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How Health Information Exchanges Support Integration for Behavioral Health Settings

Prepared for
the Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health & Human Services

by
RTI International

December 2024

Office of the Assistant Secretary for Planning and Evaluation

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This research was funded by the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation under Contract and carried out by Research Triangle Institute. Please visit <https://aspe.hhs.gov/topics/behavioral-health> for more information about ASPE research on behavioral health.



HOW HEALTH INFORMATION EXCHANGES SUPPORT INTEGRATION FOR BEHAVIORAL HEALTH SETTINGS

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December 31, 2024

Prepared for

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Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services

The opinions and views expressed in this report are those of the authors. They do not reflect the views of the Department of Health and Human Services, the contractor or any other funding organization. This report was completed and submitted on August 28, 2024.

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ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

ADHS	Arizona’s Department of Health Services
ADT	Admission, Discharge, and Transfer
AHCCCS	Arizona Health Care Cost Containment System
API	Application Programming Interface
ARS	Arizona Revised Statutes
ASO	Administrative Services Organization
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
ASTP	HHS Office of the Assistant Secretary for Technology Policy
ASU	Arizona State University
BH	Behavioral Health
BHA	Maryland Behavioral Health Administration
CDS	Clinical Decision Support
CFR	Code of Federal Regulations
CHIP	Children’s Health Insurance Program
CMS	HHS Centers for Medicare & Medicaid Services
CORHIO	Colorado Regional Health Information Organization
CRISP	Chesapeake Regional Information System for our Patients
Cures Act	21st Century Cures Act
DAP	Differential Adjusted Payment
DHIN	Delaware Health Information Network
DHSS	Delaware Department of Health and Social Services
DSAMH	Delaware Division of Substance Abuse and Mental Health
DTRN	Delaware Treatment and Referral Network
DUA	Data Use Agreement
eCMS	Electronic Consent Management System
EDI	Electronic Data Interchange
EHI	Electronic Health Information
EHR	Electronic Health Record
FERPA	Family Educational Rights and Privacy Act
FHIR	HL7 Fast Healthcare Interoperability Resources
HCC	Health Check Connect
HDH	Health Data Hub
HDU	Health Data Utility
HHS	U.S. Department of Health and Human Services
HIE	Health Information Exchange
HIN	Health Information Network
HIO	Health Information Organization
HIT	Health Information Technology
HITC	Health Information Technology Commission
HITECH Act	Health Information Technology for Economic and Clinical Health Act

HIPAA	Health Insurance Portability and Accountability Act
HL7	Health Level 7
IIHI	Individually Identifiable Health Information
IRB	Institutional Review Board
IRN	Interconnected Referral Network
LLP	Lower Layer Protocol
MCO	Managed Care Organization
MDHHS	Michigan Department of Health and Human Services
MH	Mental Health
MHCC	Maryland Health Care Commission
MiHIN	Michigan Health Information Network
NC HIEA	North Carolina Health Information Exchange Authority
NCDHHS	North Carolina Department of Health and Human Services
NDHHS	Nebraska Department of Health and Human Services
NEHII	Nebraska Health Information Initiative
NPRM	Notice of Proposed Rule Making
ONC	Office of the National Coordinator for Health Information Technology
PDMP	Prescription Drug Monitoring Program
PHI	Protected Health Information
QSOA	Qualified Service Organization Agreement
ROI	Release of Information
SAMHSA	HHS Substance Abuse and Mental Health Services Administration
SDOH	Social Determinants of Health
SHARES	ASU Substance use HeAlth REcord Sharing
SHI	Sensitive Health Information
SPI	Sensitive Personal Information
SUD	Substance Use Disorder
TI	Targeted Investments
TIPQIC	Targeted Investments Program Quality Improvement Collaborative
USCDI	United States Core Data for Interoperability

EXECUTIVE SUMMARY

States and Health Information Exchanges (HIEs) use various approaches to enhance behavioral health (BH) care integration with primary and physical health care. Although HIEs are advancing technical solutions to improve the sharing of confidential information, challenges persist. Improving BH data integration is crucial for modernizing health systems to address interrelated medical, BH, and social needs. HIEs can play a vital role in integrating care by facilitating the exchange of patient information across different health care settings. However, BH providers are less likely to send and receive information from HIEs due to multiple challenges. These include structural issues, such as limited health information technology (HIT) staff and electronic health records (EHRs) capabilities, as well as navigating through a web of regulations. The potentially complex interplay between state laws and federal laws, such as the Health Insurance Portability and Accountability Act (HIPAA), 42 CFR Part 2, and the 21st Century Cures Act (Cures Act), can intimidate providers and stymie data sharing. Although there have been efforts to align 42 CFR Part 2 and state laws to HIPAA, targeted educational efforts are critical in encouraging more providers to share patient data.

The rise of integrated care has brought challenges in managing and sharing substance use disorder (SUD) treatment information covered by 42 CFR Part 2. While many HIEs utilize technical standards such as Fast Healthcare Interoperability Resources (FHIR) to handle sensitive data, adoption among BH providers remains low. This is often due to a lack of technical infrastructure or awareness among providers, which hinders their ability to securely share SUD data in compliance with these regulations.

BH settings have historically received significantly less funding for HIT compared to their integration partners in physical care settings. This funding disparity has left many BH settings without the necessary infrastructure--such as interoperable EHRs--to effectively use HIEs for data sharing. State and federal funding efforts, although limited, have made notable strides in improving the landscape by helping certain BH providers advance their HIT capabilities and better integrate with the broader health care system.

We investigated six states that have implemented a range of initiatives to support the integration of BH with physical care, but an overarching framework did not emerge. Each state adopts its own unique strategies, policies, and funding mechanisms to expand HIE among BH providers, reflecting the diverse needs and resources of different regions. These individualized approaches highlight the complexity of advancing care integration, as states tailor their efforts to fit local contexts and priorities.

Many state statutes governing the disclosure of BH information explicitly incorporate or reference HIPAA disclosure requirements as their standard, ensuring consistency with federal privacy laws. However, fewer state statutes explicitly address or incorporate the more stringent 42 CFR Part 2 regulations, which govern the confidentiality of SUD treatment records. HIEs have found success by broadening their range of use cases, particularly those that encourage extensive participation, allowing them to leverage patient data for public health purposes. Some HIEs have formalized their role in supporting public health by partnering with state and local governments and obtaining designation as a Health Data Utility (HDU), which enhances their capacity to manage and utilize health data for community health improvement.

Examples of BH Integration Approaches and Models

- BH in primary care
- BH in specialty care (oncology, maternal care, pediatrics, rehab, etc.)
- BH in medical care (hospitals and emergency departments)
- Primary and other specialty physical care in BH settings such as community BH centers and inpatient SUD treatment
- Collaborative care models
- Integration of BH in community service and support programs
- BH services in school-based health centers

BH = behavioral health; SUD = substance use disorder.

Currently, no state has implemented a large-scale operation for obtaining patient consent to share 42 CFR Part 2 data. Pilot programs in multiple states have shown that most patients opt to share all available Part 2 data when explained their rights. Operationalizing this at scale remains a challenge, as clinicians may be unwilling to allocate substantial time during visits to explain this complex process to patients. New technologies present an opportunity to streamline this process. E-Consent tools--such as the Substance Abuse and Mental Health Services Administration (SAMHSA) Consent2Share, the Michigan Health Information Network (MiHIN) Electronic Consent Management System (eCMS), and the Arizona State University (ASU) Substance use HeAlth REcord Sharing (SHARES)--can be integrated into mobile health technology to simplify and expedite the consent process, making it more accessible for both patients and providers. Educational materials could be included in these resources to improve patient understanding and increase opt-in rates. Many states have taken steps to align their legislation with federal laws such as HIPAA. In response to the final rule issued in 2024, states should consider aligning legislation with 42 CFR Part 2 to facilitate data sharing and protect patient privacy. The complexity of interpreting how local, state, and federal regulations intersect remains a significant barrier to broader participation in HIEs. To address this challenge, some state governments have developed educational materials for providers that clarify what patient data can be shared, with whom, and under what conditions. Creating and disseminating these resources is one of the more straightforward actions state governments can take to enhance data sharing among BH providers, helping to build trust and understanding in the process.

BACKGROUND

Introduction

Improving integration of care is one of the cornerstones for modernizing BH systems by focusing on the whole-person and treating interrelated medical (physical health), BH conditions, and health-related social needs.^{1,2} Broadly defined, integrated care is a concept comprised of an infrastructure that connects, aligns, and facilitates collaboration within and across health care² providers and settings (such as physical and behavioral). HIT, EHRs and HIE are part of the integration infrastructure supporting connectivity to facilitate collection and sharing of patient data. Handling BH health information requires HIT and HIE systems to apply special security levels and safeguards to protect patient privacy and to prevent improper disclosure as required by federal and state privacy laws and regulations.

For the purposes of this study, we focus on BH integration as discussed broadly in the 2022 U.S. Department of Health and Human Services (HHS) *Roadmap for Behavioral Health Integration*² including integration of BH in physical health (e.g., primary care, hospital care, and specialty settings), physical health in BH settings, as well as in social service and other settings. The term BH is used as an umbrella to represent both mental health (MH) and SUD conditions or the specialty providers and settings delivering those services.

BH integration takes on many forms and approaches, in recognition that a patient desires to receive care where they are most comfortable and to receive treatment from an interprofessional care team.³ A 2016 study by the Milbank Memorial Fund Foundation described the physical and BH integration as a continuum starting with coordinated care (such as the use of screening, referrals, navigators, care and case managers), then moving to co-located care (BH in physical care settings and vice versa) and finally to an integrated care system (e.g., collaborative care models, providers functioning as a team with collaborative treatment planning, or a system responsible for care, payment, and population health).^{3,4} Implementing these types of integrated care models are bridging the gaps between physical and BH to improve quality and health outcomes and reduce overall costs.^{5,6}

HIT, EHRs, and HIE are foundational tools for BH integration and care collaboration within and across health care providers and settings. EHRs make information immediately available for use by a care team (e.g., co-located or integrated system care team) or for sharing electronically with another provider. To understand the concepts and interrelationships of HIT, EHRs, and HIE, the HHS Office of the Assistant Secretary for Technology Policy (ASTP)/Office of the National Coordinator for Health Information Technology (ONC) provides the following definition for each:

- **HIT** is an array of technologies that use computer hardware, software, or infrastructure to record, store, protect, and retrieve clinical, administrative, or financial information. Examples of HIT include EHRs, personal health records, electronic prescribing, and others.⁷
- **EHRs** are digital versions of patients' medical records with advanced features including real-time, patient-centered records where information is immediately availability to authorized users (within or outside the provider setting). They include evidence-based tools to support providers in decision-making and automate provider workflow to improve efficiency.⁸
- **HIE** is both the act of electronically sharing confidential health information and an organization that provides services to support electronic, secure sharing of health information.⁴ There are three common types of HIE:
 - Directed exchange where information is securely sent between care providers to support care coordination.
 - Query-based exchange allows a provider to securely search and find information on a patient from other providers, for example, to support unplanned care.

- Consumer mediated exchange where the patient aggregates their information, such as in a personal health record, and shares their information with providers.⁹

Business entities known as HIE organizations or networks (referenced as either HIEs or HINs) play a crucial role in BH integration by helping to facilitate exchange of patient information across different health care settings and services.¹⁰ For example, by integrating data between BH and physical health providers, HIEs help create the whole-person view of an individual’s health, allowing for better informed clinical decisions, treatment plans, and integration of the patient’s goals and preferences. Ensuring that BH providers, physical health providers, and others have access to the same information helps to maintain continuity of care, reducing the likelihood of treatment gaps or conflicting care plans. HIEs can also facilitate the collection of quality metrics that are essential for value-based care, where providers are rewarded based on patient outcomes, including BH improvements. Some HIEs offer resources and training for providers on how to use the system effectively, ensuring that they can maximize the benefits of integrated care. By enabling real-time, secure data sharing and fostering collaboration between health care providers, HIEs and HINs are integral to the successful integration of BH services into primary care, leading to more comprehensive, efficient, and patient-centered care.

Benefits of HIE
<ul style="list-style-type: none"> • Strengthens care coordination. • Improves safety and quality. • Empowers patients and families. • Increases efficiency and reduces costs. • Supports robust public health information.
<p>Source: <i>Sharing Data, Saving Lives: The Hospital Agenda for Interoperability</i>. 2019. American Hospital Association. https://www.aha.org/system/files/2019-01/Report01_18_19-Sharing-Data-Saving-Lives_FINAL.pdf.</p> <p>HIE = health information exchange.</p>

States and HIEs are expanding their services to support broader clinical, quality improvement, and community and public health priorities.¹¹ The emerging models, HDUs, have state-designated authority, governance structures, and enhanced capabilities to meet the needs and goals in the state.¹²

BH providers have privacy and disclosure concerns over sharing sensitive patient health information. Those concerns, coupled with lower adoption rates of EHRs capable of HIE, privacy laws and regulations, and limited technical solutions to filter psychosocial notes and SUD health data, have resulted in limited

data sharing and HIE by BH providers, impeding BH integration. The focus of this study is to understand the approaches states are deploying to increase the adoption of EHRs by BH providers, understand how HIEs support integration of BH provider information (MH and SUD) and physical health information, and the technical solutions HIEs are using to facilitate secure access and sharing of sensitive BH information.

Health Information Technology, Electronic Health Records, and Health Information Exchange Support for Behavioral Health Integration

HIT—including the use of EHR systems—and HIE serve an important role supporting integrated care including access, integration, and sharing of health data between interprofessional care teams, health care providers, community services, and other stakeholders including payers, public health entities, and more. A 2023 study by the Office of the Assistant Secretary for Planning and Evaluation (ASPE)¹³ found that providers currently implementing integrated BH and primary/physical care models consider HIT and HIE a critical component to perform fundamental data sharing and integration activities such as intake, screenings and assessment, referrals, unified care plans to coordinate across the interprofessional care team, outcome monitoring, comprehensive caseload reviews, and shared EHRs with patients and families.^{6,14}

BH EHR Adoption

Several challenges must be overcome to increase the adoption of EHRs and HIEs to support BH integration. Lack of funding is considered one of the primary reasons for lagging adoption of EHRs and HIE in BH compared

to their integration partners in physical care settings (acute care hospitals and primary care practices). This is due, in part, to ineligibility to participate in current and past EHR incentive programs administered by the Centers for Medicare & Medicaid Services (CMS).^{13,15,16} The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 offered financial incentives to providers who could demonstrate meaningful use of an EHR, among other goals.

HITECH was impressive in scope and impact: over \$10 billion was disbursed to providers and hospitals for their use of certified EHR technology,¹⁷ causing basic EHR adoption among non-federal acute care hospitals to jump from 9.4% in 2008 to 83.8% in 2015.¹⁸ However, these incentive payments were not extended to most BH providers and settings. Consequently, BH providers were (and remain) far less likely to purchase, implement or use EHR systems with the required technical standards to support HIE.

There is no definitive study of EHR adoption across the United States by BH providers or settings. Consequently, estimates vary widely. A 2022 report¹⁹ from the Medicaid and CHIP Payment and Access Commission reported only 6% of MH facilities and 29% of SUD treatment centers utilized an EHR. Findings from the SAMHSA's national surveys indicated most BH providers (between 52% and 84%) use some type of HIT to store and maintain patient health and treatment records and computerized operations,^{20,21} but those operations are not required to be used by all BH providers nor are they aligned with the EHR standards and functionality found in physical health needed to integrate and support HIE.⁵

In addition to the exclusion from HITECH, BH providers operate on lower margins and have fewer resources to invest in HIT. A 2019 report commissioned by the Bowman Family Foundation found that primary care reimbursements were 23.8% higher than those for BH care, a gap that expanded between 2015 and 2017.²² Lower reimbursements for care delivered, may limit BH providers' available financial resources to proactively invest in EHR systems.

In addition to funding concerns for adoption and maintaining HIT systems, BH providers have privacy and disclosure concerns over sharing sensitive patient health information, sometimes referred to as "HIPAA hesitancy." **Exhibit 1** summarizes the challenges to overcome to increase adoption and use of HIT, EHRs, and HIE found in the ASPE 2023 study.

BH Providers Ineligible for EHR Payment Incentives and Other Funding Under HITECH

- Psychologist.
 - Clinical social worker.
 - Community mental health center.
 - Psychiatric hospital/unit (including substance abuse).
 - Residential treatment centers (facilities for mental health and/or substance abuse).
-

Source: Dougherty, M., Williams, M., Millenson, M., & Harvell, J. (2013). *EHR Payment Incentives for Providers Ineligible for Payment Incentives and Other Funding Study*.

<https://aspe.hhs.gov/reports/ehr-payment-incentives-providers-ineligible-payment-incentives-other-funding-study#main-content>.

BH = behavioral health; EHR = electronic health record; HITECH = Health Information Technology for Economic and Clinical Health Act; MH = mental health.

Exhibit 1. BH Challenges to Increased Adoption and Use of HIT, EHRs, and HIE

Factors	Challenges
Technical	<ul style="list-style-type: none"> • Compatibility and interoperability of reporting systems (within and outside of organizations). • Lack of data standards and standardized EHR templates related to BH care and treatment.
Workforce	<ul style="list-style-type: none"> • Staff information technology literacy and training capacity. • Time constraints during appointments and impact on patient-provider relationship.
Cost	<ul style="list-style-type: none"> • Level of funding (for HIT setup, workflow redesign, continued support and technology improvements). • Capacity for maintaining EHR and other HIT systems.
Policy	<ul style="list-style-type: none"> • Lack of financial incentive alignments and policy/regulatory requirements. • Communication of benefits of adoption/integration. • Privacy concerns (Part 2 (revised), psychotherapy notes subject to the HIPAA Privacy Rule, Cures Act Information Blocking, and different state laws).

Dougherty, M., R. McGavin, M. Pilar, M. Horvath, & S. Brown. (2024). *Health Information Technology Adoption and Utilization in Behavioral Health Settings: Final Report*.

<https://aspe.hhs.gov/sites/default/files/documents/b9f858a38ff71660528cf1e4b8df00fa/HIT-adoption-utilization-bh-settings.pdf>.

BH = behavioral health; EHR = electronic health record; HIE = health information exchange; HIT = health information technology.

