

# Substance Use Disorder (SUD) Information Exchange Strategic Plan

---

Findings and Recommendations to Support Data-Informed  
Integrated Care Workflows for Persons with SUD

February 2020

*This report was developed by HealthInfoNet in partnership with community stakeholders and with support from the Maine Health Access Foundation and the Betterment Fund.*



## Table of Contents

Executive Summary.....	3
Background .....	6
Methodology & Process.....	7
Findings .....	9
<i>Collaboration among Participants Leads to Successful Project Outcomes .....</i>	<i>9</i>
<i>Data-Sharing Practices Support and Advance Treatment Community Efforts .....</i>	<i>10</i>
<i>Understanding Meaningful Engagement for the Peer and Recovery Community.....</i>	<i>10</i>
Recommendations .....	11
<i>Legal Framework.....</i>	<i>11</i>
<i>Patient Consent Materials .....</i>	<i>13</i>
<i>Clinical Treatment Workflow .....</i>	<i>13</i>
<i>Technical Operations.....</i>	<i>14</i>
Conclusion.....	16
Appendix I .....	18
<i>Current Version of the HealthInfoNet Sensitive Information Consent Form.....</i>	<i>19</i>
<i>Revised Draft Version of the HealthInfoNet Sensitive Information Consent Form .....</i>	<i>21</i>

## Executive Summary

In 2017, Maine was among the top ten states in the U.S. with the highest overdose deaths involving opioids. That year, there were 376 overdose deaths – a rate of 28.16 deaths per 100,000 persons (compared to the average national rate of 14.5 deaths per 100,000 persons)<sup>1</sup>, outpacing 2015's previous all-time high of 272 deaths by 39 percent (or a rate of 20.37 deaths per 100,000)<sup>2</sup>. The greatest rise occurred among deaths involving synthetic opioids other than methadone (mainly fentanyl), followed closely by heroin-involved deaths, while prescription opioid-involved deaths declined slightly from previous years.

On February 6, 2019, declaring it a public health emergency, Governor Janet Mills signed an Executive Order directing her Administration to immediately begin addressing the opioid crisis<sup>3</sup>. The Order effectively outlined initial actions to be taken by the Administration and its appointed Director of Opioid Response to prevent overdose deaths, increase treatment and recovery efforts, and bolster prevention strategies. Use of technology and data across physical and mental health services were identified as key tools to assist in informing and supporting the initiatives outlined in Maine's response to the opioid epidemic.

As the state of Maine's designated operator of its statewide health information exchange (HIE), HealthInfoNet understands the importance of putting in place the necessary technical infrastructure and support systems intended to bolster patient care coordination and management efforts through the exchange of critical data, especially for individuals receiving treatment for mental health and/or substance use disorders. Since its inception in 2006, HealthInfoNet has carried out a range of projects and functions in collaboration with state government, healthcare organizations, and community partners, including the connection of many behavioral health facilities across the state to enable the collection and sharing of patients' mental health information.

Given its role in working with the behavioral health community to facilitate the exchange of mental health information, HealthInfoNet sees itself as a valuable conduit for also helping to facilitate the exchange of substance use disorder (SUD) information – especially with the Substance Abuse and Mental Health Services Administration (SAMHSA) release on January 3, 2018, of its Final Rule<sup>4</sup>. The update implements new changes to the federal rules governing confidentiality and disclosures of SUD patient records, known as 42 CFR Part 2 (i.e., Part 2), including the ability for patients to consent to disclose their Part 2 data to intermediary organizations, such as HIEs, and for those intermediary organizations to in turn disclose the authorized information to the patients' treating providers.

With the release of SAMHSA's Final Rule and the Governor's Executive Order, HealthInfoNet initiated a 12-month statewide planning project, with support from the Maine Health Access Foundation and the

---

<sup>1</sup> National Institute on Drug Abuse. "Maine Opioid Summary." NIDA, 30 Mar. 2019, [www.drugabuse.gov/opioid-summaries-by-state/maine-opioid-summary](http://www.drugabuse.gov/opioid-summaries-by-state/maine-opioid-summary).

<sup>2</sup> Shepherd, Michael. "A Deadly Record: Maine Averaged More than an Overdose Death per Day in 2016." Bangor Daily News, 10 Oct. 2017, [bangordailynews.com/2017/02/02/news/state/a-deadly-record-maine-averaged-more-than-an-overdose-death-per-day-in-2016/](http://bangordailynews.com/2017/02/02/news/state/a-deadly-record-maine-averaged-more-than-an-overdose-death-per-day-in-2016/).

<sup>3</sup> State of Maine Office of Governor. "Governor Mills Signs Executive Order Directing Immediate Action to Combat Opioid Epidemic." Governor Mills Signs Executive Order Directing Immediate Action to Combat Opioid Epidemic | Office of Governor Janet T. Mills, [www.maine.gov/governor/mills/news/governor-mills-signs-executive-order-directing-immediate-action-combat-opioid-epidemic-2019-02](http://www.maine.gov/governor/mills/news/governor-mills-signs-executive-order-directing-immediate-action-combat-opioid-epidemic-2019-02).

<sup>4</sup> SAMHSA. "Confidentiality of Substance Use Disorder Patient Records." Federal Register, 3 Jan. 2018, [www.federalregister.gov/documents/2018/01/03/2017-28400/confidentiality-of-substance-use-disorder-patient-records](http://www.federalregister.gov/documents/2018/01/03/2017-28400/confidentiality-of-substance-use-disorder-patient-records).

Betterment Fund, to convene key community stakeholders, including healthcare providers, State officials, community peer advocates, and recovery community representatives, in an effort to develop a strategic plan outlining how technology and data could be used to address the opioid crisis in the state of Maine. Objectives of the project included (a) establishing a shared understanding of the crisis and its impact on surrounding communities, (b) assessing the current and future potential for sharing protected clinical data pertaining to substance use disorders, and (c) developing recommendations that could lead the state forward with implementing data-informed integrated care workflows. Community engagement in the project was structured around the following aspects of SUD data sharing: (a) legal framework, (b) patient consent materials, (c) clinical treatment workflow, and (d) technical operations.

