



CONNECTICUT

Health Strategy

Health Information Exchange (HIE) PA 24-19 Recommendations Workgroup Draft Report

Pursuant to PUBLIC ACT 24-19: AN ACT CONCERNING THE HEALTH AND SAFETY OF
CONNECTICUT RESIDENTS

JANUARY 1, 2025

Prepared for the CT General Assembly
by the Office of Health Strategy:

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Commissioner

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LEGISLATIVE RECOMMENDATIONS REPORT

I. Introduction

Pursuant to [Public Act 24-19 \(PA 24-19\), Section 23\(c\)](#), and in accordance with Connecticut General Statutes (CGS) section 11-4a, Submission of reports to the General Assembly and State Librarian, the Office of Health Strategy (OHS) hereby submits the following report of recommendations to the Joint Standing Committee of the General Assembly on Public Health. This report provides the recommendations and discussions of the designated working group established under PA 24-19. OHS is reviewing written recommendations received on or before November 21, 2024, to determine the merits and feasibility of each recommendation for inclusion in the forthcoming proposed regulations governing the State-wide Health Information Exchange (HIE). OHS will also assess whether the recommendations should apply solely to the State-wide HIE, operated under contract to OHS by Health Information Alliance (HIA), or to all HIEs operating in the state. The assessment will include a thorough evaluation of each recommendation's potential impacts, consequences, and timeframes for implementation.

The background information, discussions, and written recommendations provided in this report offer context for consideration as the agency drafts regulations related to the State-wide HIE. The recommendations outlined in this report do not necessarily reflect the consensus of all group members; nor do they represent the opinions of OHS.

II. Background

Regulatory Authority

The OHS commissioner holds the authority and responsibility to promulgate regulations necessary to implement the provisions of [CGS §17b-59d](#) (State-wide Health Information Exchange. Established.) and [CGS §17b-59e](#) (Electronic health record systems.

Connection to State-wide Health Information Exchange.) in accordance with the requirements of CGS Chapter 54. Connie, State-wide HIE was officially designated as operational by OHS in May 2021. Connecticut is one of 48 states that have HIEs to facilitate the secure, transparent, and efficient sharing of health information.

HIE Establishment

Connecticut's State-wide HIE complies with all relevant federal and state laws, including stringent data-sharing and privacy regulations. The State-wide HIE has adopted a comprehensive data privacy protection program to ensure that all health information is used and disclosed only as permitted or required by law. Those requirements are reinforced and expanded upon in both the OHS' contract with HIA, the operating entity of the State-wide HIE, and in the State-wide HIE's [data release policy](#) that details the circumstances in which the State-wide HIE may disclose health information. Since its launch, more than 3,000 provider organizations in Connecticut have contracted with the State-wide HIE and are now receiving and securely sharing clinical data from thousands of facilities across the state. This includes all the major state health systems, most large physician practices, 39 skilled nursing facilities, and other key providers.

HIA has a board of directors codified in its enabling legislation comprised of stakeholders representing consumer advocates, medical doctors, hospitals, health systems, payers, and state agencies. Additionally, HIA has two committees that report to the board:

- Finance & Audit
- Privacy, Confidentiality, and Security

All board meetings, including the committee meetings, are open to the public and agendas, minutes, and meeting recordings are publicly available on the website: <https://www.conniect.org/meetinginformation>. In addition to the two committees that report to the board, HIA has several advisory groups including a Clinical Advisory Council and

a Patient & Family Advisory Committee to support the State-wide HIE.

Public Act 24-19 Working Group

Sec. 23 of Public Act 24-19 (*Effective from passage*) requires: (a) Not later than September 1, 2025, the executive director of the Office of Health Strategy shall establish a working group to make recommendations to the office (OHS) regarding the parameters of the regulations to be adopted by, and any policies and procedures to be implemented by, the office pursuant to subsection (d) of section 17b-59e of the general statutes, as amended by this act. Such recommendations shall include but need not be limited to (1) privacy of protected health care information, (2) cybersecurity, (3) health care provider liability, (4) any contract required of health care providers to participate in the State-wide Health Information Exchange, and (5) any statutory changes that may be necessary to address any concerns raised by the working group.¹

The working group provided the following additional topics for consideration which were included within the scope of discussion and recommendations:

- Scope of “active sharing of medical records”, inclusive of out of state patients
- Patient Rights and Education
- Cost to Small Businesses
- Reproductive Health

III. Conduct of Working Group

OHS held two virtual planning sessions with various association representatives in May 2024. OHS created the PA 24-19 working group charter and formalized membership via appointments in August 2024. OHS held four noticed virtual working group meetings; the first on August 27, 2024, followed on September 27, 2024, October 22, 2024, and November 20, 2024.

¹ The intended convening for the working group was September 1, 2024.

The purpose of each meeting was to gather the members' recommendations on the statutorily identified topics and the additional topics submitted by the working group membership. In addition to the working group meetings, on November 13, 2024, OHS provided a draft recommendations report to the working group. All working group participants were given the opportunity to file additional written recommendations for statutory changes by November 20, 2024, to be included in this recommendations report. OHS respectfully submits this report to the Public Health Committee. Participant recommendations are outlined in Section D.

IV. Appointed Working Group Participants

Sec. 23 of Public Act 24-19 established the following composition of the working group: (b) [t]he working group shall consist of not more than fifteen members, including, but not limited to, (1) the executive director of the Office of Health Strategy, or the executive director's designee, who shall serve as chairperson of the work group, (2) the Health Information Technology Officer, designated pursuant to section 19a-754a of the general statutes, or the officer's designee, (3) the chairpersons and ranking members of the joint standing committee of the General Assembly having cognizance of matters relating to public health, and (4) representatives of health care provider associations in the state, which may include associations representing hospitals, ambulatory surgical centers, physicians, women's health care providers, behavioral and mental health care providers, health care services providers for the aging, gender affirming care providers, patient advocates and health care payers. OHS identified the appointed members of the working group shown in Table 1. Additional non-appointed participants in the meeting included: Antony Casagrande, OHS Legal Counsel; Richard Gold, Regulation subject matter expert and consultant who provided meeting facilitation; OHS staff, and HIA representatives and legal advisor to participate as a regulated entity and to provide feedback on the feasibility of the approaches discussed.