HIE Organizations and Networks

The passage of the HITECH Act in 2009 that provided funding for providers to adopt and use EHRs also included funding for states to build capacity for HIE--both between health care providers in a state and across state lines. In 2010, ASTP/ONC (then just ONC) announced the State Health Information Exchange Cooperative Agreement Program that funded 56 states, eligible territories, and qualified State Designated Entities received awards.²³ At that time, funding was used to advance HIE and ensure that providers eligible for HITECH incentives could meet national standards and the meaningful use requirements²⁴ by establishing privacy and security requirements, supporting Medicaid and state public health programs, track HIE capabilities and strategize gaps, and align with national standards. Today there are a variety of HIE organizations operating at the community, regional, and state level. All but three states (Iowa, New Hampshire, and Wyoming) have an active HIE organization.²⁵

Some regional or statewide HIEs have expanded their capabilities beyond just clinical data exchange to include other types of “data utilities.” HDUs are designed to provide robust clinical and non-clinical data to benefit the entire health care ecosystem, including public health, community health, and research. Without this designation, the HIE may lack the necessary infrastructure, governance, and stakeholder participation to serve these broader purposes. HDUs serve as infrastructure to enable specific, defined use cases with extra protections to ensure patient privacy and protections. They build on existing technical, organizational, and trust infrastructure in states and regions.”²⁶

HIE Data to Support Exchange and Interoperability

Data standards are integral for HIE, facilitating interoperability and data integration such that multiple systems have the ability to both exchange information and use the information that has been exchanged.²⁷ Recent years have seen a strong push to define universal data standards to support data exchange. In July 2020, ASTP/ONC released a set of data classes and elements that define core data elements and classes for interoperability known as U.S. Core Data for Interoperability (USCDI).²⁸ Recognizing the unique data in BH, ASTP/ONC together with SAMHSA launched an initiative in 2022 called USCDI+ for BH to improve data consistency and standardization, support BH integration, and more.²⁹

Standards for Exchanging Health Care Data

- Health Level 7 (HL7) Version 2 (V2) messaging standards^a
- HL7 Version 3 (V3) Consolidated Clinical Data Architecture (C-CDA)^a
- Continuity of Care Document (CCD)^a
- HL7 Fast Healthcare Interoperability Resources (FHIR)^a
- Claims and claim line feed (CCLF)^b
- X12 Electronic Data Interchange (EDI)^c

- a. Health Level Seven International. (n.d.). *Introduction to HL7 Standards*. Health Level Seven International. Retrieved August 12, 2024, from <https://www.hl7.org/implement/standards/>.
- b. Centers for Medicare & Medicaid Services. (2024). *Program Guidance and Specifications*. CMS. Retrieved August 9, 2024, from https://www.cms.gov/medicare/payment/fee-for-service-providers/shared-savings-program-ssp-acos/guidance-regulations#Data_and_Report_Sharing.
- c. X12.org. (n.d.). *Consensus-Based, Interoperable, Syntax-Neutral Data Exchange Standards: X12 Standards are the Workhorse of Business to Business Exchanges*. Retrieved August 9, 2024, from <https://x12.org/>.

The EHR system a provider organization uses generally dictates the exchange format used. While the FHIR standard set in USCDI is the gold standard, many BH providers do not have EHR systems capable of packaging and sharing FHIR resources.³⁰ Consequently, each HIE must decide which exchange formats they will accept. HIEs that attempt to “meet providers where they are at” devote substantial resources to transforming varied data into standardized formatting.

Even still, some data is unable to be integrated by an HIE, regardless of resources. There is no algorithmic way to distinguish information subject to Part 2 protections from regular health data with 100% certainty. As a result, when provider organizations share a mix of Part 2 and regular health data without indicators, the entire set of data must be subject to Part 2. Improving the technical capabilities of the EHR systems that initially

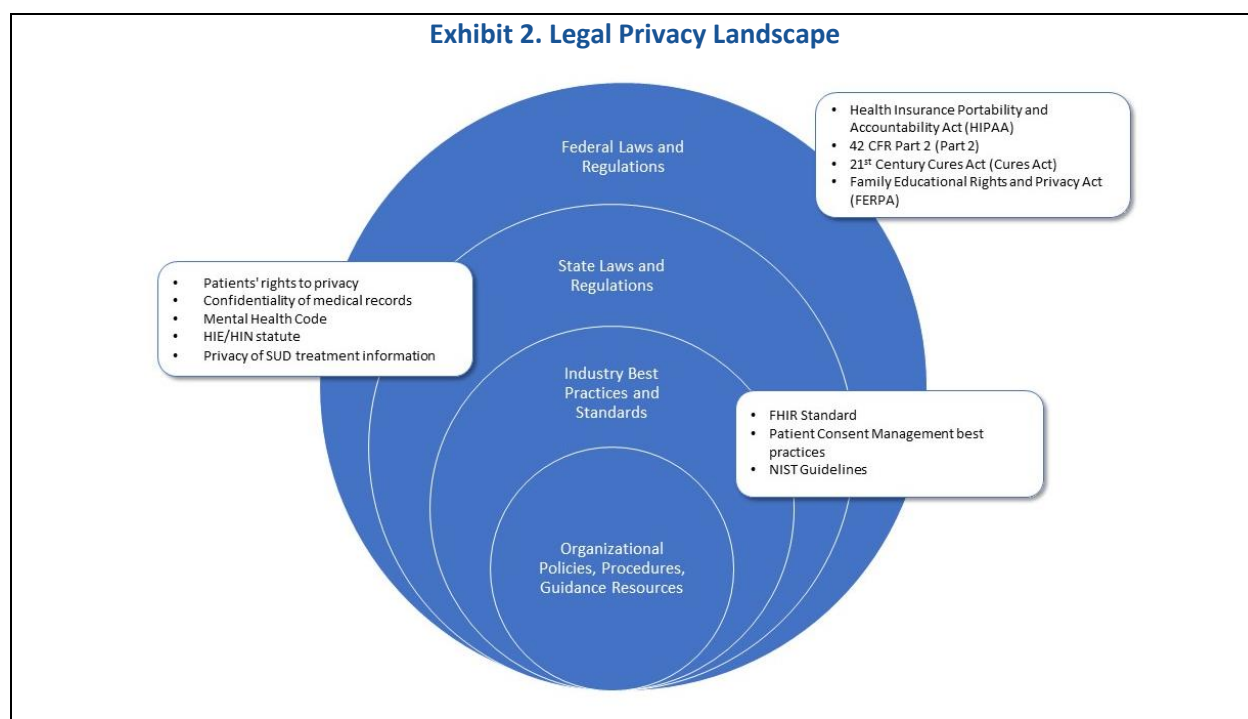
capture patient data will thus enable greater data sharing and reduce the burden on HIEs.

Privacy and Technology Considerations for BH Integration and HIE

Federal privacy and disclosure rules, including Part 2 Revised, the HIPAA Privacy Rule, and the 21st Century Cures Information Blocking Rule, impact how, when, and to whom disclosures of BH information may occur. Federal laws such as Part 2, HIPAA, and the Family Educational Rights and Privacy Act (FERPA) protect the privacy of BH information by restricting certain disclosures. Another federal law, the Cures Act, aims to promote the sharing of electronic health information (EHI) through its Information Blocking Rule.

In addition to federal laws, state laws govern disclosures of confidential health information, including disclosures of BH information. These state laws span several statutory domains, including medical information privacy, MH record and information privacy, substance use treatment record and information privacy, patient rights, and HIE as outlined in **Exhibit 2**.

Exhibit 2. Legal Privacy Landscape



The patchwork of federal and state laws creates an intricate legal landscape where laws sometimes interact smoothly and disclosure requirements are clear, although at other times, rules of the road for data sharing are not so clear. The complex regulatory landscape can make it difficult for providers to determine if, when, and how they can share BH information with other health care providers for patient care purposes.¹³ The following federal privacy and disclosure rules, along with state rules, are applicable in BH settings and relate to the use of HIT.

- **HIPAA and HIPAA Privacy Rule:** The HIPAA Privacy Rule established safeguards to protect the privacy of health information by establishing a uniform approach to health records sharing and a single consent for all future use, disclosure and re-disclosure of records. There is one exception, however, pertaining to psychotherapy notes, where special protections are required in the form of patient authorization to disclose unless required by law. These notes contain specific types of sensitive MH information from counseling sessions and are kept separate from the rest of the patient’s medical record.³¹
- **42 CFR Part 2 Revised, Confidentiality of SUD Patient Records:** Part 2 restricts the disclosure of SUD patient records in federally-funded programs and specifies conditions when patient consent is needed.³² SUD records are typically shared only with explicit written consent for each specific use, and generally cannot be shared with other persons (individuals or entities) unless there is a court order, with certain exceptions.^a The rule was revised in July 2020 to modernize care coordination, improve quality, and advance integration of care for individuals with SUDs.³³ In December 2022, HHS released a Notice of Proposed Rule Making (NPRM) substantially revising the procedures for Part 2 record use, disclosure, and re-disclosure by aligning them with the HIPAA Privacy Rule while including additional safeguards to protect SUD information per Section 3221 of the CARES Act.³⁴ The NPRM also proposes establishing a definition of SUD counseling notes under Part 2, similar to the definition of

^a The limited exceptions are codified in current regulation at 42 CFR 2.12(c), 42 CFR Part 2 Subpart D, and 42 CFR 2.33(b).

psychotherapy notes under the HIPAA Privacy Rule. The final rule was published on February 10, 2024, and went into effect on April 16, 2024, with a compliance date of February 16, 2026.³²

- **21st Century Cures Act (Cures Act) and Information Blocking Provisions:** In 2016, Congress passed the Cures Act which included provisions related to EHI and its secure access, exchange, and use. Health care providers (including BH providers), certified HIT developers, and HIE/HINs are considered actors under the rule and are prohibited from impeding access, exchange, and use of EHI. Claims of information blocking are reportable, and Office of Inspector General is given authority to investigate. The Cures Act final rule, published in 2020, provides more details on information blocking and exceptions.³⁵
- **FERPA:** Is the primary law governing privacy of student education records. Under FERPA, a school may not disclose an eligible student's personally identifiable information within student records unless the student has provided prior written consent. There are several exceptions to FERPA's general consent requirement, including disclosures to comply with a judicial order or a lawfully issued subpoena, disclosures in connection with a health or safety emergency, and disclosures to a parent at a postsecondary educational institution regarding the student's violation of law, or an institutional rule or policy related to the use or possession of alcohol or a controlled substance.
- **State BH Privacy and Disclosure Laws and Regulations:** States may also have requirements related to BH privacy and disclosure. Previous compilations of state laws governing BH privacy and disclosures include the following: In 2016, the National Association of State Mental Health Program Directors compiled a list of BH patient treatment privacy and disclosure laws and regulations.³⁶ In 2017, ONC released an application with state HIT privacy and consent laws and policies.³⁷ Each state may have multiple laws that govern disclosures of BH information within and outside of HIEs.

Technical Challenges for BH Data and Privacy Protections

To meet the federal privacy requirements and disclose information as directed by the patient through the consent process, BH providers and HIEs require technical solutions to manage consent and to prevent data from inappropriate disclosure. Doing so requires robust data sorting processes as HIEs often receive mixed data making it challenging to algorithmically sort information into sensitive and non-sensitive groups. For example, clinical notes with information about medications, diagnoses, and observations may not be clearly separated into sensitive (i.e., Part 2 related information) and non-sensitive information. Other contributing challenges in sorting data for HIEs are the variations in how each EHR template is set up and the extent to which providers use free text.

Policy Approaches to Support Behavioral Health Integration

Both federal and state policymakers are using various policy, regulatory, and funding approaches to advance EHR and HIE use in BH. Medicaid has become the largest payer of MH and SUD services¹³ with the implication that BH providers must be able to share data relevant to SUD treatment with state agencies to qualify for reimbursement. This has resulted in states working with HIEs, BH providers, and other stakeholders to implement a variety of policy levers focused on HIT/HIE approaches to support integration and overcome challenges in sharing information. States look to improve integration by implementing statutory mandates for BH providers to connect to the state HIE or offering financial incentives to BH providers for sending data to an HIE.

STUDY APPROACH, METHODS, AND DATA

First, we sought to identify federal and state policy levers that successfully connect BH providers to HIEs. Second, we examined critical resources required by HIEs from providers, developers, and policymakers to facilitate more meaningful exchange across the care continuum. Lastly, we explored policy levers that support EHR adoption and sharing of records between BH providers and the rest of the health care system. To meet these goals, we conducted case studies in six states guided by the following research questions:

1. What policy levers do states use to support adoption of EHRs or inclusion of BH providers into state HIEs?
2. What are the types of technological solutions that states have developed to support policies on data sharing and confidentiality?
3. Has the inclusion of SUD records facilitated the provision of integrated care (across settings and providers) for patients with SUD?
4. How does the advancement of HIEs/EHRs technology among other, non-BH providers (e.g., hospitals, physician offices) impact BH providers' ability to catch up with adoption of EHRs? What needs to be done for the same adoption among BH providers?

We conducted case studies examining promising practices for EHR adoption and HIE participation among BH providers and integration of SUD records in EHR systems. The case studies helped assess the needs of providers and developers to enable greater integration of BH providers with HIE systems. In addition, the studies sought to understand what types of data classes and elements HIEs typically make available to BH providers' exchange partners. Finally, the case studies explore examples of SUD record inclusion in HIE and policy levers that aid such efforts within each state. The case studies involved discussions with stakeholders that directly support Part 2 data sharing, such as state HIEs, state EHR vendors, state BH agencies (or single state agencies), state and regional health systems, county health departments, Tribal health organizations, community providers (Federally Qualified Health Centers, Certified Community Behavioral Health Clinics, community MH centers), and patient organizations.

Case Studies Approach

Eight selection criteria for state inclusion, shown in **Exhibit 3**, were developed based on research questions from our 2023 ASPE study. Findings from the prior study also informed the identification of 10 states with innovations in BH and HIE, therefore warranting potential inclusion in case studies--Arizona, Connecticut, Delaware, Maine, Maryland, Michigan, Nebraska, North Carolina, Oregon, and Washington. Two analysts and the task lead then conducted a limited and targeted environmental scan to inform state selection based on the above list and the development of interview discussion protocols. Based on our final state inclusion process, we selected Arizona, Delaware, Maryland, Michigan, Nebraska, and North Carolina to serve as case studies.

Exhibit 3. Selection Criteria

- State HIE Includes BH Providers
- Medicaid Reimbursement and Payment Policies for MH/SUD Services
- State Laws and Requirements (e.g., BH integration, privacy, consent)
- Incentive Programs for HIT/HIE Use or Exchange
- BH Integration Funding (federal or state programs)
- Data Platforms for Integration/Coordination or Reporting
- Technical Assistance Tools and Support Services
- BH Integration Priorities (e.g., Maternal Health MH/SUD)

BH = behavioral health; HIE = health information exchange; HIT = health information technology; MH = mental health; SUD = substance use disorder.

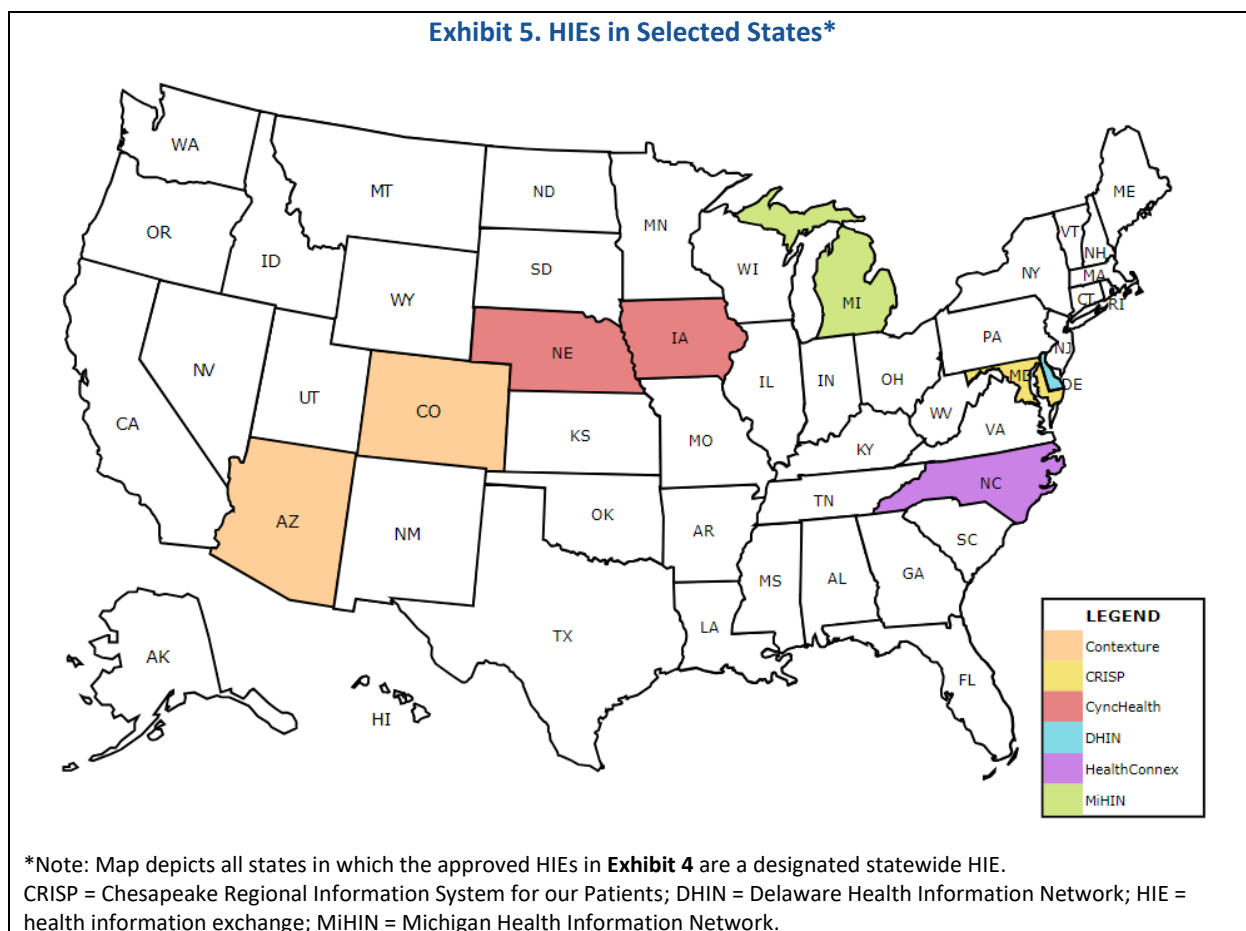
We used resources such as state HIE/HIN websites, state agency websites, and federal agency websites that provide information on funding mechanisms used by states to support BH integration, HIT adoption and use, and/or inclusion in HIE/HINs. We supplemented this by using Fastcase, a legal research database, to identify relevant state laws and policies regarding data privacy, confidentiality, and data protection for targeted states.

The HIEs of the selected six states have varying reach, with some HIE networks including other states beyond the singular selected case study state as shown in **Exhibit 5**. An overview of the selected state HIEs is available in **Exhibit 4**.