Over the course of the convening and engagement process, a few key themes emerged. First, collaboration among participants is key to a multi-stakeholder project's success. If participants are asked up-front what they need and how they can be supported in order to be successful, and are allowed to participate in sessions in ways convenient and enjoyable to them, optimal collaboration is achieved. Second, SUD data-sharing practices support and advance the treatment community's continued efforts to evolve care coordination models in ways that best serve their patients. However, successful implementation of such practices within the community depends on their integration within existing provider workflows in order to avoid further administrative burden and confusion. And third, it is important to understand how the peer and recovery community can meaningfully engage in data-sharing practices. Depending on the role of Peers and Coaches within the treatment community, they may play a pivotal role in the SUD consent education process.

With these findings taken into consideration, HealthInfoNet and its community stakeholders recommend the implementation of the following aspects of SUD data sharing:

1. **Legal Framework** – Make key revisions to the language and outline of HealthInfoNet's sensitive information consent form in consideration of the new SAMHSA Final Rule guidelines, which support provider organizations in changing their data-exchange position with the HIE to allow for the incorporation of SUD treatment information.
2. **Patient Consent Materials** – Revise the current version of HealthInfoNet's sensitive information consent form, which incorporates the knowledge and expertise in existing SUD treatment informed consent workflows and both State of Maine law and federal Part 2 regulations (per the "Legal Framework" recommendations) to promote and facilitate patients' consent to share their SUD treatment data for care coordination purposes.
3. **Clinical Treatment Workflow** – Create a robust communications and education toolkit, led by HealthInfoNet, designed to support informed patient consent workflows with the goal of providing low-barrier consent opportunities among patients with SUD in order to advance a data-driven approach in supporting SUD prevention, treatment, and recovery efforts.
4. **Technical Operations** – Leverage existing technical infrastructure maintained by the HIE to minimize costs and avoid the implementation of overly complex systems that could cause unnecessary compliance and/or security risk.

The strategic recommendations contained in this document aim to expand patients' options to better support their coordination and management of care and treatment in healthcare settings, regardless of where they are seen for care in the state and the different technologies used among their providers. This report seeks to support what is only the initial phase of SUD data-sharing innovation for the state of

Maine, and hopes to become a foundation from which others can evolve and learn as more advanced solutions become available.

## Background

Launched in 2006 with support from Maine's largest health systems, HealthInfoNet, an independent nonprofit organization, was charged to connect unaffiliated healthcare sites across the state through a secure, online network, known as a health information exchange (HIE), designed to facilitate the sharing of patients' electronic health records in the value of patient care and safety. HealthInfoNet is currently connected to more than 790 treatment locations across the state, including all health systems, all acute care and critical access hospitals, ambulatory facilities, behavioral health facilities, federally qualified health centers, post-acute care facilities, Veterans Affairs sites, laboratories, emergency medical services, pharmacies, and other provider types.

State of Maine law requires HealthInfoNet to manage patient consent choices across all of the HIE's participating providers. For non-sensitive data types, an "out-out" model is required, whereby patients' non-sensitive health information will be automatically included in the HIE unless they deliberately choose not to share (i.e., opt-out) that type of information with HealthInfoNet. When a patient opts-out, it applies to all HIE participants and locations of care. Beginning in 2011, State of Maine law enables HealthInfoNet to receive state-protected mental health information from HIE-participating providers under an "opt-in" model of consent, whereby patients' sensitive health information will not be automatically included in the HIE unless they deliberately choose to share (i.e., opt-in) that type of information with HealthInfoNet. Since 2015, HealthInfoNet has been actively collecting this information from community-based behavioral health facilities for patients with mental illnesses. Providers' access to the information within the HIE is based on individual patients' specific consent choices. A majority of patients with mental illnesses, largely insured by Medicaid, have chosen to opt-in to make accessible their mental health information in the HIE for their treating providers.

On January 17, 2017, the Substance Abuse and Mental Health Services Administration (SAMHSA) proposed its Final Rule<sup>5</sup> to 42 CFR Part 2 (i.e., Part 2) with the intent of updating and modernizing the federal rules governing confidentiality and disclosure of SUD patient records and facilitating the exchange of information within new healthcare models while also addressing the legitimate privacy concerns of patients seeking treatment for SUD.

Notably, the Final Rule expands the ways in which a patient's SUD information may be shared, including the provision that patients may now choose to consent to disclose their Part 2 data to intermediary organizations, such as HIEs, and the ability for those intermediary organizations to in turn disclose the authorized information to the patients' treating providers. After the Final Rule went into effect on January 3, 2018, SAMHSA and the Office of the National Coordinator for Health Information Technology (ONC) provided guidance specific to HIEs for implementation purposes<sup>6</sup>. Currently, there are no Maine SUD-related laws that preempt Part 2's federal regulations.

Following SAMHSA's Part 2 rule change, Maine's Governor Janet Mills signed an Executive Order on February 6, 2019, directing her Administration to immediately begin addressing the opioid crisis<sup>7</sup>. The

---

<sup>5</sup> SAMSHA. "Confidentiality of Substance Use Disorder Patient Records." Federal Register, 3 Jan. 2018, [www.federalregister.gov/documents/2018/01/03/2017-28400/confidentiality-of-substance-use-disorder-patient-records](http://www.federalregister.gov/documents/2018/01/03/2017-28400/confidentiality-of-substance-use-disorder-patient-records).

<sup>6</sup> SAMSHA. "Disclosure of Substance Use Disorder Patient Records." SAMSHA, 3 Jan. 2018, <https://www.samhsa.gov/sites/default/files/how-do-i-exchange-part2.pdf>

<sup>7</sup> State of Maine Office of Governor. "Governor Mills Signs Executive Order Directing Immediate Action to Combat Opioid Epidemic." Governor Mills Signs Executive Order Directing Immediate Action to Combat Opioid Epidemic | Office of Governor Janet T. Mills, [www.maine.gov/governor/mills/news/governor-mills-signs-executive-order-directing-immediate-action-combat-opioid-epidemic-2019-02](http://www.maine.gov/governor/mills/news/governor-mills-signs-executive-order-directing-immediate-action-combat-opioid-epidemic-2019-02).

