



## Bridging the Digital Divide:

*Using Health IT to Integrate Behavioral and Physical Health Care in Maine*



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## Acronyms

There are many terms and acronyms used throughout this document. To help the reader, a table representing some of the acronyms used is presented below.

ABBR.	DESCRIPTION AND URL
<b>42CFR</b>	Code of Federal Regulations, Title 42, Public Health, <a href="http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&amp;tpl=/ecfrbrowse/Title42/42tab_02.tpl">http://www.ecfr.gov/cgi-bin/text-idx?c=ecfr&amp;tpl=/ecfrbrowse/Title42/42tab_02.tpl</a> , <a href="http://www.gpo.gov/fdsys/pkg/CFR-2002-title42-vol1/pdf/CFR-2002-title42-vol1.pdf">http://www.gpo.gov/fdsys/pkg/CFR-2002-title42-vol1/pdf/CFR-2002-title42-vol1.pdf</a>
<b>ACC</b>	Accountable Care Communities
<b>ACO</b>	Accountable Care Organizations, <a href="https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html?redirect=/ACO/">https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html?redirect=/ACO/</a>
<b>ARRA</b>	American Recovery and Reinvestment Act
<b>BAA</b>	Business Associate Agreement
<b>Bangor Beacon Project</b>	Bangor Beacon Project - a federally funded grant program that provides communities with funding to build and strengthen their health information technology (health IT) infrastructure and exchange capabilities.
<b>CCD</b>	Continuity of Care Document - a standard intended to specify the encoding, structure and semantics of a patient summary clinical document for exchange.
<b>CIHS</b>	The Center for Integrated Health Solutions
<b>DIRECT</b>	The Direct Project specifies a simple, secure, scalable, standards-based email for participants to send authenticated, encrypted health information directly to known, trusted recipients over the Internet.
<b>EHR</b>	Electronic Health Record
<b>FQHC</b>	Federally Qualified Health Center
<b>HIE</b>	Health Information Exchange
<b>HIN</b>	HealthInfoNet
<b>HIPAA</b>	Health Insurance Portability and Accountability Act.
<b>HIT</b>	Health Information Technology
<b>HITSC</b>	Health Info Technology Steering Committee
<b>HIV</b>	Human Immunodeficiency Virus
<b>HL7</b>	Health Level 7
<b>HRSA</b>	Health Resources and Services Administration
<b>LD 1331</b>	An Act To Increase Health Care Quality through the Promotion of Health Information Exchange and the Protection of Patient Privacy

<b>ABBR.</b>	<b>DESCRIPTION AND URL</b>
<b>LWG</b>	Legal Work Group
<b>MaineCare</b>	The State of Maine's Medicaid program
<b>MeHAF</b>	Maine Health Access Foundation
<b>National Council</b>	National Council for Community Behavioral Healthcare
<b>NLC</b>	National Learning Consortium
<b>ONC</b>	The Office of the National Coordinator for Health Information Technology
<b>OSC</b>	The Office of the State Coordinator for Health Information Technology
<b>PCMH</b>	Patient Centered Medical Home
<b>PHI</b>	Protected Health Information
<b>QC</b>	Maine Quality Counts (QC) - a regional health care collaborative committed to improving health and health care for the people of Maine.
<b>REC</b>	Regional Extension Center
<b>SMI</b>	Serious mental illness
<b>SureScripts</b>	Nationwide Health Information Service Provider (HISP)
<b>VA</b>	Veterans Administration

## Executive Summary

The integration of behavioral health and substance abuse information into electronic health records is critical in order to increase health care safety, quality, access and efficiency. Since 2004 Maine has been working on a number of initiatives to coordinate clinical information systems within the mental health and substance abuse provider community. With the emergence of new health care payment reform efforts such as value-based purchasing and accountable care organizations, health care information technology (HIT) facilitated care coordination has taken on new priority across the health care delivery system and behavioral health is at the forefront. Central to this strategy has been a longstanding priority in Maine to support the collaborative engagement of providers from the behavioral and physical health sector, and consumers, so that the use and deployment of HIT enhances care at the patient and provider level. This project – funded through a contract with the National Council for Community Behavioral Healthcare – provided support for significant changes in Maine’s HIT environment in order to make behavioral health and primary care integration the norm rather than the exception.

Three major collaborators were brought together to drive these efforts: HealthInfoNet, the statewide health information exchange (HIE) organization and Regional Extension Center, the Office of the State Coordinator for Health Information Technology, and the Hanley Center for Health Leadership. In addition, a broad group of behavioral health and primary care providers, additional provider groups, and a wider range of representatives of the State mental health and substance abuse departments were convened and voluntarily participated in a number of workgroups that met over the calendar year of 2012.

### **The project was organized according to three primary action areas:**

**Action Area 1:** Advancing the implementation of recommendations and the next phase of the multi-stakeholder Behavioral Health Information Technology Hanley Strategic Action Taskforce facilitated by the Daniel Hanley Center for Health Leadership in 2011.

**Action Area 2:** Providing access to the operational statewide HIE for providers with and without EHRs.

**Action Area 3:** Consumer-driven communications to assure that consumers understand how their health data is being exchanged and why.

### **Outcomes**

While efforts continue, this project had significant impact:

- Across Maine, 20 behavioral health organizations/agencies with the ability to access health information on their clients in the HIE and five who will have the ability to share protected mental health information through the HIE for improved delivery of care and coordination with other health care providers.
- Consumers and providers have the educational tools to support informed consent for consumers.
- Providers have an implementation toolkit to support EHR implementation and connection to the HIE.
- Recommendations were made for a common set of data elements to standardize communication between health care providers.



- Strategies were developed to integrate behavioral health providers into the new emerging payment reform models in Maine.
- A Centers for Medicare and Medicaid Innovation Grant was submitted that among other things proposed an incentive to assist behavioral health providers in EHR adoption and implementation.

Despite these results, providers still face ongoing barriers and challenges to sharing behavioral health information for care coordination purposes. The cost of implementing EHRs and purchasing the interfaces to connect to the HIE is still a considerable barrier for these providers. The cost not only includes the funds needed to buy the technology but also the time and resources required to educate staff that historically has a large knowledge gap around health care technology.

A majority of behavioral health organizations in Maine treat patients for both mental health and substance abuse issues. The issue of different standards for treating Mental health information and substance abuse information under State and Federal law require complex processes of separating mental health from substance abuse information to support HIE efforts. And the challenge of educating patients about the complexities around consent for both mental health and substance abuse also present ongoing challenges.

**To address ongoing barriers and challenges, the stakeholders involved in the project made recommendations for next steps to support the ongoing integration of behavioral health providers into Maine HIT and HIE efforts. These recommendations include:**

- Continued engagement of consumers on the value of information sharing.
- Continued support for providers to implement this new technology in their facilities, including developing policies and procedures for staff connecting to the HIE.
- Develop educational services for behavioral health providers around using the medical information available to them in the exchange to support better patient care.
- Behavioral health visit notes currently are not accepted into the HIE. Convene a workgroup to develop a standardized visit notes template for future inclusion of this information in the HIE.
- The continued discussion between behavioral health providers, consumers, legal experts and CIHS on the consent options for authorization for release of mental health and substance abuse information to the HIE.
- The continued engagement with key stakeholders in the development of incentives that help behavioral health providers acquire EHRs and other systems that will lead to greater electronic information-sharing and improved coordination of care.

## Introduction

Since 2004 Maine has moved forward on an ambitious plan to promote the adoption of electronic health records (EHR), establish one of the nation's first operational statewide electronic health information exchanges (HIE), and bring an ever-widening array of providers into the exchange to improve the coordination, integration and quality of patient care.

In 2010, then Governor John Baldacci, through Executive Order, recognized HealthInfoNet as the Statewide State-Designated HIE Organization. HealthInfoNet manages a secure electronic system where health care providers share patient health information including allergies, prescriptions, medical conditions, and lab and test results to better coordinate and improve patient care. The exchange includes data on all patients regardless of payment source – commercially insured, uninsured, publicly insured, and underinsured patients are all in the database. Participating providers submit data to the exchange on a real-time basis, where it is housed in a statewide data repository organized by a master patient index linking patients across multiple health care settings. Identifying and linking the right patient is a challenging and essential component of the success of the exchange. Finally, HealthInfoNet standardizes the data across sites to guarantee that the statewide data means the same thing to all providers accessing the exchange and that the aggregated database can be analyzed across provider organizations and regions of the state.

Central to HealthInfoNet's strategy has been a longstanding priority to support the collaborative engagement of providers from the behavioral and physical health sector, and consumers, so the use and level of deployment of health information technology (HIT) enhances care at the patient and provider level. This integrated vision has guided the development of HealthInfoNet, the statewide, stated-designated HIE, since the early planning phase in 2004. HealthInfoNet has rapidly expanded, and today its secure database includes records for 80% of Maine's 1.3 million residents. Efforts to expand provider participation in the HIE continues to gain momentum. The HITECH Act and the subsequent award of the Office of the National Coordinator for HIT (ONC) funded HIE Cooperative Agreement to the State of Maine, the Regional Extension Center to HealthInfoNet, and the Beacon Community Grant to Eastern Maine Healthcare Systems have accelerated these activities.

In January of 2012, the National Council for Behavioral Health Center for Integrated Health Solutions awarded a contract to HealthInfoNet as one of five State Designated Entities (SDEs) to lead the nation in developing effective ways for HIEs to improve the integration of behavioral health and general medical care using HIT. This report and the data presented within it, represents a summary of the one-year activities supported by CIHS and the next steps for the State of Maine to sustain the activities described.

## Background

Since 2009 a series of highly focused initiatives have been launched to accelerate the integration of care for patients with behavioral health challenges in Maine. They include:

1. The development of a consortium of independent behavioral health agencies that has jointly designed and is implementing a shared EHR and innovative information-sharing approach that will serve as a model for other Maine agencies;
2. The inclusion of a behavioral health information-sharing strategy and implementation activities into the ONC funded Beacon Community project based in Bangor. This work is serving as a model for clinical integration efforts statewide and nationally;
3. The establishment of a behavioral health committee to guide the work of *Maine Quality Counts*, an independent regional quality improvement organization that is leading the development of the Patient Centered Medical Homes (PCMH), which in Maine have included a requirement for behavioral health integration;
4. The passage of legislation (LD-1331) that clarifies how patient-level behavioral health information can be shared;
5. An intensive stakeholder engagement process in 2011 that brought together a wide array of behavioral health agencies, state officials, behavioral health consumers, and HealthInfoNet to identify and address barriers to the adoption of EMRs within behavioral health provider agencies, and lay the groundwork for greater integration with physical health providers. Among other results, this process led to a first-ever “snapshot” of EMR adoption in behavioral health agencies in Maine; and,
6. The Department of Health and Human Services MaineCare (Medicaid) program announced that it would pursue a new value-based purchasing strategy that included leveraging and/or expanding current initiatives and federal opportunities towards the development of Health Homes. An explicit core competency is the capacity to provide integrated services between behavioral health and primary care with a focus on the most difficult to treat individuals who have one or more chronic illnesses, including those who have serious mental illness (SMI).

HealthInfoNet, The Office of the State Coordinator for Health Information Technology, the Maine Office of Substance Abuse, and MaineCare (Medicaid) continue to work collaboratively with providers, government agencies, purchasers and consumers to promote clinical and data integration. Several committees have been formed with public-private involvement to develop state policy and implement projects incorporating behavioral health integration with technology.

## Maine’s Existing Work to Integrate Behavioral Health and Primary Care

Promoting a health care system organized to deliver services that meet the health needs of underinsured and uninsured patients and families is a mission of the Maine Health Access Foundation (MeHAF). The central feature of the foundation’s work to promote patient-centered care is integrating behavioral and physical health care. In 2006, the foundation conducted a “visioning process” where stakeholders representing providers, consumers, public and private insurers, business leaders, policy makers, researchers and advocates could define the core attributes and structural elements of what true integrated care would look like. Nearly 1,500 Maine people participated in structured focus group

discussions to share their perceptions and insights about integrated care. Their feedback and practical advice is summarized in the publication, *Maine People Speak About Health Care Integration*.<sup>1</sup>

The project's final report served as the foundational document for a MeHAF ten-year, \$10 million Integration Initiative. The Integration Initiative combines multi-year grant-making, hands on technical assistance, in depth program support, consumer engagement, and policy development and research. Drawing on evidence-based models, this multi-faceted approach has enhanced direct client services and provided support to change the systems of care in 43 grant projects in over 100 sites and involving over 150 collaborative partners statewide.

MeHAF's one-year planning and three-year implementation grants have supported the development and enhancement of integrated approaches to care delivery across a range of clinical services, systems transformation and policy approaches. Diverse grant sites include hospitals, community health centers, mental health agencies, nursing homes, school-based health clinics, state government-run clinics, peer-run mental health advocacy and support organizations, and four statewide organizations. A core element of the Integration Initiative is to bring behavioral health care to those seen in primary care practices, as well as providing preventive and primary care services to people who seek the majority of their care in community mental and behavioral health care settings. Among the priority populations are adults with chronic diseases, people with serious and persistent mental illness, teens, children with autism spectrum disorders, high-risk infants, nursing home residents and people leaving jail.

While the Integration Initiative is built on a foundation of evidence-based care models, rather than endorsing a single approach or model to integrated care, MeHAF encourages grantees to explore current and emerging approaches that best meet the health and recovery needs of their populations. The projects seek to achieve key elements of integration, including: (1) patients' choice in the setting of care; (2) meaningful participation by patients and families in the development and delivery of services; (3) treatment delivered by both physical and behavioral health providers who serve a common population and use common medical records; and (4) solution-focused treatment for both physical and behavioral conditions that is cost-effective and informed by evidence-based and promising practice protocols. MeHAF also facilitates quarterly learning community meetings, where national and local speakers inform grantees of new research and evidence-based practice, and has initiated an integration social networking community and resource center to provide virtual and tangible materials, research, and tools to grantees and others.

To determine the elements of integrated care that lead to successful integration and improved health outcomes, the foundation is engaged in evaluation of the initiative. As part of the baseline data, the University of Southern Maine was contracted by MeHAF to conduct the *Maine Barriers to Integration Study*<sup>2</sup>, an in-depth examination of the structural, reimbursement, organizational practice, and professional cultural barriers to and opportunities for integration. This study identified difficulty in sharing patient information and records between behavioral and physical health providers as a significant barrier to integration. To strengthen the work of clinical integration, MeHAF has established a Statewide Integration Initiative Policy Committee to identify and guide policy activities and strategies that can leverage and sustain enhancements of integrated care implementation and sustainability. In

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<sup>1</sup> For more information see: <http://www.mehaf.org/media/docs/resources/grassroots-feedback-2007.pdf>

<sup>2</sup> Gale, J. D., & Lambert, D. (2008). *Maine Barriers to Integration Study*. Prepared for The Maine Health Access Foundation Contract no. 2007CON-0010

2010, the committee refined the definition of critical elements of integrated behavioral health and primary care in Maine and drafted a detailed work plan to advocate for policies that support integrated care. One of the elements in the definition is “HIT, which integrates behavioral health and primary care records and includes patients’ access to their own health information.” MeHAF is developing additional materials and training related to reimbursements for integrated care across varied settings. In 2011, MeHAF began the Integrated Care Training Academy, which provides technical assistance to organizations seeking to integrate care, including support for efforts to share health information between primary care and behavioral health.

The development of the statewide behavioral health HIT stakeholder process is another key part of the Integration Initiative. True care integration and coordination cannot occur unless relevant clinical information can be successfully shared in a secure manner across behavioral health and physical health sectors. MeHAF provided support to the Daniel Hanley Center for Health Leadership to convene the statewide behavioral health HIT stakeholder engagement process to determine how this key sector could move forward collaboratively to intersect with Maine’s HIE, HealthInfoNet. As a result of this groundwork, care integration across these sectors is becoming the norm, rather than the exception.

### 2011 Intensive Stakeholder Engagement Process on Behavioral Health and HIT

Integration of primary care and behavioral health data is a goal of HealthInfoNet and the Office of the State Coordinator as articulated in the ONC approved Statewide Health Information Exchange Strategic and Operational Plan<sup>3</sup>. In 2011, the Hanley Center catalyzed a collaborative process for aligning and accelerating mental health and substance abuse clinical information sharing. A one-day forum in March brought together over 120 mental health and substance abuse leaders from throughout Maine, including Executive Directors, CEOs, Clinical Directors, Privacy and Compliance Officers, IT Directors of health provider organizations, the Office of the State Coordinator for Health Information Technology, HealthInfoNet, leaders from state agencies, consumers and consumer representatives, statewide professional organizations, and the legal community. Participants identified key next steps needed to accelerate clinical information sharing, how to involve consumers and other key stakeholders, and other sectors that needed to be involved in the work.

Following this forum, a smaller group of over 50 committed leaders formed the Hanley Strategic Action Taskforce and worked over the rest of the year, collectively and in four different Workgroups (Consumer, Barriers-Incentives, Integration, and Staff Education). The Hanley Strategic Action Taskforce work culminated in a statewide Forum where participants presented and refined next steps towards implementation of the following recommendations to advance behavioral health integration with other health care providers.

#### Recommendations:

1. **Plan for Accountable Care.** Examine and document how clinical information sharing between mental health and substance abuse treatment providers and primary care and other health care providers promotes integration and reduces costs.

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<sup>3</sup> (2012). *Statewide Health Information Exchange Strategic and Operational Plan*. See: <http://www.maine.gov/hit/>

2. **Align laws and regulations with effective integrated care.** Share latest developments in state law and interpretations of federal regulations on health care confidentiality with attorneys advising health care providers. Support efforts to revise state regulations to allow clinical information sharing for patient care purposes.
3. **Maximize consumer participation and awareness.** Increase consumer access to their records. Gather more consumer feedback to develop educational materials that will better enable informed decision making about sharing records. Focus on strategies to reduce stigma within health care settings especially in the emergency room.
4. **Focus and simplify data sharing.** Collect minimum data sets in a uniform manner by identifying elements for inclusion in the Continuity of Care Document. Provide educational tools and technical support to health care providers to enable consistent data collection and sharing methods.
5. **Encourage cultural change in provider organizations.** Support education and tools for primary care providers to act as a resource for consumers deciding about sharing. Support staff success in using HIT with tools and training. Work with providers of health care education to build HIT competencies into foundational curricula.
6. **Significantly increase funding and incentives.** Support efforts to extend 'meaningful use' incentives to behavioral health providers. Support efforts at the state level to fund / provide incentives for EHR adoption among behavioral health providers. Survey small behavioral health providers to learn more about what incentives would be effective to encourage EHR adoption.
7. **Develop tools and encourage use of best practices.** Support information sharing about: (a) successful collaborations among providers to implement EHR; (b) lessons learned; and (c) open source EHR products being developed. Develop a toolkit and training workshop to assist providers in jointly acquiring and implementing systems.

The stakeholder taskforce group process worked well in 2011 and served as a model for the convening activities in 2012. As the recipient of the NCIHS contract, HealthInfoNet, in collaboration with the Office of the State Coordinator and the Daniel Hanley Center for Health Leadership, reconvened the statewide behavioral health HIT stakeholder group to advance the project goals. The full report and recommendations that resulted from the work in 2011, served as the foundation for the work of this NCIHS funded project over calendar year 2012.<sup>4</sup>

## The Role of HealthInfoNet as Maine's Designated Statewide HIE

Incorporated in 2006 as an independent statewide non-profit organization, HealthInfoNet is one of the leading HIE organizations in the country. It is governed by a community-based board of directors and several committees comprised of Maine people serving on behalf of doctors, hospitals, public health, state government and patients. With strong support and participation from the leading health care stakeholders in Maine, HealthInfoNet has established a true public-private partnership and achieved its goal to promote statewide data exchange and use. In 2010, then Governor John Baldacci, through Executive Order, recognized HealthInfoNet as the Statewide State-Designated HIE Organization.

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<sup>4</sup> Hanley Center for Health Leadership (2011). *Statewide Recommendations for Accelerating Integration of Mental Health and Substance Abuse Information into Electronic Health Records for the Benefit of Patients*. See: [http://www.mehaf.org/media/docs/resources/2012/01/05/Behavioral\\_Health\\_IT\\_Integration\\_Report\\_-\\_Draft\\_-\\_2011-12-12.pdf](http://www.mehaf.org/media/docs/resources/2012/01/05/Behavioral_Health_IT_Integration_Report_-_Draft_-_2011-12-12.pdf)

The clinical data collected on each patient in the HIE provides a broad clinical data set to promote higher quality and more effective health care delivery. Use of the information in the exchange by providers promotes stronger coordination of care across all settings, reduces unnecessary and/or duplicative medical testing, lowers costs and provides greater quality care. HealthInfoNet also incorporates automated laboratory result reporting to the Maine Center for Disease Control (Maine's public health authority) for 30 of the 72 diseases mandated for reporting by the State of Maine. Moreover, HealthInfoNet is able to leverage its reporting activities and a relationship with the statewide Immunization Registry (Immpact II) to support participating providers in meeting the public health requirements of the Centers for Medicare and Medicaid Services (CMS) Meaningful Use of HIT Incentive Program. These functions form the basis for an evolving public health information infrastructure that will inform population health and emergency planning efforts in Maine into the future.

As of the end of 2012, 32 hospitals, out of a total of 38 acute care hospitals representing eighty eight percent (88%) of the state's inpatient and emergency room utilization, 325 (fifty-eight percent (58%)) ambulatory practices and 5 Federally Qualified Health Centers (FQHCs) were participating in the clinical data exchange. Approximately 1.1 million patients (80% of all Mainers) have data in the exchange. By the end of 2013, HealthInfoNet will be connected to all Maine hospitals and by the end of 2014 HealthInfoNet aims to be connected to at least 80% of all ambulatory providers across the State.

## Project Goals and Action Steps

Maine's CHIS project represents three major collaborators: HealthInfoNet, the statewide HIE organization and Regional Extension Center, the Office of the State Coordinator for Health Information Technology, and the Hanley Center for Health Leadership. It also represents a wide range of private and public partners who over the project period have been and continue to be engaged in integrating behavioral health and primary care through the use of health information technology (HIT) and HIE. This project continued the efforts of Maine's health care stakeholders to make behavioral health and primary care integration the norm rather than the exception.