Exhibit 4. Selected States and HIE		
State	Description of HIE	Approved HIEs
Arizona	<ul style="list-style-type: none"> Contexture, Arizona’s current statewide HIE, is the result of a merger between the state’s former Health Currents network and the Colorado-based CORHIO. 	State Designated: Contexture
Delaware	<ul style="list-style-type: none"> DHIN was established in 1997, making it the first statewide HIE in the U.S. DHIN quickly expanded beyond its initial use case of clinical results delivery by launching the Community Health Record, an online portal which to this day allows any provider with a relationship to a patient to view their health data. 	State Designated: Delaware Health Information Network (DHIN)
Maryland	<ul style="list-style-type: none"> The state-designated HIE is responsible for building and maintaining technical infrastructure and an efficient and effective data management strategy that can support the secure statewide exchange of electronic health information. There are 16 approved HIEs operating in the state but only a single state-designated one (CRISP). CRISP accepts data from the other 15. 	State Designated: Chesapeake Regional Information System for our Patients (CRISP)
Michigan	<ul style="list-style-type: none"> The state HIE includes 13 million patients and 99% of statewide admissions. The breadth of connecting organizations requires it to offer multiple transmission options to accommodate providers with varying HIT resources. 	State Designated: Michigan Health Information Network (MiHIN)
Nebraska	<ul style="list-style-type: none"> Nebraska’s statewide HIE, founded as the Nebraska Health Information Initiative (NEHII) in 2008, merged with the Iowa Health Information Network in 2021 to become CyncHealth. CyncHealth acts as a Health Data Utility and draws authority from LB 411 to collect, analyze, and facilitate exchange of patient data. 	State Designated: CyncHealth
North Carolina	<ul style="list-style-type: none"> HealthConnex integrates data from 225 EHR systems across the state, accounting for more than 9 million patient records, and provides eHealth integration and directory linkage with other statewide and nationwide systems. 	State Designated: HealthConnex

EHR = electronic health record; HIE = health information exchange.

Exhibit 5. HIEs in Selected States*



Methods for Producing Case Study Summaries

During the selection process, we identified key personnel in industry, government, and research from previous BH technology projects and online searches. Roles included providers, HIE leadership, state agency staff, and others. We created and shared an interview guide tailored to each individual's role and organization for each selected subject matter expert who expressed interest in participating. We interviewed over 30 stakeholders in groups that ranged from one to seven participants, with no more than nine stakeholders completing the same interview; recordings for each of the nine one-hour meetings were automatically transcribed and manually cleaned and shared along with TEMI transcripts.

We integrated the interview findings with the findings from the environmental scan and statute search to produce a case study summary for each state, which are available in **Appendices A-F**.

FINDINGS

Across the six case studies of HIEs, several high-level themes and areas of opportunity emerge. State-specific statutes, legislation and governance structures are pivotal in shaping HIE operations. Achieving seamless integration and interoperability across diverse EHR systems is a recurring challenge. Technical disparities among EHR vendors, the complexity of bidirectional data exchange, and compliance with evolving data standards like USCDI v3 are significant hurdles. Below we present detailed findings, organized by the research questions, and informed by our cross-state analysis. Individual case study summaries are available in the appendices.

Analysis of State Statutes

The findings from the 2023 study indicated that alignment of federal and state privacy and disclosure rules and regulations were critical to sharing of BH data. To understand how states have supported MH and SUD records inclusion and EHR adoption while allowing for providers to securely access and share their patient's information, we conducted a review of state health information privacy statutes. This review informed the state-specific case study summaries and provided the foundation for cross-state analysis for the final report. We identified state statutes and reviewed them for relevancy to the project's scope and research questions on MH and SUD data sharing.

State laws governing disclosures of BH information represent a variety of statute types. We assigned state statutes to the following categories: HIE statutes, medical records statutes, MH and BH records statutes, patient rights statutes, and provider or health facility statutes. The type, scope, and impact of laws governing provider-to-provider disclosures varied by state, reflecting the complex nature of the regulatory landscape. We found that all states have a legal pathway for provider-to-provider disclosures of MH and SUD information, with some variation in specific disclosure requirements. Not surprisingly, state laws governing substance use-related records are more restrictive than laws governing disclosures of non-SUD health information records. As states continue to implement and operate HIEs, nuanced disclosure requirements within multiple state privacy laws will need to be embedded into data exchange policies and agreements to ensure compliant information exchange.

In addition to the types of state laws described above, the landscape of privacy laws includes federal privacy laws and regulations. For our select states, most relevant are regulations promulgated under the HIPAA Privacy Rule³⁸⁻⁴⁰ which sets privacy standards for protected health information (PHI)^b maintained by health providers, plans, and payors, and 42 CFR Part 2⁴¹ restrictions on the disclosure of confidential alcohol and substance use treatment patient records.

The extent to which state laws are more restrictive than the Privacy Rule and Part 2 varied across case study states. Among the five states with HIE statutes, two (Arizona⁴² and Delaware⁴³) have requirements for disclosures without consent that are more restrictive than HIPAA Privacy Rule requirements. The other three HIE statutes (Maryland,⁴⁴ Nebraska,⁴⁶ and North Carolina⁴⁷) have requirements that are consistent with HIPAA

^b The HIPAA Privacy Rule defines protected health information (PHI) as individually identifiable health information (IIHI) that is transmitted by electronic media, maintained in electronic media; or transmitted or maintained in any other form or medium. <https://www.ecfr.gov/current/title-45/subtitle-A/subchapter-C/part-160/subpart-A/section-160.103>.

PHI is a subset of individually identifiable information. The Privacy Rule defines individually identifiable information as health information created or received by a health care provider, health plan, employer, or health care clearing house and relates to an individual's health or condition, health care, or payment for the provision of health care, and identifies the individual or there exists a reasonable basis to believe the information can be used to identify the individual. <https://www.ecfr.gov/current/title-45/subtitle-A/subchapter-C/part-160/subpart-A/section-160.103>.

disclosure requirements. Three of the HIE statutes (Arizona,⁴² Maryland,⁴⁴ and North Carolina^{47,48}) include text indicating that the HIE statute does not interfere with other state or federal laws with more restrictive protections of IIHI.^c North Carolina's HIE statute goes a step further, explicitly exempting restricted Part 2 data from HIE submissions.

All six states defer to HIPAA regulations by incorporation or by reference. For Part 2 disclosure requirements, most states either defer to Part 2 explicitly or more generally refer to other laws (state or federal) that protect BH information. We examine key disclosure requirements of state statutes and compare them to HIPAA Privacy Rule, Part 2 disclosure requirements, and the Cures Act Information Blocking Rule requirements in the paragraphs that follow. Findings are summarized in **Exhibit 6**.

Arizona's HIE statute permits disclosures of a person's IIHI through the state's health information organization (HIO) only when: (1) the individual has not opted out; (2) the purpose of the disclosure is explained in the HIO's notice of health information practices; and (3) when the disclosure complies with the HIPAA Privacy Rule, incorporating requirements beyond the HIPAA Privacy Rule.⁴² The statute requires consent for disclosures of IIHI or de-identified information for research purposes,⁴² whereas HIPAA does not apply to information that has been de-identified using the HIPAA Privacy Rule's standards.⁴⁹ The statute does not interfere with other state or federal laws that are more protective of IIHI nor limit a HIE's duty to exchange information,⁴² signaling alignment with Part 2 and the Cures Act Information Blocking Requirements. Arizona's MH statute explicitly incorporates by reference the HIPAA Privacy Rule and Part 2.⁵⁰

Delaware's HIE statute sets out disclosure requirements for data held by the Delaware Health Information Network (DHIN). The statute permits disclosures of patient specific DHIN data as permitted under HIPAA and other federal laws. However, health information held by the DHIN is not subject to the Freedom of Information Act, or to subpoena by a court.⁴³ The statute describes additional requirements for IIHI disclosures to payers, providers, purchasers, and researchers, including Board or subcommittee review to determine whether the request is aligned with DHIN Act purposes. Public disclosures of de-identified data must be approved by the Board or subcommittee.⁴³ Delaware's MH law permits disclosures as permitted by existing law pursuant to a court order, to attorneys representing the patient, to rights protections agencies, and to departmental contractors to the extent necessary for professional consultation services, to the State Bureau of Identification, to certain rights protections agencies, and as otherwise required by law,⁵¹ aligning with the Information Blocking Rule and other laws which require certain patient records disclosures. Delaware's patient's rights section of the Substance Abuse Treatment Act permits disclosures as needed for transfer to another health care facility, as required by law or third-party contractual agreement, providing fewer non-disclosure exceptions than Part 2.⁵²

Maryland's HIE statute requires that the Maryland Healthcare Commission adopt regulations for the privacy and security of PHI obtained and released through a HIE. The statute provides that the regulations must govern access and use of PHI as required by state and federal law including HIPAA, the HITECH Act,⁵³ the Cures Act,⁵⁴ and Maryland's prescription drug monitoring program (PDMP) statute. The regulations permit disclosures without consent through the HIE to public health authorities for reporting purposes, and for "communications permitted under HIPAA or state law" when using point-to-point transmission (i.e., a secure electronic transmission of PHI). The HIE regulations extend additional protections for sensitive health information, including Part 2 information or any other information that has specific legal protections under HIPAA or the Maryland Confidentiality of Medical Records Act. The regulations explicitly require that disclosures of Part 2

^c A.R.S. 36-3801: Within the context of Arizona's HIE statute, individually identifiable information "has the same meaning prescribed in the health insurance portability and accountability act privacy standards."
<https://www.azleg.gov/viewdocument/?docName=https%3A%2F%2Fwww.azleg.gov%2Fars%2F36%2F03801.htm>.

information comply with all federal laws including Part 2.⁵⁵ Maryland’s MH statutes permit fewer disclosures of information included within MH records than the Privacy Rule. For example, disclosure of a medical record between health care providers that participate in the approved plan of a core service agency requires that a written agreement that is signed by the recipient.⁵⁶ In addition, the MH statute provides special protections for the “personal notes” of MH care providers.⁵⁷

Michigan’s laws governing disclosure of MH and substance use treatment records and information include the Michigan Mental Health Code, Public Health Code and statutes governing confidentiality of information obtained in drug treatment and MH courts. Section 748 of Michigan’s Mental Health Code permits disclosures of MH records as necessary for an individual to apply for or receive benefits; as necessary for treatment, coordination of care, or payment for the delivery of MH services pursuant to HIPAA; to a provider of MH or other services or a public agency if there is a compelling need for disclosure based upon substantial possibility of harm to the patient or to others; and to the extent required by federal law to protection and advocacy agencies.⁵⁸ Michigan’s Mental Health Code requirements for disclosure of substance use records aligns with Part 2. Such records may be disclosed without consent to medical personnel to the extent necessary to meet a bona fide emergency; to qualified personnel for the purpose of conducting statistical research, financial audits or program and evaluation if the subject of the disclosure is not identified; and upon a court order.⁵⁹ Michigan’s Public Code articulates patient rights to refuse the release of records, “except as required for transfer to another health facility, as required by law or third-party payment contract, or as required by HIPAA.”

Nebraska’s HIE statute requires that patient health information be provided in accordance with the privacy and security provisions of HIPAA and regulations adopted under the Act.⁴⁵ The HIE may aggregate, analyze, report, and release de-identified data, as defined by HIPAA. Section 81-6, 125 and allows health care providers and entities to access information available within the HIE to evaluate and monitor care and treatment of a patient in accordance with HIPAA. Nebraska’s data privacy landscape includes the Mental Health Practice Act, which prohibits licensed or certified MH providers from disclosing any information obtained from a recipient of the provider’s care. The statute includes exceptions and permits disclosures: (1) with the individual’s consent, or the consent of a personal representative or beneficiary of an insurance policy; (2) as allowed by state law, rules and regulations; (3) when the person waives privilege by bringing charges against the provider; or (4) when there is a duty to warn.

North Carolina’s Statewide Health Information Exchange Act and the Mental Health, Developmental Disabilities, and Substance Abuse Act are the primary laws addressing disclosures of MH and substance use treatment records. The HIE statute aligns with the HIPAA Privacy Rule disclosure requirements and extends requirements beyond covered entities as defined by HIPAA to include other state licensed facilities.⁶⁰ The HIE statute is to be construed to not impair any rights conferred on an individual under HIPAA and not to authorize the disclosure of PHI through the HIE to the extent that the disclosure is restricted by federal laws or regulations including Part 2. The statute permits disclosures of PHI for public health and research purposes as permitted by HIPAA and state law.⁶¹ The Mental Health, Developmental Disabilities, and Substance Abuse Act permits a range of disclosures of confidential information for care and treatment coordination.⁶² Disclosures of de-identified and confidential information are allowed for specified research and planning purposes.⁶³ A facility must disclose confidential information if a court compels disclosure, for judicial proceedings, for law enforcement purposes, and as required by other state and federal law. Part 2 rules would create additional disclosure restrictions for substance use records.

Exhibit 6. HIE Handling of BH Data in Selected States

State	HIE Handling of BH data
Arizona	<ul style="list-style-type: none"> • In Arizona, the HIE is able to manage substance use disorder (SUD) treatment data that comes from providers who provide only Part 2 services, as every incoming piece of data is sensitive. • Integrated care, in which a provider or organization delivers SUD treatment services alongside typical physical health services, requires more robust data sorting processes.
Delaware	<ul style="list-style-type: none"> • DHIN works closely with the Division of Substance Abuse and Mental Health (DSAMH) in the Department of Health and Social Services in Delaware. • The organizations entered a qualified service organization agreement (QSOA) for DSAMH to share ADT alerts with DHIN. • While the option to enter a QSOA and submit data to DHIN is available to all BH providers in the state, so far none have opted in and begun sharing Part 2 or other BH data.
Maryland	<ul style="list-style-type: none"> • In Maryland, there are about 300 participation agreements with BH provider organizations. • Entities include MH, mixed use, and Part 2 covered. Of these, 200 are very active and regularly send information with 70 organizations identifying specifically as Part 2 covered. • CRISP manages SUD treatment data with a tagging system that automatically marks any data coming from a Part 2 feed as sensitive. This sensitive data is only shared with the care team if a patient has an active consent in place.
Michigan	<ul style="list-style-type: none"> • Michigan Health Information Network (MiHIN) has also developed and piloted the Electronic Consent Management System (eCMS), a tool for collecting patient consent to share Part 2 treatment records. • Form 5515 allows patients to either share all of their BH data (excluding psychotherapy notes) or select data types, such as active conditions, medications, lab results, etc. This granularity is enabled by the consent repository as well as HL7 Security Labels, standardized tags for sensitive information, on incoming Part 2 data.
Nebraska	<ul style="list-style-type: none"> • The CyncHealth system does not currently support separating a provider's records into two data points (i.e., Part 2 versus non-Part 2 data). This has posed some challenges for integrated care providers who handle records containing both types. • For instance, providers handling SUD patients mentioned trepidation around designating a patient's diagnosis as falling under 42 CFR Part 2 if their primary diagnosis was not BH-related. By assigning patients an SUD diagnosis, they worried they would be classified as a Part 2 provider despite providing a breadth of services, and therefore would risk being flagged for inappropriate disclosure.
North Carolina	<ul style="list-style-type: none"> • The state does not yet support bidirectional exchange with providers falling under 42 CFR Part 2, though developing the technical capability to insulate Part 2 data from the system's existing query functionality is one of the HIE's near-term priorities. • Additionally, the state has undertaken many efforts to encourage adoption among BH providers, including an EHR incentive program between 2011 and 2021 that provided supplemental Medicaid reimbursement programs in exchange for meeting certain HIE integration milestones.

ADT = admission, discharge, and transfer; BH = behavioral health; CRISP = Chesapeake Regional Information System for our Patients; HL7= Health Level 7.

Policy Levers to Support Adoption of EHRs or Inclusion of BH Providers into State HIEs

In the six states included in the case studies, stakeholders were nearly unanimous in their belief that adequate funding is the primary determinant of EHR uptake and HIE connection in BH providers. This finding aligns closely with a 2016 systematic review that found the initial cost of an EHR to be the most frequently cited barrier to EHR adoption.⁶⁴

Arizona: The Arizona Health Care Cost Containment System (AHCCCS) has seen broad successes with CMS-funded programs to support the state’s Whole Person Care Initiative. Targeted Investments 1.0 (TI 1.0) for example, is a program that provided financial incentives for providers who completed a set of milestones that included receiving admission, discharge, and transfer (ADT) alerts, demonstrating bidirectional data transfer with the statewide HIE, integrating screening and referral processes, and more. The program also offered technical support from the HIE and ASU to help providers reach milestones. Over 100 adult and pediatric BH sites participated in the program, and all sites met the required integration milestones.

The TI 1.0 program ran from 2017 through 2022, with \$350 million in funding. At the program's completion, CMS approved the TI 2.0 program, with an additional \$250 million in funding.⁶⁵ TI 2.0 uses the same milestone-based system to incentivize integration with yearly lump-sum payments and features many of the same technical support options. The integration milestones are generally more robust, and as such, TI 2.0 requires that all applicants have an “EHR capable of bidirectional data sharing with the HIE.”⁶⁶

Delaware: Delaware used state funds to support integration initiatives. A 2019 mini-grant program administered by the Delaware Health Care Commission offered up to \$8,000 to support activities leading to DHIN connection, including EHR investments, information technology support, or DHIN connection fees. Provider participation did not reach the maximum of the 25 applicants, in large part due to the size of the grant. Given the large total costs of an EHR—including both the upfront cost and ongoing support and maintenance costs—few provider organizations prioritized the opportunity. Federal funds may be preferable for HIT infrastructure building for many reasons, including that they are often more resilient to political and economic fluctuations.⁶⁷

Nebraska: State policymakers have attempted to expand the reach of their HIEs through legislation, to varying degrees of success. Nebraska passed LB 411, which required health care facilities to participate in the state’s designated HIE per details determined by the state’s HIT Board no later than September 30, 2021. However, a state Medicaid HIT Plan from the same year shows that full participation is likely years away. The report surveyed providers in the state and found that 19% of respondents participate in CyncHealth, Nebraska’s designated HIE, up just slightly from 17% in 2017. Respondents listed connection fees and implementation costs as the two greatest barriers to connection. Although LB 411 states that “any connection established by July 1, 2021,... shall be at no cost to the participating health care facility,” many providers appear to have missed this window.

North Carolina: Legislative and executive funding has been critical in establishing HIE integration as a priority for BH providers. In 2023, the state Department of Health and Human Services introduced a BH investment plan that specifically pledged \$50 million to help under-resourced BH providers integrate with the North Carolina HealthConnex. Interviews with HIE stakeholders across states confirmed that aligning federal and state financial incentives and goals often drive technical innovation and growth. In addition to HIE specific innovations, funding has also helped establish North Carolina’s specific priority areas within BH. For instance, funding for health-related social needs has motivated the exploration of solutions improving maternal physical and MH in under-resourced areas across North Carolina, including facilitating the creation of the Maternal Mental Health MATTERS program as a partnership between the state government and statewide hospital systems. Financial opportunities spur conversations between policymakers, health care providers, and statewide health associations to develop solutions within certain types of health care and areas of disparity.

Maryland: Maryland elevated its statewide HIE, Chesapeake Regional Information System for our Patients (CRISP), to an HDU with the 2022 passage of HB 1127/Chapter 296. As an HDU, CRISP is responsible for collecting and aggregating health information to serve population health initiatives. This work brings CRISP into close contact with state governmental entities, which in turn optimizes the HDU’s ability to facilitate safe and

secure exchange of information. Overall, Maryland’s experience with CRISP illustrates a comprehensive approach to establishing and maintaining a robust HIE system through legislative support, stakeholder engagement, and continuous improvement in data management and patient consent processes. This case serves as an exemplary model for other states looking to enhance their HIE capabilities.