Table 1 Appointed Working Group Participants

Individual	Organization	Representing
Deidre S. Gifford , Commissioner	Office of Health Strategy (Executive Director of OHS)	OHS
Sumit Sajnani , Health Information Technology Officer	Office of Health Strategy (Health IT Officer)	OHS
Senator Saud Anwar , Co-Chair, Public Health Committee	CGA (Chairperson of the joint standing committee of the GA)	CGA
Representative Cristin McCarthy Vahey , Co-Chair, Public Health Committee	CGA (Chairperson of the joint standing committee of the GA)	CGA
Senator Heather Somers , Ranking Member, Public Health Committee	CGA (Ranking member of the joint standing committee of the GA)	CGA
Representative Nicole Klarides-Ditria , Ranking Member, Public Health Committee	CGA (Ranking member of the joint standing committee of the GA)	CGA
Jennifer Cox , JD, Legal Counsel	Connecticut Hospital Association, Cox & Osowiecki, LLC	Hospitals
Amanda Gunthel , President	CT Association of Ambulatory Surgical Centers	Ambulatory surgical centers
David Anthony Yoder , DO, MPH, FACP, and representative of CT Chapter of the American College of Physicians	American College of Physicians	Physicians
Zari S. Watkins , JD, MBA, Chief Operating Officer & Compliance Officer	Planned Parenthood of Southern New England, Inc.	Women’s health care providers
Mikayla E. Sleeter-Bozym , PhD, LPC, NCC, Owner, CT Counseling Association, Waves of Growth Therapy, LLC, Adjunct Professor, CCSU, Director of Urgent Crisis and Evidence-Based Practices, Child and Family Agency	CT Counseling Association / private practice – Waves of Growth Therapy, LLC	Behavioral and mental health care providers
Mag Morelli , President	LeadingAge Connecticut	Health care services providers for the aging
Christy Olezeski , PhD, Associate Professor of Psychiatry, Director, Yale School of Medicine Pediatric Gender Program	Owner of Affirmative Health and Wellness (primary care practice that focuses on LGBTQIA+ population and provides gender-affirming care)	Gender affirming care providers

V. Recommendations of Appointed Working Group Participants

The recommendations below, specific to regulations and policies and procedures, were provided to OHS by participants in the working group. They do not necessarily reflect the consensus of all group members; nor do they necessarily represent the opinions of OHS. The following background and discussions provide further information for consideration as OHS drafts regulations pertinent to the State-wide HIE. The working group meetings included brief presentations by subject matter experts on various topics, focusing on administrative regulatory content and operational policies and procedures that date back to May of 2021 when the State-wide HIE commenced operations. Consultant Richard Gold also provided background on the content of the proposed regulations and the core concepts behind them. Participants supplied verbal recommendations during the working group meetings on the statutorily identified topics. The discussions offered valuable insights into the existing policies, and the working group generally agreed with both the current procedures and the proposed concepts presented. Written recommendations received by November 21, 2024 are included as an appendix to this report.

Report Structure

This report outlines the recommendations developed as part of the working group discussions, structured to provide clarity and actionable guidance. At a high level, the recommendations are organized into two primary sections:

A. Recommendations to OHS for Consideration to Promulgate Regulations

These recommendations can be implemented by OHS without legislative action, as OHS possesses the requisite authority to implement them.

B. Recommendations Requiring Legislative Change

These recommendations would require legislative action by the General Assembly to implement. This may be needed for several reasons, such as expanding applicability beyond the State-wide HIE, aligning with federal or state regulations, addressing gaps in existing laws, ensuring consistency across healthcare systems, or clarifying responsibilities and enforcement mechanisms. Additionally, legislative changes might be required to introduce new processes or requirements that are not currently covered by existing statutes. Within each primary section, recommendations are further categorized by subject or topic area. For each topic, the report is divided into three subsections:

1. Background

This subsection provides a summary of the discussions that took place during the working group meetings, offering context through an overview of key concepts, relevant federal and state statutes, and OHS's preliminary thinking and positioning regarding regulatory development.

2. Recommendations

This subsection lists actionable recommendations that either diverge from or expand upon OHS' stated direction for regulation. Recommendations that aligned with OHS' existing practices or previously announced enhancements are not included here for brevity, as they did not provide additional value for this report. General opinions, information shared during discussions, or written comments not directly tied to actionable recommendations are also excluded, though all meeting recordings, materials, and minutes are publicly available. [PA 24 19 HIE Recommendations Workgroup Meeting Details \(Minutes/Recordings\)](#) To ensure transparency, all written comments submitted by members are included in the appendix.

3. OHS Response

This subsection provides OHS's analysis and response to the specific recommendations listed. It offers insight into how OHS plans to address or incorporate these suggestions and clarifies the agency's perspective on each recommendation.

Some topics appear in both sections, reflecting recommendations that span both regulatory and statutory considerations. However, recommendations are not duplicated between the two sections to maintain clarity.

It is important to note that recommendations reflect the input of individual members and were not voted on by the group. Most recommendations achieved majority approval, however full consensus may not have been present for all recommendations.

Recommendations to OHS for Consideration to Promulgate Regulations

1. Privacy Of Protected Health Care Information

Background: This discussion addressed the requirements and compliance considerations under federal and state laws and regulations, with a focus on affirmative consent for specific categories of Protected Health Information (PHI). Patients must explicitly opt-out of the State-wide Health Information Exchange (HIE) if they do not wish to have their health information shared. However, for public health reporting purposes, limited PHI may still be shared with the HIE even if a patient has opted out.

Patients can easily opt-out of data sharing with the State-wide HIE by completing a simple form available on its website: <https://www.conniect.org/optout>. Opting out is a one-time process that applies to all providers. Once a patient opts out, their health data is deleted from the State-wide HIE. Importantly, patients retain the right to opt back in at any time.

The State-wide HIE's opt-out consent model aligns with the Health Insurance Portability and Accountability Act (HIPAA) and is consistent with the practices of most healthcare organizations in Connecticut. Additionally, the HIE's consent policy requires affirmative consent to share specific types of sensitive information, such as Substance Use Disorder (SUD) data from organizations governed by 42 CFR Part 2.

The working group discussed the importance of notifying individuals in the State-wide HIE

who have recently turned 18 about their opt-out rights and the ability to make their own decisions regarding data sharing. This would include informing individuals about the status of the decision their parent or guardian previously made for them and clearly outlining their rights to opt-in or opt-out of sharing health data with the State-wide HIE. It is essential for young adults to understand that, upon reaching 18, they have the right to change their data sharing preferences at any time. Guidance should clarify that if an individual opts out, their information will be removed, except where required by law or for public health purposes. If a parent opted out and the individual later opts in, data sharing will commence from that point forward but will not include any records or medical care prior to the opt-in.

During discussions about informing patients who are turning 18 about their right to opt-in or opt-out, a concern was raised regarding how the operating entity would monitor the age of patients and notify them individually, as opposed to providers informing them at the time the Notice of Privacy Practices (NPPs) are adjusted. The operating entity could consider posting a general notice on its website indicating that patients aged 18 and older can request information about their consent status.

Recommendations:

- Privacy practices and consent: Regulations or policies should include standardized language about the disclosure of health information by the State-wide HIE to be included in the provider's notice of privacy practices, including the data types which currently require affirmative consent, and the processes by which that consent is obtained.
- Notice to individuals in statewide HIE who have recently turned 18: When a patient reaches the age of 18, notice shall be given to advise them of their right to opt-out of the State-wide HIE and the consequences of doing so, regardless of the decision that was made by their parent(s)/guardian prior to their reaching the age of majority.

- Providers with electronic health records that are combined, or comingled records should be exempt from sharing data with the State-wide HIE until the records have been separated.

