SUPPORTING INTEGRATION OF BEHAVIORAL HEALTH CARE THROUGH HEALTH INFORMATION EXCHANGE

Recommendations for Integrating Colorado’s Mental Health, Substance Use Treatment, and Medical Communities through the Development of Statewide HIE

This report was written as part of the CORHIO Behavioral Health Information Exchange Project, with support from Rose Community Foundation.
# TABLE OF CONTENTS

I. **Executive Summary** ............................................................................................................................................. 2

II. **Background on Health Information Sharing** ........................................................................................................ 4
   - a. Health Information Exchange .............................................................................................................................................. 4
   - b. Importance of Integrating Behavioral Health Information ................................................................................................... 4

III. **Behavioral Health & HIE Project Overview** ........................................................................................................... 6
   - a. Project Plan .............................................................................................................................................................................. 7

IV. **Statewide Behavioral Health & HIE Community Roundtable Meetings** ........................................................................ 8
   - a. Summary of Community Events .............................................................................................................................................. 9
   - b. Key Results .................................................................................................................................................................................. 24

V. **Recommendations/Next Steps** ................................................................................................................................. 26
   - a. Include the Behavioral Health Community in the Development of HIE across Colorado ................................................................ 27
   - b. Endorse a Statewide Integration Agenda to Promote Better Coordinated Care ................................................................. 28
   - c. Develop Targeted Education and Outreach for Colorado’s Health Care Community ............................................................ 29
   - d. Advocate for Supportive Public Policy ..................................................................................................................................... 30
   - e. Modify CORHIO’s HIE Operations ........................................................................................................................................ 33
THE HEALTHCARE DELIVERY SYSTEM IS RAPIDLY EVOLVING TO PROVIDE PATIENTS WITH MORE COORDINATED AND INTEGRATED CARE.

This is evidenced by the creation of alternative care models, such as the Patient Centered Medical Home and Accountable Care Organizations. These systems ensure effective care management, encourage consumer engagement, and represent a shift in payment methodologies for the provision of higher quality care. This can result in reduced costs and improved quality of care throughout the healthcare system. In order to realize these benefits, treating providers and consumers must have access to robust, timely, and accurate information. Through statewide health information exchange (HIE), providers can have appropriate, real-time access to their patients’ medical records. Although behavioral health is a critical component of a person’s overall health, mental health and substance use treatment information is currently not integrated with physical health information. This creates significant gaps in health records, potentially leading to fragmented, lower quality care. Being able to access and share complete patient health information, including both behavioral and physical treatment records, across clinical practice areas enables the creation of a longitudinal patient record, which can be valuable in providing a complete picture of an individual’s overall health.

The Colorado Regional Health Information Organization (CORHIO) is a nonprofit, public-private partnership that aims to improve health care quality for all Coloradans through cost effective and secure implementation of health information exchange. Through the Behavioral Health and Health Information Exchange project, described in Section III, CORHIO has partnered with many Colorado-based organizations to develop and implement recommendations to facilitate the integration of behavioral and physical health information through HIE. Through this work, CORHIO and its partners continue to emphasize the key underpinnings of patient protection, safeguarding patient privacy, ensuring confidentiality, and encouraging trust between and amongst providers and consumers.

To initiate this project, CORHIO conducted extensive research on state and national laws and regulations regarding behavioral health information sharing. This research identified two possible barriers to sharing health information: the “Disclosure of Confidential Communications” clause of the Colorado Mental Health Practice Act and the Federal Rule 42 C.F.R. Part 2. As a first step in the project activities, CORHIO worked with a variety of healthcare stakeholders to amend the Mental Health Practice Act clause, addressing this barrier by aligning Colorado statute with federal law.

In order to better understand the behavioral health community’s position on health information sharing, CORHIO facilitated a series of community meetings throughout Colorado to gather robust input on the opportunities, concerns, and priorities for including behavioral health information in HIE. The results from these meetings are included in Section IV.

The behavioral health community is largely supportive of better information sharing across care settings. The strongest recommendation in this project is to begin sharing behavioral health information today. Aside from federally-assisted substance use treatment programs, existing laws and policies do not create a barrier to appropriate sharing of behavioral health information. Both behavioral and physical health providers are covered under HIPAA - practicing under the same set of laws and regulations.
The recommendations, detailed in Section V, developed through community input and at the direction of a multi-stakeholder Steering Committee fall into five categories. These approaches all aim to support better integrated care, thus reducing barriers to effective health information sharing.