Order outlined initial actions to be taken by the Administration and its appointed Director of Opioid Response to prevent overdose deaths, increase treatment and recovery efforts, and bolster prevention strategies. Use of technology and data across the physical and mental health services were identified as key tools to assist in informing and supporting the initiatives outlined in Maine’s response to the opioid epidemic – providing a practical, and critical, opportunity for the state to leverage the HIE’s existing infrastructure and relationships to promote and facilitate the exchange of SUD information in support of a more effective care management solution for people in and/or seeking treatment.

Since SAMHSA’s Part 2 rule change, a handful of both regional and statewide HIEs across the nation have begun to work toward implementing updates to their informed consent language and workflows that would assist in changing their participating providers’ data-exchange position with the HIE to allow for the incorporation of SUD treatment information. As the State of Maine and HealthInfoNet embarked on a similar effort, lessons learned, best practices, and experience and expertise were shared among leaders in Maryland (<https://crisphealth.org/>), Arizona (<https://healthcurrent.org/>), and Colorado (<https://www.corhio.org/>)<sup>8</sup> to advise and advance next steps in collaboration. Each state varies in State law, community preferences for consent workflows, data availability, and phase of implementation. Each community involved in this collaboration recognizes the need to engage a variety of stakeholders to define processes and terms that will work within their own community needs and legal frameworks. Maine is recognized by industry peers as a national leader in this work.

## Methodology & Process

Given its experience in working with the behavioral health community, as well as its qualifications as an “intermediary organization” in SAMHSA’s Final Rule, HealthInfoNet received support from the Maine Health Access Foundation and the Betterment Fund to initiate a statewide planning project focused on convening key community stakeholders in an effort to develop a strategic plan outlining how to best facilitate the exchange of SUD information within the HIE platform.

As a first step of the project, HealthInfoNet identified key community stakeholders to include in its conversations. It was important not only to establish a diverse group of participants, including healthcare providers (from hospitals, mental health agencies, primary care practices, and emergency medical services), State officials (from the Maine Department of Health and Human Services), community peer advocates, and recovery community representatives, but to choose participants that had already started to address the integration and improvement of SUD treatment and recovery in their own communities. [Table 1](#) below provides a list of the organizations represented by participants included in the project’s convening efforts.

---

<sup>8</sup> CORHIO. “Behavioral Health Data Exchange in Colorado.” June 2017, [https://www.corhio.org/library/documents/PDF\\_Collateral/CAII\\_BH\\_White\\_Paper\\_Final\\_100217.pdf](https://www.corhio.org/library/documents/PDF_Collateral/CAII_BH_White_Paper_Final_100217.pdf)

**Table 1.** Community Stakeholder Project Participants

Alliance for Addiction and Mental Health Services, Maine ( <a href="https://thealliancemaine.org/">https://thealliancemaine.org/</a> )	Maine Health Access Foundation ( <a href="https://mehaf.org/">https://mehaf.org/</a> )
Amistad, Peer Support ( <a href="https://amistadmaine.org/">https://amistadmaine.org/</a> )	Maine Governor's Office, Director of Opioid Response ( <a href="https://www.maine.gov/future/initiatives/opioids">https://www.maine.gov/future/initiatives/opioids</a> )
Aroostook Mental Health Services ( <a href="https://www.amhc.org/">https://www.amhc.org/</a> )	Maine Office of Substance Abuse and Mental Health Services ( <a href="https://www.maine.gov/dhhs/samhs/">https://www.maine.gov/dhhs/samhs/</a> )
City of Bangor, Public Health ( <a href="https://www.bangorpublichealth.org/">https://www.bangorpublichealth.org/</a> )	Maine Public Safety, EMS ( <a href="https://www.maine.gov/ems/">https://www.maine.gov/ems/</a> )
Community Health and Counseling ( <a href="https://www.chcs-me.org/">https://www.chcs-me.org/</a> )	Northern Light Health ( <a href="https://northernlighthealth.org/">https://northernlighthealth.org/</a> )
Greater Portland Health ( <a href="http://www.greaterportlandhealth.org/">http://www.greaterportlandhealth.org/</a> )	Penobscot Community Health Care ( <a href="https://pchc.com/">https://pchc.com/</a> )
Groups Recover Together ( <a href="https://joininggroups.com/">https://joininggroups.com/</a> )	Portland Recovery Community Center ( <a href="https://portlandrecovery.org/">https://portlandrecovery.org/</a> )
HealthInfoNet ( <a href="https://hinfonet.org/">https://hinfonet.org/</a> )	Qualidigm, Maine Quality Counts ( <a href="https://qualidigm.org/">https://qualidigm.org/</a> )
Kennebec Behavioral Health ( <a href="https://kbhmaine.org/">https://kbhmaine.org/</a> )	Tri-County Mental Health Services ( <a href="https://www.tcmhs.org/">https://www.tcmhs.org/</a> )
MaineHealth, Maine Behavioral Healthcare ( <a href="https://mainehealth.org/maine-behavioral-healthcare">https://mainehealth.org/maine-behavioral-healthcare</a> )	Wellspring, Inc. Treatment Services ( <a href="https://www.wellspringmaine.com/">https://www.wellspringmaine.com/</a> )
Maine Center for Disease Control and Prevention ( <a href="https://www.maine.gov/dhhs/mecdc/">https://www.maine.gov/dhhs/mecdc/</a> )	

Community stakeholders participated in a 12-month convening and engagement process, led by HealthInfoNet and facilitated by a third-party expert, which involved regional forums, small-group workshops, and one-on-one feedback sessions organized both virtually (via web-based meetings) and physically (via on-site visits). Engagement methods and techniques were varied and flexible throughout the convening process in order to reduce common barriers to broad participation support such as time commitments, travel logistics, and technology difficulties.

Beginning with the initial convening, and continuing throughout the remainder of the project, HealthInfoNet provided a comprehensive summary of the relevant state and federal SUD laws and regulations, specifically in regards to whether and how a patient may consent to disclose their information so that it is made available to their treating providers participating in the HIE.