OHS Response:

- Privacy practices and consent: Written recommendations suggest a need for clarity on how information collected by the State-wide HIE will be used and disclosed, ensuring that the State-wide HIE continues to comply with all privacy and security requirements outlined by HIPAA. Patients currently have the right to request restrictions on how their information is used and disclosed, as well as the right to request confidential communications under HIPAA. Interaction with the State-wide HIE does not change any of the legal requirements; nor will additional requirements be imposed. Patients have the option to opt-out of the State-wide HIE, which means their information should be excluded from the data shared to the HIE and therefore will not be stored in the system, except as may be required by law or for the State's public health purposes.
- Notice to individuals in statewide HIE who have recently turned 18: OHS acknowledges the importance of notifying minors who reach the age of 18 about their options for opting out of the HIE. At the same time, it recognizes challenges such as ensuring accurate and up-to-date birthdate records, contact information, and equitable access to electronic notifications. To address these challenges, OHS supports providing sample language for healthcare providers to include in their Notice of Privacy Practices. The inclusion of such language would be voluntary unless statutorily mandated, enhancing outreach and improving access for individuals with language or accessibility barriers. Effective implementation will require coordination among the HIE, providers, and policymakers to ensure compliance and equitable access for all individuals.

- **Combined/Co-mingled Records:** Currently, certain federal and state law prohibits providers from sharing certain categories of protected health information (e.g., certain mental health records) with business associates (including but not limited to the State-wide HIE and other HIEs operating in the state) unless consent has been obtained. OHS supports continued compliance with existing federal and state protections.

1.1 Reproductive Health Data

Background: OHS is actively researching how other state HIEs manage the sharing of reproductive health information. This research encompasses sensitive topics such as abortion, miscarriage, gender-affirming care, and the protection of minors and parents in these contexts. During a recent working group meeting, a comprehensive presentation showcased the approaches adopted by other states, including Maryland and California, to address the sharing and protection of reproductive health information.

Concerns were raised by members about safeguarding confidential data, such as preventing the inadvertent disclosure of information related to an individual's sexual orientation or gender identity. The discussion confirmed that any proposed regulations would align with applicable federal and state laws and regulations to ensure robust privacy protections.

Importantly, OHS intends to include provisions in its regulations that restrict the State-wide HIE from sharing specific abortion-related data outside of Connecticut without the patient's affirmative consent or a court-ordered subpoena. This measure aims to strengthen protections for individuals' reproductive health information.

Recommendations:

- **Benchmarking with other States:** Conduct research on how other states are managing

reproductive health care and gender-affirming care to identify best practices. Classify data related to Sexual Orientation and Gender Identity (SOGI) and gender-affirming health care as a protected category of health information to ensure enhanced privacy safeguards.

- **Restricting Specific CPT Codes:** Identify and restrict the sharing of specific Current Procedural Terminology (CPT) codes related to abortion procedures. This approach, as currently implemented in Maryland, can strengthen privacy protections for individuals receiving reproductive health care.

OHS Response:

- **Benchmarking with Other States:** OHS will continue its research into initiatives by other states to safeguard sensitive health data. Proposed recommendations regarding Sexual Orientation and Gender Identity (SOGI) include requiring explicit written authorization from the patient before such information can be shared with the State-wide HIE, other HIEs operating in the state, or any business associates or third parties. Additional research is necessary to evaluate the feasibility and implications of prohibiting the sharing of SOGI and gender-affirming health care data outside of Connecticut or with HIEs, business associates, and third parties without patient consent.
- **Restricting Certain CPT Codes:** OHS will further explore steps for identifying and restricting the sharing of specific CPT codes related to reproductive and gender-affirming health care to strengthen privacy protections.

2. Cybersecurity

Background: The discussion regarding cybersecurity administrative regulations clarified that State-wide HIE takes all reasonable precautions to prevent data breaches, including ransomware and hacking. This includes both physical and technological

protections, as well as compliance with all federal and state requirements. The State-wide HIE has robust privacy and security controls and protocols, including thorough incident response and disaster recovery plans for cyberattacks. The State-wide HIE and its IT infrastructure have received the most stringent third-party security certifications – including HITRUST and NIST. These certifications require ongoing updates, training, and recertification. Additionally, HIA and its vendor (CRISP Shared Services) participate in voluntary tabletop incident exercises with other security industry leaders and conduct annual security audits including SOC-T Type 2 testing, cybersecurity testing, and HIPAA/HITECH annual penetration testing by independent cybersecurity firms. Lastly, HIA has established communication protocols for cyber incidents involving affected parties.

Recommendations: There were no specific recommendations for regulations or policies proposed by the working group participants. The importance of requiring best practice preventive measures by the State-wide HIE, such as tabletop exercises was discussed.

OHS Response: OHS supports maintaining robust security standards for State-wide HIE, consistent with legal requirements and industry standards. OHS further supports a mechanism for regular auditing of the HIE to ensure that cybersecurity requirements are implemented appropriately.

Of note, the State-wide HIE is Health Information Trust Alliance (HITRUST) certified, providing an additional layer of assurance for patients and clinicians regarding compliance with security standards. HITRUST is a non-profit organization that offers certification programs and data protection standards to help organizations manage information risk, safeguard sensitive data, and achieve compliance goals. HITRUST certification verifies adherence to stringent security regulations, including HIPAA privacy and security requirements. This certification also enables seamless communication of healthcare information among doctors, hospitals, and other providers. It is essential that all Connecticut patients receive this

level of protection. OHS recommends all HIEs obtain HITRUST certification.

3. Health Care Provider Liability

Background: This discussion reviewed the impact of amendments to Section 17b-59e. A health care provider is not required to share patient health information with the State-wide HIE if prohibited by state or federal privacy and security laws, or if affirmative consent from the patient is legally required and has not been obtained. Further, the recent amendments mandated that the State-wide HIE is responsible for any data breaches, ransomware attacks, or hacking incidents from its system, provided the health care provider is liable for any failure to comply with applicable state and federal data privacy and security laws and regulations when sharing information with the State-wide HIE.

Recommendations: There were no specific recommendations for additional regulations or policies by the working group after reviewing the amendments to CGS § 17b-59e, the State-wide HIE legislation that went into effect as of July 1, 2024.

OHS Response: OHS believes that the current state statute makes clear that the State-wide HIE is responsible for any breach or cyberattack and affirmative actions to protect against any such breach or attack. Based on the current legislation, the provider would have no liability for such a breach or any liability regarding providing notice and/or remediation costs. OHS does not believe that any additional legislation regarding this subject area is necessary.

4. Any Contract Required of Health Care Providers to Participate in The State-Wide Health Information Exchange

Background: This discussion acknowledged that there have been concerns expressed by providers regarding the current contract. OHS and the operating entity both acknowledged the concerns that providers have expressed regarding the length and complexity of the current working contract. Discussions will begin between OHS and the HIA to simplify the agreement and streamline processes.

Recommendations:

- Terms of Use: Establishment of a new provider agreement with the State-wide HIE intended to function like a “Terms of Use” agreement should be considered.

OHS Response: OHS accepts the merits of the recommendation and will continue discussion with the operating entity related to a new provider agreement for use by all mandated participating health care providers.

5. Define Scope of “active sharing of medical records”, inclusive of out of state patients (Connecting To and Actively Participating In)

Background: This discussion focused on recent amendments to State-wide HIE legislation, which clarified key terms such as “connection” and “participation.” “Connection” was defined to encompass the onboarding process, both operational and technical, with the State-wide HIE. “Participation” was defined as the active sharing of medical records with the HIE in compliance with applicable laws, including HIPAA and 42 CFR Part 2.