### The project was organized according to three primary action areas:

- **Action Area 1:** Advancing the implementation of recommendations and the next phase of the multi-stakeholder Behavioral Health Information Technology Hanley Strategic Action Taskforce facilitated by the Daniel Hanley Center for Health Leadership in 2011. To achieve this, we: (a) Developed concrete short, medium and long-term tactics/actions to implement the goals and strategies; (b) Addressed and made recommendations on specific policy and data standards that go beyond those available today to facilitate behavioral health information exchange; (c) Identified linkages with the MaineCare (Medicaid) value-based purchasing initiative and other state programs; (d) Addressed and clarified federal policy issues (42CFR Part 2) that impact behavioral health data sharing, and; (e) Evaluated and made recommendations on shared services that can reduce administrative burden and improve integration. This includes both HIE and shared service EHRs.
- **Action Area 2:** Provide access to the operational statewide HIE for providers with and without EHRs. To achieve this, we: (a) Implemented the mental health consent model (LD 1331) passed into law in 2011, (b) Developed bi-directional interfaces for five behavioral health organizations/partnerships; (c) Expanded the current CCR/CCD standard to assure all relevant data is available in the HIE; (d) Provided view only/download access to 20 behavioral health provider organizations without EHRs and to ancillary providers; (e) Implemented NwHIN Direct tools and have made them available to over 200 behavioral health providers, and; (f) Used the Maine Regional Extension Center Model to provide technical assistance to behavioral health providers needing specific HIT/HIE and workflow integration supports.
- **Action Area 3:** We developed consumer-driven communications to assure that consumers understand how their health data is being exchanged and why. To achieve this, we: (a) developed, with consumer input, educational materials for primary care and behavioral health providers to use to inform consumers about their options in sharing clinical information through the HIE, and; (b) created educational materials and strategies for primary care providers, behavioral health providers and other staff regarding consumer options and methodology for shared decision-making on clinical information sharing.



## Maine CIHS Project Governance and Management

In 2012, after the award of the CIHS contract, the Behavioral Health Strategic Action Taskforce was reconstituted with broader participation from primary care and other provider groups, and a wider range of representatives of Maine State mental health and substance abuse departments. To advance the project goals, behavioral health and primary care providers were engaged in the overall Strategic Action Taskforce and its workgroups. The workgroups are the mechanism through which the work of the three action areas/deliverables was conducted and the project goals achieved.

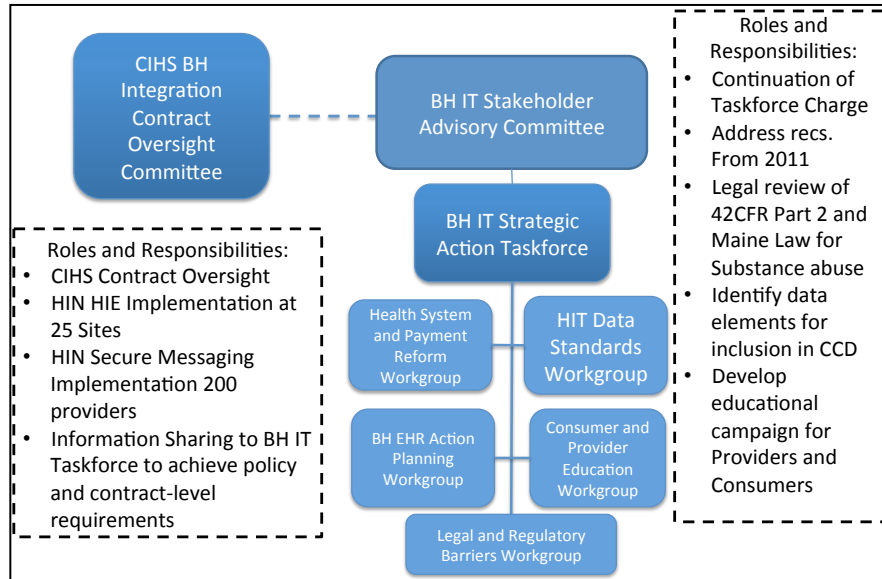
The governance structure detailed in Figure 1 was established to align contract requirements with the recommendations that resulted from the work in 2011 and the workgroup activities, which are described in detail below.

**The Contract Oversight Committee** included participation by the executive leadership of key state and stakeholder organizations as required by the grant and was responsible for; the alignment of taskforce activities with State and Federal Government activities and contract-level requirements, oversight and feedback on project planning and activities, direction and feedback on site selection for HIN HIE implementation at 25 sites. The members of this committee were active participants in the ongoing discussions around the overall project, its impact on behavioral health providers in the state, and plans for further integration.

**The Behavioral Health Information Technology (IT) Stakeholder Advisory Committee** consisted of selected statewide leaders in behavioral health and was responsible for overseeing and guiding the statewide Taskforce.

**The Behavioral Health IT Strategic Action Taskforce** consisted of a broad statewide group of Maine behavioral health providers, consumers, state policy makers, advocates, funders, and others committed to working to achieve the goals of this project. The Taskforce was responsible for developing the overall convening objectives, creating the specific workgroups, and defining the tasks for those workgroups as well as participating in the workgroups. See Appendix A for the Strategic Action Taskforce Objectives and Meeting Dates, and Appendix B for the Workgroups & Tasks.

**Figure 1: Maine CIHS Project Governance and Management Structure**



## Maine Behavioral Health Strategic Action Taskforce

The Strategic Action Taskforce developed convening objectives, created the specific workgroups, and defined the tasks for the workgroups. The five workgroups developed include the Behavioral Health EHR Action Planning Workgroup, the Data Standards Workgroup, the Legal & Regulatory Barriers Workgroup, the Consumer and Provider Education Workgroup and the Health System and Payment Reform Workgroup. Each workgroup was assigned objectives from the list included in *Figure 2 Strategic Action Taskforce Objectives*. The work, outcomes and recommendations of the workgroups are described below by individual workgroup

**Figure 2: Strategic Action Taskforce Objectives**

STRATEGIC ACTION TASKFORCE
<b>Objective 1:</b> For behavioral health providers choosing to participate in the statewide HIE, provide the following key deliverables to enable the successful implementation.
1a. Develop documentation and tools to help behavioral health providers understand the standards, tools, and processes that can be used to connect to the statewide health information exchange no matter what EHR tools are in place. (Behavioral Health EHR Action Planning Workgroup)
1b. With primary care and behavioral health provider and consumer involvement, and building upon existing standards in use in Maine and nationally, review model data standards to facilitate effective behavioral health HIE (Behavioral HIT Standards Workgroup)
1c. With consumer and provider involvement and building upon the tools in use by Maine's HIE, develop consumer and provider educational materials to assist consumers in making informed decisions about behavioral health information sharing. (Consumer and Provider Education Workgroup)
1d. With behavioral health providers, consumers, and legal experts in Maine, and the CIHS, make recommendations for consent options for authorization for the release of mental health and

substance abuse information to the Maine HIE. (Legal and Regulatory Barriers Group)
<b>Objective 2:</b> For behavioral health providers seeking to implement a ‘shared service’ EHR in partnership with other providers, develop an action plan for coordination and supports necessary. (Behavioral Health EHR Action Planning Workgroup)
<b>Objective 3:</b> For all behavioral health and primary care providers and consumers, develop a stronger mutual understanding about Accountable Care Strategies, MaineCare value-based purchasing, and other payment reform models and how these models and policies make electronic clinical information sharing for integration of behavioral health essential. (Health System and Payment Reform Workgroup)

## The Behavioral Health EHR Action Planning Workgroup

The Behavioral Health Electronic Health Record Action Planning Workgroup was organized to achieve the Taskforce Objectives 1a & 2:

- 1a. Develop documentation and tools to help behavioral health providers understand the standards, tools, and process that can be used to connect to the statewide HIE no matter what EHR tools are in place.
- 2. For behavioral health providers seeking to implement a ‘shared service’ EHR in partnership with other providers, develop an action plan for coordination and supports necessary.

The primary activity of this Workgroup was the creation of a toolkit with resources to help behavioral health providers implement EHRs. The National Learning Consortium (NLC), in partnership with the ONC, made available resources developed for medical practices and used by Regional Extension Centers since 2010.<sup>5</sup> The Workgroup adapted these tools to create the Behavioral Health EHR Implementation Toolkit.

The Toolkit follows the “Six Step Approach to EHR Implementation” provided by the NLC, with resources for each step:

1. Assess Your Practice Readiness
2. Plan Your Approach
3. Select or Upgrade to a Certified EHR
4. Conduct Training & Implement an EHR System
5. Achieve Meaningful Use
6. Continue Quality Improvement

In addition to EHR Implementation tools, the Toolkit includes sample workflow templates for using HealthInfoNet’s HIE for practices with and without an HER, a listing of EHRs currently used by Behavioral Health Providers in the State of Maine, and a sample workflow for using “Direct” for secure information exchange<sup>6</sup>.

The Workgroup was also charged with conducting a broad survey of providers of behavioral health services to assess their current use of EHRs, perceived benefits and barriers, and interest in coordinating care through HIEs. This survey informed the development of the EHR Action Plan for

<sup>5</sup> For more information see: <http://www.healthit.gov/providers-professionals/about-national-learning-consortium>

<sup>6</sup> *Behavioral Health EHR Implementation Toolkit (2012)* **ADD REFERENCE**

behavioral health providers as well as necessary changes to the Behavioral Health EHR Implementation Toolkit. The survey, focused on HIT and HIE barriers and challenges, was deployed in July of 2012 to behavioral health and provider contacts throughout the state.

Survey responses were received from 129 providers of behavioral health services from across the state (approximately 10% response rate from emailing to broadly over-inclusive list). A majority of the survey responses were from small providers without an EHR (60% of respondents did not have an EHR and almost 80% of those had less than 20 employees). See Appendix E for the Final Provider survey report. Further survey results are presented below.

**Breakdown of survey respondents with an EHR:**

- 13.4% Primary care and/or integrated primary care & behavioral health
- 18.1% Individual or small group provider of mental health or SA services
- 58% Behavioral health providers other than individual/small group
- 10.5% Miscellaneous others

**EHRs in use by behavioral health providers:**

- EHR software varied widely
- Vendors systems in use:
  - 3 or more users: Office Ally, Practice Fusion, NetSmart
  - 2 users: Centricity, Therap, and Askesis

**How providers with an EHR communicated with other providers:**

- 88% Report coordinating patient care with other providers
  - 90% via Telephone
  - 69% via Fax
  - 61% via Mail
  - 3% via HealthInfoNet (HIE)

**Breakdown of survey respondents without an EHR:**

- 8% Primary care and/or integrated primary care & behavioral health
- 46.1% Individual or small group provider of mental health or SA services
- 27.3% Behavioral health providers other than individual/small group
- 8.6% Miscellaneous others

**Most Important Barriers to Implementation for non-EHR users:**

- Up-front Costs
- Ongoing resources to maintain the system
- Privacy & Security Concerns

**Least Important Barriers to Implementation for non-EHR users:**

- Patient Push-back
- Fear of System Outage
- High Speed Secure Internet Access

**How providers without an EHR communicated with other providers:**

- 96% Report Coordinating Patient Care with other providers

- 96% via Telephone
- 66% via Fax
- 53% via Mail

**Plans for Future Use of EHR for those currently without an EHR:**

- Of the 54 respondents, 34 indicated they had no plans to implement an EHR, but would if they could secure needed resources
- Twenty of the respondents indicated they planned to implement an EHR within next 2 years

**General Survey Conclusions:**

- The majority of behavioral health providers currently coordinated care through traditional means.
- Both those with and without an EHR agreed that they would access client information through the HIE if it was available to them.
- The cost and ongoing maintenance was the most frequent identified barrier to implementing an EHR.
- There was a need for best practice and training resources for behavioral health agencies in the process of implementation and connection to the HIE.

The survey informed the development by HealthInfoNet over the contract period, of the technology to allow access to the HIE regardless of the level of HIT adoption as well as the Toolkit. The following recommendations were based on the results of the survey and the Workgroup's experience creating the Toolkit.

- Focused educational resources should be made available to behavioral health providers, especially smaller providers, (similar to the resources available through Regional Extension Centers) to assist them in joining the broader health care community in implementing electronic records.
- Efforts to capture lessons learned from mental health providers should be focused upon. Real life examples and best practices from mental health providers can be of great benefit to those who are at an earlier point in a transition to electronic information sharing. These activities could focus on several different key activities, for example, (1) the process of decision making for moving to an electronic health record (EHR); (2) evaluating and selecting an EHR; (3) implementing an EHR; (4) communicating with other health care providers electronically through the HIE or secure email; etc.

## **The Behavioral HIT Data Standards Workgroup**

The Data Standards Workgroup was organized to achieve the Taskforce Objective 1c: With primary care and behavioral health providers and consumer involvement, and building upon existing standards in use in Maine and nationally, develop model data standards to facilitate effective behavioral HIE. Their charge was to further develop behavioral health data elements that should be added to/augment the current Continuity of Care Document (CCD) standard to facilitate HIE.

### Action Steps

The Workgroup reviewed the data elements identified for HIE in 2011 and considered additional data elements that would add value for care coordination purposes amongst behavioral health and primary care/general medical providers. The following data elements were considered for inclusion in the Maine Data Elements Worksheet.

- Risk status for suicide/homicide
- Specialty of prescriber
- Allergies (note severity of reaction)

The Workgroup also discussed at length the question of including court orders/blue page/white page in the HIE and concluded that this was not feasible.

The Workgroup then compared the new data elements to those being developed at the national level for the Continuity of Care Document Standard (CCD) and matched the wording on the Maine Data Elements Worksheet with the new National Data Elements Worksheet document.

By the end of the project period the Workgroup had identified data elements that could be useful for clinicians when coordinating patient care between behavioral health and physical health providers and possible data elements for quality reporting. *Appendix C* contains the use cases identified for HIE in Maine. The Workgroup presented the data elements they recommended for inclusion in Maine's Data Elements Worksheet and the National CCD Standard at the final forum of the Strategic Action Taskforce on January 16. *Appendix D provides the full Data Elements Worksheet.*

**Figure 3: Data Elements recommended for inclusion in CCD**

<b>Social History</b> <ul style="list-style-type: none"><li>– Court orders</li></ul> <b>Medications</b> <ul style="list-style-type: none"><li>– Specialty of prescriber</li><li>– History of psychiatric medications</li><li>– Medication history</li></ul> <b>Advance Directives</b> <ul style="list-style-type: none"><li>– Behavioral Health Advance Directive</li></ul> <b>Insurance Status</b> <b>Plan of Care</b> <ul style="list-style-type: none"><li>– Treatment plan</li></ul>	<b>Person Information</b> <ul style="list-style-type: none"><li>– Guardian</li><li>– Emergency contact</li><li>– Crisis plan</li></ul> <b>Encounters</b> <ul style="list-style-type: none"><li>– Psych admission</li></ul> <b>Family History</b> <ul style="list-style-type: none"><li>– Marriage status</li><li>– Children</li></ul> <b>Functional Status</b> <ul style="list-style-type: none"><li>– Housing status</li><li>– Risk status for suicide/homicide</li><li>– History of Risk Violence</li><li>– History of Risk Suicide</li></ul>
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### The Consumer and Provider Education Workgroup

As discussed above, consumers have been involved in the HIE since its inception. In 2007 a board level Consumer Advisory Committee was established to advise and make recommendations on consumer communications, consent, project activities, data use etc. It is this early involvement of the consumer and consumer advocacy community that has led to the success of the HIE in the State of Maine, the current opt-out consent processes for general medical information and opt-in for mental health data.

Behavioral health consumers have been involved in the CIHS project through their involvement in the overall Taskforce and its workgroups, most particularly, the Consumer & Provider Education Workgroup.

The Consumer and Provider Education Workgroup was organized to achieve the Taskforce objective 1b. With consumer and provider involvement and building upon the tools in use by the Maine HIE, the workgroup developed consumer and provider educational materials to assist consumers in making informed decisions about behavioral health information sharing including:

- A comprehensive plan for educating the primary care and behavioral health provider communities regarding consumer options and methodology for shared decision making on behavioral health clinical information sharing.
- A comprehensive plan for consumer education about clinical information sharing particularly focused on behavioral health and the HIE.
- Education materials to inform consumers about their choices in sharing behavioral health data with the HIE (utilizing consumer focus groups and building upon tools in use by the Maine HIE).
- Materials to assist primary care and behavioral health providers in informing consumers about their options in sharing behavioral health data with the HIE.

The Workgroup conducted focus groups with consumers and providers of behavioral health services in which participants reviewed draft materials aimed at helping consumers make an informed decision about sharing their mental health information. Since all provider participants were from only one agency, the Workgroup distributed a survey to individuals representing both behavioral health and primary care providers. The conclusions from both were consistent. The Workgroup used the cumulative results of the focus groups and provider survey to develop and refine the consumer and provider educational materials and consent form for sharing behavioral health data.

A summary of the results from both the consumer and provider focus groups is below. The final report was presented at the final forum of the Strategic Action Taskforce on January 16, 2013.

#### Maine 2012 Consumer Focus Groups Summary of Results

Five focus groups were held in three Maine Counties with each focus group targeting a different population: adults accessing mental health services, veterans, seniors, young adults and persons with intellectual disabilities (and their guardians). Rurality and health insurance was considered when identifying potential participants.

In total, 43 people participated in the groups. All participants resided in Maine and at least 60% of participants had received physical and mental health care within the past year. Please refer to Figure 4 for additional information about focus group participants.

**Figure 4: Participants Demographics**

Participants	43		
Target audience			
Seniors (65 years +)	14.0%	Veterans	20.9%

Adults (25 – 65 years)	53.5%	Persons with IDD	2.3%
Youth (- 25 years)	53.5%	Guardians of persons with IDD	16.3%
<b>Gender</b>			
Male	46.5%	Female	53.5%
<b>Visited a primary health care provider within the last...</b>			
30 days	44.2%	6 months	27.9%
Year	9.3%	More than a year	14%
Can't remember	4.7%		
<b>Visited a mental health provider within the last...</b>			
30 days	48.8%	6 months	7.0%
Year	4.7%	More than a year	16.3%
Can't remember	9.3%	Never	9.3%
<b>Pay for medical costs through...</b>			
MaineCare	55.8%	Medicare	18.6%
Military, CHAMPUS or the VA	20.9%	Private health insurance	16.3%
Self-pay	9.3%		

### Protocol for Focus Groups

The consumer focus groups participants were presented with a mock behavioral health treatment session. They were asked to pretend they were listening to a behavioral health provider or counselor and discussing the sharing of sensitive health information with a patient. The participants were then asked, if they were the patient, how would they be feeling and thinking? The summary below details the focus areas we were looking for feedback on and the emerging themes across all focus groups.

#### Focus areas

- Benefits of sharing information
- Common Questions
- Common Concerns
- Consent Process

#### Benefits of Sharing Information

- **Acts as a surrogate patient voice.** The electronic health record can talk for a patient when s/he cannot. This may happen when a person is in crisis or is unconscious.
- **Increases the accuracy of records.** The electronic health records “talk” the same language as the doctor, so medical terms and medications don’t get miscommunicated. With time (and age), it gets difficult for patients to remember all of the correct information.
- **Decreases the patients’ burden of record keeping.** HealthInfoNet would decrease the responsibility and burden on the patient to ensure all the doctors have the necessary information. Patients spend a lot of time on the phone and driving between doctors to get their health records.
- **Decreases the need for patients to continuously repeat their story.** Patients spend a lot of time answering the same questions with different doctors. A shared system would alleviate the need to continuously ‘tell the same story.’



- **Makes doctors and patients more accountable.** HealthInfoNet will make both the doctor and patient more accountable.
- **Helps increase doctor efficacy.** Doctors make decisions based on the information they have, but doctors don't know what they don't know. Providing doctors with access to all patient records electronically, particularly medications and diagnosis, means that they can make the best treatment plan.
- **Helps ensure patient safety.** Without seeing a patient's medication history, a doctor may prescribe a medication that counteracts with the patient's current medication; or the doctor may prescribe something a patient has previously had a bad reaction to.

### Common Questions

- **What is HealthInfoNet?** Participants struggled to understand exactly what HealthInfoNet was conceptually, and asked for more information about how it was funded and the extent of government (state and federal) involvement
- **Does HealthInfoNet reach outside Maine?** Participants were not sure about the geographic boundaries of HealthInfoNet, both currently and in the future.
- **Is provider participation required?** Participants were interested in understanding why some providers were participating in HealthInfoNet and some were not. They assumed the reason for non-participation was cost related, and were concerned about how this would affect patients who wanted their records in the system. Of particular concern was whether the VA was participating in HealthInfoNet. This was seen as critical to veterans who, while the VA was their medical home, often received emergency care outside the VA and needed a way to share information across providers.
- **What is the plan for a security breach?** The security of HealthInfoNet was a concern to participants as they had their own experiences and fears about losing data, hackers, and identity theft. Participants were most concerned about identity theft because the system stored their social security number.
- **Why is substance abuse not included?** In general, participants were puzzled about substance abuse not being included. They felt that mental health and substance abuse go hand-in-hand and questioned why it was excluded from the records.
- **Why would a provider want to see my information?** While most participants saw the benefit of primary care or emergency providers accessing your mental health diagnosis and medications, they questioned the need for specialized providers accessing these records. Examples included mental health providers accessing medical records and specialists accessing mental health records.
- **What information is included?** Participants thought it was important for them to know what information was in the system so that they could provide doctors with additional information.
- **Who gets to see my information?** There were concerns about records being available to insurance companies, legal professionals in medical error cases, medical students, and healthcare administrative staff.

## Common Concerns

- **The patient loses control of information.** Some participants, particularly young adults, felt they may lose control by giving consent. The view by these participants is that right now a patient holds most of the information and is able to decide which information to tell a provider. By giving consent, they may forego the control and have to rely on the accuracy of the provider records.
- **Access is all or nothing.** Some participants were concerned that their consent would mean all their records were available to everyone. Participants suggested that there should be different levels of access among providers.
- **Mental health stigma and discrimination.** Some participants in the focus groups alluded to stigma and discrimination. They felt that patients may be treated differently by what is in their records, especially if it was something they were ashamed of.