Michigan: In addition to working closely with the statewide HIE, the Michigan Department of Health and Human Services (MDHHS) has led efforts to address structural barriers to sharing Part 2 data. First, MDHHS helped to champion Public Act 129 of 2014, which standardized the consent process for sharing Part 2 data, improving interoperability and laying the groundwork for an eCMS. Second, MDHHS commissioned a PHI Consent Tool (listed below), which summarizes “both State of Michigan and federal laws and regulations to provide clear guidance about when consent is necessary for common PHI requests”. This resource is aimed at providers who may be confused by the interplay between state and federal laws and choose to not share relevant patient data to be safe. Clearing up this “HIPAA hesitancy” encourages more effective data exchange, particularly with BH providers. Collectively, these themes showcase Michigan's comprehensive approach to developing and maintaining an interoperable health information infrastructure, with a strong emphasis on stakeholder collaboration, legal alignment, technology adoption, and educational support.

PHI Tool Screenshot

Reason Category: ALL
(Self, Continuity of Care, Personal Representative, Friends/Family, Health Care Claim Payment, Facility Operations, Research, Marketing, Psychotherapy Notes)

LEGISLATION

REASON FOR REQUEST	Michigan Mental Health Code Act 258 of 1974 (Behavioral Health (BH) not including SUD)	Michigan Public Health Code Act 368 of 1978	Michigan Medical Records Access Act 47 of 2004	Health Insurance Portability and Accountability Act (HIPAA) of 1996, Expanded to include electronic PHI in 2009	Title 42 Code of Federal Regulations (CFR) Part 2 - Confidentiality of Substance Use Disorder Patient Records - 1975 (in combination with MI Mental Health Code as it relates to SUD)
The individual asks a covered entity for some or all of their own health records.	Yellow Triangle 1	Yellow Triangle 2	Yellow Triangle 2	Yellow Triangle 2	Green Circle
For any individual's care team to be able to provide continuity of care for medical and/or behavioral health issues.	Green Circle	Green Circle	Grey Square	Green Circle	Purple Diamond 3
For a covered entity to inform an individual's personal representative about their care.	Yellow Triangle 4	Yellow Triangle 4	Yellow Triangle 2	Yellow Triangle 4	Purple Diamond 5
For a covered entity to inform a spouse, family member, or friend about an individual's care.	Red Octagon	Yellow Triangle 6	Grey Square	Yellow Triangle 6	Red Octagon *
To assist a covered entity in determining medical insurance eligibility, performing medical billing and collections activities, determining medical necessity, for utilization review (activities related to getting medical claims paid).	Green Circle	Green Circle	Grey Square	Green Circle	Red Octagon *
For the covered entity to perform facility operations (certain administrative, financial, legal, and quality improvement activities that are necessary to run the business).	Red Octagon	Green Circle	Grey Square	Green Circle	Purple Diamond 7
For a covered entity to provide de-identified information for scientific study or research purposes.	Green Circle	Green Circle	Grey Square	Green Circle	Green Circle
For a covered entity to report STIs, communicable diseases, adverse drug reactions, and/or medical device failure for public health.	Grey Square	Green Circle	Grey Square	Green Circle	Purple Diamond 8
Communication made to describe a health-related product or service (or payment for such product or service) that is provided by, or included in a plan of benefits of the covered entity making the communication.	Grey Square	Green Circle	Grey Square	Green Circle	Red Octagon
For a covered entity to sell PHI or give to a business associate (BA) to market to individuals or sell PHI.	Grey Square	Red Octagon	Grey Square	Red Octagon	Red Octagon
To review psychotherapy notes.	Grey Square	Red Octagon	Grey Square	Red Octagon	Grey Square

* Michigan Mental Health Code, as it relates to SUD, appears to be more protective than Title 42 CFR Part 2 in these instances, therefore individual consent is necessary to share SUD PHI.

● Individual consent necessary
 ● Individual consent NOT needed
 Not addressed by that legislation
 ▲ Clinician discretion applies
 ◆ SUD caveats apply

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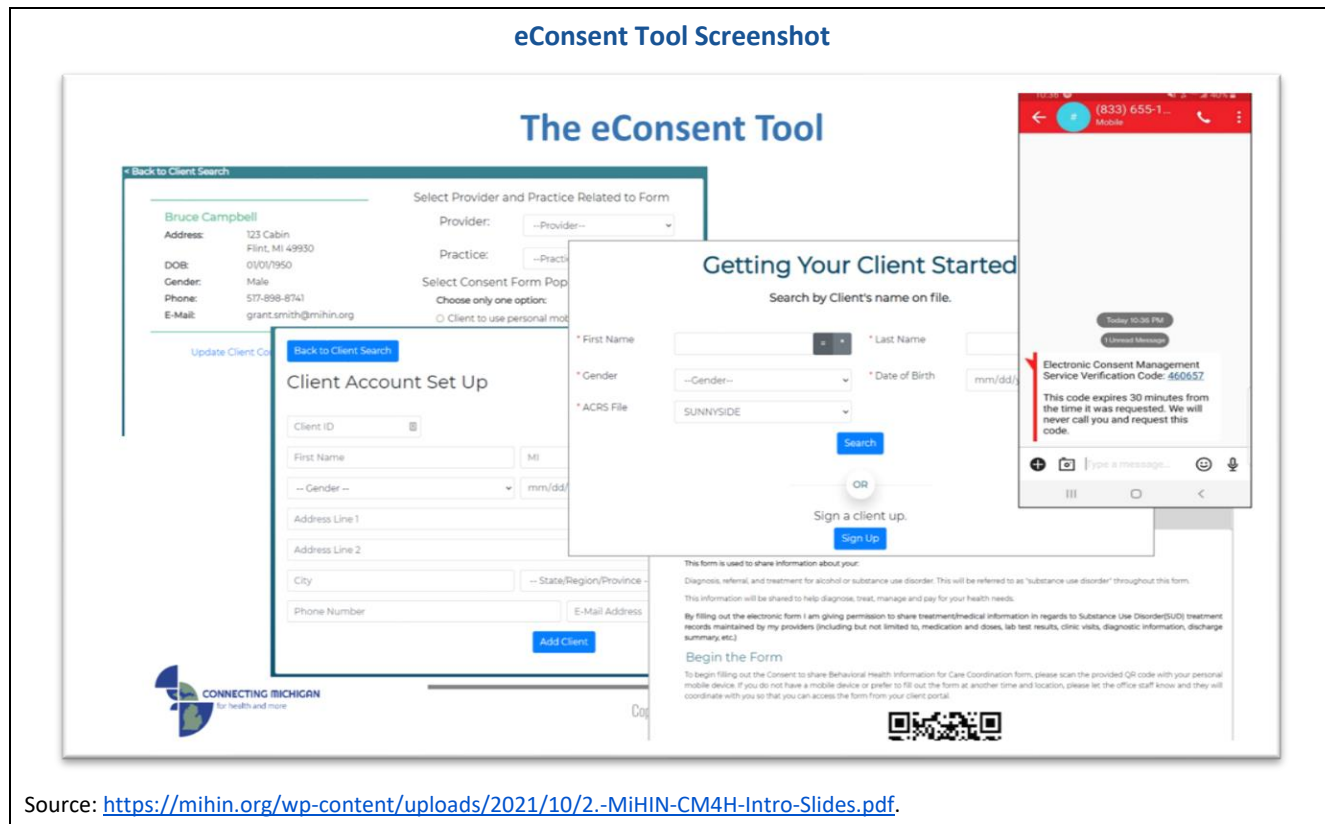
Source: <https://www.michigan.gov/mdhhs/assistance-programs/healthcare/hipaa/phi-consent-tool>.

Regulatory and Technical Considerations for Part 2 Data Sharing and Consent

Regulatory Considerations

States are taking action to address and overcome privacy/disclosure issues in BH. HIEs across states have varying abilities to manage SUD treatment data. SUD data is easy to facilitate when information comes from a provider who only delivers Part 2 services. In this case, every piece of incoming information from that provider can be considered sensitive. However, integrated care--in which a provider or organization delivers SUD

treatment services alongside typical physical health services--requires more robust data sorting processes. In some states, consent is handled differently by individual providers, which makes sharing of Part 2 data between organizations with unaligned consent forms difficult. In Michigan, MDHHS Form 5515 is required for sharing Part 2 data per Public Act 129. This is a key prerequisite for establishing an interoperable, streamlined process for managing consent: MiHIN's Electronic Consent Management Service (eCMS).



The eCMS has an easily navigable user interface to help providers and their patients complete Form 5515 to either grant or revoke consent. This eCMS module can be embedded in existing provider or consumer portals for easy accessibility. For organizations without an existing portal, MiHIN can host the tool on its own platform. For provider organizations who have previous consents already stored digitally, an application programming interface (API) can retrieve, parse, and store the consent into the centralized repository, rather than having the provider re-key the information. This repository minimizes duplicative and potentially contradictory consent paperwork that patients would otherwise complete at every care setting that may involve Part 2 information. MiHIN's focus on flexible, interoperable processes, including support for various connectivity methods (e.g., limited liability partnership, API, secure file transfer protocol), demonstrates the importance of adaptable technology solutions in reaching a broad range of providers. The use of Health Level 7 (HL7) Security Labels for sensitive information also highlights the role of technology in maintaining data privacy and enabling future interstate data sharing.

Technological Considerations

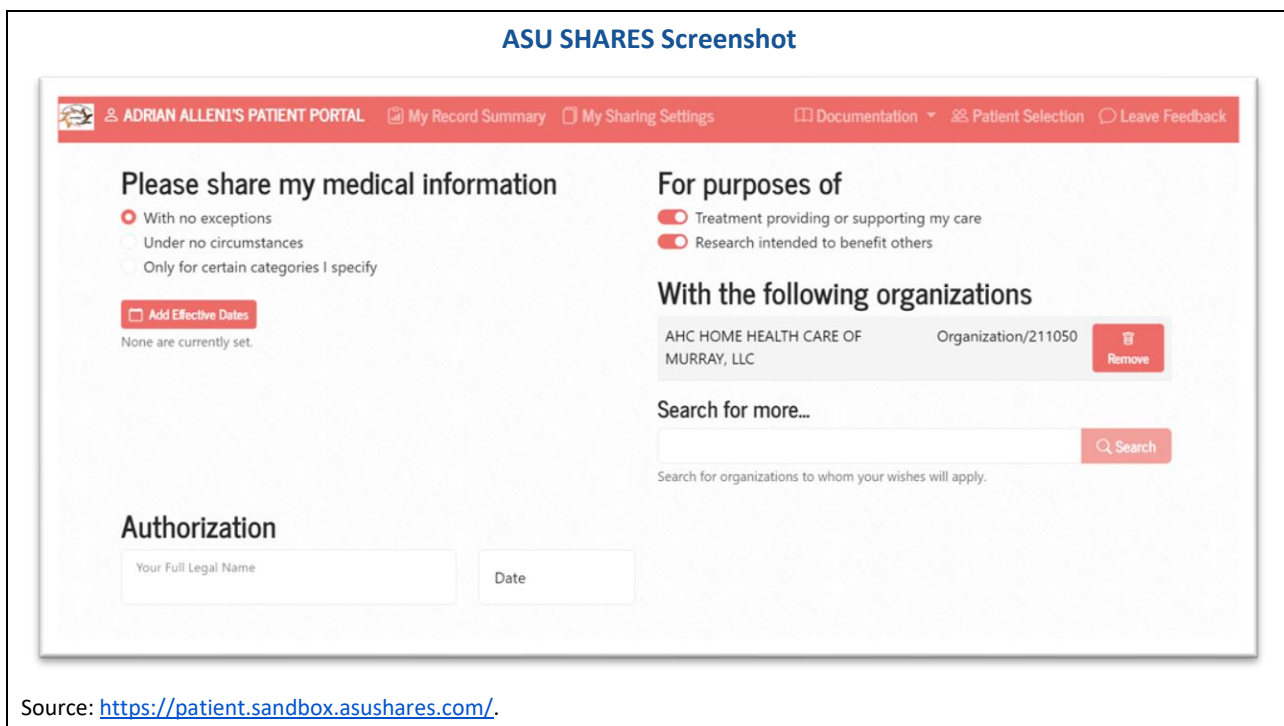
Implementing patient consent for sharing Part 2 records within clinical workflows is difficult. Technological and operational challenges include variability in EHR capabilities among providers, necessitating support and workarounds to meet integration goals.

Robust technical infrastructure is essential for HIE operations, encompassing secure data exchange platforms, support for FHIR standards, and efficient provider onboarding processes. However, multiple state interviewees

noted smaller health care entities often struggle more than larger institutions in meeting these technical requirements. Expecting an HIE to meet providers where they are technologically becomes an increasingly infeasible proposition as the number and variability in HIT among providers increases. This is especially true for BH providers, who are far less likely to have an interoperable EHR than acute care hospitals.

HL7's FHIR provides a relatively straightforward solution for managing data with varied security requirements. Since its inception, FHIR has included Security Labels to tag resources with metadata before transmission, allowing the receiving entity to accept, process, and store the resources. One tag, for example, is the Sensitive Information Security Label. This tag depends on a variety of factors, including federal law, state law, organizational evaluation of data types, and patient requests. Health data pursuant to HIPAA and no more stringent laws receives a confidentiality code "N," whereas more sensitive data may receive an "R" (restricted) or "V" (very restricted). A receiver who has the credentials to read the resource will be able to see the second level of classification, which includes options such as "SUD" (substance use disorder information), "MH" (mental health information), "PSYTHPN" (psychotherapy note information), among many others.⁶⁸ By clearly marking transmitted data on multiple levels, FHIR limits accidental disclosures.

FHIR is an exchange standard, meaning it does not govern how organizations ingest or store health data, only how it is formatted when shared between organizations. There are multiple initiatives to provide open-source technical infrastructure for organizations to handle Part 2 data. The ASU SHARES project is focused on improving data sharing and patient outcomes for individuals with SUD using EHR-agnostic health data segmentation methods.⁶⁹ Their publicly available GitHub repository has tools for managing consent on FHIR, integration for clinical decision support (CDS), and more.⁷⁰ SAMHSA offers a similar service, Consent2Share.⁷¹ The open-source software has two main components: a patient consent management tool and an access control services tool. Patient consent management allows patients to provide informed consent and determine which data they would like to share, while access control services integrate with the EHR to ensure sensitive data is only available to those with proper credentials.



Although the technology to capture, share, and retrieve Part 2 data is mature, the majority of BH care providers do not have the financial and human resources to acquire and integrate it. Many share data according to older standards, such as Consolidated Clinical Data Architecture, while some do not support any

standard. The hub and spoke model for information-sharing through an HIE does allow for some cleaning and processing of non-standard data at the HIE but pulling out all of the Part 2 data--and only that data--from a large set of patient records is not currently feasible. In the same way that a single stream recycling plant may be unable to recycle a load with small, interspersed pieces of materials, an HIE with today's technology does not have a reliable way of extracting just Part 2 data. For organizations looking to build interoperable infrastructure, there are support services available. Many HIEs have a staff dedicated to supporting onboarding directly, though an organization's experience is in large part dictated by the technological maturity and support offerings of its EHR vendor. Arizona has a relatively unique process for offering support through the Targeted Investments Program Quality Improvement Collaborative (TIPQIC). The collaborative brings together AHCCCS, the Medicaid agency in Arizona, with data science and clinical informatics experts at ASU. Through online resources, individualized coaching, workgroup sessions, and more, TIPQIC seeks to help TI 2.0 participants meet and exceed the CMS-set performance measure targets. The Differential Adjusted Payment program complemented these efforts by adding financial incentives for providers meeting specific integration-related behaviors.

In interviews, providers and HIE representatives were asked to share the types of clinical information most often handled by BH providers and the methods of preferred data exchange for BH. Though interview findings and searches of the literature did not yield a consistent list of PHI relevant specifically to BH when interfacing with HIEs, a common sentiment among stakeholders was that providers' technical capabilities and information needs were less correlated with specific care types, and more strongly associated with factors such as practice size and resources. Larger systems and hospitals were more likely than sole practitioners to have the technical staff and appropriate data streams required to exchange a diverse array of EHI. Hence, the ability to exchange certain types of clinical information often held more significance from an HIE perspective than provider level characteristics.

The Nebraska case study provides an example of this, highlighting how an interoperable network can support individual health outcomes and showcasing the effectiveness of scaling technical solutions to broader populations. To reduce maternal mortality, all patients presenting to an emergency department are automatically screened via their patient record to determine if they are postpartum. If they are, the emergency department is notified and can provide additional care, including screenings, proactive communication with the primary care team, or additional lab tests. The initial pilot in Omaha was successful, so the program was extended to cover the entire state. In addition to the technical infrastructure, stakeholder outreach and training was key in ensuring the system worked as intended. Stakeholders from CyncHealth noted that this program is replicable for other populations of interest by simply adjusting the inclusion criteria. Real-time notifications could bring personalized care to existing CDS models.

Facilitation of Integrated Care

State HIE Integration of BH Providers

Advancements in HIEs and the inclusion of BH providers in EHRs significantly enhance other providers' ability to engage with these systems, and can lead to improved care coordination, holistic patient care, and reduced administrative burdens. However, challenges such as interoperability, training, and sensitivity of BH information need to be addressed to fully realize the benefits of these advancements. The integration of BH data into HIEs is widely recognized as crucial but fraught with regulatory and technical challenges. Regulations like 42 CFR Part 2 pose additional barriers to data sharing. HIEs play a critical role in supporting public health initiatives, such as syndromic surveillance, PDMPs, and maternal health projects, serving as innovation hubs for health data analytics and contributing to broader health system goals. Managing patient consent and ensuring compliance with privacy regulations (e.g., HIPAA, state-specific laws) is a complex and critical aspect of HIE operations, with challenges in navigating consent frameworks, particularly for sensitive data like BH records and PDMP data. BH information is often more sensitive than other medical information, and there is a

need for careful handling to avoid stigma. Clear policies on disclosure and consent procedures are necessary to ensure that patients are comfortable with the sharing of their BH information.

Storing and Re-disclosing SUD Records for Non-SUD Providers

Interviewees noted that current practices of identifying providers and records requiring segmentation created hard lines between provider types and potentially impeded progress towards integrated care. As evidenced by findings from case study interviews, technical architecture to support segmentation of Part 2 data is largely still in construction. From an integrated care provider perspective, this can discourage practitioners from “calling it what it is” and diagnosing individuals under an SUD label to avoid risks of inappropriate disclosure. Such practice, however, may have unintended consequences, such as impeding continuity of care. Integrated care providers may face pressure to shirk the label of being identified as SUD providers at the expense of holistic clinical assessment, underscoring the importance of systems that can automatically insulate Part 2 data originating from non-SUD providers, such as primary care providers and other integrated care establishments.

STUDY LIMITATIONS

Our study had several limitations. First, this was a sample of just six states selected based on publicly available information. As such, these findings may not be generalizable to other states. Second, we were unable to identify comparable quantitative information on BH provider technology adoption and usage across states. While the HIEs were often able to provide the total number of participation agreements, extracting the number of BH providers was not possible given that many organizations include both BH and physical health providers. Additionally, those figures would be difficult to contextualize as proportions, as there are few resources for tracking the total number of BH providers in a state. For these reasons, our findings are primarily qualitative. Finally, our fourth research question, “How does the advancement of HIEs/EHRs technology among other, non-BH providers impact BH providers’ ability to catch up with adoption of EHRs?”, was not answered in detail. Our research and stakeholder discussions yielded few responses.