At a minimum, participation entails providing up-to-date empanelment data, ensuring appropriate user access to the State-wide HIE, and actively sharing complete medical records in a format that adheres to national standards to support interstate interoperability. The discussion included a review of national data standards defined by the United States Core

Data for Interoperability (USCDI) of the Office of the National Coordinator for Health Information Technology (ONC). These standards determine what constitutes a “complete medical record” for the State-wide HIE. The USCDI defines a comprehensive set of data categories and elements that health care providers must supply, if available and permitted by federal and state laws.

Recommendations:

- Retired providers: Exempt licensed, retired health care providers who no longer practice from connecting to and participating in the HIE.
- Granular patient choice: Granular patient choice would give patients the ability to control access to specific details of their medical records, allowing them to choose exactly which pieces of health information are shared with different healthcare providers, rather than giving blanket access to all their data.

OHS Response:

- Retired providers: OHS notes that this recommendation aligns with the statute which exempts this group since such a person “possesses no patient medical records”. C.G.S. §17b-59e (c).
- Granular Patient Choice: OHS supports the concept of granular patient choice; however, current health IT systems within Health Information Exchanges (HIEs) face significant limitations in supporting the customization of consent at a detailed level for specific data-sharing preferences, except for certain categories of sensitive information.

There is limited experience within the healthcare industry in electronically managing data-sharing decisions that address patient preferences based on a combination of variables, including diagnosis, source of treatment, type of treatment, data recipient, and purpose of

data use. Additionally, the implementation of granular consent must account for the complex and variable federal, state, and local laws and regulations that govern consent capture and management. These legal requirements must also be accurately represented electronically within HIE systems.

As technology continues to evolve and solutions become more robust, OHS supports further exploration of this concept. However, it is critical to balance these efforts with the overarching goal of maintaining patient equity to ensure quality of care across all populations.

6. Patient Rights and Education

Background: This discussion reviewed patient rights and educational requirements including proposed regulations that will specify PHI will be shared unless the patient opts-out of the State-wide HIE. Patients currently have the option to choose not to participate in the State-wide HIE. Patients should be provided with detailed instructions on how to opt-out and how to revoke their opt-out decision in the future if they choose to do so. If a patient opts-out of the State-wide HIE, their health information will not be shared unless specifically required by law or for public health purposes. A patient cannot currently elect to share their information selectively with some providers and not others.

Patients also have the right to access their PHI. This access allows patients to view their health information from providers connected to State-wide HIE in one place. Patients have the right to request a report detailing who has accessed their health record. Patients must be provided with clear processes on how to file complaints or raise inquiries through the State-wide HIE regarding the misuse of their health data. The State-wide HIE currently offers a form of this through the Accounting of Disclosures process. If patients see a disclosure that they don't understand or they want to understand further, the HIA assists with any additional

details about the access and refers them to the provider organization in question.

Patient education materials are written in plain language that is easy for the average person to understand, avoiding using jargon and technical terms. The materials meet all federal and state laws and regulations requirements for people with disabilities.

Recommendations: There were no specific recommendations for regulation or policy. The working group identified the following issues as meriting ongoing attention: patient education regarding their right to opt-out; the logistics of opting-out; and clear communication about the process of opting-out. The workgroup identified a need to prioritize education resources for individuals who lack internet access or are not technologically savvy as well as technical assistance to smaller practices for HIE integration.

OHS Response: OHS shares the workgroup's priorities. OHS encourages active participation in patient education by both the HIE and the health care provider, who has the direct relationship with the patient, with an emphasis on maintaining patient care at the forefront of that process.

7. Cost to Small Businesses

Background: The work group reviewed considerations of future costs associated with sending records to the State-wide HIE while minimizing the burden on providers, including standards or thresholds for data submission. A review of provider administrative requirements, including minimizing the impact of changes to privacy practice notifications and intake processes was provided. HIA noted its collaboration with a firm to build initial messaging and incorporate patient feedback as well as current works with electronic medical records (EMR) vendors to develop hubs that facilitate smooth transitions into the State-wide HIE reducing provider burden and cost.

Recommendations: There were no specific recommendations for regulation or policy

proposed during the meetings.

OHS Response: OHS supports continued provision of technical assistance to health care providers. Provider financial and administrative responsibilities are feasible as a cost of doing business.

Recommendations Requiring Legislative Change (if pursued)

8. Any necessary statutory changes to address concerns raised by the working group

8.1 Privacy of Protected Health Care Information

8.2 During discussions about informing patients who are turning 18 about their rights regarding consent, it was suggested that the operating entity could post a general notice on its website. This notice would indicate that patients aged 18 and older can request information about their consent status. The inclusion of such language in privacy disclosures or sharing with patients will be completely voluntary on part of providers. Requiring inclusion of such language in privacy disclosures or sharing with patients would require legislative action. **Reproductive Health**

There was a specific recommendation submitted by a participant for legislation regarding prohibiting certain particularly sensitive information from being shared by health care providers in Connecticut for any purposes and with any third parties (including but not limited to sharing with the State-wide HIE) without specific authorization by the patient. That recommendation reads as follows:

The patient must specifically consent to any sharing of sexual orientation/gender identification health information, gender affirming health information, mental health information, and reproductive health care. If the patient does not specifically consent, such health information shall not be shared.

The working group discussed whether this legislative recommendation should apply solely to the State-wide HIE or to all HIEs operating within the state, or to all disclosures of

sensitive information to business associates or other third parties (the latter of which would align the disclosure of reproductive health and gender-affirming care records with the State's current treatment of most mental health records). There was a general agreement that to achieve the goals of the State-wide HIE and to avoid confusion by patients as to the rules regarding the sharing of abortion-related health information, all HIEs operating in Connecticut should adhere to such future regulations, with at least one participant believing that the restriction should only apply initially to the State-wide HIE (thereby continuing to allow providers to share such information with other, private HIEs, without patient consent).

OHS and HIA representatives explained to members that if there are specific legal or regulatory requirements for sharing particular types of protected health care information (including but not limited to the areas of SUD, mental health, HIV/AIDS, education institution-based health information, and reproductive health, sexual orientation and gender identity information), the State-wide HIE will comply with such requirements and OHS expects providers to comply with them as well. Additionally, the HIE administrative regulations will outline the process for the release of information and the protection of confidential data.

Some members suggested that the regulations include standardized language about the disclosure of health information by the State-wide HIE to be included in the provider's notice of privacy practices. There was a specific recommendation regarding the sharing of abortion-related health information outside of Connecticut by health care providers through HIEs, including but not limited to the State-wide HIE. The recommendation reads as follows:

Any Health Information Exchange (HIE) operating within the State of Connecticut is explicitly restricted from sharing abortion-related information outside the state. This applies to both data-sharing agreements and third-party access requests, with the goal of maintaining patient confidentiality and compliance with state privacy

standards.

There was one alternative opinion that any legislation should only apply initially to the State-wide HIE.