Objectives of the convened participants included (a) establishing a shared understanding of the crisis and its impact on surrounding communities, (b) assessing the current and future potential for sharing protected clinical data pertaining to substance use disorders, and (c) developing recommendations that could lead the state forward with implementing data-informed integrated care workflows. For each objective, participants were engaged to provide input, deliberate options and arguments, and finally coalesce findings, recommendations, and conclusions relating to various aspects of SUD data sharing: (a) legal framework, (b) patient consent materials, (c) clinical treatment workflow, and (d) technical operations.

The result of these convening efforts – and therefore the fulfillment of the project's defined objectives – focused on the creation of this report, a statewide "SUD Information Exchange Strategic Plan." Corresponding to the main aspects of SUD data sharing, the design of the plan targets four (4) measurable recommendations:

- 1. Legal Framework** – Develop *legal framework* strategies and requirements to support provider organizations in changing their data-exchange position with the HIE to allow for the incorporation of SUD treatment information.



2. **Patient Consent Materials** – Develop *patient consent materials* strategies to promote and facilitate patients’ consent to share their SUD treatment data for care coordination purposes.
3. **Clinical Treatment Workflow** – Develop *clinical treatment workflow* strategies to advance a data-driven approach in supporting SUD prevention, treatment, and recovery efforts.
4. **Technical Operations** – Develop *technical operations* recommendations to facilitate the exchange of SUD information between provider organizations and the HIE.

## Findings

Over the course of the convening and engagement process, a few key themes emerged that supported the plan’s proposed recommendations. Those findings are included in the following section.

### *Collaboration among Participants Leads to Successful Project Outcomes*

Collaboration among the convened participants was key to the project’s success. Despite participants coming from diverse roles (e.g., healthcare providers, State officials, etc.) and backgrounds (i.e., rural versus urban settings), their shared interest and passion for the project’s mission helped maintain focus.

Though there were indeed challenges along the way. To start, it took longer than expected to identify the project’s community stakeholders, as well as a third-party facilitation expert to lead the conversations. Issues such as practical time constraints, a lack of key contact information, and local political sensitivities are other examples that slowed the project’s formation and initial progress.

The addition of an experienced facilitator was crucial to the project’s overall collaborative design. Not only was the facilitator skilled in engagement techniques and process methodologies, but they were known in the community from previous SUD convening projects, a subject-matter expert in the field, and a third-party entity, which maintained HealthInfoNet’s role as an independent and trusted participant throughout the conversations.

Although early in-person regional convening efforts were crucial in establishing a strong benchmark of collaboration among participants, offering varied and flexible engagement methods and techniques, such as both virtual and physical meeting options, ensured that ongoing barriers to broad participation support such as time commitments, travel logistics, and technology difficulties were mitigated.

Adaptable engagement options offered stakeholders the opportunity to participate meaningfully in the context of their own needs and comforts, which created a sense of authenticity during the convening process and supported open and honest feedback.

Other effective engagement strategies identified through the project were small workgroup methods, webinar workshops, and well-planned meeting management. Participants received invitations well in advance of meetings, with specific actions requested and timelines and targets noted to provide them enough time to properly prepare and act.

An overall takeaway from the convening effort was to meet people where they are at in terms of their comfortability and commitment. If participants are asked up-front what they need and how they can be supported in order to be successful, and are allowed to participate in the sessions in ways convenient and enjoyable to them, collaboration will be an easy mark to hit.

### *Data-Sharing Practices Support and Advance Treatment Community Efforts*

Participant interest and passion for engagement in the project was in the broadly shared community perspective that quality of care, treatment outcomes, and recovery experiences of people with SUD can be greatly improved through data-sharing mechanisms. This kind of sophisticated, forward thinking supports and advances evolving care coordination models, such as the Maine Medicaid Health Homes (<https://www.maine.gov/dhhs/oms/vbp/index.html>) initiative, and their interplay among hospital, mental health, primary care, and emergency medical services providers.

Behavioral health and emergency responder participants highlighted patient safety as the key reason for pursuing SUD data-sharing solutions. When clinical information for acutely and/or chronically ill patients is missing, less-than-ideal outcomes result. Despite the existence of bias and discrimination in clinical contexts for patients receiving SUD treatment, participants nonetheless were interested in moving forward with innovative solutions that not only promote culture change but also break down the very data silos that engender patient bias and discrimination.

Treating providers acknowledged that the multiple layers of informed consent required by SUD programs is an administrative challenge to manage. While the goal to protect patients' legal rights is understood, sentiment suggests that the requirements put in place to meet this goal are often misaligned, repetitive, and/or inefficient. Even so, participants agreed that the resulting SUD consent information proposed as a part of this project must be incorporated within *existing* provider workflows across the state in order to not introduce yet another misaligned, repetitive, and/or inefficient process. Incorporation into existing workflows also further supports established efficiencies and aims to engage patients while other routine administrative processes are completed.

### *Understanding Meaningful Engagement for the Peer and Recovery Community*

The adoption and practice of Peer Support Specialist (i.e., Peer) and Recovery Coach (i.e., Coach) roles in communities and within treatment programs have been growing rapidly over the last several years. In Maine, the Office of Substance Abuse and Mental Health Services (SAMHS) (<https://www.maine.gov/dhhs/samhs/>) leads the rollout of state-funded educational programs for Peers and Coaches. SAMHS leadership oriented HealthInfoNet to the role it is playing with the State in Peer/Coach education and expansion. The State welcomes open and inclusive education and information sharing regarding HealthInfoNet's consent work, which will support new engagement with SAMHS as clinical models evolve.

Similar to the treatment community participants, peer and recovery community participants swayed in their determinations of whether SUD data sharing is ultimately a benefit or a detriment to their patients. On the one hand, they indicated that it could be helpful to patients with chronic, co-occurring complex care needs, those transitioning from SUD/mental health to primary care treatment and/or acute care, and/or in cases where they are not able to sufficiently communicate their medical history to a new provider. On the other hand, the same concerns arose that the sharing of a patient's previous histories of SUD treatment and/or recovery may lead to bias and discrimination in future clinical contexts.