## Consent for Opting In Mental Health Information / Opting Out of the HIE

- **Simply state the options and consequences.** Participants understood that there were four choices to opt-in their information. For a description of the choices refer to *Figure 6 Consumer Choices for sharing information*.
- **Define terms and give examples.** Participants asked what constitutes an emergency, who decides if the situation was an emergency, and if the patient is told if his/her information was accessed. They suggested that examples and guidelines may help increase their understanding of the process e.g. if a participant went to the emergency room, would they have a say in deciding that they were in an emergency and that the doctor could therefore access their records? Due to the rural nature of Maine and scarcity of psychiatrists, primary care providers often treat their patient's mental health condition. Participants were not sure if that treatment would be included in the patient's existing medical record?
- **Explain the process in simple terms.** Participants asked many questions about the consent process and how it actually worked.

## Conclusions from Consumer Focus Groups

The objective of these focus groups was to gain qualitative understanding about what patients perceived as the benefits of a system such as HealthInfoNet, their concerns and questions. Participants articulated many patient benefits. We found that the patients were less concerned with stigma and discrimination than with the possibility of security breaches and the idea that all of their records would be available to all providers in the system. The majority of patients would prefer a tiered consent model where consent is tiered by provider type. This means that patients would have the ability to consent to share specific information with specific types of providers involved in their care. Patients also felt it strange that substance abuse information was not included.

## Recommendations for Future Patient-focused Educational Materials

- **Separate the educational and consenting materials.** By combining the materials, patients expected all forms for all options (e.g., consent to share information, consent to not share any information, limited consent, etc.). In addition, when given documents that end with signature requirements,

almost all participants did not read the print and simply turned to the form they needed to complete.

- **Use graphics to illustrate concepts and processes.** All participants listened to a mock session of a provider explaining what HealthInfoNet was and what decision was required. In addition, they were asked to read the educational materials. However, they were still not sure what HealthInfoNet is, and what the consent options were. It is recommended that graphics be used to convey these complex concepts.
- **Emphasize patient benefits and use quotes.** Almost all participants thought it would be beneficial to consent to sharing their mental health records. It is recommended that materials utilize the quotes from real people to emphasize the benefits to patients.
- **Address consumer concerns about security and controlling access.** These were the two greatest concerns and it is recommended that they be addressed in any educational materials produced. In particular, it is important to communicate to patients the existence of a strict role-based access policy to alleviate some fears with sharing mental health information.

### Maine 2012 Provider Focus Groups Summary of Results

To gain provider perspective and insight into the tools providers might need when talking to patients about sharing mental health records we conducted one focus group for mental health and primary care providers with a survey distributed to individuals representing both mental health and primary care providers. This distribution list was obtained through our state Medicaid program. Please refer to *Figure 5* below for details on focus group participants.

**Figure 5: Participant Demographics**

Participants		36	
Type of services provided:			
Integrated: Clinical and mental health	25%	Other	11%
Mental health	50%		
Substance abuse treatment	14%		
Role			
Direct service provider	31%	Non-direct (administrative)	66%
Other	3%		
Length of time working in the community?			
Less than 1 year	8%	1 - 4 years	8%
5 – 10 years	14%	More than 10 years	70%

### Protocol for Provider Focus Group

Following introductions, a brief educational PowerPoint was delivered to focus group participants that focused on how the statewide health information exchange (HealthInfoNet) operates and the consent options for participation.

Using a real-time polling framework, a question (survey style) was posed to participants. Each participant selected a response option by clicking his/her voting pad. The results were displayed in real-time and a discussion on the results was facilitated.

In addition to the process described above, participants were handed the existing draft consent form, developed by HealthInfoNet, asked to read through it and give their opinion, particularly in terms of suggestions for words and phrases. The same questions used in this focus group session were also sent out to the additional providers as an online survey.

The summary below details the focus areas we were looking for feedback on and the emerging themes across both the focus group and survey.

**Focus Areas. We asked providers to respond to the questions from both their own perspective and that of the consumer.**

- What benefits do you see in sharing behavioral health records electronically?
- What are the issues or barriers related to sharing behavioral health records electronically?
- What education materials do you need, they were give content
- When would the education and consent processes occur for consumers in the office?

**The Benefits of Sharing Information**

Providers identified increased communication and coordination between providers and better treatment management as the primary benefits to sharing information though the HIE. They also felt it paramount to educate consumers and providers in the value of sharing information if the system was to achieve better coordination of patient care.

**Barriers to Sharing Information**

The issue of confidentiality and loss of control over who has access to what records was a concern. This concern was more prominent in dedicated mental health service organizations than in integrated systems of care. Additionally the administrative burden to implement this process was a concern. Some providers felt sharing information with the HIE might expose the consumer to discrimination. Like in the consumer focus groups, some providers were concerned that substance abuse information was not included.

**Tools for talking with patients:**

The following tools were seen as critical (in order of frequency):

- One-page handout for patients
- Talking points for providers

The following information to convey through these tools was seen as critical (in order of frequency):

- Benefits of sharing behavioral health records (87% - particularly among behavioral health services)
- Consent options (87% - particularly among behavioral health services)
- Consent process (65% - particularly among behavioral health services)
- Which providers are participating (65% - particularly among integrated service providers)

**Process of Obtaining Consent**

There were different opinions on when during a patient visit the education and consent should occur, approximately half of survey respondents (54%) and all focus group participants felt that both education and consent should occur during the visit and that it should be undertaken by the provider (73% survey respondents and 100% focus group participants).

### Conclusions of Provider Focus Group and Survey

The objective of the provider focus group and survey was to gain qualitative understanding and insight into what providers perceived their needs to be when talking to patients about sharing behavioral health records through the HIE. Results were consistent through both the focus group and survey. Participants articulated many patient and provider benefits.

### Recommendations

- **Create brief patient educational materials and provider talking points** that include the benefits of sharing mental health records, consent options, the consent process, and which providers are participating (or provide a link to the latter).
- **Emphasize the availability of audit reports** in both materials. This will help alleviate some of the concerns of providers and patients by enabling them to see who has accessed patient-specific records.
- **Use graphics and simple language to explain concepts and processes.** It is important for the providers to be able to easily articulate and explain HealthInfoNet, the consent options, and consent processes.
- **Address concerns about controlling access** in both materials. Emphasize the existence of a strict role-based access policy to alleviate some fears with sharing health information.

The results of the focus groups were used by the Consumer and Provider Education Workgroup in conjunction with HealthInfoNet to finalize the consent form and consumer and provider educational materials. See *Figure 6* for a summary of the consumer choices for sharing clinical data in the HIE.

**Figure 6: Consumer Choices for sharing information**

Your Choices	Action you need to take	General Medical information	Mental health & HIV information
Share your medical information only.	Do nothing	Available to all participating providers	Available only in medical emergencies
Share your mental health information, HIV information, or both.	Fill out a consent form available from your participating provider or HealthInfoNet and consent to share mental health, HIV or both.	Available to all participating providers	The type of information you choose will be available to all participating providers.
Share your mental health information, HIV information, or both, with an individual provider.	During your visit, tell your participating provider they have your consent to access your mental health, HIV/AIDS information or both.	Available to all participating providers.	Available to that individual provider during that visit. You will need to give permission next time you want them to have access.
Remove all your medical information from HealthInfoNet.	Fill out an opt-out form available from HealthInfoNet, your provider, or online at <a href="http://www.hinfonyet.org/optout">www.hinfonyet.org/optout</a>	All information is deleted from your record and will not be available to your participating providers, even in an emergency.	All information is deleted from your record and will not be available to your participating providers, even in an emergency.

With the consent form and consumer and provider educational materials completed, HealthInfoNet is poised to start education in preparation for the sharing of mental health information in the spring of 2013. See Appendix F for the Consumer and Provider Focus group report, Appendix G for the HealthInfoNet Mental Health and HIV Opt-In Consent form, and Appendix H for the HealthInfoNet Brochures and Talking Points

As part of their final presentation to the final forum, the Consumer Provider Education Workgroup proposed four recommendations for future work:

1. To clarify and ensure consistency in what information will be shared, a template should be developed for a standardized visit summary for behavioral health visits.
2. A number of focus group participants felt their mental health diagnosis exposed them to discrimination and sometimes biased treatment when visiting the emergency room for a medical complaint. A coordinated educational effort should be undertaken to educate emergency medical providers to recognize and reduce this discrimination. This education should include bringing together patient and providers where patients can share their negative experiences.
3. Based on individual clinical settings, workflows, and whom the consumer/patient knows and trusts, providers should carefully consider which positions within their organization/practice setting are the most appropriate to do the consumer/provider education about HealthInfoNet and options for clinical information sharing.
4. Many hospitals and practices now provide patients with an online portal where they can access their medical information from that facility, schedule appointments and email their providers. The Workgroup recommends that provider organizations work with HealthInfoNet to find a way for patients to access their information in HealthInfoNet through these portals.

## Policy and Regulatory Issues and Addressing Legislative Changes in Maine

Under a law passed in 2011 (LD 1331), HealthInfoNet can cease blocking protected behavioral health and HIV information. This protected information includes information created by licensed behavioral health providers or facilities, HIV diagnoses and results of HIV lab tests. HealthInfoNet is required under the new law to shield this information until the patient chooses to expose it (opt it in), or if the patient is in an emergency deemed by the treating provider. Since the HIE went live in 2008, HealthInfoNet has gone beyond state law and blocked diagnoses codes for mental health conditions. These codes will now be shared along with the information described above when a patient chooses to opt-in.

### Consumer Choices or Opt-In Consent

Option 1: Opt-in all information and make available to all users, at all times.

- Consumers will communicate this decision to HIN via fax, mail or electronically. They will have the option to select behavioral health, HIV or both.
- Providers will see this information integrated into the record and HIN will add a flag to the consent field so that the provider knows this information has been opted in.

Option 2: Leave information in the HIE, but only make it visible when the patient chooses to expose it. This will be on a per user basis.

- The patient consents at the point of care.
- After the provider breaks the glass in either of these situations, a new folder containing the protected information will show up in the list. The patient will consent to behavioral health, HIV or both. Therefore there will be two folders, one for behavioral health and one for HIV.

The opt-in consent form developed is attached in **Appendix G**

### Legal & Regulatory Barriers Workgroup

The Legal and Regulatory Barriers Workgroup was constituted in order to achieve the Taskforce Objective 1d: With behavioral health providers, consumers, and legal experts in Maine, and the Center for Integrated Health Solutions, develop recommendations for consent options for authorization for the release of behavioral health and substance abuse information to the Maine statewide HIE.

The Workgroup's charge was to address and clarify state and federal legal / policy issues (e.g. 42CFR Part 2) that impact behavioral health data sharing especially in relation to HIEs. This workgroup was structured as a series of meetings with legal experts around the State of Maine focused on addressing issues related to the interpretation of 42CFR Part 2 in regard to HIE. As part of this process, legal experts on the project met with the Maine State Bar Association's health care group to explore options for the statewide HIE to accept substance abuse data. The feedback from this group was incorporated into ongoing discussions with the CIHS project teams during monthly calls to support the development of draft consent language for health information exchange of substance abuse data.

Maine continued to engage in the national discussion around 42CFR Part 2 and HealthInfoNet's legal counsel was involved in all discussions organized by the National Council. These discussions included; CIHS project teams and representatives of the Federal Substance Abuse and Mental Health Services Administration (SAMHSA).

Through these calls, the participants sought to design a standard consent form that would permit consumers with health information protected by the Part 2 regulations to consent to including that information in a HIE. Although there was significant exchange of information and understanding, ultimately SAMHSA's interpretation of the Part 2 regulations led HealthInfoNet to conclude that current technology would not permit inclusion of Part 2 protected substance abuse information in the HIE at this time primarily due to the requirement that the patient consent "to whom" the information was to be shared. While HealthInfoNet can state who is connected to the exchange at any time, as HealthInfoNet adds new providers to the exchange the complexity of managing individual providers' access to patients' data rather than an all-in or all-out approach was both too costly and added significant risk for error in the technologies. HealthInfoNet continues to work with the National Council and SAMHSA to come to a solution that can be technically managed in Maine.

### Health Systems and Payment Reform Workgroup

The Health Systems and Payment Reform Workgroup was organized to achieve the Taskforce Objective 3: For all behavioral health and primary care providers and consumers, develop a stronger mutual

understanding by behavioral health providers and primary care providers about accountable care, MaineCare value-based purchasing, and other payment reform models and how these models and policies make electronic clinical information sharing for integration of behavioral health essential.

With this objective in mind, the Workgroup set three primary goals and developed a set of ten recommendations. The three goals were established in close collaboration with other statewide organizations focused on behavioral health clinical integration, including Quality Counts, the Maine Health Access Foundation, HealthInfoNet, the State of Maine and others.

### **Primary Goals**

**Goal One:** Build awareness and engage key stakeholders (listed below) in efforts to accelerate the adoption of EHRs and other electronic systems that will lead to improved quality and coordination of care.

**Maine Health Management Coalition** (The Coalition): is a statewide nonprofit organization representing employers, payers, providers and others.

- The Coalition's new Director of Payment Reform has become an active member of the Payment Reform/Health Systems Workgroup.
- Taskforce representation has been added to the Coalition's Accountable Care Committee.
- Preliminary groundwork laid for the development of a strategy aimed at encouraging employers and payers to support incentives that will make it possible for more behavioral health providers to acquire EHR and other electronic systems.

**Maine's Emerging ACOs:** Maine has six emerging Accountable Care Organizations (see below); two of these participate in the Northern New England Accountable Care Collaborative.

- Leaders from each of Maine's emerging ACO's have been briefed on the Taskforce's work and growing interest in EHR among behavioral health providers.
- ACO's have been asked to consider ways in which they could assist unaffiliated behavioral health providers acquire EHR and other electronic systems.
- MaineCare has included a Meaningful Use like incentive program in its State Innovation proposal in partnership with HealthInfoNet.
- MaineCare also has been encouraged to include incentives (based on principles listed below in Goal two) as it develops its Accountable Care Communities Initiative (ACC).

**Maine's Congressional Delegation:** Maine's four-member Congressional Delegation includes: Senator Susan Collins (R), Senator Angus King (I), Representative Michael Michaud (D) and Representative Chellie Pingree (D):

- Staff representing two of Maine's Congressional Delegation members (all invited) attended the January 16 forum. Staff learned how mental health and other providers across Maine would benefit from the passage of proposed federal legislation extending Meaningful Use incentives to mental health providers.



- HealthInfoNet Leadership will travel to Washington, DC in April 2013 to meet with all members and their health policy staff.

**Goal Two:** Develop principles to guide the development of incentives that help behavioral health providers acquire EHRs and other systems that will lead to greater electronic information-sharing and improved coordination of care.

The workgroup recommended that the State develop strategies to encourage Maine's ACOs to assist unaffiliated behavioral health providers who wish to acquire EHRs and other electronic systems. Financial, technical and other incentives should be:

- Incorporated into emerging value-based purchasing (VBP) and Accountable Care initiatives.
- Designed to help achieve the goal of improved continuity of care as behavioral health and medical providers care for individual patients simultaneously.
- Structured to help providers acquire the resources needed to adopt EHR systems and secure email, and to share appropriate clinical information across organizational lines.
- Introduced incrementally to support providers that have no technology as well as those who have already invested in technologies
- Designed to help providers achieve measureable goals.
- Positioned to take advantage of lessons learned from the CMS Meaningful Use program
- Developed in close coordination with HealthInfoNet, Quality Counts, the Maine Health Management Coalition and emerging ACOs and MaineCare ACC.

**Goal Three:** Develop strategies to encourage Maine's ACOs to assist unaffiliated behavioral health providers who wish to acquire EHRs and other electronic systems.

Background: Interviews were conducted with senior leaders at all of Maine's emerging ACO's.

- Central Maine Health Care
- Eastern Maine Health Systems
- MaineCare ACC
- Maine General
- MaineHealth
- Maine Primary Care Association
- Northern New England Accountable Care Collaborative

The ACO leaders were briefed on the work of the Behavioral Health IT Taskforce. Given the ACOs' role in assuming greater accountability for population health, these leaders were asked to share their thoughts about the role ACO's might play in assisting unaffiliated behavioral health providers acquire EHRs and other systems that will allow improved coordination of care. Interviews with these leaders found:

- Growing understanding and awareness of the importance of developing systems to better coordinate care/share patient information with unaffiliated as well as their affiliated behavioral health provider.
- At present time larger health systems are consumed with the development of computer systems that will allow their affiliated providers to coordinate care/share patient information. While there is substantial progress being made on Medical Home initiatives, relatively little work is now under way to develop systems with unaffiliated behavioral health providers in these larger systems.
- Acknowledgement that over time ACOs will need access to data from more and more unaffiliated behavioral health providers to achieve their population health management goals.
- Strong interest in secure email as an affordable avenue for many unaffiliated behavioral health providers with no EHR and limited resources to share patient information with other medical providers.
- In some instances (Maine General, Eastern Maine Healthcare Systems, and Tri County Mental Health Services) where local or regional progress is being made to connect systems with unaffiliated behavioral health providers, interest in opportunities for other ACOs to learn from and possibly replicate this work.
- Some interest in providing technical and other assistance to unaffiliated providers, particularly if this was tied to the development of coordinated networks focused on managing the care of MaineCare beneficiaries.

### **Workgroup Recommendations**

Establish Workgroup of senior behavioral health providers to:

- Refine the principles developed in 2012 to create a set of incentives that can be used by payers, employers, ACOs, MaineCare and others to accelerate adoption of electronic systems and information sharing between unaffiliated providers.
- Develop a clear value proposition that will build a solid, data-driven case for greater coordination of care between systems and unaffiliated behavioral health providers; engage an independent third party in reviewing and refining value proposition.
- Develop a pilot study that looks at the impact that uncoordinated behavioral health utilization and costs have on a community or region (leverage research previously conducted by Dr. Elsie Freeman at Maine's Department of Health and Human Services (DHHS))<sup>7</sup>.
- Review work now under way in communities with coordinated initiatives (Maine General, Eastern Maine Health care Systems, Tri County Mental Health Services, etc....) and develop a set of best practices for other systems/ACOs.
- Present recommended incentives, value proposition and study results to a statewide meeting of ACO leadership.

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<sup>7</sup> For more information on the work of Dr. Elsie Freeman and Maine DHHS see: <http://www.maine.gov/dhhs/QI/reports.shtml>

- Partner with ACO leadership to build further understanding among Maine’s Congressional Delegation about the importance of extending Meaningful Use incentives to behavioral health providers.
- Identify and approach 2-3 private national funders with proposals to expand the proposed MaineCare behavioral health Meaningful Use pilot in Maine.
- Closely coordinate this work with other related initiatives (Quality Counts, MeHAF, etc.) to prevent redundancy and overlap.
- Build awareness among behavioral health, medical providers and consumers about recent changes in Maine law that allow for greater sharing of behavioral health information.
- Advocate for federal and foundational resources and support for electronic records in integrated care by working with MeHAF and other grantors as well as the foundation/federal agency partnership to expand and sustain integrated care.
- Provide data related to the need for electronic health records and infrastructure to support interfaces that enhance integrated behavioral health and primary care.
- Recommend potential connections between/among the missions and key initiatives of foundations and federal agencies and the behavioral health HIT work in Maine (perhaps offering to be a pilot or demonstration site).
- Work with University of Colorado/AHRQ to include EHR competencies in the development of the AHRQ Integrated Care Workforce Competencies project.

### Coordination with National and State Partners

HealthInfoNet continues to coordinate with State and national partners. HealthInfoNet is a Beacon Grant participant with Eastern Maine Healthcare Systems and their mental health hospital, Acadia, is an active participant in all the CIHS project activities and is the first mental health hospital in Maine to participate in the HIE. HealthInfoNet is also the Regional Extension Center (REC) for the State of Maine, funded under the Office of the National Coordinator for Health Information Technology. As a result, REC staff have been integral NCIHS team members and developed EHR toolkits for use by behavioral health providers throughout the State (see updates above regarding The Behavioral Health EHR Action Planning Workgroup)

The CIHS workgroups have participation by many State partners including the Office of the State Coordinator for HIT, Medicaid (MaineCare), the Office of Mental Health, the Office of Substance Abuse and the Maine Centers for Disease Control. HealthInfoNet continues to assure coordination of the CIHS project activities with its broader efforts as an HIE and key resource for HIT supports across the State of Maine.

### Behavioral Health Providers’ Connection to the HIE

The Maine CIHS project is supporting five behavioral health organizations for bi-directional HIE and 20 organizations for view/download access.

The process providers use to connect to the HIE began with the legal review of the HealthInfoNet Participant Agreement and Business Associate Agreement. This required discussions between the provider, their legal council and, in some cases, HealthInfoNet's legal council. Once the participant agreement was signed, HealthInfoNet began the onboarding process. The first step was to establish a secure connection point to the organization followed by education on the processes, communications, consent, etc., for the organization's staff and leadership. At this point "view/download" access to the exchange was granted to authorized users allowing them to access, view and download data from the HIE. This functionality allowed organizations to have early access to the benefits of the HIE while the complex and time-consuming interfaces were developed to enable bi-directional exchange. This latter activity usually took between three and six months depending on the technical skills of the organization and the involvement of the EHR vendor.

### **Infrastructure Development Required by HIE**

HealthInfoNet, through this project, has made significant changes to its HIE infrastructure. As discussed above, the core HIE structure was built to block or delete all mental health and substance abuse diagnoses, procedures and laboratory data. To facilitate the inclusion of the mental health data, a separate data store was built to support the sequestration of mental health data directly from the HL7 data intake process. This architecture allows mental health (and HIV) data to be taken into the HIE, but managed differently than general medical information and only exposed if the opt-in criteria described in previous sections of this report are met. The implementation of this process has been finalized and the consent triggers have been programmed. HealthInfoNet continues to work with behavioral health providers to incorporate their data into the exchange. It is anticipated that by late spring HealthInfoNet will go live with the bi-directional mental health exchange infrastructure.