VI. Next Steps

Of note a recommendation for OHS to continue the efforts of this designated working group to gather input on the operation of the Statewide HIE was submitted for consideration. The Health Information Technology Advisory Council (HITAC) HIE Regulations Advisory Subcommittee (RAS) was created to provide recommendations and feedback to the OHS commissioner and the health information technology officer regarding administrative rules, policies, contractual terms and conditions, and other components related to the regulatory framework of the HIE. To avoid duplication of effort, revisions to the current RAS charter will be considered to add additional members, facilitating the feedback process and ensuring it serves as the appropriate forum for discussion, rather than continuing the PA 24-19 designated working group.

VII. Appendix

Jennifer Cox, JD, Connecticut Hospital Association

Mag Morelli, Leading Age Connecticut

Amanda Gunthel, CT Association of Ambulatory Surgical Centers

David Yoder, DO, MPH, FACP, CT Chapter of the American College of Physicians

Christy Olezeski, PhD, Yale School of Medicine

November 18, 2024

Dr. Deidre Gifford
Commissioner
Office of Health Strategy

Dear Dr. Gifford:

Section 23 of Public Act 24-19 relating to the statewide Health Information Exchange (HIE) creates a working group that is tasked by law with making recommendations to the Office of Health Strategy (Office) addressing:

“the parameters of the regulations to be adopted by, and any policies and procedures to be implemented by, the office pursuant to subsection (f) of section 17b-59e of the general statutes, as amended by this act. Such recommendations shall include, but need not be limited to (1) privacy of protected health care information, (2) cybersecurity, (3) health care provider liability, (4) any contract required of health care providers to participate in the State-wide Health Information Exchange, and (5) any statutory changes that may be necessary to address any concerns raised by the working group.”

OHS established the Statewide Health Information Exchange (HIE) Recommendations Workgroup (Workgroup) to fulfill this legislative mandate. The undersigned is an appointed member of the Workgroup representing hospitals. On behalf of Connecticut hospitals and as a representative of the Connecticut Hospital Association, we respectfully submit the following recommendations.

These recommendations are made in the context of the Workgroup’s statutory assignment through the lens of hospital and health system stakeholders. Connecticut’s hospitals already participate in the statewide HIE and share the state’s goal of universal participation by all levels of providers. Unless and until a broad coalition of providers is engaged with the statewide HIE, the utility of the statewide HIE is limited. With these recommendations, hospitals and health systems look forward to the adoption of sound regulatory policies (and statutory changes) that will (1) reduce barriers to entry for providers across the care continuum, and (2) bolster the statewide HIE’s compliance with myriad state and federal laws.

At each of the three Workgroup meetings held to date, OHS staff and its consultant explained that the plan going forward is to reduce provider burden, including by reducing the paperwork burden now in place. We applaud that approach and believe it is an important part of the path forward.

Recommendations to OHS Specific to Regulations (and policies and procedures while awaiting final regulations¹)

Recommendation to OHS 1: OHS should create a concise and more user-friendly participation agreement to replace the current OHS contract format used to onboard providers who would be signing

¹ Regulations should always be the preferred method for agency actions that have the weight of regulation to ensure stakeholder and the public’s rights are protected and processes are consistent with UAPA principles. Policies and procedures that act as regulations should be a last resort, only used when necessary, and should be extinguished when final regulations are adopted.

the current “simple” data sharing agreement (titled Simple Data Sharing Organization Agreement or SDSOA).

When creating the new participation agreement, the process should solicit meaningful provider input and at all times include a simplified and common HIPAA business associate arrangement (BAA) addressing protected health information (PHI) as anticipated in Section 17b-59a(c) of the general statutes.

Recommendation to OHS 2: To ensure that patients’ privacy rights are protected, it is essential that the statewide HIE follow HIPAA, as already contemplated in Connecticut law, specifically Section 17b-59a of the general statutes.

In order to do so, all adopted regulations (and policies and procedures while awaiting final regulations) should conform to HIPAA requirements within the structure of the BAA and the HIE’s participation agreement.

This is critical as the HIE has no standing as a HIPAA entity, and no legal way to ensure that HIPAA protections and oversight are maintained, unless a BAA is in place with the providers that donate data to the HIE. HIPAA status is determined by operation of federal law, and in this instance, it must be established through a BAA with the covered entity providers donating data.

Recommendation to OHS 3: Axiomatically, the statewide HIE is responsible for meeting all state and federal laws relating to the HIE’s privacy and security of data donated to the statewide HIE. This obligation applies to the HIE’s actions and to the actions of the HIE’s subcontractor business associates, if any. Further, the statewide HIE is responsible for decisions about the use and disclosure of PHI after those data are donated to the HIE. Providers supplying data to the HIE do not direct or control the HIE’s decisions about use and disclosure of PHI. Consequently, providers should never be liable for the statewide HIE’s choices about data use or disclosure. Yet, as raised in the working group meetings, and in communications from CHA to OHS over a period of several years, many questions remain surrounding the statewide HIE’s intentions for data use and the legal pathways relating to those uses. Providers are appropriately concerned that they could face liability or regulatory responsibility for things that happen at the statewide HIE that are beyond the providers’ control.

In the 2024 legislative session, the General Assembly made excellent progress in supporting providers on this issue by granting providers statutory protections from liability for privacy issues and security intrusions caused or experienced by the statewide HIE. We applaud those efforts.

To better implement those statutory protections, and increase the chances similar protections are applied at a federal level, OHS has a significant opportunity to use regulations (and policies and procedures while awaiting final regulations) to clarify the role of the statewide HIE in the handling and use of PHI supplied by providers. Specifically, the HIE could include a plainly worded declaration that the provider does not control the actions or determinations of the HIE (including relating to use or disclosure of PHI) and making clear that no “agency relationship” exists as that term is understood under the federal common law of agency.

Such a declaration would follow the language in HIPAA Rules at 45 CFR 160.402, and the corresponding guidance set forth in the preamble to the HITECH Rule concerning degrees of control by a covered entity over the actions of a business associate. See 78 Federal Register, pages 5581-82. A concise, clear declaration would improve not only HIPAA compliance, but also would significantly reduce provider concerns by clarifying that the statewide HIE is responsible for decisions that meet a variety of requirements, including the federal Information Blocking standards and HIPAA requirements.

Recommendation to OHS 4: OHS should detail in regulation – in a transparent and understandable manner – that OHS will create and publish (and periodically update) the precise technical data specifications for data capture by (and transport methods to) the HIE, including setting forth the data elements that the HIE expects to receive if the provider has such data.

Regulations (and policies and procedure while awaiting final regulations) should assess a provider’s donation of data compliance on a “best efforts” basis. OHS should defer to a provider’s judgment on patient privacy expectations and preferences of the provider’s patients. A provider could be required to explain – if requested by OHS – if there is a deviation between the declared and expected data set and what was sent; and OHS could provide technical assistance to improve the system overall.

Recommendation to OHS 5: OHS regulations (and policies and procedures while awaiting final regulations) should require OHS to publish and update a comprehensive list of any purported “Required By Law” use cases for the statewide HIE that meet HIPAA standards for the Required By Law exception set forth at 45 CFR 164.512. CHA is not aware of any HIPAA Required By Law exceptions that apply at this time to the statewide HIE; further, to meet the threshold in HIPAA for Required By Law disclosures, a statutory change would be needed.

