients who have a "treating provider relationship" with the individual. 87 Fed. Reg. 74216 (Dec. 2, 2022).

[16] 10 N.Y.C.R.R. § 300.5(c).

[17] Privacy and Security Policies and Procedures for Qualified Entities and their Participants in New York State under 10 N.Y.C.R.R. § 300.3(b)(1), Version 3.9 (Jan. 2022), https://www.health.ny.gov/technology/regulations/shin-ny/docs/privacy_and_security_policies.pdf.

[18] N.Y. Public Health Law § 2782(1).

[19] N.Y. Public Health Law § 2782(1)(d).

[20] N.Y. Mental Hygiene Law § 33.13(a).

[21] N.Y. Mental Hygiene Law § 33.13(d).

[22] Under the SHIN-NY regulation, "all health care facilities as defined in section 18(c)(1) of the Public Health Law" must become qualified entity participants and engaging in "bi-directional access," meaning that "a qualified entity participant has the technical capacity to upload its patient information to the qualified entity so that it is accessible to other qualified entity participants authorized to access the patient information and that the qualified entity participant has the technical capacity to access the patient information of other qualified entity participants from the qualified entity when authorized to do so." 10 N.Y.C.R.R. § 300.6(a). A "health care facility" is defined as "a hospital as defined in article twenty-eight of [the Public Health Law], a home care services agency as defined in article thirty-six of [the Public Health Law], a hospice as defined in article forty of [the Public Health Law], a health maintenance organization as defined in article forty-four of [the Public Health Law], and a shared health facility as defined in article forty-seven of [the Public Health Law]." N.Y. Public Health Law § 18(1)(c).

[23] This policy reform may also permit the sharing of alerts with Non-Covered CBOs in some circumstances. Ultimately, whether hospitals will be permitted to send such alerts absent formal written consent is dependent on federal law, which may be clarified in a HIPAA rule expected to be released later in 2023.

[24] For example, an SDHN navigator may need to determine whether an individual is qualified to receive a particular service under NYHER, and in making such a determination the navigator may need more extensive information from the individual's medical record.

[25] Existing New York regulations permit the disclosure of Medicaid claims data to "qualified health information technology entities" but only if informed consent is obtained from Medicaid enrollees for the release of such data and other requirements are met. 10 N.Y.C.R.R. § 504.9(h). In contrast, federal regulations permit the disclosure of Medicaid claims for "purposes directly connected with the administration of the [Medicaid] plan," which include "[p]roviding services for beneficiaries." 42 C.F.R. §§ 431.301, 431.302. State regulatory reforms may be necessary to permit the use of claims data under NYHER.

[26] It is unclear whether Part 2 programs may share their data with CBOs if individuals sign a form that indicates that data will be shared with CBOs but does not name each individual CBO by name. The federal government is in the process of considering substantial revisions to 42 C.F.R. Part 2 to address changes required under the Coronavirus Aid, Relief, and Economic Security Act. See 87 Fed. Reg. 74216 (Dec. 2, 2022).

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