For those participants that are strictly peer and recovery stakeholders, it was determined that, due to the time required to address the acute needs of their clients, they may not have a direct role in implementing the resulting SUD consent workflows proposed as a part of this project. However, for those participants that serve in a combined treatment and peer/recovery stakeholder role, and

therefore who may have more of “care-team” approach to the Peer/Coach model (such as organizations participating in the Maine Medicaid Health Homes initiative), they may play a valuable role in the SUD consent education process.

## Recommendations

The result of this project’s convening and engagement process – and therefore the fulfillment of the project’s defined objectives – focused on the creation of a statewide “SUD Information Exchange Strategic Plan.” The recommendations proposed by HealthInfoNet and its community stakeholders are included in the following section.

### *Legal Framework*

To support provider organizations in changing their contractual position with the HIE to allow for the incorporation of a patient’s SUD treatment information, HealthInfoNet and its community stakeholders recommend pursuing the following changes to HealthInfoNet’s HIE Participation Agreement and coinciding patient consent form for sensitive information.

SAMHSA’S Final Rule requires organizations that receive, store, process, or disclose patients’ SUD information to agree in writing that it (1) is fully bound by Part 2, (2) will resist, in judicial proceedings if necessary, any efforts to obtain access to information pertaining to patients except as permitted by Part 2, and (3) will use appropriate safeguards to prevent the unauthorized use or disclosure of the protected information. This is called a Qualified Service Organization Agreement (QSOA). A QSOA is similar to a business associate agreement (BAA) used to protect the disclosure of protected health information governed by HIPAA. HealthInfoNet drafted a two-page addendum to its existing HIE Participant Agreement to comply with this requirement as part of the legal framework’s recommendations.

Furthermore, HealthInfoNet’s sensitive information consent process will incorporate the following changes:

1. **To Whom** – There is overall stakeholder agreement around the universal approach, or the general designation, of “to whom” a patient may disclose their information. In this model, HealthInfoNet would act as the intermediary for a patient’s SUD data disclosure between treating providers so that all of a patient’s SUD information could flow to the HIE and HealthInfoNet would be responsible for complying with the privacy and disclosure requirements.
  - a. In determining “to whom” they may consent to disclose their information, the patient will be given the choice of consenting to an all-or-nothing disclosure. Meaning, patients may consent to either disclose *all* of their SUD information to the HIE AND all of its treating provider participants, or choose *not* to disclose *any* SUD information to the HIE.

### Relevant notes:

- HealthInfoNet maintains a temporary mechanism for participating providers to allow a “one-time” verbal consent access of sensitive information, as well as emergency access that is required by Part 2 regulations.

- Patients consenting to disclose their information to only certain providers via the HIE presents technical challenges that would make operationalizing this feature too complex for HealthInfoNet, the patient, and HIE-participating providers.
  - HealthInfoNet acknowledges that, though specifically authorized in the Final Rule as a means to disclose patient SUD information, a general designation requires a culture change for both providers and patients. Currently, some organizations do not allow general designation within their own SUD consent forms.
2. **Amount and Kind:** The Final Rule permits a patient to consent to disclose “all of their SUD information” to an intermediary such as HealthInfoNet, but it also requires “one additional granular data option” consisting of either a blank fill-in-the-data text box, or one data option, or several data options to either consent or not consent to disclose a subset of all of their information.
- a. Stakeholder consensus for the consent form’s “granular option” was to give patients a choice of consenting to disclose all of their SUD information (e.g., allergies, diagnoses, visit information, lab results, etc.) with the exception of “documents” – a specific data category commonly known within the HIE industry. Documents can be defined as “care plans, visit notes, discharge summaries, etc. commonly used in SUD programs.”

Relevant notes:

- Allowing patients to not share SUD-related documents as the granular option was decided for the following reasons: (a) documents often include detailed personal information that patients feel protective of and may not want to share broadly and (b) documents represent the most challenging data type within an HIE infrastructure to manage sharing and privacy rules from a technical perspective, particularly so with the integration of mental health and SUD treatment data categories managed today under different legal compliance requirements.
  - Though unambiguous in requiring a granular option on the consent form, SAMHSA’s Final Rule does not provide more specificity as to what an acceptable “granular option” can be. HealthInfoNet expects its HIE participants to further collaborate on the “amount and kind” scope of the legal recommendations. This collaboration will coincide with the Participation Agreement QSOA addendum process.
3. **Timeframe:** The Final Rule requires that a Part 2 compliant consent form list the date, event, or condition upon which the consent will expire, if not revoked prior. Therefore, it is not sufficient for a consent form to state that disclosures will be permitted until the consent is revoked by the patient. An expiration timeline of one (1) year following the date of a patient’s signature on the consent form was determined as a reasonable timeframe to comply with this requirement.

Relevant notes:

- Maine law does not require an expiration timeline for mental health information consent, which has the potential to confuse patients and providers.

- While technically challenging to parse out data between mental health and SUD information, there was stakeholder consensus to keep each data source’s expiration timelines separate. The addition of a renewal date for mental health information consent would not only likely decrease data sharing, rather than enhance it, but also increase provider workflow burdens and patient safety issues related to data gaps when information becomes unavailable to treating providers.

### *Patient Consent Materials*

To promote and facilitate patients’ consent to share their SUD treatment data for care coordination purposes, HealthInfoNet and its community stakeholders recommend the revision of the current version of HealthInfoNet’s sensitive data consent form. See [Appendix I](#) to view HealthInfoNet’s current consent form and the draft of the revised consent form, which incorporates the knowledge and expertise in existing SUD treatment informed consent workflows and both State of Maine law and federal Part 2 regulations (per the “Legal Framework” recommendations section).

Key revisions to the draft version of the sensitive information consent form include:

1. Inclusion of mental health, substance use disorder, and HIV consent options in order to maintain a single, comprehensive patient authorization form for all sensitive data-sharing options
2. Granularity of SUD data-sharing options that comply with the guidance provided in the “Legal Framework” recommendations section
3. Definition of a one-year SUD data-sharing consent expiration timeframe, per the “Legal Framework” recommendations section

The consent form will apply to all care locations across the state regardless of where the forms are completed or processed, and, as is currently true for HealthInfoNet’s general medical information consent workflow, patients will have the option to opt-out of previous opt-in choices (i.e., revoke their opt-in status) of SUD data-sharing at any time. HIE participating providers will not need to track patients’ consent choices; however, it is important for providers to maintain a policy or notice of privacy practice inclusive of HIE consent to support informed patient consent efforts.