### **Bi-directional Connections to the HIE for Behavioral Health Organizations**

Five behavioral health organizations in Maine choose to partner on a single EHR package. These organizations agreed to be pilot sites for bi-directional connection to the HIE during the project period. The organizations are using an EHR vendor called ClaimTrak and will be interfacing using the HL7 messaging standard. The remaining 20 organizations will access the view/download function of the HIE only.

Initially, HealthInfoNet and the five organizations tested sending data from all five organizations to the HIE. Using a secure VPN connection, participants now have the ability to send ADT (encounter messages) data to the HIE and HealthInfoNet's systems are now configured properly to accept these messages through a secure VPN connection. HealthInfoNet has implemented the appropriate handling of this sensitive data to make it acceptable within the HealthInfoNet clinical portal. Due to a change in ClaimTrak's pricing structure, connection progress has slowed. HealthInfoNet is working with the five organizations and ClaimTrak to find the most feasible manner to connect to the HIE at the lowest cost.

Efforts are also being made to bring down the overall cost of the HIE subscription fees through leveraging State and federal grant programs, seeking out new funding sources and partners, and promoting low-cost connections to the HIE including new tools such as NwHIN Direct.

## View/download Connection to the HIE for Behavioral Health Organizations

Twenty organizations were selected for view/download access to the HIE. The process began with a series of educational webinars for all users of the HIE portal to familiarize them with the use of the portal and answer questions. These webinars have continued regularly as each new set of users connect to the HIE. HealthInfoNet has also run webinars and provided on-site technical assistance related to basic HIE connection activities to address provider concerns over the complexity of the technologies.

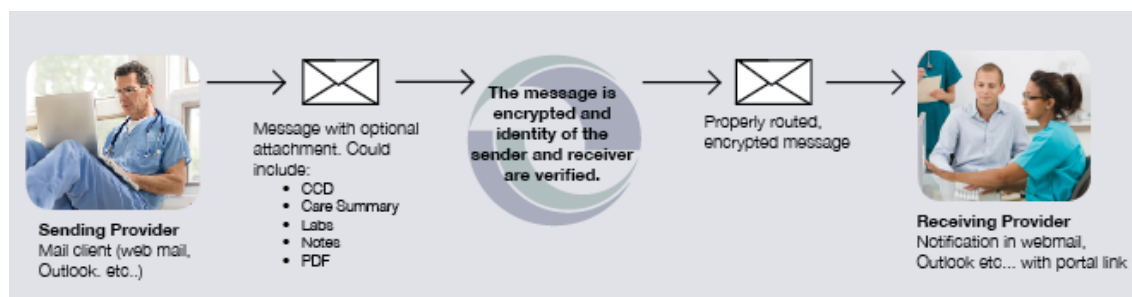
Currently, 20 agencies have created accounts for a total of 214 identified users and 54% of those had access to the HIE through the view/download function. We anticipate all users and organizations will have access by late spring 2013.

## Behavioral Health Provider use of NwHIN DIRECT

HealthInfoNet contracted with Surescripts to be the NwHIN Health Information Service Provider (HISP) for the Direct Project and went live with the tool in August of 2012. HealthInfoNet spent the next several months working on policies, procedures, end-user agreements and communications materials to prepare for deployment to up to 200 behavioral health and primary care providers.

As of the end of January 2013, HealthInfoNet is piloting the NwHIN service with 100 primary care, behavioral health, and specialty users at Maine Medical Partners and Maine Mental Health Partners, both part of MaineHealth; a large integrated delivery system in Southern Maine. HIN has set up user accounts and is working on the pilot evaluation plan, including a pre and post survey. All users will also be set up with HIE accounts to evaluate how the two services complement each other. The pilot, will last for 90 days, after which, the service will be extended to additional Patient Centered Medical Home practices. This pilot project will help HealthInfoNet refine processes and workflows to ensure a smooth implementation of the technology for additional behavioral health providers joining in the spring. Figure 7 provides a simple graphic that HealthInfoNet uses to explain the NwHIN Direct solution to current and future providers.

**Figure 7: HealthInfoNet Direct Process**



## Conclusions and Next Steps

As the recipient of the NCIHS contract, HealthInfoNet, in collaboration with the Office of the State Coordinator and the Daniel Hanley Center for Health Leadership reconvened the statewide behavioral health HIT stakeholder group to advance the project goals. Using the stakeholder taskforce group process from 2011, five individual workgroups were developed. Over the project year, the workgroups gathered feedback from providers and consumers on educational materials, conducted research on information needed to improve communication between mental health and primary care providers, drew on expertise locally and nationally to develop tools and resources to support EHR implementation, and engaged policymakers in funding to support this integration.

### As a result of this funding:

- Maine now has 25 behavioral health organizations with the ability to access health information on their clients in the HIE with the remaining seven due to come on in the spring of 2013. Five of those will have the ability to share protected mental health information through the HIE for improved delivery of care and coordination with other health care providers by late spring of 2013.
- Consumers and providers have educational tools to support informed consent for consumers.
- Providers have an implementation toolkit to support EHR implementation and connection to the HIE.
- Recommendations were made for a common set of data elements to standardize communication between health care providers.
- The Taskforce has developed strategies to integrate behavioral health providers into the new emerging payment reform models in Maine and proposed a payment structure to assist in EHR adoption.
- Multiple dissemination activities have been conducted to date to educate providers, states, and national stakeholders on the lessons learned from this project including:
  - Webinars conducted monthly throughout the contract period by HealthInfoNet to the Maine provider community
  - May 2012: Presentation to Functional Interoperability and Health Information Exchange CoP (ONC) on HIE and Provider Engagement
  - July 2012: Presentation to PCMH Behavioral Health Integration Core Team Meeting on CHS Project Overview and invitation for PCMH team participation
  - August 2012: HealthInfoNet staff traveled to North Carolina to discuss HIE Consent, architecture, challenges and opportunities for mental health and substance abuse inclusion
  - September 2012: HealthInfoNet presented to the Massachusetts Health Data Consortium Behavioral Health Workgroup on Consent Options for Behavioral Health HIE and linkages with health reform efforts
  - October 2012: HealthInfoNet presented at the Multi-state Coordination and Communication Series (ONC) on CHS Project Overview

Despite these results, providers still face ongoing barriers and challenges to sharing behavioral health in the HIE. The cost of implementing and connecting to the HIE is still a considerable barrier for these providers. The cost not only includes purchase of technology, but the time and resources required to educate staff with a historically large knowledge gap around health care technology. Many, if not most, of the organizations that participated in the project treat patients for both mental health and substance abuse issues. The process of separating mental health from substance abuse information in the electronic record is complex and difficult. Also the implementation of the opt-in consent process and the communications about the HIE in general will require additional time in an already cramped registration and visit process.

**Recommendations and next steps developed to support the ongoing integration of behavioral health providers into the HIE include:**

- Continued support by SAMHSA and the National Council on interpreting 42CFR in the context of HIE and work on addressing the “to-whom” issue preventing substance abuse data from being exchanged
  - Maine behavioral health providers, consumers, legal experts need to continue to convene and discuss consent options for authorizing for release of mental health and substance abuse information to the HealthInfoNet
- Continued engagement by federal, state and local stakeholders in promoting behavioral health EHR standardization, reduced costs and interoperability
  - Focused engagement of key Maine stakeholders in the development of incentives (through grants and ACO activities) that help behavioral health providers acquire EHR and other systems that will lead to greater electronic information-sharing and improved coordination of care
- Continued support by federal, state and other stakeholders for providers to implement HIE into their facilities, including developing policies and procedures for staff connecting to the HIE
- Continued engagement of consumers by providers and the HIE on the value of information sharing
- Development of an educational series by the HIE for behavioral health providers around using the medical information available to them in the exchange to support better patient care
- Behavioral health visit notes currently are not accepted into the HIE. The group recommended a workgroup to develop a standardized visit notes template for future inclusion of this information in the HIE

## Appendices

***Appendix A: Strategic Action Taskforce Objectives and Meeting Dates***

***Appendix B: Workgroups & Tasks***

***Appendix C: Maine Use Cases***

***Appendix D: Data Elements Worksheet***

***Appendix E: Final Provider Survey Report***

***Appendix F: Consumer and Provider Focus Group Report***

***Appendix G: HIN Mental Health and HIV Opt-In Consent Form***

***Appendix H: HIN Brochures and Talking Points***



# Behavioral Health Clinical Information Sharing

## 2012 Taskforce Objectives & Meeting Dates



### Overall Objectives

As a result of our work with Maine behavioral health and primary care and other healthcare practitioners and stakeholders through December 2012, we will have:

1. For behavioral health providers choosing to participate in the statewide health information exchange, provided the following **key deliverables** to enable the successful implementation of access to Maine state health information exchange:
  - a. Documentation and tools to help behavioral health providers understand the standards, tools, and processes that can be used to connect to the statewide health information exchange no matter what EHR tools are in place.
  - b. With consumer and provider involvement and building upon the tools in use by Maine health information exchange, consumer and provider educational materials [concerning both behavioral and general healthcare] to assist consumers in making informed decisions about behavioral health information sharing;
  - c. With primary care and behavioral health provider and consumer involvement, and building upon existing standards in use in Maine and nationally, model data standards to facilitate effective behavioral health information exchange; and
  - d. With behavioral health providers, consumers, and legal experts in Maine, and the Center for Integrated Health Solutions, recommendations for consent options for authorization for the release of mental health and substance abuse information to the Maine statewide health information exchange.
2. For behavioral health providers seeking to implement a “shared service” Electronic Health Record in partnership with other providers, provided **a key deliverable** to enable enhanced electronic communication through a proposed Action Plan; and
3. For all behavioral health and primary care providers and consumers,, developed a stronger mutual understanding by behavioral health providers and primary care providers about accountable care, MaineCare value-based purchasing, and other payment reform models and how these models and policies make electronic clinical information sharing for integration of behavioral health essential.

### Taskforce Meeting Dates

Wednesday, March 14, 2012	9:00 am – 1:00 pm	Maple Hill Farm
Wednesday, April 25, 2012	9:00 am – 12:45 pm	MMA
Wednesday, May 30, 2012	9:00 am – 1:00 pm	MHA
Wednesday, June 20, 2012	9:00 am – 1:00 pm	MHA
Wednesday, September 26, 2012	9:00 am – 1:00 pm	MMA
Wednesday, October 31, 2012	9:00 am – 1:00 pm	MHA - tentative

### Final Forum

Wednesday, December 12, 2012	8:30 am – 2:00 pm	TBD
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# Behavioral Health Clinical Information Sharing

## 2012 Workgroups & Tasks



### Overall Objectives

As a result of our work with Maine behavioral health and primary care and other healthcare practitioners and stakeholders through December 2012, we will have:

1. For behavioral health providers choosing to participate in the statewide health information exchange, provided the following **key deliverables** to enable the successful implementation of access to Maine state health information exchange:
  - a. Documentation and tools to help behavioral health providers understand the standards, tools, and processes that can be used to connect to the statewide health information exchange no matter what EHR tools are in place.
  - b. With consumer and provider involvement and building upon the tools in use by Maine health information exchange, consumer and provider educational materials [concerning both behavioral and general healthcare] to assist consumers in making informed decisions about behavioral health information sharing;
  - c. With primary care and behavioral health provider and consumer involvement, and building upon existing standards in use in Maine and nationally, model data standards to facilitate effective behavioral health information exchange; and
  - d. With behavioral health providers, consumers, and legal experts in Maine, and the Center for Integrated Health Solutions, recommendations for consent options for authorization for the release of mental health and substance abuse information to the Maine statewide health information exchange.
2. For behavioral health providers seeking to implement a “shared service” Electronic Health Record in partnership with other providers, provided **a key deliverable** to enable enhanced electronic communication through a proposed Action Plan; and
3. For all behavioral health and primary care providers and consumers, developed a stronger mutual understanding by behavioral health providers and primary care providers about accountable care, MaineCare value-based purchasing, and other payment reform models and how these models and policies make electronic clinical information sharing for integration of behavioral health essential.

### Workgroups and Major Tasks

#### Consumer & Provider Education

Through engagement with consumer and provider constituencies, detail out the essential elements in an effective internal and external communication plan including

- A Comprehensive Plan for Educating the Primary Care and Behavioral Health Provider Communities regarding consumer options and methodology for shared decision making on behavioral health clinical information sharing
- A comprehensive plan for Consumer education about clinical information sharing particularly focused on behavioral health and the Health Information Exchange

- Educational materials- to inform consumers about their choices in sharing behavioral health data with the HIE (utilizing consumer focus groups and building out from tools in use by the Maine HIE)
- Educational materials for primary care and behavioral health providers to use to inform consumers about their options in sharing behavioral health data with the HIE

#### Data standards Group

Further develop BH data elements that should be added to/augment the current Continuity of Care Document (CCD) standard to facilitate electronic sharing through a Health Information Exchange

#### Behavioral Health EHR Action planning group

Produce a proposed action plan unique to the behavioral health world to be used as template for providers with varied electronic capabilities connecting with the HIE (based on an expanded survey of behavioral health providers, outlining all functional areas and their potential dependencies, and organizing the range of actions in a stepwise or similarly digestible format) and including recommendations on shared services that can reduce administrative burden and improve integration across behavioral health and primary care

#### Health System & Payment Reform Work Group

Identify linkages with MaineCare value based purchasing initiative and other state programs  
Produce digestible grid that cross-references pertinent concepts across the pending payment reform landscape and payment models and ties back to Electronic Health Records.  
Through this work, help the state, providers, and consumers understand and integrate Health Information Technology, payment, and public policy.

#### Legal & Regulatory Barriers Group

Address and clarify state and federal legal/policy issues (eg 42CFR Part 2) that impact behavioral health data sharing especially in relation to Health Information Exchanges. This work will help to inform a Continuing Legal Education presentation at a Health Law Section meeting of the Maine Bar scheduled for June 4, 2012 and further advise about potential future education efforts.

## Behavioral Health

### Use Case Examples

11/2011

- Emergency services
- Hand-off between BH and primary care provider
- Coordination of patient treatment among BH providers
- Hand-off between psych hospital or inpatient psych unit and community BH provider
- Coordination of care between physical health specialist and BH provider

#### I. Emergency Department and BH Provider:

**Definition:** Coordination of care between primary/community care location(s) and the hospital emergency department.

**Example:** At 2am, an individual with a significant history of mental illness calls the local Crisis Hotline saying she is feeling suicidal. She just had a fight with her boyfriend and he has left her saying he won't be coming back. She says she is planning to take all of her medications because life just isn't worth it anymore. She reports she is taking the medications as she is talking to the hotline. She also sounds intoxicated.

Later this individual is seen at the emergency room and is non responsive.

#### II. BH Provider and Primary Care Provider:

**Definition:** Coordination of care between a behavioral health provider and a primary care provider.

**Example:** An older woman who has been seen at the community mental health agency for a long standing history of schizoaffective disorder is having significant weight gain & occasional shortness of breath. The psychiatrist is managing her psychiatric medications, but wants to be sure that her underlying diabetes is managed appropriately and wants an initial evaluation by the PCP because of potential cardiac concerns.

#### III. BH Provider and BH Provider:

**Definition:** Coordination of care between two behavioral health providers

**Example:** A man with depression has been seeing a licensed clinical social worker working independently in the community for psychotherapy. The Social worker now believes that medication might be a useful adjunct to the therapy he is providing and so would like to refer this man to the psychiatrist who works in the office down the hall. The social worker with the agreement of the client plans to continue providing psychotherapy in addition to the medication.

#### IV. Inpatient Psych Facility and Community BH Provider

**Definition:** Coordination of care between an inpatient behavioral health facility and a community behavioral health provider

**Example:** A child was hospitalized for severely self-destructive behavior. He lived several hours away from the psychiatric hospital that treated him and was discharged to a multidisciplinary treatment team at a community mental health agency near his home.

V. Physical Health Specialist and BH Provider:

**Definition:** Coordination of care between a physical health specialist and a BH provider.

**Example:** An older man with a history of paranoid schizophrenia is also HIV positive. He is not always willing to take the medications that help to regulate his symptoms. Close communication between his psychiatrist and HIV specialist is critical to his continued stable physical and mental health.

## Behavioral Health Exchange Data Elements Worksheet

[illegible]

\*Including: Who is parent with guardianship (divorces scenario)  
Is the state the guardian? (Child Protective Services)

**\*\*Coordination with Dept of Corrections/local jails?**  
Raises additional questions about confidentiality

\*\*\*Further thinking needed---gap exists now

Entire set of instructions or certain elements?  
(Medications, plan for further treatment  
developed by social workers, discharge diagnosis-baseline)

**1. Emergency Services:** At 2am, an individual with a significant history of mental illness calls the local Crisis Hotline saying she is feeling suicidal. She just had a fight with her boyfriend and he has left her saying he won't be coming back. She says she is planning to take all of her medications because life just isn't worth it anymore. She reports she is taking the medications as she is talking to the hotline. She also sounds intoxicated. Later this individual is seen at the emergency room and is non responsive.

**2. Hand-off between Behavioral Health Provider and the Primary Care Provider:** An older woman who has been seen at the community mental health agency for a long standing history of schizoaffective disorder is having significant weight gain & occasional shortness of breath. The psychiatrist is managing her psychiatric medications, but wants to be sure that her underlying diabetes is managed appropriately and wants an initial evaluation by the PCP because of potential cardiac concerns.

**3. Coordination of patient treatment among BH Providers:** A man with depression has been seeing a licensed clinical social worker working independently in the community for psychotherapy. The Social worker now believes that medication might be a useful adjunct to the therapy he is providing and so would like to refer this man to the psychiatrist who works in the office down the hall. The social worker with the agreement of the client plans to continue providing psychotherapy in addition to the medication. (Notes: The question of independent practitioners' access to data via exchange needs to be addressed by larger group, as well as the individual patient's role in determining who has access to specific information via the patient portal. There was consensus that psychotherapy notes would not be included in an exchange.)

**4. Hand-off between psych hospital or inpatient psych unit and community BH Provider:** A child was hospitalized for severely self-destructive behavior. He lived several hours away from the psychiatric hospital that treated him and was discharged to a multidisciplinary treatment team at a community mental health agency near his home.

**5. Coordination of care between physical health specialist and BH Provider:** An older man with a history of paranoid schizophrenia is also HIV positive. He is not always willing to take the medications that help to regulate his symptoms. Providers are questioning his competency. Close communication between his psychiatrist and HIV specialist is critical to his continued stable physical and mental health. (Note: Over time, nursing homes will be added to HealthInfoNet, but are not currently included.)

Note: An additional use case could be added regarding jails/prisons. Patients who are jailed sometimes do not get medications right away and wind up in ED. HealthInfoNet has had some dialog about this in the past, but not currently.



## Accelerating Behavioral Health Information Sharing

### **Behavioral Health Electronic Health Record Provider Survey Results 2012**

Since 2005, Maine has moved forward on an ambitious plan to establish one of the nation's first operational statewide electronic health information exchanges (HIE), and bring an ever-widening array of providers into the HIE to improve the coordination, integration, and quality of patient care. Central to this strategy has been a longstanding priority to support the collaborative engagement of providers from the behavioral and physical health sector, and consumers, so the use and level of deployment of HIT enhances care at the patient and provider level. In 2012, Maine was selected as one of five states in the country to receive National Council for Community Behavioral Health funding, supported by the federal Center for Integrated Healthcare Solutions, to move behavioral health providers forward in connecting to the state's HIE, HealthInfoNet. This funding enables Maine to make behavioral health and primary care integration the norm rather than the exception.

An important step in moving behavioral health providers forward in connecting to the state's HIE is to understand their attitudes toward the HIE and electronic health records as well as their current technological capacity to connect. In 2011, the Hanley Center for Health Leadership led the Accelerating Behavioral Health Information Sharing Taskforce in a survey of behavioral health providers. This survey gathered significant data that formed an initial base for discussion of the strengths and challenges in behavioral health information sharing. The survey respondents in 2011 consisted of 36 behavioral health providers that were mostly large multiservice organizations.

**To build on and expand that initial base, in August 2012, a more broadly comprehensive follow up survey was distributed to over 1200 MaineCare providers<sup>1</sup> with 129 providers responding.** The 2012 Survey was organized to differentiate between providers who currently are using an electronic health

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<sup>1</sup> The distribution list included categories of providers that were clearly providing behavioral health services as well as other categories that would include both behavioral health and nonbehavioral health providers (eg. Physicians, nurse practitioners etc) . The list was intentionally over inclusive in an effort to reach those providers that are providing behavioral health services in an integrated or other setting that would otherwise be missed.

record and those who are not. Approximately 40% responded to questions for those using an EHR and 60% responding to questions for those without an EHR. The following information and conclusions are drawn from the 2012 survey.

#### Demographics:

**Of the providers responding to questions for those using an EHR**, about one third were larger organizations (100+ employees) and about half were small (less than 20 employees).

- 58% behavioral health providers but not practicing as an individual or in a small group
- 18% individual or small group providers of mental health or substance abuse services
- 13% provide integrated primary care and behavioral health services.

**Of the providers responding to questions for those NOT using an EHR**, over three quarters were small (less than 20 employees). Only 12% were larger organizations (100+ employees).

- 46% individual or small group providers of mental health or substance abuse services.
- 27% behavioral health providers not practicing as an individual or in a small group
- 8% provide integrated primary care and behavioral health services.

## **THE RESULTS**

### **THOSE BEHAVIORAL HEALTH PROVIDERS USING AN EHR**

#### Electronic Record Use in Behavioral Health:

About half of the survey respondents using an EHR reported that they use the EHR for both clinical and administration/financial services. There appears to be no clear EHR software product that is dominant in this market. Only three products were reported to be used by 3 providers, those are NetSmart, Office Ally, and Practice Fusion. Anassazi, Askesis (PsychConsult), Athena, Centricity, ClaimTrak, Evolv (DeFrans), and Saddleback were each identified as used by 2 providers. Twenty four other different software products were identified as used by the remaining providers (see list attached).

#### How the EHR is used:

The survey explored how providers use and value the EHR in two major arenas: clinical and administrative.