Federal law does not allow Required By Law mandates to be equivocal or flexible; any such mandate must be precise. Strict adherence to this rule is essential to providers’ HIPAA compliance pursuant to 45 CFR 164.512, as well as providers’ obligations under 45 CFR 164.526 and 164.528 (at a minimum). Also, we note that the statewide HIE regulations (and policies and procedures while awaiting final regulations) should expressly recognize that 42 CFR Part 2 does not have a similar broad Required By Law exception.

Recommendation to OHS 6: It is imperative that OHS and the statewide HIE decouple the patient-centric HIE activities from instances where the same HIE vendor or HIE technical systems might be used (as a state contractor) to facilitate mandatory reporting or other exchange of PHI that would not require patient consent. (See e.g., 45 CFR 164.512(a)-(l)).

Each of these two functions is governed by a different part of HIPAA and the two need to be treated separately. HIPAA principles do not support shifting a declared “purpose” for use and disclosure of PHI ad hoc or for reporting convenience. Changing purposes for data use is generally not consistent with HIPAA compliance.

To remedy this issue, OHS regulation (and policies and procedures while awaiting final regulations) must separate and decouple when the state wishes to utilize contractual relationships with the HIE vendor(s) from the HIE vendor role as the statewide HIE.

For example, the statewide HIE Opt Out should not reference that a provider might use the same vendor to process data for mandatory reporting or to bolster Connecticut's prescription drug monitoring program (PDMP). Providers' mandatory reporting obligations are completely different actions and legal requirements from the patient-centric statewide HIE's statutory authority.

Recommendation to OHS 7: The more elaborate Qualified Data Sharing Organization Agreement ("QDSOA") should remain in place for organizations that have signed on to participate in the statewide HIE through the QDSOA but the QDSOA should be reworked in a collaborative and comprehensive manner over the next 2-3 years to be more understandable, to align better with HIPAA and other state and federal privacy laws, and to remove significant unnecessary burden for participating providers.

Legislative Recommendations

Pursuant to Subdivision (5) of subsection (a) of Section 23 of Public Act 24-19, the following are recommendations for statutory changes that may be necessary to address concerns raised by the Workgroup for improving the statewide HIE:

Legislative Recommendation 1: Strengthen the statewide HIE enabling statutes to ensure that HIPAA remains the standard for the protection of PHI to the extent possible, as expected by Section 17b-59a(c)(3) of the general statutes. This can be achieved by expressly stating that there must be adherence to HIPAA business associate arrangement rules and principles applied to data donated to the statewide HIE by providers or other covered entities for the purposes of the patient-centric HIE.

Legislative Recommendation 2: Declare in statute that providers are only required to share those portions of a patient's record that are consistent with a patient's privacy preferences. Consistent with such preferences, providers are expected to make a good faith effort to share the maximum amount of data allowed by state and federal law with the statewide HIE. Providers making a good faith effort should be free from penalty or coercion. Because Connecticut has chosen an "Opt Out" model for the statewide HIE, where many patients may know very little about the statewide HIE, it is important that providers be able to act in the best interests of patients.

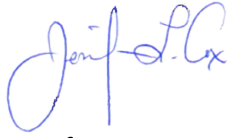
Legislative Recommendation 3: Require OHS to separate the functions that are specific to the patient-centric, statewide HIE from other contractual relationships or services that the state might seek from the vendor that operates the statewide HIE (or any vendor).

This is a clarification that will remedy an issue in the operational structure of the statewide HIE. This issue has created critical barriers to achieving full HIE participation. The issue can be fixed by this recommended statutory change and would result in a more functional and robust statewide HIE for all stakeholders.

Legislative Recommendation 4: Require OHS to create a provider waiver for providers that face undue hardship or for which participation is infeasible based on cost or resources.

Connecticut's hospitals and the Connecticut Hospital Association welcome future opportunities to assist in furthering the success of the statewide HIE.

Respectfully submitted,

A handwritten signature in blue ink that reads "Jennifer L. Cox". The signature is written in a cursive, flowing style.

Jennifer L. Cox, JD
Connecticut Hospital Association
Cox & Osowiecki, LLC
jcox@coxlawoffices.com

Member of Statewide Health Information Exchange (HIE) Recommendations Workgroup (as outlined in Public Act 24-19 § 23).

LeadingAge Connecticut
CT Association of Ambulatory Surgical Centers
CT Chapter of the American College of Physicians

November 18, 2024

Re: Recommendations to OHS regarding the parameters of the regulations to be adopted by, and any policies and procedures to be implemented by, OHS regarding the State-wide Health Information Exchange

Dear Commissioner Gifford:

Public Act 24-19, § 23 required the Office of Health Strategy (“OHS”) to establish a working group to make recommendations to OHS regarding the parameters of the regulations to be adopted by, and any policies and procedures to be implemented by, OHS regarding the State-wide Health Information Exchange (“HIE” or “Connie”). As appointed members of the PA 24-19 Recommendations Working Group, we have appreciated the opportunity to serve and at the request of OHS, we are pleased to submit the following recommendations to you as Chair.

Please note that most of these recommendations have already been discussed at the three meetings of the PA 24-19 Recommendations Working Group and many have been positively acknowledged by OHS, but we are reiterating them here in both an Executive Summary and a format providing additional detail and commentary, to ensure that they are on record.

We note that while these issues and recommendations were discussed at the meetings, most of them are not included in the draft report that was recently circulated to the working group members and therefore we request that these submitted recommendations be included in the body of the report and that this letter be attached as an addendum to the report. We also request that we be given an opportunity to speak to the submitted recommendations at the next working group meeting to ensure that they are on record.

We want to also acknowledge that we greatly appreciate the representation of OHS and its vendor, Health Information Alliance, that the HIE policies and/or regulations will minimize any burden and expense on providers to the greatest extent possible and ask that this too be formally stated in the report as a recommendation.

We want to again emphasize that we fully support the state’s goals related to a state-wide HIE. We remain troubled, however, because many of the steps being taken to implement Connie exceed the statutory mandate, conflict with existing law, jeopardize the confidentiality of sensitive data, and unfairly impose risks and obligations on providers.

The implications of the statewide health information exchange storing, disclosing, and using the protected health information of millions of people in Connecticut and beyond are enormous. It behooves the working group to fulfill its statutory mandate and to continue to engage in a meaningful dialogue about how best to implement Connie without overly burdening providers or compromising patient care.

We look forward to discussion on the recommendations and other topics pertinent to implementation of the HIE so that the policies and/or regulations can represent the collaboration between state agencies, patients, and providers that is necessary to make Connie a success.