### *Clinical Treatment Workflow*

To advance a data-driven approach in supporting SUD prevention, treatment, and recovery efforts, HealthInfoNet and its community stakeholders recommend the implementation of a robust communications and education toolkit, led by HealthInfoNet, designed to support informed patient consent workflows with the goal of providing low-barrier consent opportunities among patients with SUD.

Components to be included in HealthInfoNet’s communications and education toolkit include:

1. In-depth education and training for SUD treatment staff by HealthInfoNet, in partnership with participant compliance and clinical operations leadership
2. Inclusion of the revised sensitive data consent form, paired with patient consent workflow education, within existing provider workflows (e.g., SUD program intake appointment processes)

#### Relevant notes:

- HealthInfoNet patient consent workflows should be incorporated into inpatient treatment programs at the time of discharge coordination, rather than during admission processes, to enable optimal patient participation in their consent choices.
- HealthInfoNet patient consent workflows should not be performed during acute-care episodes when patients' informed consent capacity may be compromised.
- HealthInfoNet patient consent workflows should involve Peer Support Specialist and Recovery Coach roles whenever possible to promote awareness and patient support; however, the roles should not become primary points of contact for patients in regards to consent education.

Despite providing a communications and education toolkit to HIE-participating providers, including staff education and training materials, patient brochures and forms, and compliance guidance, it is ultimately each participant's responsibility to execute HealthInfoNet's consent requirements based on state and federal laws within their respective organization(s).

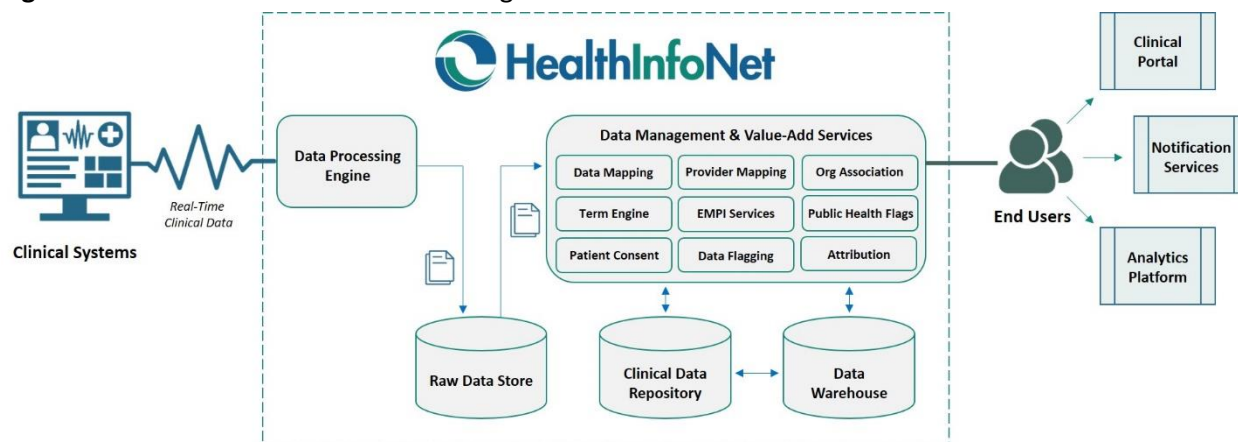
#### *Technical Operations*

HealthInfoNet's HIE platform features a clinical portal, terminology engine, data warehouse, customizable notifications, and a community information module. HealthInfoNet uses international best-practice clinical data aggregation methods to collect discreet patient information across diverse clinical systems and has established data mapping, standardizing, and other critical value-add methods to allow patient records to be aggregated, flagged, and measured appropriately across time and care locations.

Additionally, HealthInfoNet uses an Enterprise Master Person Index (EMPI) software to manage and consolidate all of a patient's clinical information into one unified and unique record. The EMPI is specially customized to identify a unique patient's consent choices. Each patient's most recent consent choice(s) and corresponding effective date(s) are logged and maintained within the HIE platform to manage data inclusion rules on a per patient basis across all participant connections. EMPI information is maintained at all times for all patients in order to track the appropriate inclusion and use of patient information in the HIE.

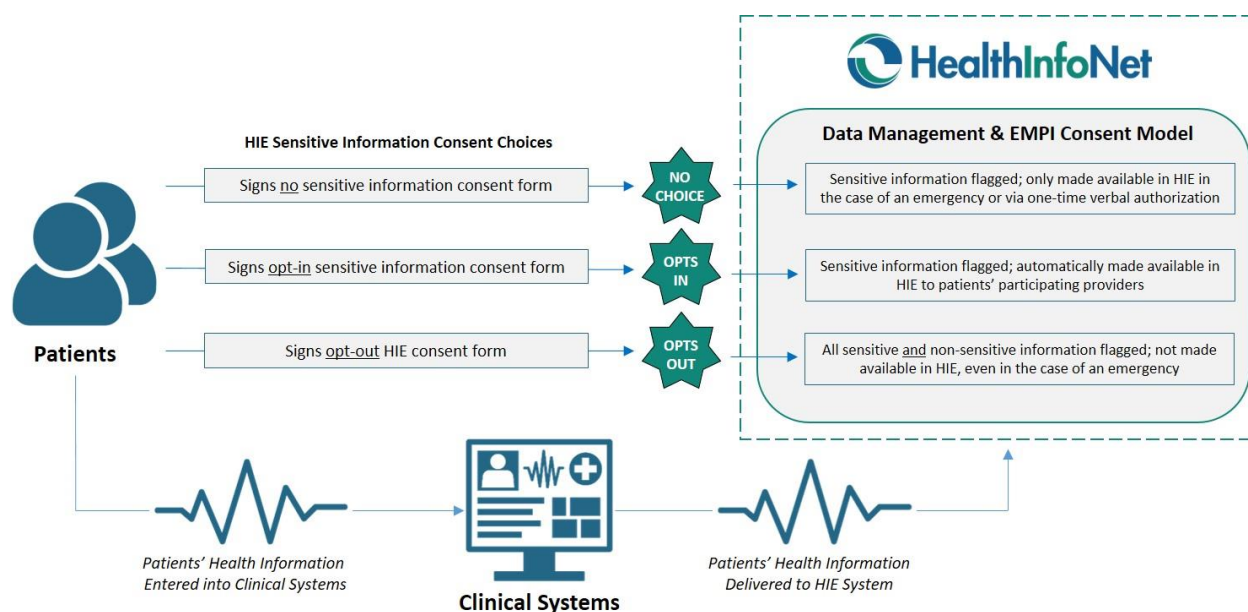
To facilitate the exchange of SUD information between patients, provider organizations and the HIE, HealthInfoNet and its community stakeholders recommend leveraging existing technical infrastructure maintained by the HIE to minimize costs and avoid the implementation of overly complex systems that could cause unnecessary compliance or security risk. [Figure 1](#) below provides a high-level diagram of HealthInfoNet's infrastructure design and workflow.