In the **clinical area**, the items ranked **highest in importance** were:

- Clinical Documentation-e.g. assessments/reviews/care, treatment plans/progress notes/discharge summaries-- (89%)
- Medical Documentation—e.g. physician orders/labs/history & physical/medication lists/allergies-- (53%)
- Accessing Information quickly from other providers within your organization (53%)
- Remote Access (45%)



- Medication Logs (40%).

Most frequently ranked as of **Medium importance** were:

- Sharing information with other providers (Health Information Exchange-HIE) (53%)
- Diagnosis Tracking (47%).

Items ranked **least in importance** were:

- Transcription Interface (58%)
- Covering for other providers' patients (39%)
- Clinical Decision Support (37%).

In the area of **administrative functions**, the items ranked **highest in importance** were:

- Statistical reporting including productivity (58%)
- Authorizations Tracking (50%)
- Authorizations (44%) as the next most commonly used areas.

Items most frequently listed as of **medium importance** were:

- Informed Consents (47%)
- HIPAA notices (47%)
- Rights of Recipients (44%)
- Scanning & Archiving (40%)

Advance Beneficiary Notices (ABNs) were ranked as **least important** (48%).

#### Barriers to Implementation:

For those respondents already using an EHR, the top two barriers listed as **most important** were:

- Ongoing resources to maintain the use of the system (54%)
- Up front costs/implementation resources (48%)

Six items were identified as nearly equal at **medium importance**:

- Privacy & Security Risks (45%)
- Inability to connect/interface with other system to incorporate information on my patients (45%)
- High Speed Secure Internet Access (44%)
- Technical Support from Vendors or other third parties (43%)
- Fear of System Outage and inability to access the system when down (41%)
- Lack of Technical Knowledge of staff (36%).

Patient push-back was by far the most common item indicated as of **least importance** (69%).

### Impact of EHRs on the Work:

The majority of these respondents indicated their EHR improved functioning in the following areas: Access to Records (80%), Compliance (76%), and Efficiency (64%). The only area with a notable indication of decreased functioning was 20% of respondents reported decreased efficiency with their EHR (though note that 64% of respondents reported improved efficiency). In the area of Quality of Care, 42% of respondents indicated an increase in their quality of care while 58% saw no change. In terms of Patient Safety, 36% indicated an increase while 62% indicated no change.

Coordination of Care: This year we explored whether and how providers coordinated care for their clients. Ninety one percent of those respondents with an EHR report coordinating with other providers to support their clients.

The most widely used means of coordinating care were:

- Telephone (91%)
- Fax (69%)
- Mail (61%)
- HealthInfoNet (3%)

Ninety six percent of respondents indicated that they would access clinical information from other sources if it were available to support their understanding of the complete medical profile for all (58%) or some (38%) of their clients. However, 79% indicated they would not be willing to pay a fee to use such a resource.

### **THOSE BEHAVIORAL HEALTH PROVIDERS NOT USING AN EHR**

#### How providers without an EHR think about its uses

The survey gathered information from those responding providers who did not have an EHR to examine their vision of the use and value the EHR both clinically and administratively.

In the **clinical area**, the items ranked **highest in importance** were:

- Clinical Documentation-e.g. assessments/reviews/care, treatment plans/progress notes/discharge summaries-- (65%)
- Accessing Information quickly from other providers within your organization (47%)
- Sharing information with Other Providers (Health Information Exchange) (42%)

Most frequently ranked as of **Medium importance** were:

- Medical Documentation, (51%)
- Clinical Decision Support (46%)
- Diagnosis Tracking (42%)

Items ranked **least in importance** were:

- Transcription Interface (47%)
- Medication Administration Logs (38%)
- Remote Access (36%)

In the area of administrative functions, the items ranked highest in importance were:

- Authorizations (45%)
- Informed Consents (44%).

All of the remaining options were selected as of medium importance in the following ranking: Advance Beneficiary Notices (ABNs), Scanning & Archiving, Statistical reporting including productivity, Authorizations Tracking, Authorizations, Rights of Recipients, and HIPAA notices.

#### Plans to Implement an EHR:

About 16% of these providers indicated that they planned to implement an EHR within the next year, with another 8% planning to implement within 2 years. Thirty-eight percent of respondents indicated that they had no plans to implement an EHR, but would if they could secure necessary resources. The remaining respondents (38%) indicated they had no plans to implement an EHR, citing reasons such as concerns about privacy & security, no perceived need with their small practice, and concerns about decreased quality of care with 'providers who look at screens instead of patients.'

#### Barriers to Implementation:

For those respondents who are NOT using an EHR, the barriers listed as **most important** were:

- Up front costs/implementation resources (75%)
- Ongoing resources to maintain the use of the system (52%)
- Privacy & Security Risks (52%).

Items identified as of **medium importance**:

- Technical Support from Vendors or other third parties (49%)
- Inability to connect/interface with other system to incorporate information on my patients (41%)

Items indicated as of **least importance** were:

- Patient push-back (51%)
- High Speed Secure Internet Access (46%)
- Fear of System Outage
- Inability to access the system when down (44%)
- Lack of Technical Knowledge of staff (38%)

### Interest in Resources

Providers indicated strong interest in a variety of potential EHR related resources: Best practices (85%), Training Resources (81%), Consumer education materials (75%), Education Resources regarding Privacy & Security (66%), Information about HealthInfoNet (55%), Shared Administration (40%), and Work Flow Redesign (36%).

### Coordination of Care

Ninety seven percent of those respondents without an EHR reported coordinating with other providers to support their clients. Like the group with an EHR, the telephone was the most widely used means of coordinating with 96% of respondents using that tool followed by fax (66%), and mail (53%). Seventy nine percent of respondents indicated that they would access clinical information from other sources if it were available to support their understanding of the complete medical profile for all (46%) or some (33%) of their clients, with 20% indicating that they would use this resource for few patients. Consistent with the other group, eighty percent indicated they would not be willing to pay a fee to use such a resource.

## CONCLUSIONS

This survey builds on the Maine Behavioral Health Provider Survey conducted in early 2011 by the Hanley Center for Health Leadership and captures feedback from a more diverse population of providers including significantly more small providers of behavioral health services. An important step in moving behavioral health providers forward in connecting to the state's HIE is to understand their attitudes toward the HIE and electronic health records as well as their current technological capacity to connect. Consistent with the 2011 results, this survey shows that behavioral health providers recognize and are demonstrating significant benefits from implementation of electronic records. Both this year and last, behavioral health providers, both those with and without EHRs, see the most value in Electronic Health Records in the documentation of clinical information and ready access to the record information. The major barrier identified last year and for both groups this year is the cost of purchasing and maintaining the EHR. Both groups of providers are actively coordinating care for their patients and indicate a strong interest in accessing clinical information from other sources (the HIE) if it were available to support their understanding of the complete medical profile of their patients. An area for future focus may be on the use of the EHR for care coordination as even among those with EHR's, the most common form of communication for care coordination was via the phone, rather than electronically.

The data collection method used this year that differentiated between those providers that have an EHR and those who do not, has confirmed some hypotheses developed last year. The providers without an EHR are much more likely to be smaller, significantly impacted by the financial and resource costs of EHR implementation, and somewhat less likely to see the value of an EHR for their practice. These providers are also somewhat more likely to be concerned about privacy and security risks of an electronic record. That said, even among this group, there is a significant proportion who would implement an EHR if resources were available and who are interested in various EHR-related educational resources.

These data suggest that there is fertile ground for broader implementation of EHRs among even smaller behavioral health. There is broad agreement on the value of an EHR in promoting better coordination of care for consumers of both behavioral health and general health services. Behavioral Health providers, especially smaller providers, would benefit from additional resources—educational and financial—to assist them in joining the broader healthcare community in implementing electronic records. In particular, nearly all of these providers are coordinating care for their patients and over 55% expressed interest in learning more about HealthInfoNet. Additional information that might support the collaborative efforts of smaller providers is particularly relevant. Although the sample size of this and the 2011 surveys limit how broadly the results can be generalized, the surveys provide a reasonably comprehensive snapshot of the benefits and barriers for behavioral health providers in Maine and their willingness and desire to move into electronic clinical information sharing.

List of Software Products identified as in use by Providers

Netsmart, Product is called MIS & TIER --3

Office Ally -- 3

Practice fusion --3

Anassazi Version 3.0 --2

Askesis Inc. - PsychConsult Provider -- 2

Athenahealth, Inc. V12.7 version Athena Collector and Athena Clinicals --2

GE Centricity CPS 10 -- 2

ClaimTrak --2

Evolv by Defran Systems --2

Saddleback Software - 2

Alteer Office, ver 6

Altos, OncoEMR, Version 2.6.110.29

AMAZING CHARTS VERSION 6

CaseWorks Web

Clinical Fusion

CompuGroup

Echart (designed in-house)

Eclinical Works, Version 9.0

EHR we had developed by Brave River

Epic 2010

Intivia InSync

Meditech

Netalytics, Methasoft 6.1

NextGen SMART Management Inc

Office Therapy by Docutrac 9.0.044 Therascribe by Wiley and Sons 5.0

Provider (ECR)

SuccessEHS

Therap

Unicare Profiler Version

Vantage Med Therapist Helper 6.2.0

Valant EMR

Vendor: KBH, Product: Neo Version V1

Welford Chart Notes 6.1 Medcom information systems



# PROVIDERS TALKING TO PATIENTS ABOUT SHARING MENTAL HEALTH RECORDS ON A STATEWIDE HEALTH INFORMATION EXCHANGE

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*SUMMARY OF PATIENT AND PROVIDER FOCUS GROUPS AND PROVIDER SURVEY*

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**December 2012**

## **BACKGROUND**

### **HEALTH INFORMATION EXCHANGE IN MAINE**

Since 2005, Maine has been moving forward on an ambitious plan to establish one of the nation's first operational statewide electronic health information exchanges (HIE), and to bring an ever-widening array of providers into the HIE with the aim of improving the coordination, integration and quality of patient care. Central is the longstanding priority to support the collaborative engagement of providers from the behavioral and physical health sector, and consumers, to ensure that the level of deployment and use of the HIE enhances care at the patient and provider level.

Currently, HealthInfoNet provides a system where information from patients' electronic medical records is accessible to participating medical providers. A change in Maine law now allows for certain 'sensitive health information' (mental health records and HIV/AIDS diagnosis) to be shared across a system like HealthInfoNet. Unlike with general medical records, a patient has to consent to have their 'sensitive health information' shared using HealthInfoNet, except in a medical emergency.

### **CENTER FOR INTEGRATED HEALTH SOLUTIONS' BEHAVIORAL HEALTH AND PRIMARY CARE HIE INTEGRATION PROJECT**

In 2012, the State of Maine and HealthInfoNet received a grant to help support the electronic sharing of health records among behavioral health providers and general medical providers in Maine. The grant was awarded by the Center for Integrated Health Solutions, which is funded by the Substance Abuse and Mental Health Services Administration and the Health Resources Services Administration.

The grant enables Maine to make behavioral health and primary care integration the norm rather than the exception. True care integration and coordination cannot occur unless relevant clinical information can be successfully shared in a secure manner across behavioral health and physical health sectors. This funding will allow Maine, for the first time, to achieve this.

To achieve the goals of the grant by 2013, Maine undertook to:

1. Address and clarify federal policy issues that impact on behavioral health data sharing;
2. Provide access to the HIE for providers, regardless of their level of electronic health record adoption;
3. Develop, with consumer input, educational materials for primary care and behavioral health providers to use to inform consumers about their options in sharing clinical information through the HIE; and
4. Educate primary care providers, behavioral health providers and other staff regarding consumer options and methodology for shared decision-making on clinical information sharing.

The Behavioral Health and Primary Care Integration Strategic Action Task Force was created, with statewide membership, as one of the vehicles through which the objectives of the grant would be achieved.

The Consumer and Provider Education Workgroup, a sub-committee of the Accelerating Behavioral Health Information Sharing Strategic Action Task Force, consists of representatives from community agencies, self-advocates, state officials, and statewide foundations. The Workgroup's charge is: "Through engagement with consumer and provider constituencies, detail out the essential elements in an effective internal and external communication plan including: (i) a comprehensive plan for educating the primary care and behavioral health provider communities regarding consumer options and methodology for shared decision making on behavioral health clinical information sharing; (ii) a comprehensive plan for consumer education about clinical information sharing, particularly focused on behavioral health and HIE; (iii) educational materials to inform consumers about their choices in sharing behavioral health data within the HIE; (iv) educational materials for primary care and behavioral health providers to use to inform consumers about their options in sharing behavioral health data within the HIE."

## FORMATIVE EVALUATION

Hanley Center for Health Leadership engaged Partnerships For Health to facilitate patient and provider focus groups aimed at answering the following questions:

1. What educational materials do patients need in order to decide whether or not to consent to their mental health records being shared electronically through HealthInfoNet?
2. How should providers talk with their patients about sharing their mental health records electronically through HealthInfoNet?

This report documents the methodology and results of the patient and provider focus groups. In addition, a provider survey was developed and incorporated into the results.

## SECTION 1: CONSUMER PERSPECTIVE

### METHODOLOGY

Five focus groups were held in three Maine counties between September and October 2012. Each focus group targeted a different population – adults accessing mental health services, veterans, seniors, young adults, and persons with intellectual disabilities (and their guardians). In addition, we asked recruiters to consider rurality and health insurance when identifying potential participants.

In total, 43 people participated in the groups. All participants resided in Maine. At least 60% of participants had received physical and mental healthcare within the last year. Refer to Table 1 for additional information about focus group participants.

For simplicity, **medical records** refer to existing electronic records that have data on the physical condition of a patient.

**Mental health records** refer to patient data that is classified as 'sensitive information' and not currently included in the electronic record.

**HealthInfoNet** refers to the statewide health information exchange.

We learned a lot from the focus groups – what concerned them and what didn’t. The findings provided in the following paragraphs describe their perceived benefits of the system and explains their concerns. These insights can help inform the content and tone of the educational materials and consent form. Because this evaluation was conducted among small samples of our target audience, the findings should be viewed as instructive, but not definitive.

**Table 1: Participants Demographics**

Table 1: Participants Demographics			
Participants		43	
Target audience			
Seniors (65 years +)	14.0%	Veterans	20.9%
Adults (25 – 65 years)	53.5%	Persons with IDD	2.3%
Youth (- 25 years)	53.5%	Guardians of persons with IDD	16.3%
Gender			
Male	46.5%	Female	53.5%
Visited a primary healthcare provider within the last...			
30 days	44.2%	6 months	27.9%
Year	9.3%	More than a year	14%
Can't remember	4.7%		
Visited a mental health provider within the last...			
30 days	48.8%	6 months	7.0%
Year	4.7%	More than a year	16.3%
Can't remember	9.3%	Never	9.3%
Pay for medical costs through...			
MaineCare	55.8%	Medicare	18.6%
Military, CHAMPUS or the VA	20.9%	Private health insurance	16.3%
Self-pay	9.3%		

While focus groups vocalized similar benefits, questions, and concerns, two groups self-differentiated themselves.

## The Veterans Focus Group

“The thing that separates this group from your other focus groups is we’re all military and war veterans and some are career veterans. We do not trust the government. That’s a given, it’s not debatable.” *Veterans Focus Group participant*

## And the Young Adults Focus Group

“Different age groups deal with different issues. Like ours is the privacy and the sanctioning of the information as to who and what, whereas older people would like to know what’s the security.” *Young Adult Focus Group participant*

This is their individual and collective voice...

## RESULTS

This report details the emerging themes across all focus groups. In addition to this report, a summary of the findings to inform the Committee discussions (Appendix A), a PowerPoint presentation to the Task Force (Appendix B), and a one page summary for dissemination (Appendix C) were developed.

### Benefits of HealthInfoNet

#### ***Acts as a surrogate patient voice***

The record can talk for a patient when s/he cannot. This may happen when a person is having a breakdown or is unconscious.

“Being someone who’s bipolar: if I’m down (in Portland) and I start flipping out for some reason who knows why. Is it drug related? Is it something that made me angry? If they looked at my record (they would know), she is bipolar and this is what’s been going on.” *Senior Focus Group participant*

“I’d like to give my consent and know that wherever I was, and whatever emergency, whatever happened, those people have access.” *Veterans Focus Group participant*

#### ***Increases the accuracy of records***

The records talk the same language as the doctor, so medical terms and medications don’t get miscommunicated. With time (and age), it gets difficult for patients to remember all of the correct information.

“You get yourself mad and upset because the doctor does not understand what you’re saying...” *Senior Focus Group participant*

“...Not only that but you don’t know the terms. My doctor said I have a seasonal depression and I have to start this light, and I may not know the name of the light but hopefully (the doctor) who I’m talking to is smart enough to know it’s a mood box.” *Senior Focus Group participant*

#### ***Decreases patients’ burden of record keeping***

HealthInfoNet would decrease the responsibility and burden on the patient to ensure all the doctors have the necessary reports. Patients spend a lot of time on the phone and driving between doctors to get their health records.

“About 8 years ago. I was in the VA system but I was in Wal-Mart shopping. I had a massive heart attack. I went to Farmington hospital and was resuscitated there and sent down to Lewiston. When I had recovered, I went down to Togas to get my meds because they were viciously expensive in the pharmacies. They wouldn’t even talk to me until I went to Lewiston, got my records, took them down there so that they could put my records in their system - only then they would treat me as if I had a heart attack. I assume this would change that kind of scenario, so the VA could access any information I had from Farmington or Lewiston.” *Veteran Focus Group participant*

"I moved around a whole lot in my life. DHHS case, blah blah blah, family moving, and whatnot. Tracking down doctors is a bad thing, this kind of helps." *Young Adult Focus Group participant*

### ***Decreases the need for patients to continuously repeat their story***

Patients spend a lot of time answering the same questions with different doctors. A shared system would alleviate the need to continuously 'tell the same story.'

"If you're going to a new doctor, you have to tell them everything that's going on that you've said a billion times... I can guarantee (that) everyone in this room has had to tell their stories over and over and are not a fan of it... I've had to do it 4 times this year alone." *Young Adult Focus Group participant*

### ***Makes doctors and patients more accountable***

HealthInfoNet will make both the doctor and patient more accountable.

"A lot of people that we serve are not necessarily reliable reporters. They want to tell the physician what they think the physicians want to hear without being honest about their symptoms." *IDD Focus Group participant*

"(The) physician is more accountable to peers and guardian." *IDD Focus Group participant*

"People who seek drugs or medications, those are the people this HealthInfoNet would probably help, so the doctors knew what was going on. But those are probably the people that wouldn't consent." *IDD Focus Group participant*

#### **BENEFITS**

- ❖ Acts as a surrogate patient voice
- ❖ Increases the accuracy of records
- ❖ Decreases the patients' burden of record keeping
- ❖ Decreases the need for patients to continuously repeat their story
- ❖ Makes doctors and patients more accountable
- ❖ Helps increase doctor efficacy
- ❖ Helps ensure patient safety

### ***Helps increase doctor efficacy***

Doctors make decisions based on the information they have, but doctors don't know what they don't know. Providing doctors with access to all patient records, particularly medications and diagnosis, means that they can make the best treatment plan.

Participant 1: "In some kind of emergency, what does your mental (health) have to do with them giving you care at a hospital?" *Young Adult Focus Group participant*

Participant 2 in response: "The best care that they can. So they're not just going into it blind. They have some sort of document and (know) what your triggers are, or what medicines you've been on and what medicine you haven't. So they can figure out the best way to help you." *Young Adult Focus Group participant*

HealthInfoNet would allow doctors to communicate with one another and know what is going on in the patient's life.

"It keeps all doctors informed. Before doctors weren't keeping in contact with each other. This way they can keep in contact with each other and they will all know what's going on." *Adult Focus Group participant*

## **Helps ensure patient safety**

Without seeing a patient's medication history, a doctor may prescribe a medication that counteracts with the patient's current medication; or the doctor may prescribe something a patient has previously had a bad reaction to.

"If they don't have my records to see what medications I'm taking, I'm taking 9 or 10 different pills, up to 12 sometimes, if they don't have all that and he serves me a pill I'm allergic to... that's going to throw off the whole balance of my other pills." *Senior Focus Group participant*

## **Common Questions**

### **What is HealthInfoNet?**

Participants struggled to understand exactly what HealthInfoNet was conceptually and asked for more information about how it was funded and the extent of government (state and federal) involvement.

"Is there a cost to the patient / provider for participating?" *IDD Focus Group participant*

"The governor doesn't have anything to do with this, does he?" *Adult Focus Group participant*

"Anything that has to do with the Feds is questionable." *Veterans Focus Group participant*

### **Does HealthInfoNet reach outside Maine?**

Participants were not sure about the geographic boundaries of HealthInfoNet, both currently and in the future.

"If hospitals merge with out-of-state hospitals, how will this play-out, does HealthInfoNet expand?" *IDD Focus Group participant*

"Is this only for what happened while you were here in the state of Maine, not outside of the state. Now I've spent years in Minnesota ... how does that (information) get to here?" *Veteran Focus Group participant*

### **Is provider participation required?**

Participants were interested in understanding why some providers were participating in HealthInfoNet and some were not. They assumed the reason for non-participation was cost related, but were concerned about how this would affect patients who wanted their records in the system.

"Is it going to be mandated by the state... that all doctors or all medical (providers) have to provide this service?" *Adult Focus Group participant*

### **COMMON QUESTIONS**

- ❖ What is HealthInfoNet?
- ❖ Does HealthInfoNet reach outside Maine?
- ❖ Is provider participation required?
- ❖ What is the plan for a security breach?
- ❖ Why is substance abuse excluded?
- ❖ Why would a provider want to see my information?
- ❖ What information is included?
- ❖ Who gets to see my information?



Of particular concern was whether the VA was participating in HealthInfoNet. This was seen as critical to veterans who, while the VA was their medical home, often received emergency care outside the VA and needed a way to share information across providers.

*“Isn’t it a big blind spot if Togas is not included?” Veterans Focus Group participant*

Pragmatically, they asked how they could be the bridge between HealthInfoNet and non-participating doctors.