OPPORTUNITIES

Several areas of opportunity can be pursued to address adoption of EHRs in the BH setting, and address privacy concerns and concerns related to data sharing. Enhanced legislative frameworks are needed to facilitate HIE participation and address data sharing barriers, especially for BH data, and to develop policies that support sustainable funding models for HIEs. Improved interoperability solutions, such as investing in technologies and standards like FHIR APIs and USCDI+, can enhance interoperability and ease the technical burden on smaller providers, encouraging EHR vendors to adopt and support common data standards to simplify integration processes. Providing targeted incentives and technical support to BH providers can encourage their participation in HIEs, and developing specific guidelines and tools can address the unique challenges of integrating BH data. In conjunction with incentives, there would be a research opportunity to continue to evaluate the advancement of adoption of EHRs for BH providers and identify progress and challenges to adoption.

Expansion of public health initiatives leveraging HIE capabilities can support more comprehensive efforts, such as real-time disease surveillance, population health management, and emergency preparedness, fostering collaborations with public health agencies to maximize the impact of HIE data. Enhanced privacy and consent mechanisms, such as user-friendly, technology-enabled consent management systems, can allow patients to easily control their data sharing preferences while ensuring privacy and security measures keep pace with evolving threats and regulatory requirements. Additionally, providing grants, subsidies, or other financial incentives to help smaller providers meet the technical requirements of HIE participation, along with training and technical assistance programs, can support the onboarding and integration process.

CONCLUSION

HIEs are essential in facilitating the sharing of BH data, enhancing the integration between physical health, BH, and social services. However, BH providers have historically received less funding for HIT, resulting in EHRs in BH settings often lacking the technical capabilities required for HIE participation. Federal funding has started to address this gap, but challenges remain, particularly in handling SUD information governed by 42 CFR Part 2. Although there are HIE standards, such as FHIR, for managing sensitive data, adoption among BH providers is limited, partly due to insufficient technical infrastructure and awareness. While states have been encouraged to expand BH provider participation in HIEs, there is still no uniform approach to achieving this goal, as each state has unique policies, strategies, and funding mechanisms. Some HIEs have formalized partnerships with state and local governments as HDUs to improve health care outcomes by ensuring accessible, accurate, and secure health data. While large-scale patient consent operations for sharing Part 2 data do not exist, early efforts in several states show that many patients are willing to consent to sharing SUD data, suggesting that streamlined consent processes may be more effective. To promote data sharing, state governments have developed educational materials for both providers and patients, clarifying what patient data can be shared, with whom, and under what conditions.

APPENDIX A. DETAILED CASE STUDIES BY STATE: ARIZONA

Grey Literature and Expert Interview Findings

Background

The current state of Arizona’s behavioral health (BH) integration can be traced back to a 2015 decision to move the Arizona Department of Health Services (ADHS) Division of Behavioral Health Services into the state’s Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS). This came in response to difficulties managing interrelated physical and BH care needs across two distinct agencies.

A 2017 issue brief identified multiple benefits of this consolidation.⁷² As a single purchaser for both physical and BH care claims that work with both Medicaid and non-Medicaid funding, AHCCCS could standardize payment models and align incentives across the state. One of the first goals with new configuration was to bring BH providers into the statewide health information exchange (HIE). The statewide HIE at the time was Health Currents, which has since merged with the Colorado Regional Health Information Organization as Contexture.⁷³ This initial push prioritized and onboarded over 70 BH providers across the care spectrum in Arizona, spanning psychiatric hospitals, integrated care clinics, substance use disorder (SUD) facilities, general MH, and more. Clinics onboarded with this funding were supported in connecting to the HIE both to receive and to share patient health data, including SUD treatment data pursuant to 42 CFR Part 2 if applicable. Contexture stakeholders reported that, in 2024, roughly 400 of the 1,100 Contexture participants in Arizona submit data to the HIE, while the remaining 700 only receive data. Data was not available on the number of BH providers who submitted and/or received data.

To support as many connections as possible, Contexture accepts incoming data in multiple formats, including Health Level 7 (HL7) Version 2 (V2), HL7 V3, claims and claim line feed, the X12/EDI standard, and flat file formats.⁷⁴ The ability to exchange data and the format used are impacted by the electronic health record (EHR) system implemented by the provider organization. Interviewees in Arizona shared their belief that BH providers in Arizona are generally more well-equipped than those in other states. Many centers in the state exchange data via the HL7 V2.3 standard per their EHRs’ capabilities. However, especially in the initial rollout, Contexture had to support providers with fewer resources to “meet them where they are”. For example, two critical inpatient psychiatric facilities lacking an EHR needed specialized assistance to be able to integrate admission, discharge, and transfer (ADT) alerts into their existing system. On the other end of the spectrum, Federally Qualified Health Centers in the state were more likely to have extensive health information technology (HIT) resources to integrate information across the health care delivery ecosystem.

42 CFR Part 2 Data

Arizona does not have state laws that place more stringent standards on sharing SUD treatment data. Local stakeholders interviewed reported many of the same barriers to SUD treatment data sharing that have appeared in other states. HIEs are more readily able to manage SUD treatment data that comes from providers who provide only Part 2 services, as every incoming piece of data is sensitive. With integrated care, in which a provider or organization delivers SUD treatment services alongside typical physical health services requiring more robust data sorting processes. At present, it is extremely challenging for an HIE to receive mixed data and algorithmically sort that data into sensitive and non-sensitive groups because, for example, the medications, diagnoses, and observations value sets are not separated cleanly into regular and Part 2 data. Other contributing challenges to sorting data upon receipt include the variations in how each EHR is set up and to the extent providers use free text. Including metadata or special indicators with each submission to the HIE could serve as a high-fidelity process for separating these data, but this requires more mature EHR technology than many BH providers currently have. Given the mandate to protect Part 2 data, Contexture is incentivized to take a conservative approach and consider all data from integrated service providers to be sensitive.

Contexture representatives considered the Final Rule issued in February 2024 to be a step in the right direction as it confirms that HIEs are business associates and can thus receive Part 2 data.⁷⁵ While the Final Rule also attempted to simplify the handling of SUD treatment notes, making them analogous to psychotherapy notes under HIPAA, most health technology is not capable of tagging these unique data elements effectively to manage the distinct use and disclosure rules.

The technology to handle Part 2 data is still maturing. Contexture ran an analysis of 17 separate vendors prior to adopting NextGen's Health Data Hub (HDH) in 2020. They found that no vendor had ideal functionality out of the box, and they have since worked closely as an early adopter of HDH to define and test the features needed to meet Part 2 requirements.

Finally, integrating patient consent for sharing Part 2 records into existing clinical workflows remains challenging. Contexture ran a pilot study in Arizona and Colorado that compared general consent, in which a patient can opt-in to sharing their Part 2 data with all providers they see, and designated consent, in which a patient can choose which providers see their Part 2 data. The pilot revealed difficulties in implementing designated consent, as patients struggled to understand differences between providers and practices. The additional time required to walk a patient through the process was not seen as worthwhile given that most patients opted to either share all or none of their data.

Whole Person Care Initiative

Multiple key programs fall under the state's Whole Person Care Initiative. The program, which offers a slew of social determinants of health (SDOH)-related support services to Arizonans covered by Medicaid, was awarded a Medicaid Innovation Award in 2022.⁷⁶

The Targeted Investments (TI) program was created to improve integration between acute care and BH care. The Centers for Medicare & Medicaid Services (CMS)-funded initiative provided financial incentives for providers who completed a set of milestones that included receiving ADT alerts, demonstrating bidirectional data transfer with Contexture, integrating screening and referral processes, and more. The program also offered technical support from the HIE and Arizona State University (ASU) to help providers reach milestones. Two distinct colleges within ASU, Engineering and Health Solutions, collaborated to support providers with data-driven dashboards and guidance implementing quality improvement techniques. Over 100 adult and pediatric BH sites participated in the program, and all sites met the required integration milestones.

The TI program ran from 2017-2022 with \$350 million in funding. At the program's completion, CMS approved the TI 2.0 program with an additional \$250 million in funding.⁶⁵ TI 2.0 uses the same milestone-based system to incentivize integration with yearly lump-sum payments and features many of the same technical support options. The integration milestones are generally more robust, and as such, TI 2.0 requires that all applicants have an "EHR capable of bidirectional data sharing with the HIE."⁶⁶

The success of the TI 1.0 program and early positive indicators from TI 2.0 show that robust financial incentives for provider organizations can be effective when paired with technical assistance. The program was supported by a well-resourced HIE and university. In addition to providing support to TI applicants, ASU serves as a source of research and innovation. The ASU SHARES (Substance use HeAlth REcord Sharing) group, for example, provides open-source software for a variety of substance use treatment data workflows, including Clinical Decision Support (CDS), Fast Healthcare Interoperability Resources (FHIR)-based consent management, and more.⁶⁹

TI 2.0 also incentivized screening caregivers during pediatric primary care appointments as part of a broader push to reduce maternal health mortality inequities. Though these are completed during pediatric visits and

stored in the pediatrician’s EHR, the health data belongs solely to the caregiver. As such, the completed screening document must be stored behind a confidential separator so as not to be accidentally released with the child’s records. This revealed a key limitation of most EHR systems, as documents stored in this way are far less likely to be reviewed on subsequent visits, potentially preventing necessary follow-up care or referrals. As with SUD treatment data subject to Part 2 rules, the conflicting values of data privacy and data availability for care will require thoughtful technology development and implementation.

Another incentive program that AHCCCS oversees is the Differential Adjusted Payment (DAP) program. The DAP program began in 2016 and adds a percentage increase to each Medicaid claim for providers that meet a variety of positive behaviors. For example, BH providers who integrate with the HIE are eligible for an additional 1.0% on every Medicaid claim.⁷⁷ The DAP program has been incentivizing BH providers to connect with the HIE since 2018. It began with just 64 providers and has now increased to 338 providers in 2024. DAP and TI are distinct but complementary programs that allow AHCCCS flexibility in setting and modifying integration priorities for different provider types.

CommunityCares is Arizona’s statewide closed loop referral system, and participation in CommunityCares is incentivized by both TI 2.0 and DAP. The tool allows providers to screen patients for SDOH-related needs and refer those patients to available community-based organizations, automatically matching patients to resources based on location, language, eligibility requirements, and more. While the tool has the purported ability to integrate within a site’s EHR, most providers are not yet able to access CommunityCares from within their EHR requiring double entry. This has harmed uptake as providers are unwilling to enter screening results into two separate systems. Efforts are ongoing to integrate CommunityCares into multiple EHR systems. In parallel, a group at ASU is working on an automated process for pulling screening results from the EHR into a reportable format using FHIR standards, which could provide an alternate workaround if successful.

State Statute Review Summary

Arizona’s statutory landscape includes a patchwork of statutes governing identifiable information exchange through a state Health Information Organization (HIO) and associated regulations, and statutes addressing disclosures of mental health (MH) treatment records, substance use treatment records and opioid related data as reported to the state chronic disease surveillance system.

Arizona’s HIO statute includes an opt-out provision and does not preempt more stringent state and federal laws. Although the HIO statute has fewer pathways for disclosure of identifiable MH records than the state’s general MH treatment record statute, both statutes enable flow of data and information about BH treatment. The state’s substance use treatment records statute maintains the protections provided by 42 CFR Part 2. The HIO statute penalty framework includes a rebuttable presumption of good faith, which can mitigate data sharing hesitancy by BH providers. The notice, consent, and de-identification requirements align tightly with the HIPAA Privacy Rule.

Disclosure Requirements

Arizona’s HIO statute defines an HIO as an “organization that oversees and governs the exchange of individually identifiable health information (IIHI) among organizations according to nationally recognized standards.” The statute permits disclosures of an individual’s IIHI through the HIO only when an individual has not opted out, the purpose of the disclosure is explained in the HIO’s notice of health information practices, and when the disclosure complies with 45 CFR Part 164, Part (E) of HIPAA and regulations adopted under the Act.⁴²

HIOs may disclose IIHI or de-identified information accessible through the HIE for research and grant application purposes with patient consent. The consent must be in at least a 12-point type and describe the

purposes of the transfer. Arizona’s HIO statute does not preempt state or federal laws, including 42 CFR Part 2, that are more protective of IIHI nor limit, change or otherwise affect an HIO’s right or duty to exchange information, including IIHI. This means that HIPAA’s requirements for an alteration or waiver of authorization for IIHI disclosures that meet HIPAA’s definition of private health information (PHI) and the Privacy Rule requirements for disclosures of limited datasets, including the requirement for a data use agreement, would still apply to covered entities.

Except as otherwise provided in state or federal law, IIHI accessible through an HIO is not subject to a civil litigation subpoena unless the medical records release process described in Arizona Revised Statutes (ARS) §12-2294.01 is followed and a court has determined that the information sought from the HIO is not available from the original source and either is relevant or is likely to lead to the discovery of admissible evidence.⁷⁸

ARS 36-509 is the primary governing statute for *MH treatment records*. Under this statute, MH records are generally confidential. The statute permits health care entities to disclose MH records only as authorized by state or federal law OR when the disclosure meets requirements for one or more statutory exceptions. These exceptions include disclosures to “physicians and providers of health, MH or social and welfare services involved in caring for, treating, or rehabilitating the patient,” persons authorized by the patient or the patient’s representative to receive the patient’s health records and information, and to a person maintaining health statistics for public health purposes as authorized by law. ARS 36-509 provides many exceptions to the general confidentiality rule and is less restrictive than the HIO statute.

Substance use treatment records are governed in part by Arizona’s chronic disease surveillance system statute. Arizona law requires that health care professionals, administrators of health care institutions, and other health care professionals to report suspected opioid overdoses, suspected opioid deaths, and cases of neonatal abstinence syndrome to ADHS via the ADHS chronic disease surveillance system.⁷⁹ Arizona’s administrative code outlines detailed rules for reporting opioid overdoses and creates an exception to required reporting for any disclosures prohibited by 42 CFR Part 2.⁸⁰

However, the new Part 2 rule permits disclosure of records without patient consent to public health authorities, provided the records are de-identified according to the standards set forth in the HIPAA Privacy Rule. ADHS may share surveillance data to persons authorized by the department for research and evaluation purposes, however there is no exception for sharing for payment, treatment, and operations purposes without consent.

Penalties

The HIO statute applies a good faith standard for assessing civil penalties. A health care provider participating in an HIO is not liable for damages in any civil action for use or disclosure of health information that is made in good faith pursuant to the law. The HIO is presumed to have acted in good faith. This presumption may be rebutted by clear and convincing evidence. ARS §36-3809 does not preclude liability for that portion of any damages resulting from intentional or gross negligence by a HIO. The HIO statute is slightly more forgiving than the HIPAA Privacy Rule because it shifts the burden of proof away from the disclosing provider. Like the Privacy Rule, the HIO statute may impose penalties for violations that occur due to willful neglect.

Notice Requirements

HIOs must maintain a written notice of health information practices that describes the IIHI accessible through the HIO, categories of persons who have access to information through the HIO, the purposes for which access to information is provided, the individual’s right to opt-out of having the individual’s IIHI accessible through the HIO, along with an explanation of how an individual may opt-out, and a statement informing the individual of the right not to have the individual’s IIHI accessible through the HIO, except as otherwise provided by state or

federal law. An individual has a right to be notified, pursuant to 18-552 and 45 CFR Regulations Part 164, Subpart D, of a breach at the HIO that affects the individual's IIHI.⁸⁰

Patient Consent Requirements

The HIO statute permits disclosures of an individual's IIHI through the HIO only when an individual has not opted out, the purpose of the disclosure is explained in the HIO's notice of health information practices, and when the disclosure complies with 45 CFR Part 164, Part (E) of HIPAA and regulations adopted under the Act. Consent is required for disclosures for research and grant writing purposes.⁴² Patients must opt-in to enable HIE data sharing for research or commercial uses.

De-identification Standard

Disclosures of IIHI must comply with 45 CFR Part 164, Part E, which sets out de-identification standards for safe harbor and expert determination.

APPENDIX B. DETAILED CASE STUDIES BY STATE: DELAWARE

Grey Literature and Expert Interview Findings

Background and Services

The Delaware Health Information Network (DHIN) was established in 1997, making it the first statewide health information exchange (HIE) in the United States.⁸¹ DHIN quickly expanded beyond its initial use case of clinical results delivery by launching the Community Health Record, an online portal which to this day allows any provider with a relationship to a patient to view their health data. Today, over 90% of DHIN-enrolled practices receive their ordered test results exclusively through the service. DHIN tracks chart views from different care settings and reports that BH providers represent about 1% of all chart views.

DHIN works closely with the Division of Substance Abuse and Mental Health (DSAMH) in the Department of Health and Social Services (DHSS) in Delaware. The organizations entered a qualified service organization agreement (QSOA) for DSAMH to share admission, discharge, and transfer (ADT) alerts with DHIN. While the option to enter a QSOA and submit data to DHIN is available to all behavioral health (BH) providers in the state, so far none have opted in and begun sharing Part 2 or other BH data.

DHIN offers a patient-facing portal called Health Check Connect (HCC) which allows patients to view, download, and transmit their health information.⁸² This tool was developed in response to the Stage 2 Meaningful Use EHR Incentive Meaningful Use Program requirements⁸³ to facilitate patients receiving electronic copies of their medical records even if they received care from a smaller organization that did not have an electronic health record (EHR) with a dedicated patient portal. Though HCC does not have the complete functionality of a vendor-supplied portal, it is not tethered to a particular health system or location, allowing patients to bring their data in DHIN to any care setting. As of 2024, over 20,000 patients are enrolled in HCC, of which about 90% are active users, defined as individuals with a log in in the preceding 12 months.

DSAMH complements the above services with the Delaware Treatment and Referral Network (DTRN), an electronic referral system for BH and SUD treatment. DTRN allows inpatient, outpatient, criminal justice, and other organizations to identify supporting services and coordinate patient transition. Patients are also able to find SUD treatment directly via a public portal. Usage statistics have been generally positive: in early 2022, less than four years after the initial Go Live in September 2018, the system reached 100,000 referrals.⁸⁴ A fiscal year 2019 report noted that all health system emergency departments in Delaware and multiple out of state organizations were participating, two-thirds of referrals were responded to within 30 minutes, and the closed loop referral system closed on 70% of referrals.

In addition to supporting care coordination and treatment, DTRN is also a potential data source for population health efforts. A white paper from Bamboo Health, a health care technology solutions company and the vendor supporting DTRN, shared aggregate data on referred patients, including demographics, substances used, active conditions, payment method, and more.⁸⁵

Another similar resource is DHIN's Health Care Claims Database, which leverages the largest database of claims data in the state to produce public reports on a variety of health care usage topics. The aggregate data can be shared under Delaware §1030745 for any of these four reasons:

1. The facilitation of data-driven, evidence-based improvements in access to and quality of health care.
2. The improvement of the health of Delawareans generally.
3. Lowering the growth in per capita health care costs.
4. Providing an enhanced provider experience that promotes patient engagement.

Some approved data requests support studies into BH priorities, such as assessing the statewide capacity of providers to deliver SUD services or establishing affordability standards for BH spending in primary care settings.⁸⁶ In supporting these research activities, DHIN occupies a space between HIE and Health Data Utility (HDU).