THE RECOMMENDATIONS INCLUDE THE FOLLOWING:

1. Include the behavioral health community in the development of statewide health information exchange – starting today

2. Endorse a broader, statewide health integration agenda to promote better coordinated, less fragmented care

3. Develop a communication and outreach plan that supports education for all stakeholders regarding HIE and targeted education for physical health professionals on working with the behavioral health community

4. Support revisions to public policy to address barriers to information sharing and partner with key constituencies, including advocating for a revision to restrictive federal substance use treatment program regulations

5. Modify CORHIO’s Health Information Exchange (HIE) Operations
   a. Develop a granular consent model
   b. Enable consumer access to treatment data available within the exchange

This document begins to define the next steps in the process of exchanging behavioral health data across health care settings so that information moves along with individuals across the health care continuum. CORHIO worked closely with members of the Behavioral Health and Health Information Exchange Steering Committee to validate and enhance these recommendations. CORHIO will continue to partner with Colorado’s behavioral and physical health communities to implement these recommendations and, on an ongoing and collaborative basis, determine the best strategy to include the behavioral health community in the development of HIE across Colorado – leading to better, more coordinated, and more effective care. This seamless information sharing will support CORHIO’s mission, “Shared health information for all individuals in every Colorado community promoting the right care at the right time and place.”

CORHIO would like to thank the members of the Behavioral Health and HIE Steering Committee for their valuable input into the development of this report.

THE FOLLOWING ORGANIZATIONS COMPRIZE THE PROJECT’S STEERING COMMITTEE:

- Colorado Association of Alcohol and Drug Service Providers (a.k.a.) the Colorado Providers Association
- Colorado Behavioral Healthcare Council
- Colorado Department of Human Services, Division of Behavioral Health
- Colorado Mental Wellness Network
- Community Reach Center
- Colorado Regional Health Information Organization (CORHIO)
- Federation of Families for Children’s Mental Health - Colorado Chapter
- Mental Health America of Colorado
- National Alliance on Mental Illness – Colorado Chapter
- Quality Health Network
A. HEALTH INFORMATION EXCHANGE

Throughout the country, utilization of health information technology, such as electronic health records (EHRs), has increased in hospitals, clinics, and physician offices. This shift has the potential to revolutionize the healthcare delivery system. EHRs capture robust information on patient encounters, which can be used in evidence-based decision support, quality management, and outcomes reporting. Transformations in health care delivery and payment reform are driving communities to think differently, focusing on care coordination and integration of services. Although patient information is stored electronically on an increasing basis, a critical gap in patient care remains. There is a need to exchange health information among all the healthcare providers and organizations involved in a patient’s care.

Health information exchange (HIE) is a way to enable the secure sharing of clinical information among all care delivery settings, across multiple EHRs. HIE enables the creation of a trusted, longitudinal patient record that spans across the healthcare continuum. This creates continuity in patient care, providing for an accurate and complete picture of a patient’s health and thus providing the tools for improving treatment quality, patient safety, and reducing overall healthcare spending.

COLORADO-BASED HIE INITIATIVES

The Colorado Regional Health Information Organization (CORHIO) has been designated by the State of Colorado to implement and ensure the development of HIE across Colorado. CORHIO is a nonprofit, public-private partnership aiming to improve health care quality for all Coloradans through cost effective and secure implementation of HIE. Quality Health Network (QHN), a recognized leader in HIE, is also a nonprofit entity that has been exchanging data in the Mesa County area since 2005 and is now providing exchange across the Western Slope. Both CORHIO and QHN ensure that health information is shared effectively, while maintaining confidentiality, privacy, and security of patient data. The long-term potential of this shared information has been described well by one of CORHIO’s leading provider participants: “Providers in communities will become communities of providers”.

B. IMPORTANCE OF INTEGRATING BEHAVIORAL HEALTH INFORMATION

In Colorado, 35.8% of adults reported having poor mental health in 2010. Studies have shown that the average life expectancy for those with serious mental illness ranges from 13 to 30 years less than the rest of the population. Much of this can be attributed to fragmented, inconsistent, and episodic care. Individuals requiring behavioral health services have a unique need for integrated care due to frequent use of the healthcare system, and a greater need to coordinate care among diverse providers.