*“If I am going to a doctor that is not participating, and I want the information from that doctor in the HealthInfoNet system, is there a way I can get that information into the system?” IDD Focus Group participant*

### ***What is the plan for a security breach?***

The security of HealthInfoNet was a concern to participants as they had their own experiences and fears about losing data, hackers, and identity theft. Participants were most concerned about identity theft because the system stored their social security number.

*“The problem that I have is the social security number. The government, computers, and the internet as a whole. I don’t care what you have for security, I don’t care if it’s encrypted, there is a hacker somewhere with the knowledge to get whatever information that he desires. If he had my social security number, all the information that I have is available to him.” Veterans Focus Group participant*

There was general consensus that any internet system could be hacked into and rather than assuring patients that the system was hacker-proof, participants wanted to know what the back-up plan was to deal with security breaches.

*“It seems like lately there has been a lot in the news about security breaches as far as hackers. Even though you have the strongest and highest computer systems, all computers are vulnerable. What do you do, how do you deal with the situation if the HealthInfoNet computers are hacked?” IDD Focus Group participant*

In addition, participants were concerned about what would happen if the data was lost.

*“Everything is electronic, on a computer, and nothing is on paper. Say something happens and it all got wiped out, now what?” Young Adult Focus Group participant*

### ***Why is substance abuse excluded?***

In general, participants were puzzled about substance abuse not being included. They felt that mental health and substance abuse go hand-in-hand and questioned why it was excluded from the records.

*“It’s already in your record in paper form, but it wouldn’t be put on (the system)? That’s weird.” Young Adult Focus Group participant*

***Why would a provider want to see my information?***

While most participants saw the benefit in primary care or emergency doctors accessing your mental health diagnosis and medication, they questioned the need for specialized providers accessing your records. Examples included mental health providers accessing your medical records and ENT specialists accessing your mental health records.

“If someone is treating you for mental health, your records are not available to the ear, nose, and throat doctor that’s looking to see if you have tonsillitis.” *Veterans Focus Group participant*

***What information is included?***

Participants thought it was important for them to know what information was in the system so that they could provide doctors with additional information.

They were unsure about how far back the data would go. Some participants were concerned that a person could be judged on something that happened when they were very young.

“There’s stuff that’s happened to me... that I don’t want people knowing.” *Young Adult Focus Group participant*

While participants understood that *psychotherapy notes* were excluded, they did not understand what psychotherapy notes referred to.

“Include my behavioral health information... Now, what information are they talking about? I’ve been in numerous groups, individual therapy, psychotherapy, seen psychiatrists, and psychologists: and they take notes. A lot of the things that I deal with... is my experience in war. I don’t want that broadcasted - sometimes I don’t even tell the therapist because I’m unsure.”  
*Veterans Focus Group participant*

Participants from the IDD Focus Group thought it was important that guardianship be identified in a patient’s electronic records and that the records should include a psychiatric directive.

***Who gets to see my information?***

There were concerns about the records being available to insurance companies, legal professionals in medical error cases, medical students, and healthcare administrative staff. Participants emphasized that the normal professional requirements of HIPAA were still operating.

“I would definitely not want some med student accessing my records, seeing something dumb that I did and going back to his college buddies and laughing ‘ha ha... I read about this guy.’”  
*Young Adult Focus Group participant*

## Common Concerns

### ***The patient loses control over information***

Participants, particularly young adults, felt they were losing control by giving consent. Currently, a patient holds most of the information and is able to decide which information to tell a provider. By giving consent, they forego the control and have to rely on the accuracy of the provider records.

### ***Access is all or nothing***

Participants were concerned that their consent would mean all their records were available to everyone.

#### **COMMON CONCERNS**

- ❖ The patient loses control of information
- ❖ Access is all or nothing
- ❖ Mental health stigma and discrimination

Participants suggested that there should be different levels of access among providers.

“There are some things that people have in the past that they want to forget and don’t ever want them brought up again. Which is probably some peoples’ concerns, if it’s in there, in an emergency, they’re going to see it no matter if you want them to or not. If you don’t want them to see it, you’re pretty much S.O.L. because they’re going to see it anyway.”

*Young Adult Focus Group participant*

### ***Mental health stigma and discrimination***

Participants in the focus groups often alluded to stigma and discrimination. They felt that patients may get treated differently by what is in their records, especially if it was something they were ashamed of themselves.

“You decide to opt-in, but the challenge then becomes, regularly your notes say that you’re a behavior problem. You’re looking for a new doctor; can the doctor open that up (the record) and decide they are not going to take you on as a patient?” *IDD Focus Group participant*

“My sister had a mental illness and she was admitted to an emergency room with cardiac concerns and my parents went with her but didn’t disclose any of her medications and she was treated one way. Later when the medications were disclosed and the mental illness was apparent, it seemed that the treatment changed... and not as much effort was made. She died of a heart attack. That certainly colors my view of how much to disclose about medications.” *IDD Focus Group participant*

“I think some things need to be kept private because they have a bad stigma (attached) to it. Like if I found out I had HIV, I wouldn’t want anybody to know. I can see where people would want to keep that stuff private.” *Adult Focus Group participant*

## Consent Process

### Simply state the options and consequences

Participants understood that there are four choices. These are listed below with the corresponding consequences.

OPTION	CONSEQUENCE
<b>1: Do nothing</b>	Their medical records are available to providers participating in HealthInfoNet and their mental health records would be available in an emergency.
<b>2: Consent to have their mental health records included</b>	Their medical and mental health records are available to providers participating in HealthInfoNet.
<b>3: Do nothing and provide time limited consent</b>	Their medical records are available to providers participating in HealthInfoNet and their mental health records would be available in an emergency. In addition, they could provide individual providers with time-limited access to their records on HealthInfoNet.
<b>4: Opt-Out of HealthInfoNet</b>	Their medical and mental health records are not available to any providers, even in an emergency.

### Define terms and give examples

Participants asked what constituted an emergency, who decided if the situation was an emergency, and if the patient was told if his/her information was accessed. They suggested that examples and guidelines may help increase their understanding.

For example, if a participant went to the emergency room, would they have a say in deciding that they were in an emergency and that the doctor could therefore access their records?

“What I might think is an emergency they might not or vice versa. I might be confused and ask ‘Did they access that information or did they not?’ Would I be told they accessed it?” *Adult Focus Group participant*

“One of the questions that I have is what would they consider an emergency. If you’re knocked unconscious and you can’t give consent, I can understand that. But if you say no and they consider it an emergency, could they go behind you and still look at your information - regardless that you haven’t given permission?” *Young Adult Focus Group participant*

“What constitutes a medical emergency? Are they going to have guidelines [about what] constitutes an emergency?” *Adult Focus Group participant*

Due to the rurality of Maine and scarcity of psychiatrists, primary care providers often treat their patient’s mental health condition. Participants were not sure if that treatment would be included in the patient’s existing medical record?

#### CONSENT PROCESS

- ❖ Show what HealthInfoNet is
- ❖ Simply state the options and consequences
- ❖ Define terms and give examples
- ❖ Explain the process in simple terms

*"If your primary care provider also diagnosis / prescribes your mental health medications, how are they separated? Where is the line?" IDD Focus Group participant*

If the treatment is included in the existing medical record, participants thought it was misleading to say that a patient has a choice to opt-in.

*"Does the list of medication include mental health? If yes, it is misleading that a patient actually has to opt-in." IDD Focus Group participant*

*"Since you have to consent for your mental health and they already show your medications and what you're on, so if you're on Prozac they're automatically going to know you're depressed or something." Young Adult Focus Group participant*

### ***Explain the process in simple terms***

#### ***Participants asked many questions about the consent process and how it actually worked.***

*Do you only give consent once?*

Participants asked if there was a way for them to only give consent once, i.e., did the one consent hold for all providers and did it only have to be completed initially (or annually). In addition, they asked if there was a list available of participating providers.

*"So you don't need to keep signing forms (for the records) to go from one (provider) to another then?" Adult Focus Group participant*

*"Is there a mechanism that indicates I filled out the consent form so I don't have to continuously fill it out?" IDD Focus Group participant*

*Can you complete the form online?*

Being able to complete the form online was seen as important, especially to guardians who did not always accompany their ward to appointments.

*What happens if you change your decision?*

Participants had several questions regarding changing their decision after opting-in or opting-out of the system. In addition to questioning whether or not this was possible, they were also interested in the logistics of the process. For example, if you change your mind and decide not to share your information, how long will it take to remove your information and how do you know that it has actually been removed?

*[If you decide to opt-out after opting-in] "... The information will be on there and then they'll have to take it off. How do you know if the information has been taken off and what is the time frame for that to happen?" Adult Focus Group participant*

*"There should also be a section 'if you sign this portion you take back the permission. You want your information deleted off HealthInfoNet.' Is that even possible? It just says you can have it deleted... But you can never completely delete something offline. Once it's been on there, it's on there pretty much forever. You can go back and find it... They'll probably tell you they deleted it but it'll still be there." Young Adult Focus Group participant*

### *How does limited consent work?*

Participants, particularly those from the Young Adult Focus Group, liked the idea of limited access because it gave them more control, but they thought it made things more complicated because it was a grey area and opened things up for abuse/unauthorized access. Participants questioned how limited consent would operate.

“My information is in the system, I go into the (doctor’s) office and say, for today only you have access. How does this access get opened-up and how do I know the provider isn’t going to keep going in? Is there an on/off button?” *IDD Focus Group participant*

“What if you give someone permission one time, can’t they just go back in and use the same password and stuff to look at it again?” *Young Adult Focus Group participant*

“Does the computer generate new passwords each time?” *Young Adult Focus Group participant*

### **Consent Form**

Initially, almost all participants failed to read the first page of the Consent to Share Sensitive Health Information document and focused on the second page (form). The following comments and questions follow the format of the document.

### **About HealthInfoNet**

Section 1, Paragraph 2: The sentence reads “You will need to take action for certain mental health and HIV/AIDS related information to be included.”

Participants were not sure *what* specific actions they would need to take. They liked the suggestion of adding: ‘The actions you need to take are stated below.’

“It says that you will need to take action for certain health and HIV/AIDS related information to be included; so what is the action you need to take? It really doesn’t explain the action that we need to take.” *Adult Focus Group participant*

There was also uncertainty as to what *certain* mental health and HIV/AIDS related information meant.

“It says you need to take action for **certain** mental health and HIV related, so what’s certain health?” *Adult Focus Group participant*

Participants thought it would be helpful to add an introduction explaining how electronic mental health records are new. It was a common understanding that all of their health records were already electronic, so a paragraph explaining that physical records are currently available and emphasizing that it is only mental health records that are new would be helpful. They also suggested adding “**Read this first**” on the front page in large font.

### ***Sharing mental health and/or HIV/AIDS information in HealthInfoNet***

Participants did not understand the full meaning of Section 2. They thought it meant that, if they give consent, their information would be shared if they are in an emergency. They did not initially understand that it meant that their information would be shared if they give consent OR were in a medical emergency.

### ***Your choices for sharing sensitive information***

Participants found the meaning of the options confusing and questioned whether it was only for persons who were currently receiving mental health treatment.

For people who were not currently receiving mental health treatment, participants asked if they were excluded (i.e., you could only sign the form if you had seen a mental health provider) or if it was a good idea for them to give consent proactively rather than waiting for a crisis.

Participants liked having a choice to consent or not, but thought it could be emphasized more on the form. They thought the options could be simplified and concretely stated. There were 2 suggested formats: (i) add an option "I do not consent" with a signature line; or (ii) simply state "Do you consent?" with yes and no checkboxes.

*"It's the first time they've actually given us a choice whether we want to sign it or say 'screw it I don't want anything released at all.'" Young Adult Focus Group participant*

Participants also suggested that the Consent Form contain a statement about how providers will still operate under their own professional conduct and HIPAA and would use the information appropriately.

### ***I choose to include my sensitive health information in HealthInfoNet***

#### ***Address***

Participants were not sure if a mailing address, physical address, or both were required.

#### ***Social security number***

Directly below social security number is a sentence that reads: "This is used to verify your identity only. It is not made available in the system." Participants felt that this sentence did not alleviate their concerns because the number would be in the system and available to hackers even if it wasn't shown on the screen to providers.

*"Well, not made available in the system and not BEING in the system is two entirely different things. If it's in a system, even though somebody can't access it, a computer hacker could. And that's a big concern, because more than once all of us here have had our social security numbers compromised." Veterans Focus Group participant*

#### ***Check box: "I want to include my behavioral health information in my HealthInfoNet record."***

Participants thought this should read 'mental health' rather than 'behavioral health.' They saw mental health and behavioral health as being two different things. They defined behavioral health as the actions or behavior that took place and mental health as what happened in their head.

“Isn’t mental health and behavioral health two different things. Cause my behavior is a lot different than my mental health.” *Young Adult Focus Group participant*

## The Patients’ Ideal System

### No social security numbers

Participants discussed whether or not there was an alternative to social security numbers that would make the impact of a security breach less daunting.

“If I have your social security number, I can do untold damage to you, and... I have got two letters in the last seven years that told me my information was on a hard drive on a laptop that disappeared and god knows where that is; and god knows who has it; and god knows what they’ll do with it... Why couldn’t we use that information (VA claim number) to access all of our health care?” *Veterans Focus Group participant*

### PATIENTS’ IDEAL SYSTEM

- ❖ No social security numbers
- ❖ Patients decide who sees what
- ❖ Patients have access to their records
- ❖ Crisis counseling hotlines have access
- ❖ Links family records

### Patients decide who sees what

Participants want to be able to restrict the view of their records. They imagined a system where a patient could decide which type of provider could see which types of data.

For example, some participants did not want their mental health provider to see their medical records. Others wanted to consent to having their mental health records shared, but not their HIV/AIDS status. There were additional requests to have a section that was always off-limits except with expressed consent of the patient – even in an emergency.

“What if there’s something in your physical medical records that you don’t want everybody to see? Say my mental health case manager got in, as part of the HealthInfoNet, and he looks at my physical stuff: What if there’s something in there I don’t want them to know about my past?” *Young Adult Focus Group participant*

“Is it possible to have another portion be not (available) even in an emergency? That you have to give permission, (and even in) an emergency it won’t let them see it?” *Young Adult Focus Group participant*

### Patient has access to their records

Participants felt that it was important for patients to be able to review their personal information and be able to fix errors.

“What if the information is wrong that’s on there and you know that it’s wrong? How do you know that the information that’s on there is correct? And that it is about you (and) not about somebody else?” *Adult Focus Group participant*



### ***Crisis-counseling hotlines have access***

Participants thought that giving access to crisis-counseling hotlines would be beneficial because it would help the crisis counselor understand the history of the person they were speaking to and provide a record for the primary health care provider to follow-up with the patient.

*“Sometimes crisis (counselors) would need to know your background. I’ve had them come to my house... and sometimes I don’t want to tell them the whole story. If I called them, they could access it on their computer and ask me exactly what’s bothering me.” Young Adult Focus Group participant*

*“But even if it’s your first time calling, they would have access to put this into your record so that it gets shipped to your doctor that you called for suicide help. Next time you see him, he hopefully will bring it up or at least it’s in there so god forbid anything else happens.” Senior Focus Group participant*

### ***Links family records***

Participants suggested that their electronic record be linked with those of their family members. There were two main benefits to this: (i) Providers would be able to understand the patient's home situation and family health; and (ii) Providers would be more aware of genetic conditions.

*“If another family member of yours came down with Alzheimer’s, they could see where the link is. It’s important because I’m bi-polar and my kids have ADHD. At first I felt I gave it to them because I didn’t realize it’s hereditary. By looking back at records you can see, okay so my mother, my brother, myself all have it. Luckily my husband is clear, but my sons will have it in their records so when they have kids they’ll be able to go back into their history and see: ‘this is what mom and I had and this is what I have to do to watch for my own kids ... The same thing with my husband’s heart attack, and the 3 boys. His heart attack had nothing to do with what he ate, it was hereditary,’ it was bound to happen.” Senior Focus Group participant*

## **CONCLUSION**

The objective of these focus groups was to gain qualitative understanding about what patients perceived as the benefit of a system such as HealthInfoNet, their concerns, and questions. Participants articulated many patient benefits.

We found that the patients were less concerned with stigma and discrimination than with the possibility of security breaches and the idea that all of their records would be available to all providers in the system. The majority of patients would prefer a tiered consent model where consent is tiered by provider type. This means that patients would have the ability to consent to share specific information with specific types of providers involved in their care. This is different from the limited consent which is time-limited. While such a model may not currently be feasible, it is important to communicate to patients the existence of a strict role-based access policy to alleviate some fears with sharing mental health information.

In general, participants were confused about what their options were and how limited consent could be operational. In addition, they suggested numerous potential ways in which the system could be developed to suit the patient's needs.

## RECOMMENDATIONS

Based on the results from the focus groups, the following are recommended for future patient-focused educational materials.

- ❖ **Separate the educational and consenting materials.** By combining the materials, patients expected all forms for all options (e.g., consent to share information, consent to not share any information (opt out of HealthInfoNet), limited consent). In addition, when given documents that end with signature requirements, almost all participants did not read the print and simply turned to the form they needed to complete.
- ❖ **Use graphics to illustrate concepts and processes.** All participants listened to a mock session of a provider explaining what HealthInfoNet was and what decision was required. In addition, they were asked to read the educational materials. However, they were still not sure what HealthInfoNet is, and what the consent options were. It is recommended that graphics are used to convey these complex concepts.
- ❖ **Emphasize patient benefits and use quotes.** Almost all participants thought it would be beneficial to consent to sharing their mental health records. It is recommended that materials utilize the quotes from people to emphasize the benefits to patients.
- ❖ **Address consumer concerns about security and controlling access.** These were the two greatest concerns and it is recommended that they are addressed in any educational materials produced. In particular, it is important to communicate to patients the existence of a strict role-based access policy to alleviate some fears with sharing mental health information.

### RECOMMENDATIONS

- ❖ Separate the educational and consenting materials
- ❖ Use graphics to illustrate concepts and processes
- ❖ Emphasize patient benefits and use quotes
- ❖ Address consumers concerns about security and controlling access

## LIMITATIONS AND FUTURE EVALUATION

The formative, exploratory, and descriptive nature of the focus groups limits the findings. First, the participants represented self-identified persons receiving mental health treatment (and their guardians where applicable). We do not know how less engaged patients perceive the benefits of sharing their mental health records, or if their information needs may be different. Secondly, while every effort was made to engage all participants, some ideas and perspectives may have been left out given the flow of the focus groups.

Future evaluation efforts may benefit from developing an anonymous survey and/or focus groups that react to developed educational materials. We would recommend that recruitment be made from existing groups and be scheduled around patients' routine care in an effort to involve more patients.

## SECTION 2: PROVIDER PROSPECTIVE

### METHODOLOGY

One focus group was held in November 2012. Despite recruitment efforts, all participants were from one behavioral health organization. In follow-up in an effort to obtain more diverse perspectives, a survey was distributed widely.

In total, 9 staff from a behavioral health organization participated in the focus group and 27 people completed the survey. All participants resided in Maine. Refer to Table 1 for additional information about participants.

We learned a lot from the focus group and survey – what concerned them and how their role may be supported. The findings provided in the following paragraphs describe their perceived benefits of the system and explains their concerns. These insights may be used to revise the educational materials and to review the manner in which implementing organizations are supported. Because this evaluation was conducted among small samples of our target audience, the findings should be viewed as instructive, but not definitive.

Table 2: Participants Demographics

Table 1.1 Participants Demographics			
Participants		36	
Type of services provided:			
Clinical	0	Integrated: Clinical and mental health	25%
Mental health	50%	Other	11%
Substance abuse treatment	14%		
Role			
Direct service provider	31%	Non-direct (administrative)	66%
Other	3%		
Length of time working in the community?			
Less than 1 year	8%	1 - 4 years	8%
5 – 10 years	14%	More than 10 years	70%

### RESULTS

This report details the emerging themes across both the focus group and survey. In addition to this report, a summary of the findings to inform the Committee discussions (Appendix D) was developed.

#### Benefits of HealthInfoNet

Increased communication and coordination between providers results in better treatment management.

#### BENEFITS

- ❖ Better treatment management

## Barriers to HealthInfoNet

### *From the provider perspective*

Confidentiality and loss of control over who has access to what records. More pronounced in mental health services. Higher proportion of persons in integrated services did not see any barriers to sharing. Additional barriers included administrative burden and getting the interoperability of the different systems.

#### BARRIERS

- ❖ Confidentiality
- ❖ Loss of control over who has access to what records
- ❖ Discrimination

### *From the provider's patient's perspective*

The most frequent barrier selected was “loss of control over who has access to what records” (72%), followed by confidentiality (59%) and discrimination (40%). There was not a marked difference in respondents from different types of practices. The focus group provided a deeper description of these barriers:

- ❖ Typically, a patient signs a release to obtain information from a specific provider (such as their PCP). On either side of the release, people and time limits are identifiable. The concern with HealthInfoNet is that patients will be asked to sign a blanket release where no providers are identified.
- ❖ Within organizations, there are policies and practices that minimize the risk of a breach of confidentiality. Once the information is sent outside the organization, these safety nets no longer exist.
- ❖ Organizations' policies and procedures govern what information is captured in their electronic medical records. There is great variety/level of disclosure across different organizations. Therefore the 'comfortable' level of disclosure may differ from one organization to another.
- ❖ Administrative burden. Initially will require extra staff time. But the hope is that it will save time in the long run (by decreasing the number of individual release forms that need to be sent between providers).
- ❖ Important to emphasize the audit reports.

## Tools for Talking with Patients

The following **information** was seen as critical (in order of frequency):

- ❖ Benefits of sharing mental health records (87% - particularly among mental health services)
- ❖ Consent options (87% - particularly among mental health services)
- ❖ Consent process (65% - particularly among mental health services)
- ❖ Which providers are participating (65% - particularly among integrated service providers)

#### EDUCATIONAL TOOLS

- ❖ One-page handout for patients
- ❖ Talking points for providers

In both the focus group and in the survey, a one-page patient handout (82%) and talking points for providers (91%) were seen as useful. The one-page patient handout was less important for substance abuse treatment services and co-occurring behavioral health services.