**Figure 1. HealthInfoNet Infrastructure Diagram**



Furthermore, HealthInfoNet proposes to continue with the current data aggregation and EMPI consent model. Today, when a participating provider shares sensitive information with the HIE, the data is categorized as “sensitive” and then sequestered and managed in separate database environments. In other words, sensitive information is stored and managed apart from “non-sensitive” (i.e., general medical) information. When a participating provider then chooses to share sensitive information with HealthInfoNet, all patient records are shared from the participant and access to the records are managed by patients’ individual consent choices and current state law. Participating providers must take action to log their sensitive data access in the HIE clinical portal when viewing the information via the emergency exception or verbal consent workflow. All HIE access workflows are logged and audited by both HealthInfoNet and its participating providers as part of the HIE infrastructure. [Figure 2](#) below provides a high-level diagram of HealthInfoNet’s sensitive information data management and EMPI consent model.

**Figure 2. HealthInfoNet Data Management & EMPI Consent Model**





Key technical recommendations for the exchange of SUD information include:

1. HealthInfoNet transitioning each participant interface connection from the current model of sensitive data “blocking” or “discarding” logic to a new model of sensitive data “flagging” or “categorization” logic
2. HealthInfoNet retrieving *all* sensitive data categories *for* all patients from each participant’s interface connection (as defined by future Participant Agreement)
3. HealthInfoNet managing data storage and user access based on the applied sensitive data flagging/categorization supplied by each participant’s interface connection logic AND each patient’s consent choice
4. HealthInfoNet managing data access rules based on storage and tracking of patient consent choices as part of patient identity management
5. HealthInfoNet managing access provisioning for “emergency” exceptions required by State of Maine mental-health opt-in law and federal law (i.e., Part 2)

## Conclusion

Overall, this project’s convening and engagement process has demonstrated that there is broad stakeholder and community support to work toward comprehensive care coordination models and improved quality of care outcomes for people with SUD through the use of technology and data across physical and mental health services.

Yet despite this support, the continued existence of bias and discrimination in clinical settings for patients receiving SUD treatment and/or recovery services greatly impacts the ability to advance innovative solutions aimed at engendering data-informed integrated care workflows in support of SUD prevention, treatment, and recovery efforts. This challenge comes to light especially when considering the role that HealthInfoNet, the state of Maine’s statewide HIE, could play in facilitating the exchange of patients’ SUD information across treating providers.

Cultural context impacts the way in which the recommendations put forth in this “SUD Information Exchange Strategic Plan” are viewed and implemented. If those working in physical and mental health services choose to educate themselves about addiction science and evidence-based treatment<sup>9</sup>, and therefore begin to promote system-wide improvements in the value of clinical culture change, the stigma associated with SUD will effectively be eradicated over time. In turn, a culture change will evolve, including the elimination of historical data silos, in support of SUD data-sharing practices.

HealthInfoNet and its community stakeholders understand that there are risks to consider and mitigate, as well as decisions to make that require time and ongoing collaboration among all involved stakeholders in the SUD treatment and recovery communities, in regards to the proposed recommendations to implement new legal frameworks, patient consent education materials, clinical treatment workflows, and technical operations. As long as that process may take, HealthInfoNet will

---

<sup>9</sup> Gardiner, Trip. “Addiction Is a Brain Disease.” *YouTube*, Knox County Community Health Coalition, 12 June 2019, [www.youtube.com/watch?v=HPmSbliV-Nw&feature=youtu.be](https://www.youtube.com/watch?v=HPmSbliV-Nw&feature=youtu.be).



continue to support collaboration and facilitate efforts to reduce potential barriers until solutions are identified and agreed upon by all.

This project, and the recommendations provided, are a result of the state of Maine's progressive history of collaboration aimed at giving residents greater choice. The strategic recommendations contained in this document expand patients' options to better support their coordination and management of care and treatment in healthcare settings, regardless of where they are seen for care in the state and the different technologies used among their providers. This report seeks to support what is only the initial phase of SUD data-sharing innovation for the state of Maine, and hopes to become a foundation from which others can evolve and learn as more advanced solutions become available.

# Appendix I

---

- Current Version of the HealthInfoNet Sensitive Information Consent Form
- Revised Draft Version of the HealthInfoNet Sensitive Information Consent Form

*This report was developed by HealthInfoNet in partnership with community stakeholders and with support from the Maine Health Access Foundation and the Betterment Fund.*

*Current Version of the HealthInfoNet Sensitive Information Consent Form*

[See next page]

# Form to share Mental Health/HIV Information

If you **do not want to share** your Mental Health/HIV information, **do nothing with this form.**

## What is HealthInfoNet?

HealthInfoNet is a secure computer system that brings your health information from different healthcare providers into one statewide electronic health record. Your providers use this information to make better decisions about your care. It can also help them prevent mistakes, especially in an emergency. Your health record includes information about your medicines, allergies, test results, and more.