A study done by JEN Associates found that those with Serious Mental Illness (SMI) have a disproportionate use of medical services compared to those without SMI. The results demonstrated that those with SMI have 3.5 times higher rates of emergency room visits, public-private partnership aiming to improve health care quality for all Coloradans through cost effective and secure implementation of HIE. Quality Health Network (QHN), a recognized leader in HIE, is also a nonprofit entity that has been exchanging data in the Mesa County area since 2005 and is now providing exchange across the Western Slope. Both CORHIO and QHN ensure that health information is shared effectively, while maintaining confidentiality, privacy, and security of patient data. The long-term potential of this shared information has been described well by one of CORHIO’s leading provider participants: “Providers in communities will become communities of providers”.

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1. As utilized throughout this report, “behavioral health” is intended to be a collective term for both mental health and substance use disorder - as applied to providers, consumers, treatment, services, and organizations, as appropriate.
four times the rate of primary care visits, and five times the rate of specialist visits. In a California study, of the Medicaid patients that visited the ER 31 or more times within the span of 12 months, 56% had co-occurring mental illness and substance use disorder and about 90% had at least one (mental illness and/or substance use disorder). In addition, those with SMI have high rates of co-occurring mental and medical disorders. This group is nearly three times more likely to have diabetes and three times more likely to have chronic respiratory disease, compared to the general population.

Fortunately, models that integrate care to treat individuals with mental health and medical comorbidities have proven effective. Colorado health care providers are continuously working to promote the integration of all health services in a patient-centric care model, including mental health and substance use treatment providers. Many providers believe that HIE can assist these efforts through sharing critical patient information, such as medical history and medication lists, to better coordinate patient care.

CORHIO also views behavioral health as an important component in implementing Colorado’s statewide vision of improving quality, cost-effectiveness, and accessibility of patient information through HIE. There is a demonstrated need to share behavioral health information, but there are unique challenges due to privacy, policy, and legal concerns that must be addressed. Amanda Kearney-Smith, director of the Colorado Mental Wellness Network and member of the project’s Steering Committee, represents the voice of the mental health consumer community in Colorado. “Unfortunately, there is still a stigma associated with mental health conditions and some people fear that their diagnosis may fall into the wrong hands and will be used against them,” said Kearney-Smith. “We have to be sure to strike a careful balance between protecting individual privacy with the need to have comprehensive information available for high-quality health care treatment and services.” Once behavioral health information is shared appropriately, de-identified aggregate data can be provided for research purposes. This can also help serve the treatment of the behavioral health community at large and promote interventions targeted to specific communities.

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IN SEPTEMBER 2010, THE ROSE COMMUNITY FOUNDATION AWARDED CORHIO A TWO YEAR GRANT TO SUPPORT THE "BEHAVIORAL HEALTH AND HEALTH INFORMATION EXCHANGE" PROJECT

This project aims to identify and address policy and practice barriers to integrating behavioral and physical health care services through HIE. Led by CORHIO, this project includes partnerships with a variety of behavioral health organizations, allowing area experts, providers, and consumers to fully examine and address these expressed issues around the electronic exchange of behavioral health information.

THE FOLLOWING ORGANIZATIONS COMPRISE THE PROJECT’S STEERING COMMITTEE:

- Community Reach Center
- Colorado Regional Health Information Organization (CORHIO)
- Federation of Families for Children’s Mental Health - Colorado Chapter
- Mental Health America of Colorado
- National Alliance on Mental Illness – Colorado Chapter
- Quality Health Network

The structure of the project and its activities provides for broad participation by many organizations and individuals through regional community meetings, ongoing workgroups, and coalition efforts that may be needed to enact policy and practice changes necessary to improve integration. The project’s goal is to develop and implement recommendations, based on consensus among behavioral health consumers and providers, to improve the exchange of behavioral health information and facilitate coordination of behavioral and physical health services.
The Behavioral Health and HIE Project Steering Committee members assisted CORHIO staff in developing the following project structure and timeline. This approach provides for the most collaborative and inclusive process to arrive at carefully crafted, comprehensive recommendations and activities to improve the integration of behavioral HIE in Colorado. This provides all stakeholders with the opportunity to provide input on improving the quality of mental health and substance use treatment services and increasing cost-effectiveness for providers, consumers, and the health system as a whole.