Infrastructure and Funding

For many BH providers in Delaware, submitting data to DHIN is out of reach due to their EHR status. Of the 72 BH providers in DTRN, only 12 have an EHR (17%). DHIN and DSAMH representatives noted that the gap in HIT adoption between traditional health care settings and BH dates back to the HITECH Act. The extensive funding and support for EHR adoption, among other health information technology (HIT) priorities, rapidly improved the infrastructure in traditional health care settings. BH settings, however, received less funding, and thus saw lower adoption of EHRs.

Recently, state agencies have leveraged separate funding sources to attempt to close this gap. A 2019 mini-grant program led by the Delaware Health Care Commission offered up to \$8,000 for up to 25 applicants.⁸⁷ The funding could be used for activities leading to DHIN connection, including EHR investments, information technology support, or DHIN connection fees. Interviewed stakeholders reported that uptake was lower than expected and offered multiple possible explanations.

First, the amount of funding was not enough for an organization to substantially upgrade its HIT infrastructure. To acquire an EHR, an organization will need more financial and human resources. Second, smaller organizations that are less likely to have an existing DHIN connection may not have the staff to discover, evaluate, and respond to such grant opportunities. Most BH providers in the state are at or near workload capacity, and large, strategic investments in HIT infrastructure are not within reach for such organizations. Therefore, mini-grants are more likely to support peripheral improvements on a practice, such as upgrading Wi-Fi or adding iPads to support intake, than the large-scale infrastructure required for bidirectional HIE connection.

DSAMH stakeholders discussed other methods to support EHR adoption in the state, including an earlier plan to evaluate existing EHR vendors and offer a set of subsidized EHRs to providers in the state. While this particular plan was tabled due to the COVID-19 pandemic, DSAMH envisions itself as a facilitator to support DHIN onboarding among BH and other providers.

42 CFR Part 2 Data

In order to share SUD treatment data under the 42 CFR Part 2 requirements, organizations must first enter into a QSOA with DHIN to specify what data will be shared under which conditions. There has been additional interest, as stakeholders reported that the largest health system in Delaware approached DHIN with the intent of sharing Part 2 data years earlier. However, only DSAMH has devoted the resources to enter the QSOA. The barriers mirror those listed above: hospital staff that were already overburdened and unable to commit to additional initiatives during the COVID-19 pandemic.

Integrated care organizations may consider either the technical or administrative burden of separating Part 2 data from other health data too steep to overcome. Unfortunately, these organizations decline to share any health data as a result.

Despite these challenges, DHIN has developed the technical infrastructure to support consent management for Part 2 data. Within the patient-facing HCC, a Patient Consent Tool allows patients to set and edit which providers are allowed to view their SUD treatment records.⁸⁸ One final barrier to achieving patient consent is that patients must be made aware of the Consent Tool to opt-in. It is expected that this step would often fall to

the providers, who could explain the rationale behind sharing SUD treatment records with a broader care team. However, this represents a significant departure from existing clinical workflows. DHIN was originally designed to be an opt-out system that ingests and shares data for all HIPAA use cases, unless a patient specifically requested that their data be shared only with the ordering provider. As such, providers rarely set aside valuable visit time to discuss data sharing. Provider and patient-facing education resources could help bridge this gap.

State Statute Review Summary

Delaware's regulatory landscape for mental and BH data exchange includes a robust statute governing DHIN, dedicated statutes governing MH information disclosures, and a statute establishing patient rights for persons receiving substance use treatment services. The statute allows disclosures pursuant to the HIPAA Privacy Rule's treatment, payment, and operations (TPO) exception and as permitted by other federal laws governing disclosures of protected health information (PHI). Other disclosures require patient consent and a series of administrative reviews and approvals. The DHIN statute works in tandem with state laws governing disclosures of MH information that allow disclosures for treatment and care coordination.

Disclosure Requirements

DHIN is the state's designated provider of HIE services. The DHIN statute provides that patient-specific health information and data may be disclosed only with patient consent or under DHIN's rules, regulations, or orders. The statute permits an exception for disclosures made in the patient's "best interest to those having a need to know," including disclosures made for TPO purposes, required disclosures to public health authorities, and disclosures for other purposes as permitted HIPAA and other federal law and regulations addressing the privacy of PHI.⁴³

The statute requires that DHIN provide a Delaware resident with access to their own health information, if and to the extent that access is permitted by HIPAA and DHIN's contract with the data sending organization. The statute also permits a Delaware resident with the ability to direct DHIN to disclose their health information to a third party that the resident approves, in accordance with HIPAA and the DHIN's contract with the data sending organization.

Health information and data held by DHIN are not subject to the Freedom of Information Act, Chapter 100 of Title 29, or to subpoena by a court without a patient's consent.

DHIN must provide a health care payer, provider, purchaser, or researcher with access to clinical data in DHIN's possession, if and to the extent that the access is permitted by HIPAA and DHIN's contract with relevant data sending organizations for one or more of the following cases: facilitating data-driven, evidence-based improvements in access to and quality of health care, improving the health of Delawareans generally, lowering the growth in per capital health costs, and providing an enhanced provider experience that promotes patient engagement. In these cases, DHIN may not provide patient-specific data without written consent of the patient.

Clinical data may be provided to a payer, provider, purchaser, or researcher if a majority of the DHIN Board of Directors, or the data request subcommittee, determines that the clinical data should be provided to the requesting person in accordance with the purposes outlined in the statute. Requests for limited data sets or identifiable data must go through Board or subcommittee review for a determination of whether the request complies with the purposes of the DHIN Act. The statute permits third-party and public releases of fully de-identified data or analytic evaluations as approved by the Board or appropriate subcommittee.

The DHIN statute is slightly more stringent than HIPAA. Whereas the HIPAA Privacy Rule permits disclosure of PHI and limited data sets for research purposes under certain conditions, the DHIN statute includes an additional requirement of Board or subcommittee review and approval. For releases of fully de-identified data, the HIPAA Privacy Rule does not apply to data deemed de-identified per HIPAA's definition of de-identified data. The DHIN statute allows for third-party and public releases of de-identified data if approved by the Board.⁸⁹

Delaware's statutory landscape of data privacy rules also includes a more general confidentiality *statute that governs disclosures of MH data*. Del. Code Tit. 16 §1210 et seq govern the use of PHI collected by the DHSS, the Maternal and Child Death Review Commission, the Child Protection Accountability Commission, and the Drug Overdose Fatality Review Commission. PHI is defined as information that relates to an individual's physical health or MH status, condition, treatment, service, products purchased, or provision of care and that reveals the identity of the individual whose health care is the subject of the information, or about which there is a reasonable basis to believe such information could be utilized (either alone or with other information that is or should reasonably be known to be available to predictable recipients of such information) to reveal the identity of that individual. §1212 generally prohibits disclosures of PHI without the informed consent of the individual or the individual's lawful representative. Such disclosures must be accompanied by a statement describing the DHSS's disclosure policy. The statute allows disclosure without informed consent for several exceptions including an exception for patient treatment and care coordination.

Del. Code Tit. §5161 outlines the rights of patients in *MH hospitals or residential centers*. The statute deems information reported to the DHSS and clinical records maintained with respect to patients non-public but does permit disclosures to persons outside of the Department when in conformity with existing law and with the consent of the patient. The statute sets out other exceptions including disclosures in pursuant of a court order, to Departmental contractors to the extent necessary for professional consultation services and to the State Bureau of Identification.

§5182 governs *community mental health (MH) patients' rights*. The statute provides that personal and medical records shall be treated confidentially and shall not be made public without consent of the patient or the patient's representative, except as are needed for a patient's transfer to another health care institution or as required by law or third-party payment contract.

Finally, the Substance Abuse Treatment Act⁹⁰ establishes a set of *rights for patients who receive substance use treatment services*. The language for confidentiality of personal and treatment records is identical to the language in §5182 (i.e., "personal and medical records shall be treated confidentially and shall not be made public without the consent of the patient, except such records as are needed for a patient's transfer to another health care institution or as required by law or third-party payment contract"). Additionally, the statute prohibits release of personal or medical records to any person inside or outside the facility who has no demonstrable need for such records.

Penalties

A violation of DHIN's rules or regulations regarding access or misuse of health information or data held by DHIN must be reported to the office of the Attorney General and is subject of prosecution and penalties under the Delaware Criminal Code or federal law.⁴³

Notice Requirements

DHIN must publish information regarding the process patients need to undertake in order to opt-out and a description of what HIE services will be affected by the opt on its website: [Title 1 Authorities, Boards and Commissions, Delaware Administrative Code, 100 Delaware Health Information Network](#).

Patient Consent Requirements

DHIN, may upon receipt of an appropriate authorization (as that term is defined in HIPAA) and subject to such other terms and conditions as may be established by DHIN, provide an individual's health information to such third parties as may be directed by that individual.

De-identification Standard

Title 1 of Delaware Administrative Code governing the DHIN defines de-identified data as "de-identified data as defined in HIPAA" and limited data set as "a limited data set as defined in HIPAA."

APPENDIX C. DETAILED CASE STUDIES BY STATE: MARYLAND

Grey Literature and Expert Interview Findings

Background

The Maryland General Assembly passed Chapter 689 (House Bill 706), Electronic Health Records--Regulation and Reimbursement (2009) that required the Maryland Health Care Commission (MHCC) and Health Services Cost Review Commission to designate a health information exchange (HIE) for the state. In August 2009, Chesapeake Regional Information System for our Patients (CRISP) was competitively selected as the state-designated HIE. The MHCC has redesignated CRISP every 3 years.⁹¹ The state-designated HIE also serves as a HDU for Maryland. The Maryland General Assembly passed Chapter 296 (House Bill 1127) Public Health--State Designated Exchange--Health Data Utility (2022) requiring the state-designated HIE to operate as a Health Data Utility (HDU). An HDU has advanced technical capabilities to support electronic exchange of clinical, non-clinical, administrative, and public health data to enhance care delivery, bolster population health, and expand public health reporting.

CRISP receives admission, discharge, and transfer (ADT) messages in real-time from all Maryland and Delaware acute care hospitals as well as six of eight in Washington, D.C. Maryland is unique among case study states in that acute care hospitals are required to connect to CRISP. The U.S. Government Accountability Office issued a report from 2021 to 2023 found that of the ten states surveyed, Maryland had the highest proportion of hospitals that reported “often” using HIE organizations to exchange information.⁹² Today, approximately 16 HIEs are registered with MHCC to operate in the Maryland.

Participation

CRISP participants are able to share and query for clinical information on patients under their care. Notably, about 300 participation agreements are from behavioral health (BH) entities, which includes mental health (MH), mixed use, and 42 CFR Part 2--Confidentiality of Substance Use Disorder Patient Records individuals. Of these, 200 are very active and regularly send information with 70 organizations identifying specifically as 42 CFR covered. Part 2 providers participating with CRISP receive encounter notifications that have their rosters masked so the relationship between the patient and the covered entity is hidden unless they have explicit consent from the patient allowing them to submit and receive notifications from the HIE.

Representatives at CRISP recommended engaging stakeholders beyond just patients and providers to build trust and improve offerings, such as patient advocates, professional organizations, and state agencies.⁹³ Patient advocates can be particularly strong allies: besides being generally energetic and well-connected in their communities, they are intimately aware of the need for a patient’s data to move with them across every care setting. Professional organizations are well-positioned to disseminate operational and practical information to their provider membership. Finally, state agencies are key partners. By offering their expert understanding of the technical infrastructure and capabilities of the system, representatives at CRISP can support new state programs or interventions during their development and implementation. This partnership in particular has been strengthened as CRISP transitioned to an HDU.

42 CFR Part 2 Data and Consent

CRISP manages substance use disorder (SUD) treatment data with a tagging system that automatically marks any data coming from a Part 2 feed as sensitive. This sensitive data is only shared with the care team if a patient has an active consent in place. Previously, the sensitive data sharing extended only to Continuity of Care Documents. During an interview with CRISP representatives in spring of 2024, however, they shared that ADT notifications were being rolled out under the same tagging system. This would only apply to ADT notifications coming from Part 2 facilities. ADT notifications coming from other settings, such as emergency

rooms, are HIPAA covered and can thus be shared with all members of an individual’s care team including Part 2 providers without special consent.

Once providers sign a qualified service organization agreement (QSOA), they have access to a specialized consent tool that allows patients to set sharing preferences for their SUD and MH data in CRISP.⁹⁴ This tool allows patients to consent to sharing either all sensitive data or just the contact information of their SUD or MH providers. Because it was created before the 42 CFR Part 2 Final Rule allowed a single consent for “all future uses and disclosures for treatment, payment, and health care operations”,⁷⁵ the tool requires a patient to select an expiration date for their consent no more than five years from the present date. Though the consent tool has been available via the CRISP portal for multiple years in Maryland and longer in Washington, D.C., patient consent forms are still not frequently filed.

Efforts in Maryland to obtain patient consent for Part 2 data exchange predate CRISP’s involvement. A 2015 Joint Chairmen’s Report describes the collaboration between the newly formed Behavioral Health Administration (BHA), the Administrative Services Organization (ASO), and Medicaid managed care organizations (MCOs).⁹⁵ The stakeholders considered several processes to allow MCOs to share SUD treatment data, including designating the ASO as a central transmitter of data between MCOs and SUD providers. However, even with a QSOA, this solution “posed legal and logistical challenges given the complexities inherent to Part 2 and the limited guidance available”. Consequently, the MCOs moved to obtain consent from each patient individually using Release of Information (ROI) forms. This process involved significant initial and ongoing effort to maintain. First, the ROI forms needed to be developed by Medicaid and the BHA before being integrated into the ASO’s provider portal. Then, providers needed to present and explain the ROI form at the initial patient visit. If the ROI was signed, then the authorization and claims data could be released to the enrollee’s MCO. The patient was also able to specify additional providers to whom their Part 2 data could be shared to further care coordination.

Summary statistics on the rate at which ROI forms were presented and signed are presented in the report. It was found in the report that MCOs labored to improve the frequency with which providers presented the ROI form to patients. By the end of the six-month period, only 21% of patients had not been given the opportunity to consent. Critically, of the patients who were presented with the ROI, about 99% gave consent to share their SUD treatment data.

In the intervening years, the ASO organization has changed, and there has not been a more recent report on consent rates. However, sources in other states have shown consistently low consent rates, indicating that more patients may be willing to share their Part 2 data if given a visible and low-friction option for consenting.

State Statute Review Summary

Maryland Statutory Code includes an HIE statute accompanied by regulations with detailed provisions for data exchange and a general statute that provides confidentiality requirements for MH records. Maryland’s HIE regulations include an opt-out provision, a requirement that disclosures are made in accordance with state and federal law, and a special provision for disclosures 42 CFR Part 2 information.

Disclosure Requirements

Maryland’s HIE statute requires the MHCC adopt regulations for the privacy and security of protected health information (PHI) obtained or released through a HIE. The regulations must govern access and use of PHI as required by state or federal law including HIPAA, HITECH, the 21st Century Cures Act, and Title 21, Maryland law (Subtitle 2A concerning the state’s Prescription Drug Monitoring Program [PDMP]).⁴⁴

Regulations adopted pursuant to the HIE statute are found in Maryland Administrative Code,⁹⁶ which establishes patient rights related to access, use and disclosures of patient information through an HIE. Under these regulations, patients have the right to have information concerning the accessibility of their PHI through an HIE, the risks and benefits of participating in an HIE, and the right to opt-out of an HIE at any time except when a disclosure is limited to:

- Core elements of the master patient index.
- A disclosure required under federal or state law.
- Results of a diagnostic procedure sent to the ordering health care provider, or another provider as designated by the ordering provider.
- Information regarding prescription medications dispensed or filled by a pharmacy, sent to the ordering health care provider or another provider as designated by the ordering health care provider.
- Public health authorities for reporting purposes required, authorized or otherwise compliant with applicable law.
- Communications permitted under HIPAA or state law without patient consent or authorization when using point-to-point transmission.

Under Maryland Administrative Code, disclosures of sensitive information receive special protections. Sensitive health information (SHI) is defined as a subset of PHI, which consists of Part 2 information or any other information that has specific legal protections in addition to those required under HIPAA or the Maryland Confidentiality of Medical Records Act. Disclosures of sensitive information must comply with all relevant state and federal laws including 42 CFR Part 2.⁹⁷

If federal or state law requires written consent or authorization for access, use or disclosure of SHI, a person shall obtain consent or authorization consistent with the applicable law prior to the access, use or disclosure of sensitive information to and through an HIE to an authorized recipient.⁹⁸

The HIE may disclose SHI to medical personnel who have a need for the information about a patient for the purpose of treating a condition which poses an immediate threat to the health of any individual and which requires immediate medical intervention, as permitted by Part 2; and in an emergency, if a health care professional makes a professional determination that an immediate disclosure is necessary to provide for the emergency health care needs of a patient or recipient. The regulations also indicate that only point-to-point transmission is allowed, unless specified security controls are in place.⁹⁹

A health care provider that is a Part 2 program shall identify itself as such and clearly indicate on all its patient records that such records may only be disclosed by a point-to-point transmission through an HIE, if appropriate patient consent or authorization has been obtained, or as otherwise permitted in the regs.¹⁰⁰ A participating organization that receives Part 2 information may not re-disclose without patient consent or authorization as permitted by applicable federal and state laws and regulations¹⁰¹ and must maintain Part 2 records in accordance with applicable law.¹⁰²

An HIE may disclose de-identified data or a limited data set to a care management organization for purposes related to population care management if approval is obtained from an internal review committee designated by the care management organization, which entered into a data use agreement (DUA) with the HIE and attested that the request is for population management purposes; and limited to the minimum necessary to complete the function.

An HIE may disclose Individually Identifiable Health Information (IIHI) to a care management organization for purposes of population care management when the following conditions are met:

- An internal review committee approves the disclosure.
- The care management organization has entered into a DUA with the HIE.
- The care management organization has attested that the request for health information is for population health management purposes and is limited to the minimum information necessary to complete the purpose of the request.

In addition, appropriate notice must be provided to the health care consumers whose information is being requested and either the health care consumer has authorized the disclosure, or an external and independent review committee has waived the need for authorization.¹⁰³

The HIE statute and regulations described above operate in tandem within Maryland’s overarching confidential medical records statutory provisions which apply generally to medical records. (§4-302). Under this section of the statute, health care providers are required to keep patient medical records confidential. The statute permits exceptions only as provided within the statute or as otherwise provided by law. Here the general rule of non-disclosure gives way to exceptions embedded within the HIE section of the statute and corresponding regulations.

The HIE, as mentioned above, gives explicit deference to 42 CFR Part 2 for governance of substance use records. An additional nod to 42 CFR Part 2 for the governance of these records is found within Maryland’s Substance Abuse Disorders Law,¹⁰⁴ which provides that “the disclosure and use of the records of individuals served by alcohol abuse and drug abuse treatment programs shall be governed by the federal regulations on the confidentiality of alcohol and drug abuse patient records, 42 CFR Part 2.”