## Process of Obtaining Consent

While there was diversity on when during a patient visit the education and consent should occur, approximately half of survey respondents (54%) and all focus group participants felt that both education and consent should occur during the visit and that it should be undertaken by the provider (73% survey respondents and 100% focus group participants).

Alternate persons included patient specialists and case managers. Survey respondents from integrated services were less uniform in their responses with 28% suggesting a support staff (such as medical assistant) or administrative staff (14.3%).

## Feedback on Existing Materials

### *Educational one-pager*

The focus group reviewed the educational one-pager and made the following points:

- ❖ *Caregiver* normally refers to family member or friend not healthcare provider.
- ❖ *Social security disclaimer* on educational one-pager does not match the consent form.

### *Consent Form*

The focus group also reviewed the consent form and made the following points:

- ❖ *Sensitive information* can mean a range of things. For some, age may be sensitive.  
“When I read sensitive information, my brain goes to the most sensitive information that’s in that chart.”
- ❖ *Notarization requirement* was unclear to participants. They initially thought that they would have to have all the forms notarized (rather than the notarization only being required if a patient was downloading the form from home). It was suggested that this was made clearer by saying “when downloading...”

## Additional Survey Comments

“It is so important that patients/consumers be educated about the benefits to them for sharing information and the risks of not sharing. For so long, the focus of our system has been on the consumer rights for preserving confidentiality to the point where critical information doesn't get shared. Any information needs to accent the positive aspects - and providers need to be educated to avoid stigma and labeling that lies at the core of the need to preserve confidentiality at all costs.”

“Live demonstrations of how it works by potentially connecting to 'the cloud', peer mentoring, stories, stories, stories, hand-holding, asking for feedback after the person's records first enters the cloud about how they are feeling about it. In other words, offering support to those who have concerns, questions, and worries.”

“Sharing efforts within and between organizations to develop collaborative practices.”

“Patient portals are helpful for patients who are inclined to get information in that way. We really need to use a variety of options to make it as easy and comfortable as possible to understand information sharing benefits as well as challenges.”

## CONCLUSION

The objective of this focus group and survey was to gain qualitative understanding and insight into what providers perceived their needs to be when talking to patients about sharing mental health records. Results were consistent through both the focus group and survey. Participants articulated many patient and provider benefits. The primary concern was the organization’s loss of control over access to their patient’s records and the increased potential for breach of confidentiality as a result. This concern was more pronounced in mental health services and less evident in integrated services.

Almost all participants recommended that the educational and consent processes occur between the patient and provider during a visit.

Participants requested a one-page patient handout and talking points for providers.

## RECOMMENDATIONS

Based on the results from the focus group and survey, the following are recommended for assisting providers in obtaining patient consent to share their mental health records.

- ❖ **Create brief patient educational materials and provider talking points** that include: the benefits of sharing mental health records; consent options; the consent process; and which providers are participating (or provide a link to the latter).
- ❖ **Emphasize the availability of audit reports** in both materials. This will help alleviate some of the concerns of providers and patients by enabling them to see who has accessed patient-specific records.
- ❖ **Use graphics and simple language to explain concepts and processes.** It is important for the providers to be able to easily articulate and explain HealthInfoNet, the consent options, and consent processes.
- ❖ **Address concerns about controlling access** in both materials. Emphasize the existence of a strict role-based access policy to alleviate some fears with sharing health information.

### RECOMMENDATIONS

- ❖ Create brief patient educational materials and provider talking points
- ❖ Emphasize the availability of audit reports
- ❖ Use graphics and simple language to explain concepts and processes
- ❖ Address concerns about controlling access

### **LIMITATIONS AND FUTURE EVALUATION**

The formative, exploratory, and descriptive nature of the focus group and survey limits the findings. First, the participants represented self-selected staff. Participants in the focus group were from a behavioral health organization that was not currently participating in HealthInfoNet. The results of the focus group may have been different if participants had real-time experience with HealthInfoNet. Similarly, the system to obtain patient's consent and to include patient mental health records has not begun. Feedback is therefore limited to potential experiences. Secondly, while every effort was made to engage all participants, some ideas and perspectives may have been left out given the flow of the focus group or the structured questions of the survey.

Future evaluation efforts may benefit from developing an anonymous survey and/or focus groups that react to developed educational materials. We would recommend that recruitment be made from organizations participating in HealthInfoNet.

## APPENDIX A: SUMMARY OF RESULTS OF PATIENT FOCUS GROUPS TO INFORM DISCUSSION ON EDUCATIONAL MATERIALS

### BENEFITS


1. Acts as a surrogate patient voice
2. Increases the accuracy of records
3. Helps keep the system transparent
4. Decreases the patient's burden
5. Helps increase doctor efficacy
6. Helps ensure patient safety

### QUESTIONS

1. HealthInfoNet
  - What is HealthInfoNet?
  - How far does HealthInfoNet reach?
  - Why is substance abuse excluded?
  - Is provider participation required?
  - What information is included?
  - Who gets to see my information?
  - Why would a provider want to see my information?
2. Consent Options
  - What constitutes an emergency?
  - Where is the line between medical and mental health records?
  - Do you only give consent once?
  - Can you complete the form online?
  - What happens if you change your decision?
  - How does limited consent work?



## APPENDIX B: PRESENTATION ON CONSUMER FOCUS GROUPS



### Developing Consumer-focused Materials – What Consumers Need To Know

**Michelle Mitchell**  
on behalf of the  
Consumer & Provider Education Group

### Focusing the Focus Groups

What educational materials do patients need in order to consent to their records being shared electronically through HealthInfoNet?


- ❑ Information needs
- ❑ Confusing terms and concepts

### Focus Group Participants

Participants 43			
<b>Target audience</b>			
Seniors (65 years +)	14.0%	Veterans	20.9%
Adults (25 – 65 years)	53.5%	Persons with IDD	2.3%
Youth (-25 years)	53.5%	Guardians of persons with IDD	16.3%
<b>Gender</b>			
Male	46.5%	Female	53.5%
<b>Visited a primary health care provider within the last...</b>			
30 days	44.2%	6 months	27.9%
Year	9.3%	More than a year	14%
Can't remember	4.7%		
<b>Visited a mental health provider within the last...</b>			
30 days	48.8%	6 months	7.0%
Year	4.7%	More than a year	16.3%
Can't remember	9.3%	Never	9.3%
<b>Pay for medical costs through...</b>			
MaineCare	55.8%	Medicare	18.6%
Military, CHAMPUS or the VA	20.9%	Private health insurance	16.3%
Self-pay	9.3%		

### Focus Areas

- ❖ Benefits
- ❖ Common Questions
- ❖ Common Concerns
- ❖ Consent process
- ❖ Patients' ideal system



## BENEFITS

- ❖ Acts as a surrogate patient voice
- ❖ Increases the accuracy of records
- ❖ Decreases the patients' burden of record keeping
- ❖ Decreases the need for patients to continuously repeat their story
- ❖ Makes doctors and patients more accountable
- ❖ Helps increase doctor efficacy
- ❖ Helps ensure patient safety

"...you don't know the terms. My doctor said I have a seasonal depression and I have to start this light, and I may not know the name of the light but hopefully (the doctor) who I'm talking to is smart enough to know it's a mood box." Senior Focus Group participant

"You get yourself mad and upset because the doctor does not understand what you're saying..." Senior Focus Group participant

"I'd like to give my consent and know that wherever I was, and whatever emergency, whatever happened, those people have access." Veterans Focus Group participant

## An accurate alternative to the patient voice



"About 8 years ago... I had a massive heart attack. I went to Farmington hospital and was resuscitated there and sent down to Lewiston. When I had recovered, I went down to Togas to get my meds. They wouldn't even talk to me until I went to Lewiston, (and) got my records..." Veteran Focus Group participant

"I moved around a whole lot in my life. DHHS case, blah blah blah, family moving, and whatnot. Tracking down doctors is a bad thing, this kind of helps." Young Adult Focus Group participant

"If you're going to a new doctor, you have to tell them everything that's going on that you've said a billion times..." Young Adult Focus Group participant

## Decrease patients' burden



"A lot of people... are not necessarily reliable reporters. They want to tell the physician what they think the physician want to hear without being honest about their symptoms." IDD Focus Group participant

"(The) physician is more accountable to peers and guardians." IDD Focus Group participant

## Makes doctors and patients more accountable



"It keeps all doctors informed. Before, doctors weren't keeping in contact with each other. This way they can keep in contact with each other and they will all know what's going on." *Adult Focus Group participant*

"If they don't have my records to see what medications I'm taking, I'm taking 9 or 10 different pills, up to 12 sometimes. If they don't have all that and he serves me a pill I'm allergic to... that's going to throw off the whole balance of my other pills." *Senior Focus Group participant*

## Increases doctor efficacy & patient safety




"Is there a cost to the patient / provider for participating?" *IDO Focus Group participant*

"The governor doesn't have anything to do with this, does he?" *Adult Focus Group participant*

"Is this only for what happened while you were here in the state of Maine, not outside of the state. Now I've spent years in Minnesota... how does that (information) get to here?" *Veteran Focus Group participant*

"Is it going to be mandated by the state... that all doctors or all medical (providers) have to provide this service?" *Adult Focus Group participant*

## What is it?



## COMMON QUESTIONS

- ❖ What is HealthInfoNet?
- ❖ Does HealthInfoNet reach outside Maine?
- ❖ Is provider participation required?
- ❖ What is the plan for a security breach?
- ❖ Why is substance abuse excluded?
- ❖ Why would a provider want to see my information?
- ❖ What information is included?
- ❖ Who gets to see my information?

"It seems like lately there has been a lot in the news about security breaches as far as hackers. Even though you have the strongest and highest computer systems, all computers are vulnerable. What do you do, how do you deal with the situation if the HealthInfoNet computers are hacked?" *IDO Focus Group participant*

"Everything is electronic, on a computer, and nothings on paper. Say something happens and it all got wiped out, now what?" *Young Adult Focus Group participant*

"I don't care if it's encrypted, there is a hacker somewhere with the knowledge to get whatever information that he desires. If he had my social security number, all the information that I have is available to him." *Veteran Focus Group participant*

## What is the plan for a security breach?



"It's already in your record in paper form, but it wouldn't be put on (the system)? That's weird." Young Adult Focus Group participant

## Why is substance abuse excluded?



Participant 1: "In some kind of emergency, what does your mental (health) have to do with them giving you care at a hospital?" Young Adult Focus Group participant

Participant 2 in response: "The best care that they can. So they're not just going into it blind. They have some sort of document and (know) what your triggers are, or what medicines you've been on and what medicine you haven't. So they can figure out the best way to help you." Young Adult Focus Group participant

## Why would a provider want to see my information?



"I would definitely not want some med student accessing my records, seeing something dumb that I did and going back to his college buddies and laughing 'ha ha...' I read about this guy." Young Adult Focus Group participant

"There's stuff that's happened to me... that I don't want people knowing." Young Adult Focus Group participant

"The thing that separates this group from your other focus groups is we're all military and war veterans and some are career veterans. We do not trust the government. That's a given, it's not debatable." Veterans Focus Group participant

## Who gets to see what?



## COMMON CONCERNS

- ❖ The patient loses control of information
- ❖ Access is all or nothing
- ❖ Mental health stigma and discrimination



"Different age groups deal with different issues. Like ours is the privacy and the sanctioning of the information as to who and what, whereas older people would like to know what's the security." *Young Adult Focus Group participant*

## The patient loses control of information



"A person with intellectual disabilities, who has a guardian, blood pressure dropped and he ended up in the emergency room where he was seeing an unknown doctor, who knows nothing about him.

Doctor: Well, he's lived a good life.

Guardian: Yea, well what are you going to do for him?

Doctor: He needs a pacemaker, but he's lived a good life.

Guardian: If I was on that table would you give me a pacemaker?

Doctor: Well yea.

Guardian: Then he gets one." *IDD Focus Group participant*

## Mental health stigma and discrimination



"There are some things that people have in the past that they want to forget and don't ever want them brought up again. Which is probably some peoples' concerns. If it's in there, in an emergency, they're going to see it no matter if you want them to or not. If you don't want them to see it, you're pretty much S.O.L. because they're going to see it anyway." *Young Adult Focus Group participant*

## Access is all or nothing



## CONSENT PROCESS

- ❖ Show what HealthInfoNet is
- ❖ Simply state the options and consequences
- ❖ Define terms and give examples
- ❖ Explain the process in simple terms

## Show what HealthInfoNet is



## Simply state the options and consequences

OPTION	CONSEQUENCE
1: Do nothing	Their medical records are available to providers participating in HealthInfoNet and their mental health records would be available in an emergency.
2: Consent to have their mental health records included	Their medical and mental health records are available to providers participating in HealthInfoNet.
3: Do nothing and provide time limited consent	Their medical records are available to providers participating in HealthInfoNet and their mental health records would be available in an emergency. In addition, they could provide individual providers with time-limited access to their records on HealthInfoNet.
4: Opt-Out of HealthInfoNet	Their medical records are not available to any providers, even in an emergency.

## Define terms and give examples

**What constitutes an emergency?**  
 "What I might think is an emergency they might not or vice versa. I might be confused and ask 'did they access that information or did they not?' Would I be told they accessed it?" Adult Focus Group participant

**Where is the line between medical and mental health records?**  
 "If your primary care provider also diagnosis / prescribes your mental health medications, how are they separated? Where is the line?" IDD Focus Group participant

## Explain the process in simple terms

- ❖ Do you only give consent once?
- ❖ Can you complete the form online?
- ❖ What happens if you want to change your decision?
- ❖ How does limited consent work?

"My information is in the system, I go into the (doctor's) office and say, for today only you have access. How does this access get opened-up and how do I know the provider isn't going to keep going in? Is there an on/off button?" IDD Focus Group participant

## PATIENTS' IDEAL SYSTEM

- ❖ No social security numbers
- ❖ Patients decide who sees what
- ❖ Patients have access to their records
- ❖ Crisis counseling hotlines have access
- ❖ Links family records

## CONCLUSION & RECOMMENDATIONS

- ❖ Separate the educational and consenting materials
- ❖ Use graphics to illustrate concepts and processes
- ❖ Emphasize patient benefits and use quotes
- ❖ Address consumers concerns about security and controlling access

QUESTIONS

COMMENTS

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## Small Group Discussions

- ? What would be useful for providers in communicating these issues to consumers?
- ? What, if any, additional direct consumer education materials are needed?
- ? How might we want to disseminate these results beyond the Final Forum and Report?

## APPENDIX C: ONE PAGE DISSEMINATION OF RESULTS FROM PATIENT FOCUS GROUPS

### What education materials do patients need in order to decide whether or not to consent to their records being shared electronically through HealthInfoNet?

In the fall of 2012, Partnerships For Health conducted 5 focus groups in 3 different counties in Maine. Forty-three people spoke with us about this important decision. This is a summary of their voices...

#### Benefits of HealthInfoNet

##### 1. An accurate alternative to the patient voice

"I'd like to give my consent and know that wherever I was, and whatever emergency, whatever happened, those people have access."

##### 2. Decreases patients' burden

"If you go to a new doctor, you have to tell them everything that's going on that you've said a billion times before."

"About 8 years ago, I had a massive heart attack. I went to Farmington hospital and was resuscitated there and sent down to Lewiston. When I recovered, I went down to Togas to get my meds. They wouldn't even talk to me until I went to Lewiston and got my records..."

##### 3. Makes doctors and patients more accountable

"The physician is more accountable to peers and guardians."

##### 4. Increases doctor efficacy and patient safety

"If they don't have my records to see what medication I'm taking. I'm taking 9 or 10 different pills, up to 12 sometimes. If they don't have all that and he serves me a pill I'm allergic to...that's going to throw off the whole balance of my other pills."

#### Concerns about HealthInfoNet

##### The patient loses control of information

"Different age groups deal with different issues. Ours is privacy and the sanctioning of the information as to who and what..."

##### Access is all or nothing

"There are some things that people have in their past that they want to forget and don't ever want them brought up again... in an emergency, they're going to see it no matter if you want them to or not."

##### Mental health stigma and discrimination

"I think some things need to be kept private because they have a bad stigma (attached) to it."

#### What Patients Want To Know Before Making a Decision

- ❖ Show what HealthInfoNet is
- ❖ Simply state the options and consequences
- ❖ Define terms and give examples
- ❖ Explain the process in simple terms
- ❖ Answer specific questions

#### FOR MORE INFORMATION:

About **HealthInfoNet** contact Amy Landry



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About the **focus groups** contact

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## APPENDIX D: SUMMARY OF PROVIDER FOCUS GROUP & SURVEY RESULTS TO INFORM DISCUSSION ON EDUCATIONAL MATERIALS

### 1. BENEFITS OF HEALTHINFONET

Increased communication and coordination between providers results in better treatment management.

### 2. BARRIERS TO HEALTHINFONET

#### From the provider perspective:

Confidentiality and loss of control over who has access to what records. More pronounced in mental health services. Higher proportion of persons in integrated services did not see any barriers to sharing. Additional barriers included administrative burden and getting the interoperability of the different systems.

#### From the provider's patient's perspective:

The most frequent barrier selected was "loss of control over who has access to what records" (72%), followed by confidentiality (59%) and discrimination (40%). There was not a marked difference in respondents from different types of practices. The focus group provided a deeper description of these barriers:

- ❖ Typically, a patient signs a release to obtain information from a specific provider (such as their PCP). On either side of the release, people and time limits are identifiable. The concern with HealthInfoNet is that patients will be asked to sign a blanket release where no providers are identified.
- ❖ Within organizations, there are policies and practices that minimize the risk of breach of confidentiality. Once the information is sent outside the organization, these safety nets no longer exist.
- ❖ Organizations' policies and procedures govern what information is captured in their electronic medical records. There is great variety / level of disclosure across different organizations. Therefore the 'comfortable' level of disclosure may differ from one organization to another.
- ❖ Administrative burden. Initially will require extra staff time. But the hope is that it will save time in the long run (by decreasing the number of individual release forms that need to be sent between providers).
- ❖ **Important to emphasize the audit reports.**

### 3. TOOLS FOR TALKING WITH PATIENTS

The following **information** was seen as critical (in order of frequency):

- ❖ Benefits of sharing mental health records (87% - particularly among mental health services)
- ❖ Consent options (87% - particularly among mental health services)
- ❖ Consent process (65% - particularly among mental health services)
- ❖ Which providers are participating (65% - particularly among integrated service providers)

In both the focus group and in the survey, a one-page patient handout (82%) and talking points for providers (91%) were seen as useful. The one-page patient handout was less important for substance abuse treatment services and co-occurring behavioral health services.

#### **4. PROCESS OF OBTAINING CONSENT**

While there was diversity on when during a patient visit the education and consent should occur, approximately half of survey respondents (54%) and all focus group participants felt that both education and consent should occur during the visit and that it should be undertaken by the provider (73% survey respondents and 100% focus group participants).

Alternate persons included patient specialists and case managers. Survey respondents from integrated services were less uniform in their responses with 28% suggesting a support staff (such as medical assistant) or administrative staff (14.3%).

#### **5. FEEDBACK ON EXISTING MATERIALS**

The focus group reviewed the educational one-pager and made the following points:

- ❖ *Caregiver* normally refers to family member or friend not healthcare provider.
- ❖ *Social security disclaimer* on educational one-pager does not match the consent form.

The focus group also reviewed the consent form and made the following points:

- ❖ *Sensitive information* can mean a range of things. For some, age may be sensitive. “When I read sensitive information, my brain goes to the most sensitive information that’s in that chart.”
- ❖ *Notarization requirement* was unclear to participants. They initially thought that they would have to have all the forms notarized (rather than the notarization only being required if a patient was downloading the form from home). It was suggested that this was made clearer by saying “when downloading...”

#### **6. ADDITIONAL SURVEY COMMENTS**

- ❖ “It is so important that patients/consumers be educated about the benefits to them for sharing information and the risks of not sharing. For so long, the focus of our system has been on the consumer rights for preserving confidentiality to the point where critical information doesn't get shared. Any information needs to accent the positive aspects - and providers need to be educated to avoid stigma and labeling that lies at the core of the need to preserve confidentiality at all costs.”
- ❖ “A talking points handout from HealthInfoNet that providers can give to their patients/clients.”
- ❖ “What happens when a patient wants to cancel their consent? How can they be assured that their records won't continue to be transmitted electronically? How can they get an accounting of what was sent?”
- ❖ “Live demonstrations of how it works by potentially connecting to 'the cloud', peer mentoring, stories, stories, stories, hand-holding, asking for feedback after the person's records first enters the cloud about how they are feeling about it. In other words, offering support to those who have concerns, questions, and worries.
- ❖ “Sharing efforts within and between organizations to develop collaborative practices.”

- ❖ “We work primarily with adolescents who are hesitant to trust adults and the systems they manage.”
- ❖ “Patient portals are helpful for patients who are inclined to get information in that way. We really need to use a variety of options to make it as easy and comfortable as possible to understand information sharing benefits as well as challenges.”

# HealthInfoNet Consent to Share Mental Health and HIV/AIDS Records

Please **READ** the HealthInfoNet educational materials before filling out this form

Choose from the following options.

☐ I want to include my mental health information in my HealthInfoNet record.

☐ I want to include my HIV/AIDS information in my HealthInfoNet record.

☐ I would like to reverse my previous consent and hide the following information. Choose one or both.

☐ Mental Health

☐ HIV/AIDS

You can choose to do nothing with this form. If you do nothing, your general medical information will be available to participating providers and your mental health and/or HIV/AIDS information will be available only in a medical emergency.

You can still provide consent for individual providers. To do this, tell your participating provider during your visit that they have your consent to access your mental health, HIV/AIDS information or both. The information will be available to that individual provider during that visit. You will need to give permission the next time you want them to have access.

To remove all your medical information from HealthInfoNet, even in an emergency, you need to fill out a separate opt-out form. These are available from your provider or HealthInfoNet.

First Name	Middle Name	Last Name	
Address	City	State	Zip Code
Date of Birth (Month/Day/Year)	Sex (male/female)	Daytime Telephone	Email

By signing, I understand the information I've indicated above will be available to my providers using HealthInfoNet.