**PLANNING PHASE, JANUARY - APRIL 2011:**
- Created issue brief providing background on current state and federal policy framework for sharing behavioral health information between treating providers.
- Collaborated with behavioral health community efforts to amend the “Disclosure of Confidential Communications” clause of the Colorado Mental Health Practice Act through Senate Bill 11-187, enabling mental health providers to share data under the same set of rules as physical health providers.
- Finalized plan for collecting statewide community input on behavioral health information sharing.

**PHASE 1: RECOMMENDATION DEVELOPMENT, MAY 2011 - SEPTEMBER 2012:**
- **April – December 2011: Community Roundtable Series**
  Facilitated six regional meetings throughout the state with behavioral health providers, consumers, and community members. Also facilitated statewide meeting of behavioral health community representatives involved in policy and state level initiatives. These meetings allowed stakeholders to discuss opportunities and challenges in sharing behavioral health information, as well as begin identify strategies for better integration.

  - **January 2012 - March 2012:**
    Work with the Steering Committee to develop a document summarizing the results of the community meetings and release recommendations for appropriate inclusion of behavioral health information in statewide HIE.

  - **April 2012 – May 2012:**
    Convene providers, policymakers, consumers, and advocacy groups to validate recommendations and develop a shared vision for implementation.

**PHASE 2: STATEWIDE IMPLEMENTATION & ADVOCACY, JUNE 2012 - ONGOING:**
- CORHIO will work with project Steering Committee members as well as other stakeholder organizations to implement the recommendations described in this report, including consumer, provider and policymaker education as well as policy advocacy, as appropriate.

The following sections will describe the roundtable series results and outline a clear strategy for moving forward with appropriately sharing behavioral health information.
SIX COMMUNITY MEETINGS WERE HELD ACROSS COLORADO, CONVENING 124 TOTAL CONSUMERS, PROVIDERS, AND OTHER BEHAVIORAL HEALTH STAKEHOLDERS.

Meetings took place in collaboration with community mental health centers and other behavioral health community organizations (listed below), to meet where providers, consumers, and community members could feel most comfortable having an open and honest dialogue. This geographical diversity ensured that the results represented a broad cross-section of perspectives and attitudes regarding HIE.

- New Beginnings Wellness and Recovery Center, Alamosa, CO
- AspenPointe Pathways ACCESS Center, Colorado Springs, CO
- Mental Health Center of Denver, Denver, CO
- Centennial Mental Health Center, Sterling, CO
- CHARG Resource Center, Denver, CO
- Axis Health System, Durango, CO

The meetings began with a brief introduction to the project, CORHIO, and health information exchange. Next, time was devoted to educate the group on facts and trends pertaining to behavioral health and physical health (i.e. utilization statistics, comorbidity rates). The remainder of the meeting was dedicated to an in-depth roundtable discussion regarding sharing behavioral health data for treatment purposes.

Using keypad polling technology to help facilitate community participation, the meeting structure allowed participants to vote anonymously by selecting a number that represented a multiple choice answer. The results of the group votes were then displayed on a projector, where the topic and responses were opened for discussion. This allowed for an optimal blend of education, targeted Q&A, and open discussion.

THE PRIMARY OBJECTIVES OF EACH MEETING WERE TO DISCUSS THE FOLLOWING:

- **Opportunities:** Determine possible benefits of exchanging behavioral health information.
- **Concerns:** Discuss issues/barriers related to exchanging behavioral health information.
- **Priorities:** Discover the best ways to include the behavioral health community appropriately as Colorado develops statewide HIE.
The questions began with simple demographic information, to establish a mutual understanding regarding the audience at each location. To encourage open dialogue, participants were not introduced at any point during the meeting. All responses were compared by demographic categories to determine any similarities or differences among participant cohorts. In any reviews of the discussion or data, all participants are only listed by their position in the meeting to protect confidentiality.

This breakdown demonstrates excellent representation from both providers and consumers. Some participants chose to answer “other” for confidentiality. Others either fit into multiple categories (i.e. provider and community member) or did not fit in any categories (i.e. health center billing and IT staff).
As evidenced in the previous page, there was also significant diversity in the age range of participants. Age cohorts were not broken up in equal sections, but were segmented in an attempt to group respondents into categories with perceived generational differences in uses of technology. This has the potential to produce different perspectives on technology use and safety. When analyzing the results, this question was asked to ascertain if there were any differences among various generations regarding readiness to accept new technologies and to identify if there were differing concerns among age groups.