Maryland law affords special protection for *the MH records and “personal notes”* of MH care providers. §4-307 applies a relevancy standard to disclosures without authorization. Only information in the record relevant to the purpose for which information is sought may be released. To the extent a MH provider determines it necessary and appropriate, the provider may maintain a personal note for a patient. §4-307(2) defines a personal note as information that is: (1) the work product and personal property of a MH provider; and (2) not discoverable or admissible as evidence in any criminal, civil, or administrative action except those where the patient has initiated an action for malpractice, an intentional tort, or professional negligence against the health care provider. Under the statute, personal notes are not part of a medical record if the MH care provider keeps the personal note in the provider’s sole possession for the provider’s own personal use, maintains the personal note separate from the patient’s medical record, and does not disclose the personal note to any other person except the provider’s supervising health care provider that maintains the confidentiality of the personal note, consulting health care provider that maintains confidentiality of the personal note, or an attorney of the health care provider that maintains confidentiality of the personal note.⁵⁷

§4-307(C) requires that when a MH record information is disclosed without patient authorization, only the information in the record relevant to the purpose for which disclosure is sought may be released. This requirement echoes HIPAA’s minimum data necessary rule.

A health care provider may disclose a medical record relating to a psychological test as provided under §4-305(b)(2)(i) if the person given access to the medical record to sign an acknowledgement of the duty not to re-disclose any patient identifying the information to a person for educational or research purposes, subject to the applicable requirements of an institutional review board.

§4-307 does not restrict access to or disclosure of a medical record which is also an education record under the federal Individuals with Disabilities Education Act, the federal Family Education Rights and Privacy Act, or any federal and state regulations that have been adopted under these laws.

A health care provider may disclose a medical record that relates to and identifies more than one recipient in group or family therapy only with authorization of a person in interest for each recipient, or as otherwise provided by law.

The statute permits disclosures of medical records between or among the health care providers that participate in the approved plan of a core service agency or local BH authority for delivery of MH services, if the patient has received a current list of participating providers and has signed written agreement with the core service agency or local BH authority to participate in the client information system developed by the agency.

Penalties

§4-309 establishes robust penalties for both refusals to disclose records and disclosures which violate Subtitle 3 subsections within Subtitle 3 (Confidentiality of Medical Records). A health care provider or any other person who “knowingly and willfully violate any provision” of the subtitle is guilty of a misdemeanor and if convicted, subject to a fine up to \$1,000 for the first offense, not exceeding \$5,000 for each subsequent conviction. A health care provider of any other person, who fraudulently obtains a medical record is guilty of a misdemeanor and on conviction is subject to a fine up to \$50,000, imprisonment for up to a year, or both and steeper penalties if the offense is committed under false pretenses. If the offense is committed with intent to sell, transfer, or use IHI for commercial advantage, personal gain, or malicious harm, penalties may include a fine of up to \$250,000, imprisonment for up to ten years, or both. A health care provider or any other person who knowingly violates any provision of Subtitle 3 is liable for actual damages.

Notice Requirements

Maryland’s HIE is required to provide to the patient, upon written notice or request by the patient: (1) the participating organization that disclosed the PHI to the HIE; and (2) the date the PHI was disclosed to the HIE, if known by the HIE.

In addition to applicable HIPAA notification requirements, a participating organization is required notify each individual whose PHI, including SHI, is breached, or is maintained, accessed, used, or disclosed in a manner that constitutes a non-HIPAA violation in accordance with Regulation .08 of this chapter.

Patient Consent Requirements

See above.

De-identification Standard

10.25.18.02 (16)--health information that neither identifies nor provides a reasonable basis to identify an individual and that meets the standards and specifications provided in 45 CFR 164.514(a)-(b) and specifications provided in 45 CFR 164.514(a)-(b).

APPENDIX D. DETAILED CASE STUDIES BY STATE: MICHIGAN

Grey Literature and Expert Interview Findings

Background

Michigan's Public Act 137 of 2006 created the Health Information Technology Commission (HITC), a 13-member group tasked with "facilitat[ing] and promot[ing] the design, implementation, operation, and maintenance of an interoperable health care information infrastructure".¹⁰⁵ HITC membership includes representatives from the Michigan Department of Health and Human Services (MDHHS), hospitals, purchasers, consumers, and other relevant stakeholder groups. In 2010, the HITC oversaw the launch of the Michigan Health Information Network (MiHIN), which was created with funding from the HITECH Act. Today, MiHIN's network is made up of 148 hospitals, 665 outpatient facilities, 298 skilled nursing facilities, and 44 physician organizations connected to the system. In total, the network covers over 13 million patients and 99% of admissions in the state.¹⁰⁶

MiHIN's operating process is guided by the discovery, evaluation, and implementation of distinct use cases. Their "Use Case Factory" lists five core domains: care coordination, public health, results delivery, quality information and administration, and network infrastructure. Use cases across multiple domains support BH integration.¹⁰⁷

BH Integration Use Cases

Admission, discharge, and transfer (ADT) notifications are a fundamental component of care coordination across multiple care settings. As ADT notifications are required of hospitals, psychiatric hospitals, and critical access hospitals per the Centers for Medicare & Medicaid Services (CMS) Interoperability and Patient Access Final Rule, the baseline ability to transmit these notifications does not separate MiHIN from the majority of health information exchanges (HIEs) in the United States. However, MiHIN's efforts to expand access to the notifications among BH providers and other historically less integrated settings has had positive results in the state. By leveraging the electronic endpoint and desired form of communication (e.g., Direct Secure Messaging or Lower Layer Protocol [LLP]), MiHIN ensures that providers can receive ADT notifications within their existing workflows. As of 2023, MiHIN reports 1,400 sending sites and 8,209 receiving sites, totaling over 7 million sent and 12 million received ADTs per week.¹⁰⁸

Another use case with major implications for behavioral health (BH) is the Interconnected Referral Network (IRN). This network allows providers across the state to submit, track, and manage referrals to multiple other care settings, including mental health (MH) and addiction treatment centers. As with ADT notifications, the broad scope of the IRN requires flexible, interoperable processes to reach the full range of Michigan providers. To this end, the payload is clearly defined through a detailed message requirements list which specifies the category, data type, and format of 25 required and five optional fields. However, the connectivity method can vary based on organizational capabilities, as MiHIN offers support setting up LLP over Virtual Private Network, API, or Secure File Transfer Protocol connections.¹⁰⁹ This network harmonizes with another use case on Social Determinants of Health (SDOH) screening. Social needs screenings completed at any care setting can be documented and shared with other members of the patient's care team. The status of the referral in the IRN is also shared and updated as the patient receives care.¹¹⁰

42 CFR Part 2 Data

Two pieces of state legislation help facilitate the transfer of BH data. Public Act 559 aligned the Michigan Mental Health Code with HIPAA rules and requirements, explicitly allowing sharing for TPO purposes.¹¹¹

Public Act 129 standardized the consent form required for sharing Part 2 data.¹¹² Previously, consent was handled differently by individual providers, which frustrated sharing Part 2 data between organizations with

unaligned consent forms. By introducing Form 5515 and requiring all providers to honor it, MDHHS set the stage for an interoperable, streamlined process for managing consent: MiHIN's Electronic Consent Management Service (eCMS).

The eCMS uses an easily navigable user interface to help providers and their patients complete Form 5515 to either grant or revoke consent. This eCMS module can be embedded into existing provider or consumer portals to be more readily accessible. For organizations without an existing portal, MiHIN can host the tool on its own platform. For provider organizations who have previous consents already stored digitally, an API can retrieve, parse, and store the consent into the centralized repository, rather than having the provider re-key the information. This repository minimizes duplicative and potentially contradictory consent paperwork that patients would otherwise complete at every care setting that may involve sensitive personal information (SPI).¹¹³

The eCMS was piloted with three prepaid inpatient health plans and three substance use disorder (SUD) clinics from 2019-2021. Forty-eight patient consents were obtained during the pilot, and multiple lessons learned are now informing the general release. One pain point was in identifying the proper recipient of the SPI. Form 5515 prompts patients to "list the specific names of health care providers, health plans, family members, or others [who should see and share your records]". Some patients struggled with the potentially opaque distinction between a provider and their organization. Even when a patient understands the difference and wants to share data only with a given provider, there is a step between writing down the name of the provider and creating the linkage in the system that may require additional identifying information, such as the address, organization, or national provider identifier number.

Messages with Part 42 data have an Health Level 7 (HL7) Security Label, or "Privacy Tag" embedded. This allows the receiving entity, MiHIN, to check the consent on file before the message is shared with any related providers. Importantly, these Security Labels allow for both granularity and upscaling beyond Michigan. First, because they can be attached to individual messages, patients are able to consent to only sharing certain components of their health data, such as just diagnoses, medications, or lab results. This aligns the system with Section 3 of Form 5515 which prompts patients to either share all BH data (excluding psychotherapy notes) or only certain types of data. Second, because HL7 standards are nationally recognized, this infrastructure could allow for a future interstate Part 42 data sharing system.

State Support

Because of MiHIN's governance model, many of the above functionalities were developed in collaboration with stakeholders at MDHHS. There are also key efforts on the MDHHS side to further BH integration.

MDHHS administers a state data hub for all Medicaid claims. This serves as the backend enabling CareConnect 360, a care management tool and portal that allows Medicaid beneficiaries to share integrated physical and BH-related information. This holds physical health care claims currently, but it has the underlying infrastructure to access SUD claims. A pilot to test integration between Maternal Infant Health Program providers and CareConnect360 is underway and demonstrates an initial opportunity to share progress notes thus indicating a future potential for SUD claims.¹¹⁴

MDHHS contracted an organization to review all state and federal legislation governing sharing health information. This includes a wide variety of complicating factors, such as presence of SUD data, data for minors, emergency situations, and special requirements regarding victims of crime and family violence. They then represented their findings in multiple forms of varying depth, from a three-page Quick Tips guide to a 15-page reference grid to the full 41-page comprehensive tool. These references are geared towards providers, who can quickly review them to confirm or deny whether they can share Protected Health Information (PHI) or

Part 42 data in a given situation. Because multiple stakeholders have reported “HIPAA hesitancy” as a primary barrier to enhanced data sharing, quick-reference provider-facing materials such as these could greatly improve the proportion of shareable data that makes it into the HIE and to other care settings.

State Statute Review Summary

Michigan’s primary laws governing disclosures of health and SUD treatment information is the Michigan Mental Health Code. Other laws governing disclosures of BH information include Michigan’s, Public Health Code, and land drug treatment court and MH court statutes. The Mental Health Code aligns with HIPAA and 42 CFR Part 2, with a somewhat broader exception for research, evaluation, accreditation, and statistical purposes.

Disclosure Requirements

Michigan’s Mental Health Code states that “information in the record of a recipient, and other information acquired in the course of providing MH services to a recipient, shall be kept confidential and is not open to public inspection”.¹¹⁵ Disclosures of information within MH records may be made to a MH service provider with the service recipient’s consent or with the consent of the recipient’s legal guardian, court appointed personal representative or executor of the estate of a deceased recipient.¹¹⁶ The statute provides several exceptions to the general confidentiality rule. Information may be disclosed without consent as necessary for the recipient to apply for or receive benefits or as necessary for treatment, coordination of care, or payment for the delivery of MH services, in accordance with HIPAA.⁵⁸ Information may be disclosed as necessary for research, evaluation, accreditation, or statistical purposes. In these cases, the individual who is the subject of the information must not be identified unless identification is essential to achieve the purpose for which the information is sought or if preventing the identification would clearly be impractical, but not if the subject of the information is likely to be harmed by the identification. Information may be disclosed to a MH provider or other health service provider or public agency, if there is a compelling need for disclosure based upon a substantial probability of harm to the recipient or other individuals.⁵⁸

Information that is confidential under the statute shall be disclosed under an order of subpoena, to a prosecuting attorney as necessary for the attorney to participate in proceeding governed by the Mental Health Code, or as required by another provision of law.¹¹⁷

Michigan’s Mental Health Code limits the scope of confidential information that may be shared without consent. The service recipient’s identity must be protected unless identifying the recipient is necessary for the authorized purpose for which the disclosure was sought. Similar to HIPAA’s minimum necessary standard rule, confidential information disclosures under Michigan’s Mental Health Code must include only the information necessary to achieve the authorized purpose for which the disclosure was requested. Chapter 2A of Michigan’s Mental Health Code has specific restrictions for disclosures of SUD service records. Under the Code, such records are confidential and may be disclosed only for purposes authorized under the law. An individual may consent in writing to the disclosures to health professionals for the purpose of diagnosis and treatment of the individual, governmental personnel for the purpose of obtaining benefits to which the individual is entitled, and any other person authorized by the individual. Disclosures without consent are allowed to medical personnel to the extent necessary to meet a bona fide medical emergency, for mandatory reporting (i.e., elder and/or child abuse and neglect), and when there is a duty to warn. Disclosures without consent are also allowed to qualified personnel for the purpose of conducting statistical research, financial audits, or program evaluation provided that the individual is not identified in work products or any other manner. A court may order disclosure of whether a person is under treatment by a program.⁵⁹ These exceptions align with 42 CFR Part 2 exceptions, including disclosures made for medical emergencies, research activities, audit and evaluation activities and valid court orders.

Mich. Comp. Law §330.1141a. governs the exchange of *confidential MH and SUD information*. This provision of the Mental Health Code requires that MDHHS develop a standard release form for exchanging confidential MH and SUD information for use “by all public and private agencies, departments, corporations, or individuals that are involved with treatment of an individual experiencing serious mental illness, serious emotional disturbance, developmental disability, or SUD.” The parties described above must honor and accept the standard release form created by the department, unless subject to a federal law or regulation that provides more stringent requirements for the protection of IIHI.

Michigan’s standard release form is designed to meet the requirements of 42 CFR Part 2 and Michigan’s Mental Health Code for care coordination purposes.

The Mental Health Code’s disclosure rules are mostly consistent with HIPAA disclosure requirements. The Code’s “research, evaluation, accreditation, or statistical purposes exception” is a bit broader than HIPAA’s exceptions for research and health oversight activities. The Mental Health Code’s research exception, for example, does not define research whereas HIPAA defines research as “any systematic investigation designed to develop or contribute to generalizable knowledge” and limits the exception to purposes that meet this definition. The Mental Health Code allows disclosures of PHI without consent when de-identification is not practicable. The HIPAA Privacy Rule requires consent or a waiver of authorization by an institutional review board or Privacy Board for such disclosures.

Chapter 600, Act 236 of Michigan Code governs confidentiality of information obtained in *substance treatment courts*. §600.1072 provides that any statement or other information obtained as a result of participating in an assessment, treatment, or testing while in a drug treatment court is confidential and is exempt from disclosure under the freedom of information act, 1976 PA 442, MCL 15.231 to 15.246, and shall not be used in a criminal prosecution, unless it reveals criminal acts other than, or inconsistent with, personal drug use. §600.1093 provides similar language concerning any statement or other information obtained in *MH courts*.

Michigan’s Public Health Code Act describes the rights of patients and health facility residents, including rights to confidential treatment of records. Patient and residents are “entitled to confidential treatment of personal and medical records,” and may refuse the release of records “except as required for transfer to another health care facility, as required by law or third-party payment contract, or as required by HIPAA”.¹¹⁸

Finally, the Michigan Medical Records Access Act requires that health care providers and health facilities, as defined within this law, provide a patient or the patient’s authorized representative access to the patient’s medical record. The statute’s definition of health care provider expressly excludes psychiatrists, psychologists, social workers, and professional counselors who provide only MH services. This means that most BH providers would not be covered by this law, but by other state laws governing disclosure of MH and substance use records.

Penalties

N/A

Notice Requirements

All breaches must provide a description of the breach to affected users, efforts to mitigate risk of future breaches, and contact information for additional assistance.

Patient Consent Requirements

Michigan has a policy that all patients are opted into the HIE but may opt-out at any time.

De-identification Standard

N/A

APPENDIX E. DETAILED CASE STUDIES BY STATE: NEBRASKA

Grey Literature and Expert Interview Findings

Background

First established as the Nebraska Health Information Initiative (NEHII) in 2008, Nebraska's statewide health information exchange (HIE) became the regional CyncHealth when it merged with the Iowa Health Information Network in 2021.¹¹⁹ Prior to the creation of NEHII, there existed Health Information Organizations (HIOs) managed by non-state actors in Nebraska that facilitated data exchange in specific domains. One of these HIOs, the Electronic Behavioral Health Information Network, facilitated exchange of behavioral health (BH) data using a NextGen platform, and was eventually subsumed into NEHII.¹²¹

CyncHealth acts as a Health Data Utility (HDU). In 2021, LB 411 was passed, which gave CyncHealth the legal standing and directive to collect and analyze health data for broader public health goals, in addition to the traditional treatment-oriented services HIEs provide.¹²² As part of the legislation, all health care facilities and payers were required to participate in CyncHealth by the end of fiscal year 2021, with those joining before July 1, 2021, not paying connection costs.

The participation details are determined by the state health information technology (HIT) Board, which CyncHealth administers per 2020 state law LB 1183. The Board's membership is defined in the law, and includes representatives from the HIE, the legislature, the Nebraska Department of Health and Human Services (NDHHS), and multiple care settings.¹²²

HIT Landscape

NDHHS publishes a State Medicaid Health Information Technology Plan containing a landscape analysis and the future vision every four years. The most recent plan, released in 2022, included a survey of providers in the state, with BH providers accounting for 23% of the 221 total responses.¹²³ The data are a helpful look into the current state of HIT adoption.

In 2021, 73% of respondents had adopted an electronic health record (EHR) system, a steady increase from 48% in 2011 and 63% in 2017. The EHR adoption rate is lower in BH providers (57%) than other provider types (78%). Of those with an EHR, 72% shared clinical data electronically with external entities. Of those without an EHR, a majority report the cost of implementation and staff training to be a primary barrier to purchasing an EHR.

The figures for HIE integration are generally lower than EHR adoption. Only 19% of respondents participate in CyncHealth, up slightly from 17% in 2017. While the reported barriers are also primarily financial--the most cited were connection fees (49%) and implementation costs (44%)--many reported that they did not find value in the services an HIE provides (38%). BH providers were more likely to see the benefit in HIE participation, with 46% calling it either "important" or "very important".

Interoperability and Infrastructure

One unique feature of CyncHealth is that their participation agreement requires organizations to establish a bidirectional data exchange. Because the organization uses the U.S. Core Data for Interoperability (USCDI) v3 standards that are set to become the baseline in 2026, onboarding a hospital requires setting up multiple HL7 feeds. This represents a significant amount of work, as each feed requires a Virtual Private Network-secured connection and both technical and clinical validation. The implementation is generally a shared effort between CyncHealth, the clinic, and the organization's EHR vendor. Consequently, meeting the participation agreement requirements can be more difficult for smaller organizations and those with less mature EHR systems.

Even after implementation, bidirectional exchange does not guarantee complete HIE to EHR integration, which has consequences for clinical workflows. One BH provider noted that their EHR vendor did not provide support for ingesting data from the HIE. As a result, providers at this clinic must log into their EHR on one screen and the HIE on another. Any information that they would want to pull into their EHR must be done by manually keying it in. In theory, a HL7 Fast Healthcare Interoperability Resources (FHIR) Application Programming Interface (API) could automate this process, but variations in local mappings across EHRs would require additional labor to ensure that all incoming data is being properly received, sorted, and stored in the clinic's EHR.