**Are my records private and secure?** HealthInfoNet encrypts all information and uses secure connections. Only those involved in your care can look at your information. To find out who has seen your record, visit [www.hinfonet.org/audit](http://www.hinfonet.org/audit). No system is completely secure, but HealthInfoNet makes every effort to keep your records safe.

**Maine has separate rules about Mental Health/HIV information.** This information is kept private *unless you indicate you want it shared*. You can authorize any provider to see your information at any time. Your other providers will only be able to see your information if you have a medical emergency. Your choice will not affect your ability to get medical care. If you decide later that you do not want to share your information, you can revoke your choice by contacting HealthInfoNet or by visiting [www.hinfonet.org/patients/your-choices](http://www.hinfonet.org/patients/your-choices).

<b>I choose to share my Mental Health/HIV Information.</b>			
Fill out this form and mail it to HealthInfoNet, 60 Pineland Drive, Portland Hall, Suite 230, New Gloucester, ME 04260 or fax it to 207-541-9258.			
<b><i>This form must be witnessed and signed by healthcare staff, Notary Public, or HealthInfoNet staff. It needs to be handed to your participating provider or in person at HealthInfoNet's office.</i></b>			
If you are unable to do this, you may have the form notarized and mailed to us. Once we receive this form, your Mental Health/HIV information will be available to all your providers using HealthInfoNet.			
Please check the box next to your choice(s)			
<input type="checkbox"/> I choose <b>to share</b> my Mental Health information			
and/or			
<input type="checkbox"/> I choose <b>to share</b> my HIV information			
First Name		Middle Name	Last Name
Address		City	State Zip Code
Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female	Date of Birth: ____/____/____ (month / day / year )	____ - ____ - ____ Social Security Number (not required)	
Phone Number		Email	
Signature of Patient or Guardian <b>required</b>		_____ Date (month / day / year )	
Witness Signature <b>required</b>		Witness Print Full Name <b>required</b>	Healthcare Organization <b>required</b>
On ____/____/____, I attest that the above signer is personally known to me or established his/her identity by presenting government-issued photo identification.			

If you have questions, call HealthInfoNet at 1-866-592-4352 or 207-541-9250, or email us at [info@hinfonet.org](mailto:info@hinfonet.org)

*Revised Draft Version of the HealthInfoNet Sensitive Information Consent Form*

[See next page]

**About HealthInfoNet:** HealthInfoNet is a secure computer system that brings patients' health information from different healthcare providers into one statewide electronic health record. Providers use this information to make better decisions about their patients' care, especially in an emergency.

**Note:** If you do not want to share your mental health, substance-use disorder, and/or HIV information with HealthInfoNet, do nothing with this form.

PATIENT INFORMATION	
Full Name: _____	DOB (mm/dd/yyyy): ____/____/____
Address: _____	Social Security Number: _____
City: _____	Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female
State: _____ ZIP Code: _____	Phone Number: _____
I CHOOSE TO SHARE THE FOLLOWING INFORMATION	
<p>I understand that the information to be shared may contain sensitive information, and that only if I check one or more of the wanted options below will I authorize the specified type(s) of information. Note: Your choice to or not to share information will not affect your ability to get medical care. If you decide later that you do or do not want to share your information, you can revoke your choice(s) by contacting HealthInfoNet.</p>	
<b>Mental Health Information</b>	<input type="checkbox"/> <b>I CHOOSE TO SHARE</b> my mental health information
<b>Substance-Use Disorder Information</b>	<input type="checkbox"/> <b>I AUTHORIZE</b> the disclosure of all of my substance use disorder information from participating providers to HealthInfoNet and all of my current, past, and future treating providers of HealthInfoNet's Health Information Exchange for the purpose of care coordination; <b>OR,</b> <input type="checkbox"/> <b>I AUTHORIZE</b> the disclosure of all of my substance use disorder information from participating providers, <b>EXCEPT for documents</b> (e.g., treatment plans, visit notes, discharge summaries, admission histories, etc.) to HealthInfoNet and all my current, past, and future treating providers of HealthInfoNet's Health Information Exchange for the purpose of care coordination.  <u>Notes:</u> <ul style="list-style-type: none"> <li>Psychotherapy/progress notes are not shared by HIE participating providers</li> <li>I understand that my SUD records are protected under federal law and regulations, and that I may obtain a list of providers to which my records have been disclosed. I understand that I may revoke this authorization at any time except to the extent that action has been taken in reliance on it. Unless I revoke my authorization earlier, it will expire automatically one (1) year from the date of my signature.</li> </ul>
<b>HIV Information</b>	<input type="checkbox"/> <b>I CHOOSE TO SHARE</b> my HIV information
PATIENT/WITNESS CONSENT	
<p>Only those involved in a patient's care can look at their information. For those patients who choose to share their information, they are able to find out who has seen their records by completing an audit form found online here: <a href="http://www.hinfo.net/org/audit">www.hinfo.net/org/audit</a>.</p> <p>This form must be witnessed and signed by healthcare staff or HealthInfoNet staff. If patients are unable to do this, they may have the form notarized and mailed to HealthInfoNet. Once HealthInfoNet receives this form, the patient's mental health, substance-use disorder, and/or HIV information will be available to all of the patient's HIE-participating providers.</p> <p>Signing this form indicates that the patient or guardian understands matters discussed on this form, and releases the providers, its employees, officers and trustees, medical staff members, HealthInfoNet, and business associates from any legal responsibility or liability for the disclosures of the above information to the extent indicated and authorized herein.</p>	
FOR PATIENT/GUARDIAN ONLY [ALL FIELDS REQUIRED]	
Patient/Guardian Signature: _____	Date: _____
Printed Name of Guardian (if applicable): _____	
FOR WITNESS ONLY [ALL FIELDS REQUIRED]	
Witness Signature: _____	Date: _____
Printed Name of Witness: _____	Organization: _____

**Form Instructions:** If you would like to share your mental health, substance-use disorder, and/or HIV information with HealthInfoNet, please **fax this form to 207-541-9258**. If by mail, send to HealthInfoNet at 60 Pineland Drive, Portland Hall, Suite 230, New Gloucester, ME 04260. For questions, contact HealthInfoNet's Customer Support team at 1-866-592-4352.