The question depicted to the left was used to get a better understanding of the audience, and determine if there were any significant differences in opinion among genders.
This question was asked to determine each participant’s “health home,” or where they go to receive the majority of their care. There are extreme differences among the various cohorts in where primary care is received. Patients and community members were likely to seek the mental health center as their primary source of care, with only 14-20% identifying a primary care physician. Although 60% of patients use their mental health center as their primary source of care, the remaining 40% were divided across PCPs, hospitals, community clinics, and other care settings. Many participants felt that more than one answer applied. This demonstrates the need for information to be shared across many providers to support care coordination and better consumer experience. This figure also demonstrates the high use of hospitals among those self-identifying as consumers (7% as compared to 0% in other groups).
2. OPPORTUNITIES

The next set of questions focused on the opportunities available for better integrated care through health information technology, better information sharing, and HIE.

The vast majority of participants, 88%, agreed that behavioral health should be considered along with physical health as part of a person’s overall health care. The discussion centered on the underlying principle that patients’ mental health state and substance use can impact their physical health. Participants felt it was particularly important to have a shared medication management strategy and treatment plan among providers. Although there was a majority of agreement, there were a few participants that disagreed, citing the distrust and social stigma that can surround mental health or substance use diagnoses.

COMMUNITY CORNER

“I strongly agree because your mental health is a piece of your complete health, if you’re not feeling well mentally, you won’t feel good physically, and vice versa.”
- CONSUMER

“When I started doing Cognitive Behavioral Therapy, my life got significantly better. It helped my mental health, and, in turn, my behavior and physical health. I wouldn’t have found my psychiatrist without my primary care doctor, so it is a two way street.”
- CONSUMER

“They [physical and behavioral health] need better integration, because they affect each other. There are many medical problems that come from substance abuse and mental health.”
- PROVIDER

“I have had negative experiences. Once I told my doctor about my mental condition, every symptom I have goes with that diagnosis. For example, when I was lethargic, she told me it was in my head. So, now I’m scared to let my physicians know, because they will begin attributing everything to my mental condition.”
- CONSUMER

“I disagree. Your confidentiality is gone already. A medical doctor shouldn’t be giving someone mental health medication or diagnoses. I’ve had many surgeries. The help I need and get in my mental health center should be separate.”
- CONSUMER
SHARING OF INFORMATION AMONG PROVIDERS

Across all six events, only one participant felt that better information sharing was not needed. This again demonstrates both the patient and provider’s desire to have more information available to improve treatment and outcomes. A reoccurring concern was that government agencies or other unauthorized parties may obtain access to behavioral health records. This indicates that a strict role-based access policy would alleviate some fears with sharing behavioral health information. In addition, when sharing data, patients would like the ability to consent to share information to only specific providers involved in their care.

COMMUNITY CORNER

When I had an ultrasound done at the same place that I had open heart surgery, the lady said that there wasn’t anything in my chart about heart surgery...and I showed her my scar! That is scary stuff. What if I was unconscious.
- CONSUMER

“I brought my information with me, and my doctor didn’t even look at it. She prescribed meds without looking at my mental medication and I was in a coma for four days. She claimed she didn’t know. It would be better if every doctor knew exactly what medications you are using.”
- CONSUMER

“My experience is that the people don’t want the government to have anything to do with their personal lives. Having their information leaked to the system is a big fear.”
- CONSUMER

“I think it’s important for your medical doctor to know your medication, there are poisons that result from mixing medication.”
- CONSUMER

“If I go to a doctor with a broken arm, my disorders are none of his business.”
- CONSUMER
CONSUMER ACCESS TO MEDICAL RECORDS

Consumers and providers demonstrated interest in patients obtaining access to their medical records. Approximately 87% of consumers agreed that better communication with patients is needed for more integrated care. The positive impacts that were mentioned included the potential for patient-controlled record release and the enabling of consumers to be more engaged and empowered in their care. Questions arose around liability if the patient lost the record. Also, there was some worry regarding the patient’s perception of the information in their record, without a healthcare provider to help interpret the content.