**Signature of Patient or Guardian**

**Date (Month/Day/Year)**

Please include printed name and contact of guardian

## Do one of the following to get this form to HealthInfoNet

1. Return this form to your provider, have them witness below, and forward to HealthInfoNet by fax at 207-541-9258 or mail to 125 Presumpscot Street Box 8, Portland, ME 04103.
2. Contact HealthInfoNet at 866-592-4352 to schedule a time to come to HealthInfoNet's office in person with your government-issued photo ID. HealthInfoNet is located at 125 Presumpscot Street, Portland.
3. If you can't do one of the two first options, you may contact HealthInfoNet and ask to be sent a form that can be notarized. You can also download this form from HealthInfoNet's website at <http://www.hinfonet.org/patients/your-choices>. This can then be sent by mail or fax to HealthInfoNet.

### Provider or HealthInfoNet Witness Only

On \_\_\_/\_\_\_/\_\_\_, I attest that the above signer is personally known to me or established his/her identity by presenting government-issued photo identification.

Signature

Print Name

Employer/Organization

## **Mental Health or HIV/AIDS HealthInfoNet Access Script**

Before speaking with the patient, check their consent status relative to MH or HIV/AIDS information on the demographic screen in the clinical portal. This will tell you whether the patient has chosen to include this information in their record already as well as if they have chosen to opt everything out. In either of these cases, you do not need to use this script.

If the patient has not consented to include MH or HIV/AIDS information in their record, individual users can have access to this information if the patient agrees during the visit. The following script can be used to request consent. If the patient agrees, the user must attest to consent in portal and access to the information selected will be available for that particular visit only.

### **Patient Script:**

(Facility Name) uses HealthInfoNet, a secure statewide computer system that helps us more easily coordinate your care. I use this system to quickly see your medical information from your other health care providers to help me make the best possible decision about your care.

Right now I only see your general medical information. If you have information related to mental health treatment or HIV/AIDS you'd like me see to help care for you, please let me know. I need your permission to access this information.

***If the patient has additional questions see talking points and FAQs.***

## HealthInfoNet Talking Points and FAQs

### Thank them

- Thank you for asking about HealthInfoNet. We're excited to be participating. Let me tell you a little bit about it.

### Tell them about HealthInfoNet

- HealthInfoNet provides a secure statewide computer system for doctors and other health care providers in Maine to share important patient health information that can help improve your care.
- The system combines information from all your participating health care providers to create a single electronic patient health record.
- While we've always shared information with other providers when necessary to support your care, HealthInfoNet makes it easier, faster and more secure.

### Explain what is in their HealthInfoNet record

- Your HealthInfoNet record contains prescriptions, immunizations, allergies, lab and test results, image reports, conditions, diagnoses or health problems and medical visit notes like visit summaries and hospital discharge summaries. However, office visit notes from mental health providers are not included. Not all providers include all of these things. Ask your participating provider what they include from their location.

### Explain the benefits and risks

- It's hard to remember all the details of your medical history. When your information is in HealthInfoNet it can prevent the need to tell your story over and over to each new provider.
- Having access to your HealthInfoNet record helps us work more closely with other providers, make better decisions about your care, and reduce the chance of medical errors. This is especially important in emergency situations.
- HealthInfoNet follows the highest information security standards available. However, as with any electronic system, there is some risk of unauthorized access or misuse of information, even by authorized users. (See security measures listed in FAQs below)

### You have several choices for sharing your information

- You do not have to participate in HealthInfoNet, and can have your information removed. You simply have to opt-out and HealthInfoNet makes that easy.
- When you opt-out, your information is deleted and will not be available to providers using HealthInfoNet, even in an emergency.
- There are three options for opting out: by mail, by phone or online. The quickest method of opting out is online.
  1. Visit [www.hinfonyet.org/optout.html](http://www.hinfonyet.org/optout.html)
  2. Fill out an opt-out form, available at (insert where they are available in your facility)
  3. Call HealthInfoNet at 207-541-9250 or Toll Free at 866-592-4352
- If you have been treated by a mental health care provider or for HIV/AIDS, this information is only available in HealthInfoNet if you give permission or are in a medical emergency. If you want providers like your primary care doctor or staff caring for you in the hospital to see this information, you need to give them permission. Would you like me to explain to you how you can do that? (see section below) I can also provide you with a form that explains these choices.

**Explain how they give permission for providers to see mental health and HIV/AIDS information**

- Different from general medical information, information from your mental health care providers and about HIV/AIDS is only available in HealthInfoNet if you give permission or are in a medical emergency. This includes specifically:
  - Information created by a licensed mental health facility or a licensed mental health provider like your counselor, psychiatrist or psychiatric hospitals.
  - HIV/AIDS diagnoses and results of HIV/AIDS lab tests.
- If you want providers like your primary care doctor or staff caring for you in the hospital to see your mental health, HIV/AIDS information, or both, you need to give them permission. You can do this in one of the following ways:
  - Fill out a consent form available from your participating provider or HealthInfoNet. By filling out and submitting this form, you are agreeing to have your mental health, HIV or both types of information available to all providers participating with HealthInfoNet.
  - During your visit, give your provider permission to access your mental health, HIV/AIDS information or both. This information will be available to that individual provider for that visit only. You will need to give permission each time you want them to have access in the future.

## Frequently Asked Questions

### QUESTIONS ABOUT HEALTHINFONET

#### **Who is behind HealthInfoNet?**

- HealthInfoNet is a Maine-based nonprofit organization founded in 2006. It is independent and is not owned by insurance companies, healthcare providers, employers or the government. It was started by a group of people representing patients, healthcare providers, payers and public health.

#### **Is participation required or mandated?**

- No. Participation is voluntary for patients and their providers. Your choice to opt-out will not affect your ability to receive medical care.

### QUESTIONS ABOUT THE HEALTHINFONET RECORD

#### **What medical information is included in my record? Is everything included?**

- Medical information included in your HealthInfoNet record is the following.
  - Patient demographics, insurer, primary care provider
  - Visit History
  - Laboratory and Microbiology Results
  - Radiology Reports
  - Adverse Reactions/Allergies
  - Prescription Medication History
  - Diagnosis/Conditions/Problems (primary and secondary)
  - Immunizations
  - Dictated/Transcribed Documents like hospital discharge summaries and provider visit notes
  - Vital Signs

#### **Is there any information that is not shared?**

- Your HealthInfoNet record does not include information from substance abuse treatment facilities or programs.

#### **How far back will my records go?**

- You may have records dating back to as early as December of 2008, because this is when a large number of organizations starting participating in the system. Your medical information from (name of organization) was included starting on (go live date). Your original medical record is not being replaced; it will be maintained just as it has always been.

#### **How can I find out if my doctor or local hospital is taking part in HealthInfoNet?**

- You can visit HealthInfoNet's website ([Participating Healthcare Organizations](#)) for a list of those participating. However, it's best to ask your doctor or hospital to be sure.

#### **What information is used to identify patients in the system?**



- Information used to identify patients in the system is: name, date of birth, sex, address, Medical Record Number (used by your provider), and Social Security Number. Your Social Security Number is never shared and is not visible to HealthInfoNet users.

**What if I receive care at a health care organization that is not participating in HealthInfoNet, what happens to my records?**

- Only providers who are participating in HealthInfoNet can access and include information in the system. If your provider does not participate in HealthInfoNet, they will continue to update your medical record in their own system, and they will share your medical records as they always have, by mail, email or fax. However, the goal is that all providers in Maine will participate in the future.

**What if there is a mistake on my record, how will I get that fixed?**

- Your HealthInfoNet record includes information created by the health care providers caring for you. If you know of an error, please let your provider know about that, so that they can update the information. Once they do this, it will be automatically updated in HealthInfoNet.

**How can I access my information in HealthInfoNet?**

- HealthInfoNet's system is not set up for patient access at this time. You can review your HealthInfoNet record with your provider if you like.

**CONSENT QUESTIONS**

**I don't want any of my information included, can you opt-out for me?**

- No. Only the patient, the parent (if patient is a minor), or guardian can opt-out. We cannot do this for you. This is a privacy precaution.
- However, if you fill out the opt-out form, I can send it to HealthInfoNet for you.

**If I opt-out, how do I know my information was deleted and that I won't be included again?**

- HealthInfoNet sends you a confirmation email or letter when you opt-out. HealthInfoNet keeps your demographic information, such as your name and birth date, to make sure none of your health information is included in the future.

**What if I change my mind and want to include my information in HealthInfoNet?**

- If you opt-out and later decide to have your information included, you will need to go online and fill out the opt-in form at [www.hinfony.org/optin.html](http://www.hinfony.org/optin.html) or call HealthInfoNet to do this over the phone.
- Your medical record in HealthInfoNet will only contain health information created after you decided to opt back into the system.
- You will then need to separately choose to include mental health and HIV information as explained above. You can also reverse your consent to include your mental health and/or HIV information. This can be done on the same form you filled out to consent to sharing this information.

**It says that my mental health and/or HIV/AIDS information can be accessed in a medical emergency without my consent. Is this true and who decides I'm in a medical emergency?**

- Yes, unless you have opted out of HealthInfoNet, Maine State law allows a provider to access your mental health, HIV/AIDS information in one of two situations.
  - If your provider believes it is necessary to prevent a serious threat to the health or safety of others.
  - If your provider believes it is necessary to prevent or respond to imminent and serious harm to your health.
- These legal provisions are included in 34-B MRSA 1207(1)(I) and 5 MRSA 19203(11).

## **SECURITY QUESTIONS**

### **Who is able to see my health information in HealthInfoNet?**

- Only authorized users with correct identification and unique passwords can use HealthInfoNet. This may include your doctor, nurses, medical assistants, pharmacists and other clinical staff involved in your care.
- And, before they can view your record they must confirm they are involved in your health care and have a need to see your information. This is recorded in the system.

### **How can I find who has viewed my record? Is there a record of who has viewed my health information and why?**

- HealthInfoNet keeps track of everyone who accesses your record, when they accessed it, and what information they looked at. Visit [www.hinfonyet.org/audit](http://www.hinfonyet.org/audit) or contact HealthInfoNet to request an audit report of this information.
- This audit report will include when a provider accesses a patient's mental health and/or HIV/AIDS data in an emergency situation described above.
- Please let us know if you have questions and concerns about access to your records here at (name of organization). We are also able to run audit reports of what (name of organization) providers have accessed your in HealthInfoNet.

### **How is the system checked for security failures/hackers?**

- Security tests are performed on an ongoing basis, to make sure that the records remain secure.
- Information is always encrypted and sent over private and secure computer connections.
- The system keeps track of everyone who views your record, including what parts they look at and when they look at it. You can request a report of this information by filling out the form at [www.hinfonyet.org/audit](http://www.hinfonyet.org/audit) or by calling 866-592-4352.

### **Is it against HIPAA rules for you to have shared my information?**

- No. HIPAA does not require patient consent when information is used to support treatment, as is the case with HealthInfoNet. In its contract with participating organizations HealthInfoNet is defined as a business associate under HIPAA. This allows HealthInfoNet to act as a "virtual medical record department" to collect and store medical records, and allow authorized providers to review and upload records. Having a third party manage medical records is common practice.

### **What happens if there is inappropriate access or use ("breach") of my HealthInfoNet record?**

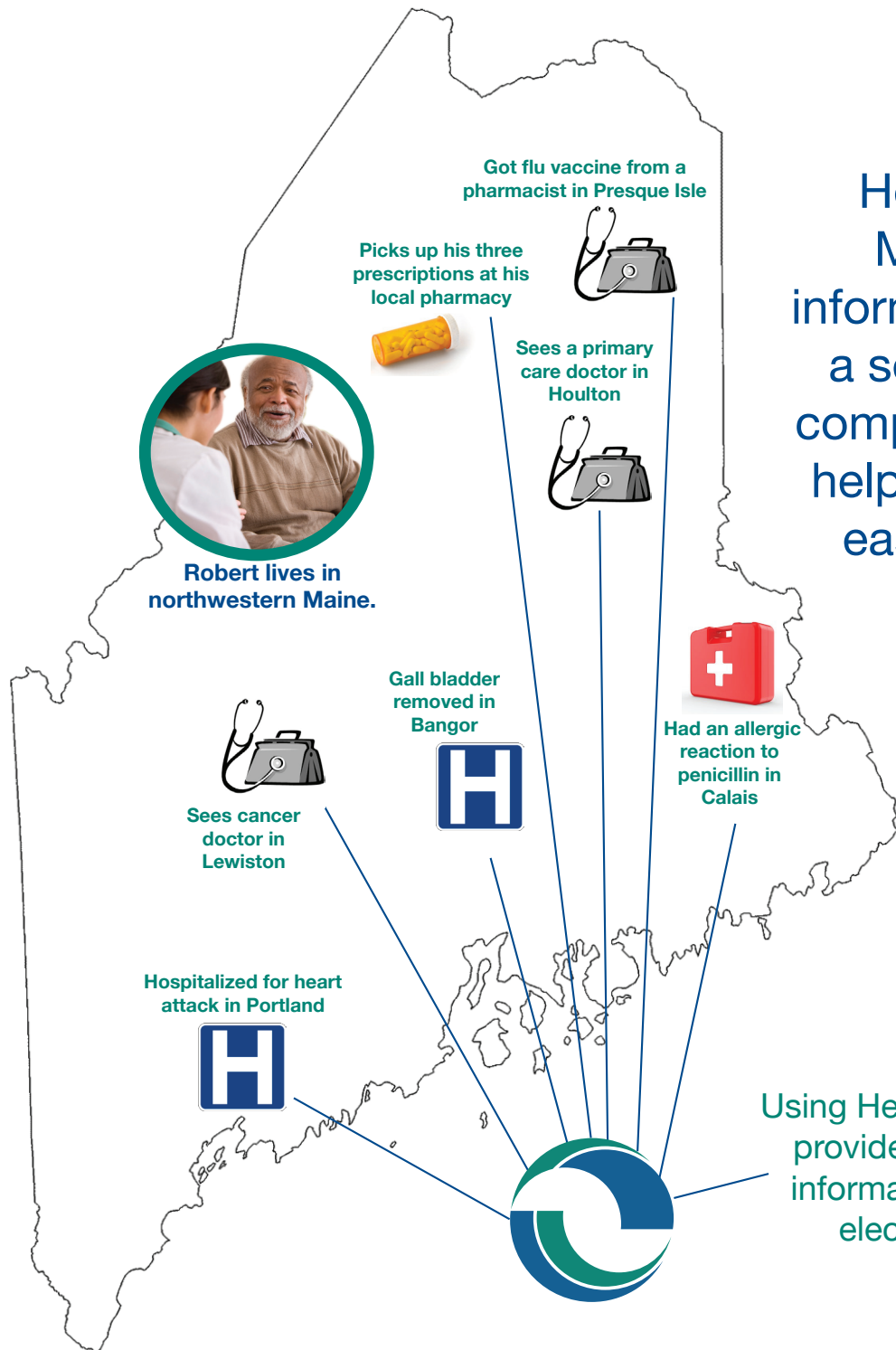
- HealthInfoNet must follow all state and federal health record privacy laws, including HIPAA. These laws require HealthInfoNet and/or your provider to inform you if there is a breach of your

personal health information. If you feel your HealthInfoNet record has been inappropriately accessed, please contact us.



# HealthInfoNet

HealthInfoNet is  
Maine's health  
information exchange,  
a secure statewide  
computer system that  
helps you get better,  
easier, safer care.



Using HealthInfoNet Robert's  
providers can find all this  
information in one secure  
electronic location.

## Better. Easier. Safer.

# About HealthInfoNet

## HealthInfoNet helps you get better, easier, safer care.

- **HealthInfoNet is a secure computer system for doctors, hospitals and other medical providers to share information that can improve your care.** HealthInfoNet combines your key medical information from separate health care sites to create a single electronic patient health record. Currently this record includes only information from your Maine-based providers. Always be sure to tell your provider if you've had medical care out of the state. Providers already share patient health records through fax, email, and mail when needed for your care. HealthInfoNet makes it easier, faster, and more secure.
- **HealthInfoNet allows your providers to quickly access the information they need to make more informed decisions about your care, especially in an emergency.** Without using HealthInfoNet, providers have only the information you've shared with them or they've entered into your medical record. But with HealthInfoNet, they see a more complete record, including prescriptions, test results and other information entered by all your participating providers.
- **HealthInfoNet protects public health.** HealthInfoNet helps prevent the spread of disease by quickly reporting certain illnesses and conditions (like Lyme disease or food poisoning), to public health experts at the Maine Centers for Disease Control and Prevention (Maine CDC). By law, the Maine CDC must keep this information private.



## HealthInfoNet is a Maine-based, independent, nonprofit organization.

- **Maine-based:** The Board of Directors includes individuals who are active and prominent in the medical community in Maine and represent a variety of health care organizations and interests.
- **Independent:** HealthInfoNet is independent and is not owned by insurance companies, health care organizations, employers or government.
- **Nonprofit:** HealthInfoNet is a private nonprofit organization. It is funded by many sources including charitable foundations, Maine health care providers, and state and federal government.

## HealthInfoNet can help providers work together, make better decisions, and reduce mistakes.

### HealthInfoNet provides a number of benefits for you.

- Better coordination between providers
- More accurate and complete records
- Fewer medical errors
- Healthier patients
- Improved patient safety
- Fewer repeat tests and procedures
- Less paperwork for you and your providers
- No need to remember all your medical history and tell your story over and over
- Reduced health care costs



Ann Sullivan  
Kennebunkport

"I see a lot of doctors who work in many different locations. HealthInfoNet will make it easier for my doctors to get all my medical information. I think it will reduce the cost of health care by avoiding repeat tests and medical mistakes. It also helps those treating me make a better whole person diagnosis."

# Information Included in HealthInfoNet

## HealthInfoNet includes important information about your health.

You don't have to do anything for information from providers like your primary care physician or community hospital to be included. Your record will include:

- Conditions, diagnoses, prescriptions, allergies, lab and test results, visit notes and documents like hospital discharge summaries and image reports.
- Your name, birth date, address, sex, phone number and social security number (if you give it to your provider). This information is used to make sure your information is entered into the correct record.

Unless you are in a medical emergency, you will need to give permission "consent" for the following information to be available in your record. Your consent choices are explained on the next page.

- Information created by a licensed mental health facility or a licensed mental health provider like your counselor, psychiatrist or psychiatric hospitals.
- HIV/AIDS diagnoses and results of HIV/AIDS lab tests.

Under Maine State law, this information is **only** available in HealthInfoNet if you consent, or if your provider believes it is needed to prevent a serious threat to your health. Information that may indicate a mental health or HIV diagnosis may be included such as visit notes from your primary care providers and medications you're on.

*Information from federally funded alcohol or drug abuse evaluation/treatment programs can not be included in HealthInfoNet according the Federal law.*

## Privacy and Security

**While there are risks with any electronic system, HealthInfoNet takes every precaution to keep your records private and secure.**

- HealthInfoNet follows the highest information security standards available.
- Information is always encrypted and sent over private and secure computer connections.
- Before someone can view your record, they have to confirm they are involved in your health care and have a need to see your information. This is recorded in the system.
- Only authorized users with correct identification and passwords can access your record.
- Information that identifies you won't be sold, and your name won't be added to any mailing list.
- The system keeps track of everyone who views your record, including what parts they look at and when they look at it. You can request a report of this information by filling out the form at [www.hinfonet.org/audit](http://www.hinfonet.org/audit) or by calling 866-592-4352.
- Of course, no electronic system is completely secure and there is some risk of unauthorized access or misuse of information, even by authorized users.



"I've worked with computer systems in Maine for many years and can say that HealthInfoNet uses layers of protection to keep records private and secure. "

- Ralph Johnson, CIO  
Franklin Memorial Hospital

# Your Choices

## You have several choices for sharing your information

Your Choices	Action you need to take	General Medical information	Mental health & HIV information
Share your medical information only.	Do nothing	Available to all participating providers	Available only in medical emergencies
Share your mental health information, HIV information, or both.	Fill out a consent form available from your participating provider or HealthInfoNet and consent to share mental health, HIV or both.	Available to all participating providers	The type of information you choose will be available to all participating providers.
Share your mental health information, HIV information, or both, with an individual provider.	During your visit, tell your participating provider they have your consent to access your mental health, HIV/AIDS information or both.	Available to all participating providers.	Available to that individual provider during that visit. You will need to give permission next time you want them to have access.
Remove all your medical information from HealthInfoNet.	Fill out an opt-out form available from HealthInfoNet, your provider, or online at <a href="http://www.hinfo.net/optout">www.hinfo.net/optout</a>	All information is deleted from your record and will not be available to your participating providers, even in an emergency.	All information is deleted from your record and will not be available to your participating providers, even in an emergency.

## Frequently Asked Questions

- **Is participation required or mandated?** No. Participation is voluntary for patients and their providers. Your choice to opt-out will not affect your ability to receive medical care.
- **If I opt-out, how do I know my information was deleted and that I won't be included again?** HealthInfoNet sends you a confirmation email or letter when you opt-out. HealthInfoNet keeps your demographic information, such as your name and birth date, to make sure none of your health information is included in the future.
- **Can I change my mind about sharing my information?** Yes. If you opt-out, you can later participate again ("opt-in"). Contact HealthInfoNet or go online to [www.hinfo.net/optin](http://www.hinfo.net/optin). Your record will only include information from medical visits that happen after you opt-in. You will then need to separately choose to include mental health and HIV information as explained above. You can also reverse your consent to include your mental health and/or HIV information. This can be done on the same form you filled out to consent to sharing this information.
- **What happens if there is inappropriate access or use ("breach") of my HealthInfoNet record?** HealthInfoNet must follow all state and federal health record privacy laws, including HIPAA. These laws require HealthInfoNet and/or your provider to inform you if there is a breach of your personal health information. If you feel your HealthInfoNet record has been inappropriately accessed, please contact us.

**For more FAQ's visit [www.hinfo.net.org](http://www.hinfo.net.org) or contact us at [info@hinfo.net.org](mailto:info@hinfo.net.org) or 866-892-4356**