Respectfully submitted by the following PA 24-19 Recommendations Working Group Members:

Mag Morelli, President
LeadingAge Connecticut

Amanda Gunthel, President
CT Association of Ambulatory Surgical Centers

David Anthony Yoder, DO, MPH, FACP
Representing the CT Chapter of the American College of Physicians

Executive Summary

I. Privacy of protected health care information

1. The policies and/or regulations should clarify exactly how information collected by the HIE will be used and disclosed.
2. The policies and/or regulations should prohibit the HIE from collecting reproductive health or gender affirming care information, until the HIE has a process for protecting such information in accordance with state and federal law.
3. The policies and/or regulations should include an exemption or waiver process for providers with only comingled records (records containing information that cannot legally be disclosed to the HIE without patient consent that are not segregated from the remainder of the records) until such providers are able to reasonably separate the records to allow for lawful connection with and participation in Connie.
4. The policies and/or regulations should set forth the process through which the HIE will manage requests under 45 CFR 164.522, the HIPAA requirement that covered entities provide individuals with the right to request restrictions of uses and disclosures and confidential communications.
5. The policies and/or regulations should confirm that providers will not be responsible for administering any part of the “opt out” process and set forth the process through which the HIE will implement those requests, including how minors will be handled and the circumstances under which the “opt out” is not effective.
6. The policies and/or regulations should require OHS to draft language regarding the HIE for inclusion in providers’ Notice of Privacy Practices, which providers may adopt with the next substantive federally mandated revision of the Notice of Privacy Practices. This would make the language uniform across provider settings.

II. Cybersecurity: The policies and/or regulations should set forth robust security standards for the HIE, consistent with legal requirements and industry standards, and provide a mechanism for regular auditing of the HIE to ensure that cybersecurity requirements are implemented appropriately.

III. Health care provider liability

1. The policies and/or regulations should clearly state that HIE is directly responsible for all its disclosures.
2. The policies and/or regulations should include a clear and detailed description of the process for resolution of HIPAA breaches or other breaches that violate federal law or another state’s law.

3. To the extent that a HIE breach or other security incident is not the exclusive fault of the provider, the HIE should take responsibility for legally required actions, including notifications, mitigation, and payment of any penalties.

IV. Any contract required of health care providers to participate in the State-wide Health Information Exchange

1. The policies and/or regulations should prohibit the HIE from mandating that providers enter any HIE participation contract that imposes obligations or limitations on providers that are not required by statute.
2. The policies and/or regulations should require that providers and the HIE enter into a HIPAA Business Associate Agreement, as legally required.
3. The policies and procedures should require that any required provider participation contract (Terms of Use) be limited in length and easy to understand.
4. The policies and procedures need to outline the process for managing the revision of contracts that providers already signed with Health Information Alliance.

V. Any statutory changes that may be necessary to address any concerns raised by the working group

1. The HIE statute should be revised to require OHS to study the financial and administrative burden on providers. This study should be completed in a timely manner so as to influence the regulations. Providers should be protected from excessive costs and administrative burden through options such as a temporary waiver process. The legislature should also enact legislation to protect providers from future Connie operating costs.
2. The HIE statute should be revised to provide that no provider is affirmatively required to seek consent from health care consumers to share information with Connie.
3. The HIE statute should be revised to clarify the scope of the medical record required to be shared through the HIE. Patients should be able to provide granular consent to “opt out” of disclosure from certain providers and/or of certain parts of their record. Providers, in consultation with their patients, should have discretion to determine whether certain parts of the medical record should be withheld from disclosure to the HIE.
4. The HIE statute should be revised to clarify that retired health care providers who no longer actively practice but maintain licensure are exempt for participation in the HIE.
5. The HIE statute should be revised to clarify that the State of Connecticut is solely responsible for patient education and to set forth parameters on scope and accessibility of the Connie public education campaign.

VI. Other recommendations

1. Members of the working group established by Public Act 24-19, § 23 should be provided with draft OHS policies for comment and discussion at least 60 days before policies are released for public comment. Additional working group meetings should then be convened to discuss and suggest revision to the draft policies.
2. We want to emphasize that additional working group meetings should be convened to provide the opportunity for continued discussion among the group members regarding questions about Connie and its intended operation.
3. OHS should seek technical assistance from other federal and state agencies regarding Connie compliance with privacy laws.

Recommendations Pursuant to Public Act 24-19, § 23

I. Privacy of protected health care information

1. The policies and/or regulations should clarify exactly how information collected by the HIE will be used and disclosed. For example:
 - The policies and/or regulations should detail how information will be used, other than for treatment, and set forth the procedure for the approval of all data use cases.
 - The policies and/or regulations should detail how information will be shared with state and federal agencies, public health agencies, insurance companies, or any other non-treatment related providers.
 - The policies and/or regulations should detail how research requests be handled.
 - The policies and/or regulations should explain if “break the glass” rules will be implemented which would allow individuals and/or entities that do not have a treatment relationship with the individual to, nevertheless, access the individual’s records within the HIE. To the extent that such rules are implemented, the policies and/or regulations should specify how they will be implemented to protect inappropriate disclosures.
 - The policies and/or regulations should specifically detail how the HIE will manage subpoenas, court orders, and other third-party requests and will comply with the federal Information Blocking regulations, while still maintaining compliance with both applicable federal and state privacy laws and the defined use case descriptions.
2. The policies and/or regulations should prohibit the HIE from collecting reproductive health or gender affirming care information, until the HIE has a process for protecting such information in accordance with state and federal law.
3. The policies and/or regulations should include an exemption or waiver process for providers with only comingled records (records containing information that cannot legally be disclosed to the HIE without patient consent that are not segregated from the remainder of the records) until such providers are able to reasonably separate the records to allow for lawful connection with and participation in Connie.
 - Public Act 24-19, § 22 states that providers are not required to share patient information with the HIE if sharing such information is prohibited by any other law or affirmative consent from the patient is legally required and such consent has not been obtained.

- Many health care providers have electronic records that do not segregate information that can legally be disclosed to the HIE and information that cannot legally be disclosed to the HIE. Without this exemption, providers will be faced with the impossible task of manually reviewing of all its information on an ongoing basis to prevent violating laws that prohibit the sharing of certain sensitive information.
4. The policies and/or regulations should set forth the process through which the HIE will manage requests under 45 CFR 164.522, the HIPAA requirement that covered entities provide individuals with the right to request restrictions of uses and disclosures and confidential communications.
 - For example, patients that pay for services in full out of pocket have the right to request that their provider not share information about such services with their insurer. The policies and/or regulations should explain how the HIE will ensure that the information is prevented from disclosure to the insurance company in these instances.
 5. The policies and/or regulations should confirm that providers will not be responsible for administering any part of the “opt out” process and set forth the process through which the HIE will implement those requests, including how minors will be handled and the circumstances under which the “opt out” is not effective.
 6. The policies and/or regulations should require OHS to draft language regarding the HIE for inclusion in providers’ Notice of Privacy Practices, which providers may adopt with the next substantive federally mandated revision of the Notice of Privacy Practices. This would make the language uniform across provider settings.

II. Cybersecurity: The policies and/or regulations should set forth robust security standards for the HIE, consistent with legal requirements and industry standards, and provide a mechanism for regular auditing of the HIE to ensure that cybersecurity requirements are implemented appropriately.

III. Health care provider liability

1. The policies and/or regulations should clearly state that HIE is directly responsible for all its disclosures.
2. The policies and/or regulations should include a clear and detailed description of the process for resolution of HIPAA breaches or other breaches that violate federal law or another state’s law.
3. To the extent that a HIE breach or other security incident is not the exclusive fault of the provider, the HIE should take responsibility for legally required actions, including notifications, mitigation, and payment of any penalties.