COMMUNITY CORNER

“"We are supportive of clients having access to their records. We are advocates for them, and we want them to have the right to their medical information. However, we have to be thoughtful about this. Sometimes there is a need for targeted release, just to make sure it is not hurtful for the patient to receive the information.”
- CONSUMER

"I don't want to have to be the one in charge. I want my doctor to do that. I have a bad memory and enough things going on in my life.”
- CONSUMER

"Both the client and the provider need to understand the history. The client should be well informed, and able to represent themselves, but the provider needs basic information so the client isn't expected to remember everything.”
- CONSUMER

"I understand why you want to do this, but I don't agree with it. Too many people just don't understand mental health.”
- CONSUMER

"I would like to have my records with me, and bring them with me to as many doctors as I want to.”
- CONSUMER

"I am just too worried about losing them! I'm already paranoid about losing my cellphone, let alone all of my medical information.”
- CONSUMER

"My experience over the last 16 years, in three different states, has been that with many doctors, they immediately discredit anything you have to say, and that goes doubly if you are a woman. If a woman goes into the ER with chest pains, they say it's heartburn and in your mind.”
- CONSUMER

"If there is a suicide attempt, or sensitive information in a chart, sometimes there needs to be a clinical, supervisory component, to make sure the information shared is not hurtful for a patient to receive. You just have to be cautious, and have targeted release.”
- PROVIDER

PHYSICIAN EDUCATION

Unfortunately, when discussing information sharing between providers, the concerns that arose in the earlier discussion of behavioral and physical health integration – regarding the perceived differences in medical treatment for those with a mental health diagnosis – were expressed again. This indicates a compelling need to not only share data, but to better educate physical providers on behavioral health issues. An additional takeaway is that some consumers did not feel that their treating provider would use the data in any meaningful way, even if given access. This again falls into a need for better provider education.
In addition to the community roundtable meetings, CORHIO surveyed the Colorado behavioral health community at the state level. Over 97% of participants agreed that the ability to securely exchange behavioral health and physical/medical health information electronically across providers will add value to the healthcare system. In the community meetings, questions were asked to further investigate this and determine the circumstances where better information sharing would add value. Nearly all of meeting participants agreed that it was vital to share information in emergency situations, with slightly smaller percentages also agreeing that information should be shared for treatment planning. Only two participants throughout the series felt that information should not be shared in any circumstances.

Participants suggested the creation of a simple care summary to be shared among all treating providers, to avoid major medication interactions and other avoidable conflicts. This would assist in transitions across care settings. Again, the groups discussed the need for better mental health education for physical health professionals.

“Obviously, when you go into the ER you’re already anxious and upset, and never remember to bring a big bag of meds.”
- CONSUMER

“I only want mental health providers to have access for treatment planning. I see my mental health center as my primary care.”
- CONSUMER

“Community Corner
“I want everyone involved in my treatment to have access, giving me the best care possible.”
- CONSUMER

“EMERGENCY SITUATIONS
BETWEEN PROVIDERS FOR PRIMARY CARE AND TREATMENT PLANNING
WITH CLIENTS/PATIENTS USING PERSONAL HEALTH RECORDS
UNDER NO CIRCUMSTANCES

TOTAL NUMBER OF RESPONSES

IF PATIENT INFORMATION SHOULD BE SHARED, THEN UNDER WHAT CIRCUMSTANCES? (SELECT ALL THAT APPLY)

- Client / Patient
- Provider
- Community Member
- Other

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This question was used to determine the community’s perception on the appropriate role-based access to behavioral health data. This information can help in developing an appropriate tiered consent structure by role. This resulted in strong agreement that mental health providers should have access to behavioral health data, but most participants also felt that primary care and specialists should also be given appropriate access to data. Participants felt that “specialists” should be further segmented out, feeling that a gynecologist or dermatologist would not need as much information as a hospital physician. Concerns also arose with the concept of sharing behavioral health information with social services or other government agencies. This again supports the concept of a tiered consent structure by role and strong role-based access policies.

The overall numbers for substance use treatment providers receiving access to patient information are lower. This could be because the community felt substance use treatment information needs further restrictions, that federal rules are too restrictive, or that those not using substance use treatment providers did not see them as a priority. Also, participants felt that retail clinics should not have access to a full history, only medication lists, and only for clinical staff.