Building and maintaining a robust data sharing infrastructure enables a broad set of use cases. As an HDU, CyncHealth supports public health efforts through syndromic surveillance, electronic lab reporting, and immunization reporting. Stakeholders from CyncHealth reported that about 40 participants are currently submitting to public health feeds via the HDU.

A partnership with NDHHS to reduce maternal mortality highlights how an interoperable network can support individual health outcomes and showcases the effectiveness of scaling technical solutions to broader populations. All patients presenting to an emergency department are automatically screened via their patient record to determine if they are postpartum. If they are, the emergency department is notified and can provide additional care, including screenings, proactive communication with the primary care team, or additional lab tests. The initial pilot in Omaha was successful, so the program was extended to cover all of Nebraska. In addition to the technical infrastructure, stakeholder outreach and training was key in ensuring the system worked as intended. Stakeholders from CyncHealth noted that this program is replicable for other populations of interest by simply adjusting the inclusion criteria. Real-time notifications could bring personalized care to existing CDS models.

Prescription Drug Monitoring Program (PDMP)

Nebraska is the first state with a PDMP that tracks all prescription drugs, not just controlled substances.¹²⁴ While supporting all prescription drugs is not a substantially more challenging technical problem, it does greatly increase the number of reporting entities. In addition to hospitals and pharmacies, BH providers, dentists, and even veterinarians must submit their prescription data daily. CyncHealth is then tasked with managing this multitude of connections and following up on any connection that goes down for more than a day, which they note can once again be challenging for smaller providers that have fewer individuals on the provider end to manage data connections.

There are multiple important benefits of a universal PDMP. First, it enables surveillance of all prescription drugs, which enables more robust public health and research efforts. A universal PDMP also allows every provider in the state to view a complete medication list for each patient they have an active relationship with. For patients who receive care at multiple settings or have complex medical records, this can streamline care and reduce the potential for negative drug interactions.

42 CFR Part 2

CyncHealth reports ongoing collaboration with technology vendors to ensure that patient data is accurately documented so that as much of the patient record can be shared as possible, pending patient consent. The consent process in the state comes with many caveats--for instance, patients are unable to opt-out of the PDMP, creating a technical challenge wherein CyncHealth must design solutions that allow patients to opt-out of some systems while keeping them enrolled in others. Some consent streams in Nebraska still operate through paper authorization, requiring participants to submit notarized forms to opt-out of the system.¹²⁵ In other cases, such as with Part 2 data, it is not immediately clear whether the same consent principles apply,

nor if there is a systematic manner that consent is managed for Part 2 data. With this in mind, when probed for the barriers underpinning universal record sharing, stakeholder interviews pointed to technological constraints and vendor limitations, rather than consent regulation, as the primary constraint to scaling systems.

One BH provider noted that most systems are ill-equipped to segment data at the granularity needed for integrated care. CyncHealth, for example, requires providers to complete an attestation during onboarding in which they are either listed as a Part 2 provider or not. However, a provider may see some patients as an substance use disorder (SUD) treatment professional and others as a general mental health (MH) counselor. Even a provider working with a single patient may have some visits that cover SUD treatment and others that do not. As such, the technology needs to support highly granular “tagging” of Part 2 data at the level of individual observations. Until it does, providers are caught in a dilemma between segmenting all information for their patients--limiting the sharing of non-sensitive data--and marking all information as non-sensitive, leaving the possibility of improper disclosures.

State Statute Review Summary

Disclosures of mental and BH records are governed by three primary Nebraska statutes. These include the Population Health Information Act which informs establishment of a statewide designated HIE, the Mental Health Practice Act which addresses disclosures by MH practitioners, and the state prescription drug monitoring system statute. Nebraska statutes defer often to the HIPAA Privacy Rule. The Mental Health Practice Act allows disclosures without consent if state law or regulations permit but does not include preemption text in this section for more stringent HIPAA rules. The primary statutes do not address data sharing requirements for disclosures of substance use treatment records, except for prescription records. Regulations and policies that clearly articulate requirements for disclosures of mental and substance use records may be forthcoming.

Disclosure Requirements

Nebraska’s *statewide HIE* is governed by the Population Health Information Act.⁴⁵ Under this law, patient health information shared with the HIE shall be provided in accordance with the privacy and security provisions set forth in HIPAA and regulations adopted under the act. Provisions within the Population Health Information Act do not apply to state owned or state operated facilities or assisted living facilities, nursing facilities, or skilled nursing facilities, as such terms are defined in the Health Care Facility Licensure Act.

Nebraska’s designated HIE is required to have an agreement in place with NDHHS, which allows the designated HIE to collect, aggregate, analyze, report, and release de-identified data, as defined by HIPAA. §81-6, 125 and allows health care providers and entities to access information available within the HIE to evaluate and monitor care and treatment of a patient in accordance with HIPAA.

Nebraska’s *MH practitioners’ statute* prohibits persons who are licensed or certified under the Mental Health Practice Act or who hold a “privilege to practice in Nebraska as a professional counselor under the Licensed Professional Interstate Compact from disclosing any information acquired” from a person in a consultant’s professional care. The statute allows disclosures when there is written consent from the person, or in the case of death or disability, of the person’s personal representative, or any other person authorized to sue on behalf of the person, or the beneficiary of any insurance policy.” Disclosures without consent are permitted if state law permits the disclosure or if the state licensure board determines by rule or regulation: when a person waives confidentiality by bringing charges against the licensee, when the counselor has a duty to warn of and protect from a patient’s threatened violent behavior, and as permitted under the HIPAA Privacy Rule.^{126,127}

Nebraska's *prescription drug monitoring system* provides information to improve the health and safety of patients. To this end, Neb. Rev. Stat 71-2454 provides that this system "make the prescription drug information available to the statewide HIE for access by its participants if such access is in compliance with the privacy and security protections set forth" in HIPAA and regulations adopted under the Act. Patients are not allowed to opt-out of the prescription drug monitoring system. However, if a patient opts out of the statewide health exchange, the prescription drug information regarding that patient will not be accessible by HIE participants. Under this statute, patient identifying data, while generally prohibited from disclosure, is available to the statewide HIE and its participants, and to prescribers and dispensers as provided in the statute.

The statute permits the statewide HIE to release to patients their prescription drug information upon the patient's request. The statewide HIE, in accordance with the privacy and security provisions set forth in HIPAA, may release data for statistical, public policy, or educational purposes after removing information which identifies or could reasonably be used to identify the patient, prescriber, dispenser, or other person who is the subject of the information, except as otherwise provided in the statute.

Penalties

There is "no monetary liability against persons licensed or certified under the Mental Health Practice Act or who are privileged to practice in Nebraska as a professional counselor under the Licensed Professional Counselors Interstate Compact for failing to warn of and protect from a patient's threatened violent behavior for failing to predict and warn of and protect from a patient's violent behavior, except when the patient has communicated to the MH practitioner a serious threat of physical violence against himself, herself, or a reasonably identifiable victim or victims."¹²⁸

Notice Requirements

Patient health information shared with the HIE shall be provided in accordance with the privacy and security provisions set forth in HIPAA and regulations adopted under the act.

Patient Consent Requirements

§81-6-125(6) provides that an individual shall have the right to opt-out of the designated HIE. The designated HIE shall adopt a patient opt-out policy consistent with HIPAA and other federal requirements. The policy does not apply to mandatory public health reporting requirements.

De-identification Standard

§81-6-125(5) requires that the designated HIE and NDHHS enter into an agreement no later than September 30, 2021, to allow the HIE to collect, aggregate, analyze, report, and release de-identified data, as defined by HIPAA Privacy Rule's de-identification standard.

APPENDIX F. DETAILED CASE STUDIES BY STATE: NORTH CAROLINA

Grey Literature and Expert Interview Findings

Background

Pursuant to the Statewide Health Information Exchange Act, North Carolina established the North Carolina Health Information Exchange Authority (NC HIEA), a centralized body with an accompanying advising board of multiple stakeholders to oversee and administer the state-designed health information exchange (HIE).¹²⁹ The HIE network that resulted was NC HealthConnex, and all health care organizations, including behavioral health (BH) providers, receiving state funds are required to submit patient information tied to Medicaid reimbursement to the system through its accompanying portal. To date, the HealthConnex portal has integrated data from 225 different EHR systems across the state governing more than 9 million distinct patient records. The portal provides both eHealth integration with other intra-state and extra-state health systems and a provider directory linking health care providers across a majority of the state. The statutes facilitating NC HIEA and HealthConnex provide federally derived stipulations on privacy surrounding BH data.

State Laws and Requirements

The law governing both the NC HIEA and the HIE system in general is the Statewide Health Information Exchange Act. The law mentions privacy and security primarily in the context of the Privacy Rule and Security Rule within HIPAA, as well as its specific provisions governing sensitive data, such as psychotherapy notes.¹³⁰ With respect to BH, a representative from a BH provider is required to be one of the 12 members of the NC HIEA's advisory board (see Article 90-414.8). Aside from this, the Act does not mention BH integration specifically. Certain health care organizations were required to begin submitting data by January 1, 2023. The COVID-19 pandemic has resulted in multiple extensions of the deadline for implementation by the General Assembly. Priority deadlines were implemented for certain health care delivery organizations, including hospitals, physicians, physician assistants, and nurse practitioners, who provided Medicaid services and had an electronic health record (EHR) system; Managed Care Organizations (MCOs); and prepaid health plans with contracts to deliver Medicaid.

HIE Capabilities

HealthConnex is administered through the NC HealthConnex Clinical Portal.⁷⁷ The portal is managed and administered by SAS Institute, NC HIEA's technical partner which also manages the NC HIEA Technical Support Help Desk. SAS is also directly involved with onboarding practices and working with their EHR vendors to connect the practice to the HIE. Practices receive access after signing the participation agreement. The platform also facilitates eHealth Exchange with other health information networks both in-state and out of state, including Atrium Health, Carolina eHealth Network, East Tennessee Health Information Network, Georgia Health Information Network, Georgia Regional Academic Community Health Information Exchange, MedVirginia, OCHIN, PULSE, Sentara, and VADoD.

Current capabilities of the HIE do not track by provider types (in other words, it is not the case that BH providers specifically pose an issue), but issues using the HIE very much do correlate with practice size. Larger practices with commonly used EHR systems and dedicated information technology teams are easier to work with than sole practitioners. The NC HIEA's partnership with Unite Us, a social care referral platform, enabled the creation of NCCare360, a Social Determinants of Health (SDOH) module integrated into the HIE.¹³¹ A priority of the organization is to integrate this module with the separate SDOH features offered by Epic, Cerner, and other systems to facilitate exchange, as well as to incentivize FHIR integration and adoption of data standards among participants. Another long-term priority for the NC HIEA is to potentially establish HealthConnex as a Health Data Utility (HDU), with the hope that having this status and framework will open

new sources of public health modernization and innovation funding, quality improvement support, and areas of collaboration with policymakers.

BH EHR Incentives

The NC HIEA has targeted prior incentive programs for HIE integration specifically towards BH providers. The NC Medicaid EHR Incentive Program, targeted at BH providers including those handling mental health (MH) and substance use disorder (SUD), incentivized practices to enroll in EHR systems and integrate their system with HealthConnex through supplemental Medicaid reimbursement payments beyond the North Carolina Department of Health and Human Services (NCDHHS) fee schedule.¹³² This program ran for 11 operating years from 2011 to 2021. While there do not appear to have been any BH-targeted incentive programs since, in 2023, the Governor's office released a comprehensive \$1B funding plan to address the state's MH and SUD crisis.¹³³ Measures in the investment plan addressed all aspects of BH across the state, from community-based health integration efforts to the intersection of MH and justice. Crucially, \$50M in funds have been appropriated specifically towards BH health data integration through HealthConnex. Additional support for BH data integration and modernization has emerged in the time since, including awards to community BH clinics across the state and more than \$4 million in funding to support maternal BH care in under-resourced and historically marginalized communities. Given these diverse sources of support for BH care, the state has the ability to invest in further HIE innovations, such as technical support for Part 2 integration, or to scaffold further incentive programs that build on lessons learned from the EHR incentive program. In alignment with other areas of funding specified by the plan, one such priority for the NC HIEA is integrating their work with other stakeholders in government that benefit from health data exchange. This has enabled the NC HIEA to work with special populations, such as the state's corrections population.

42 CFR Part 2 Data

From interviews with staff members within the NC HIEA, it became clear that state-level innovations to support new data types were primarily driven by the passage of state and federal policies. Stakeholders noted that it is difficult to anticipate how new developments (like the payer-to-payer Fast Healthcare Interoperability Resources [FHIR] Application Programming Interface [API] mandate) will interact with extant policies, necessitating that NC HIEA administrators fully understand the stipulations of policies before developing innovations in response. In a similar vein, the NC HIEA prioritizes their response to policy developments based on the concentration of federal financial support for innovation. Aside from policy, the other primary impetus for HIE operation was participants' own technical needs and ensuring that HealthConnex in its current form can support the current capacities of health care organizations across North Carolina. Thus, if participants do not currently have internal support for certain data streams or standards, they are unlikely to exist as priorities at the HIE level.

While NC HealthConnex maintains connections to BH providers, they do not yet support 42 CFR Part 2 data exchange. Developing the technical capabilities to segregate Part 2 data is one of the organization's near-term priorities. They are adapting their query functionality to insulate Part 2 data in response to the changing rules. Until this functionality is developed, Part 2 providers engage with HIE data exchange unidirectionally.

State Statute Review Summary

North Carolina's Statewide Health Information Exchange Act; Mental Health, Developmental Disabilities, and Substance Abuse Act; and the Emergency Medical Service Act are the primary laws addressing disclosures of MH and substance use treatment records. The HIE statute aligns with the HIPAA Privacy Rule disclosure requirements and extends requirements beyond covered entities to include other state licensed facilities. The statute explicitly defers to 42 CFR Part 2 and other federal laws that restrict disclosures of PHI.

Disclosure Requirements

North Carolina's *Statewide Health Information Exchange Act*,¹²⁹ notwithstanding any federal or state law or regulation to the contrary, permits covered entities that participate in the HIE network to disclose an individual's protected health information (PHI) through the HIE network to other covered entities for any purpose permitted by HIPAA. Covered entity is defined broadly in the statute, to include "any entity described in 45 CFR §164.103 or any other facility or practitioner licensed by the state to provide health care services."⁶⁰

The statute does not impair any rights conferred upon an individual under HIPAA, including the right to receive a notice of privacy practices, the right to request restriction of use and disclosure, the right of forms of communication, and the right to receive and accounting of disclosures.⁶¹

Additionally, nothing in the statute should be interpreted to authorize disclosure of PHI to the extent that the disclosure is restricted by federal laws or regulations, including the federal drug and alcohol confidentiality regulations set forth in 42 CFR Part 2 or restrict the disclosure of PHI through the HIE network for public health purposes or research purposes, so long as disclosure is permitted by both HIPAA and state law. The statute does not apply to the use or disclosure of PHI in any context outside of the HIE network, including the re-disclosure of PHI obtained through the HIE network.¹³⁴

NC Gen Stat §122C-52 describes patient rights to confidentiality concerning MH and substance use records. Confidential information acquired in treating a patient is confidential. The statute sets out a number of exceptions including disclosures by HIPAA covered entities.

Penalties

Pursuant to 90-414.12, a covered entity that discloses PHI in violation of the HIE Exchange Act is subject to:

- Any civil penalty or criminal penalty, or both, that may be imposed on the covered entity in accordance with the HITECH Act and regulations adopted under the Act.
- Any civil remedy under the HITECH Act and associated regulations that is available to the Attorney General or to an individual who has been harmed by a violation of this Article.
- Disciplinary action by the appropriate licensing board or regulatory agency with jurisdiction over the covered entity.
- Any penalty authorized under Article 2A of Chapter 75 of the General Statutes if the violation of this Article is also a violation of Article 2A of Chapter 75 of the General Statutes (identity theft).
- Any other civil or administrative remedy available to a plaintiff by state or federal law or equity.

To the extent permitted under or consistent with federal law, a covered entity or its business associate that in good faith submits data through, accesses, uses, discloses, or relies upon data submitted through the HIE network shall not be subject to criminal prosecution or civil liability for damages caused by such submission, access, use, disclosure, or reliance.

North Carolina's Mental Health, Developmental Disabilities, and Substance Abuse Act includes the patient's right to confidentiality, prohibits individuals or facilities having access to confidential information from disclosing the patient's information unless disclosures meet the requirements statutory exceptions, and harmonizes the statute's disclosure restrictions with those of federal statutes or regulations that prohibit the disclosure of MH, development disability, and substance use information.¹³⁵

The act includes exceptions for abuse reports, court proceedings,¹³⁶ for client care,⁶² and for research and planning.⁶³ Facilities must disclose confidential information when a court of competent jurisdiction compels the disclosure.¹³⁶ Any facility may share confidential client information held by the facility with any other

facility for purposes of client’s care, treatment, or habilitation.⁶² The statute then provides specific people and purposes that may share data for care, treatment, or habilitation purposes. Facilities may share de-identified information with the Secretary of NCDHHS, including contracting case management programs, for development of reports, planning and study. Facilities may share confidential information with the Secretary when specifically required by other state or federal law and for research and evaluation purposes. A facility may disclose confidential information to persons responsible for research, or audits if there is a justifiable and documented need for the information. Reports resulting from research and audits must not identify any clients.⁶³

Provider-to-provider data sharing may also be subject to the Emergency Medical Services Act. Under this statute, medical records compiled and maintained by NCDHHS, trauma hospitals, and emergency medical services (EMS) providers are strictly confidential and not considered public records. De-identified data may be shared for statistical purposes. Identifiable health Information may be shared without consent to health care personnel providing care to the patient, pursuant to a court order, to a medical or peer review committee, to a statewide data processor, and pursuant to any other law. The law also permits disclosures for research under rules adopted by the North Carolina Medical Care Commission which shall include the determination of an institutional review board (IRB) regarding whether the research project:

- Is of sufficient importance to outweigh the intrusion into the patient’s privacy that would result from the disclosure.
- Is impracticable without the disclosure of identifying health information.
- Contains safeguards to protect the information from re-disclosure.
- Contains safeguards against identifying, directly or indirectly, any patient in any report of the project.
- Contains procedures to remove or destroy at the earliest opportunity, consistent with the purposes of the project information that would enable the patient to be identified, unless and IRB authorizes retention of identifying information for purposes of another research project.¹³⁷

Patient Consent Requirements

Each individual has the right on a continuing basis to opt-out or rescind a decision to opt-out of the HIE. NC Gen. Stat. 90-414.10. “Opt-out” is defined as an individual’s affirmative decision communicated in writing to disallow disclosures of the individual’s PHI by the NC HIEA to covered entities through the HIE network.⁶⁰

De-identification Standard

Under this law, patient health information shared with the HIE shall be provided in accordance with the privacy and security provisions set forth in HIPAA and regulations adopted under the act.

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SUGGESTED CITATION

Dougherty, M., McGavin, M., Lewis, R., Barnes, K., Athimuthu, P., Adegun, A., & Mallonee, E. How Health Information Exchanges Support Integration for Behavioral Health Settings (Final Report). Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. December 31, 2024.

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