- While PA 24-29 § 22 provides immunity for health care providers from liability directly related to a breach, ransomware or hacking of the HIE, federal authorities and authorities from other states are not limited by Connecticut law. Therefore, further protection for providers is still needed.

IV. Any contract required of health care providers to participate in the State-wide Health Information Exchange

1. The policies and/or regulations should prohibit the HIE from mandating that providers enter any HIE participation contract that imposes obligations or limitations on providers that are not required by statute.
 - The current version of the Simple Data Sharing Organization Agreement includes provisions that go above and beyond legal requirements, imposing additional burdens on providers.
 - Examples of such provisions include requiring providers to maintain certain types of insurance coverage; mandating providers indemnify the HIE; imposing limitations of liability for the HIE; and demanding technology obligations on providers that are not otherwise required by law. These provisions may be appropriate for commercial arrangements but are not appropriate for legally required agreements with a state contractor that the provider is required by law to enter and has no ability to negotiate.
2. The policies and/or regulations should require that providers and the HIE enter into a HIPAA Business Associate Agreement, as legally required.
 - The Business Associate Agreement should include all legally required provisions, with the HIE as the business associate and the provider as the covered entity.
 - The Business Associate Agreement should require the HIE, as business associate, to comply with CGS §§ 52-146w and 146x (governing subpoena response for reproductive health care and gender affirming care).
3. The policies and procedures should require that any required provider participation contract (Terms of Use) be limited in length and easy to understand.
 - The current version of the Simple Data Sharing Organization Agreement is about 50 pages long, with 6 different attachments, including an attachment that is just a list of 123 definitions, which are different than the 2 ½ pages of definitions in the agreement itself.
4. The policies and procedures should outline the process for managing the revision of contracts that providers already signed with Health Information Alliance.

V. Any statutory changes that may be necessary to address any concerns raised by the working group

1. The HIE statute should be revised to require OHS to study the financial and administrative burden on providers. This study should be completed in a timely manner so as to influence the regulations. Providers should be protected from excessive costs and administrative burden through options such as a temporary waiver process. The legislature should also enact legislation to protect providers from future Connie operating costs.
2. The HIE statute should be revised to provide that no provider is affirmatively required to seek consent from health care consumers to share information with Connie.
 - Providers have serious and well-founded concerns about the damage to the provider-patient relationship that would be caused if providers were required to request consent from each patient to disclose health information to the HIE.
3. The HIE statute should be revised to clarify the scope of the medical record required to be shared through the HIE.
 - The current statute merely states that providers must actively share “medical records with the exchange.” There are many different components of medical records, including admission files, progress notes, lab results, billing records, photographs, imaging, prescription lists, etc.
 - Connie representatives that told certain providers that only admission and discharge information must be disclosed, while other providers were told that they need to set up a live feed of all other information directly into the HIE.
 - Patients should be able to provide granular consent to “opt out” of disclosure from certain providers and/or of certain parts of their record.
 - Providers, in consultation with their patients, should have discretion to determine whether certain parts of the medical record should be withheld from disclosure to the HIE. For example, plastic surgeons should have the discretion not to share nude and/or other highly sensitive photos of patients into the HIE.
4. The HIE statute should be revised to clarify that retired health care providers who no longer actively practice but maintain licensure are exempt for participation in the HIE.
5. The HIE statute should be revised to clarify that the State of Connecticut is solely responsible for patient education and to set forth parameters on scope and accessibility of the Connie public education campaign.

VI. Other recommendations

Public Act 24-19, § 23 specifically states that the statute's list of recommendation topics is not exhaustive. Therefore, we also make the additional following recommendations:

1. Members of the working group established by Public Act 24-19, § 23 should be provided with draft OHS policies for comment and discussion at least 60 days before policies are released for public comment. Additional working group meetings should then be convened to discuss and suggest revision to the draft policies.
 - The working group did not receive a draft of policies under consideration by OHS, or even an outline or list of topics that would be covered in the policies, despite repeated requests from various provider representatives. This lack of knowledge of the content of the OHS draft HIE policies has thwarted the effectiveness of the working group.
 - The statutory timeframe for the provider community to review the policies is inadequate. The policies will have a direct substantial impact on the provider community. Providers that are already participating with Connie might have to comply with the policies with only 30 days' notice. According to CGS § 17b-59e, OHS has authority to implement policies necessary to administer Connie while in the process of promulgating regulations, provided OHS holds a public hearing at least 30 days prior to implementing the policies. 30 days is woefully insufficient to address problematic policies that could adversely affect providers. Providing the working group with a copy of the draft policies well in advance is an effective way to ensure the collaboration between the state agency and the provider community through the working group, as intended by Public Act 24-19.
2. We want to emphasize that additional working group meetings should be convened to provide the opportunity for continued discussion among the group members regarding questions about Connie and its intended operation.
 - The working group meetings allowed various speakers to make general presentations and/or provide commentary. There was little open discussion and without a true give and take among working group members, the recommendations of the working group will merely be a collection of different opinions, rather than the end result of true thoughtful collaboration among stakeholders.
3. OHS should seek technical assistance from other federal and state agencies regarding privacy laws.

- There are many different federal laws that are applicable to the HIE, including HIPAA, the Information Blocking regulations, and 45 CFR Part 2 regarding substance use disorder information.
- We recommend that OHS request technical assistance from federal agencies, such as OCR, ONC, and SAMHSA, that implement these regulations to ensure that the HIE is not running afoul of any of these provides technical assistance with 45 CFR Part 2.
- Similarly, there are many different Connecticut laws that will directly impact the HIE's operations, including CGS § 52-146d et seq. regarding mental health diagnosis and treatment records; CGS § 52-146p regarding social worker privilege; CGS § 52-146q regarding licensed marriage and family therapist privilege; CGS § 52-146s regarding professional counselor privilege; CGS § 19a-583 regarding HIV-related information; and PA § 22-19, regarding reproductive health care services. The Connecticut Attorney General should be consulted to review all relevant state law and ensure that the HIE policies will be consistent with Connecticut legal mandates and restrictions.

Peluso, Tyra

Subject: FW: PA 24-19 HIE Recommendations Workgroup | Meeting Material Oct. 22, 2024

From: Olezeski, Christy <christy.olezeski@yale.edu>

Sent: Thursday, October 24, 2024 9:56 AM

To: Tibor, Amy <Amy.Tibor@ct.gov>

Subject: Re: PA 24-19 HIE Recommendations Workgroup | Meeting Material Oct. 22, 2024

EXTERNAL EMAIL: This email originated from outside of the organization. Do not click any links or open any attachments unless you trust the sender and know the content is safe.

Hi Amy--

Some recommendations based on our meeting this week:

- There should be communication to those turning 18 to let them know that their parent has either opted in or out of Connie and they have the right to opt in/out at 18/any time. There should also be guidance that if their parent opted in and they opt out that their information will be scrubbed and if their parent opted out and they opt in that their information sharing will start at that time (not incl previous medical care/records).
- There should be clear information about what sensitive information is NOT being shared for patients. If there is not current specific legislation/guidance on this, I recommend including the following in the sensitive health information not to be shared: SOGI data, gender affirming care, mental health care and reproductive care.

Christy L. Olezeski, Ph.D. (she/her)

Associate Professor

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