The “other” category was open for discussion. Those who voted other included alternative care settings such as home health, long-term care, nursing homes, and community clinics. Participants also felt that patient and caregiver access should be another option, encouraging consumers to have insight and input into their record.
COMMUNITY CORNER

“As a behavioral health patient, I have stronger feelings about confidentiality that should be respected by my providers.”
- CONSUMER

“The federal regulations are strict for substance use disorder. But, it’s important information to have for the person’s best possible health. You can’t take some medications when abusing substances, or there might be a bad reaction.”
- CONSUMER

“If you’re going to share any information, medication and allergy lists should be shared. It’s for patient safety.”
- PROVIDER

This question was used to help shape priorities regarding the most important types of information and data to share among providers. Participants prioritized the sharing of physical health information but also agreed that the sharing of mental health and substance use treatment information would be valuable in a patient’s care. (The asterisk indicated for these two responses was used to clarify that psychotherapy and other private notes taken by behavioral health providers are not and will not be shared through HIE.) A recurring issue was the need to share medication and allergy lists to prevent negative interactions. It is worth noting that the second and third options for response (“basic info when patient goes in and out of hospital” and “medication and allergy lists”) can be considered part of the first option. These two were specifically pulled out, though, to determine whether they would be of higher, lower, or equal priority to “complete” physical health and behavioral health information sharing.

Those that voted “other” wanted to include the caveat that a patient should be able to control the release of information. The exception was noted that information should always be available in an emergency situation with no potential for affirmative consent. In addition, participants requested that health plans, pharmacies, and urgent care be given access to the data.
3. CONCERNS

In order to make sound policy decisions, there is a need to develop a better understanding of the behavioral health community’s concerns with HIE. Participants were asked to choose their top three concerns.

As evidenced by the chart above, the top concern among the behavioral health community is inappropriate use of data. These concerns were somewhat mediated when it was explained that disclosure of patient data is restricted only to those that are authorized to access it, and is compliant with HIPAA restrictions. This was followed closely by privacy, which was particularly prevalent in rural areas. Behavioral health patients were concerned that information regarding their diagnosis would be shared throughout their small communities. Both of these points demonstrated the need for better education regarding health IT and HIE, and indicate a desire for an HIE consent model including tiers of access privileges by provider type or location. However, many of the concerns that were voiced were not related to electronic records and HIE but to health records in general. This included sharing of data with the government and insurance companies, inaccurate information in the medical record, and the concerns regarding privacy and inappropriate use. Fortunately, policies and operational safeguards can be built to form an even stronger trust environment with electronic data, including the ability to track individual access to a patient’s record.
As a member of the behavioral health community, what are your top three concerns with HIE? (Multiple choice, broken down by role)

The above chart provides detail on participant responses regarding concerns, broken down by type of attendee. Those who chose “other” expressed diverse reasons, including the information being incomplete, experiences with physician bias against mental health patients, and the cost to implement electronic sharing of records. The results were analyzed by cohort, to determine if there is a need for targeted education or outreach to a specific group.

There were no significant differences among role cohorts by type of concern. Both patients and providers shared apprehensions about inappropriate use, privacy, technical security, inaccurate information, and the lack of control over sharing patient records. The recommendations discussed in this report are targeted to begin addressing and mitigating these concerns.
The results were also compared by age group, again, to determine correlation between type of concern and age.

Slight differences were found among groups. The 56-65 age group was most concerned about inappropriate use, privacy, and technical security and had minimal concerns around lack of control and inaccurate information. On the other hand, the 46-55 age group was closer to being equally concerned with all factors. The 21-30 and 31-45 age groups had slightly less of a concern regarding technical security than other groups. The 21-30 age group was highly concerned with lack of control over sharing of records. These results will be particularly helpful when planning effective education sessions to various stakeholders.
Listed below are key discussion points, representative of the feedback from the community meetings. Most of the concerns noted were alleviated by providing the audience with additional information regarding HIE policies, as well as explaining the practices of audit logs and technical safeguards.

**LACK OF CONTROL OVER SHARING PATIENT RECORDS**

- “Now, if there is information on having a psych condition, you can’t get insurance coverage. I would be concerned about pre-existing exclusions until 2014.”
  - CONSUMER
- “Would this affect people in regards to obtaining/keeping health insurance? How might this affect prior conditions?”
  - CONSUMER

**INAPPROPRIATE USE**

- “What if people share codes, to get access to my file? What if they use my information to gossip about me?”
  - CONSUMER

**PRIVACY**

- “I don’t want my family or friends knowing my information.”
  - CONSUMER
- “I am worried about counselors sharing information with each other.”
  - CONSUMER
- “My medical records are between my physician, my psychiatrist and me. If someone else could get ahold of them, I’d be very concerned.”
  - CONSUMER
- “Small communities thrive on others’ juiciness; privacy would be a big issue, and even if they’re bound by confidentiality rules it doesn’t mean that they will be followed.”
  - CONSUMER

**TECHNICAL SECURITY**

- “What safeguards do you have against use and misuse of the information?”
  - PROVIDER
- “How can you be sure no unauthorized people get access to the information?”
  - CONSUMER
- “[The hospital in my community] let me know about a security breach there, it made me worry about hacking in general.”
  - PATIENT

**INACCURATE INFORMATION**

- “My fear is whether the person is entering the information right, regardless if it’s electronic or paper.”
  - CONSUMER
- “I want to be able to access and verify that my information is correct, and to be able to correct it if I need to.”
  - CONSUMER
- “How can you really match people? What if I get mismatched?”
  - CONSUMER

**OTHER**

- “Every person who evaluates you may have a different opinion and it lives forever in your record, not necessarily inaccurate but different.”
  - CONSUMER
- “My fear is there might be limited or not enough information for the doctor.”
  - CONSUMER
- “What is going to make doctors actually review this? They don’t right now.”
  - CONSUMER
- “Who pays for this? Is it cost effective for doctor’s offices?”
  - CONSUMER
4. PRIORITIES

The final set of questions was developed to understand the behavioral health community’s perspective on the importance of health information exchange. This information helps CORHIO and its partners understand what priorities are most important moving forward. It also indicates if the community feels that there will be negative consequences if behavioral health information is not included in the broader healthcare information sharing paradigm.

Over 92% of all participants agreed that it was important to include behavioral health in the development of community and statewide HIE in Colorado. Of the 8% that disagreed, all but one identified themselves as a patient. Overall 87% of behavioral health patients agreed or were neutral about the statement. Those that disagreed restated their concerns regarding social stigma and differences in treatment. Those that agreed still emphasized the need to make sure their core concerns were addressed, particularly regarding appropriate access to behavioral health information.

COMMUNITY CORNER

“I don’t want to be lumped into a behavioral health category, due to the misinformation on mental health, and how people treat mental health patients.”

CONSUMER

“I think there should be a tiered system, where the client or patient can clear levels of providers into the system.”

CONSUMER
Although still quite strong, this question received somewhat less agreement, with 89% of participants agreeing or neutral about the statement. Explanations of possible negative consequences included the potential to have incomplete information (i.e. incomplete medication lists). The remaining 11% continued to feel that the potential negative impacts outweighed the positive results of increased information sharing.

**COMMUNITY CORNER**

“I think it’s important to look at the parity. If we’re left out in the negotiations, and left out in the beginning, we stand to lose a lot.”

- PROVIDER

“About ten years ago, if I went into the ER, I wouldn’t tell them my psychiatric medications because I knew I would be treated differently. As I understand it better, I know that there are potential drug interactions, and have just learned to accept the differences in treatment in exchange for better overall care.”

- CONSUMER
Throughout the community events and stakeholder meetings, a few reoccurring themes consistently rose to the top. These themes constitute the primary focus for developing recommendations for the effective inclusion of behavioral health information in the development of HIE across the state. Overall, Colorado’s behavioral health community is largely supportive of integration and better coordination between physical and behavioral health and views HIE as an important tool to support such efforts.

**SHARING BEHAVIORAL HEALTH INFORMATION AMONG PROVIDERS AND CONSUMERS**

- **There was significant interest in consumer access to data within the HIE, but both providers and patients also expressed significant concerns.**
  - Many consumers were interested in having access to their records, but interest varied. This was due to concerns regarding ownership of records and responsibility for loss of information.
  - From a consumer perspective, the primary driver for requesting record access is to ensure the information being shared is accurate and appropriate and to make any necessary updates.
  - Providers voiced concerns in the concept of sharing all health information openly with patients. They believe some information in a behavioral health record is sensitive and may damage a patient’s recovery. Providers would prefer the opportunity to walk a patient through the medical record, to explain the information listed, and translate complicated medical terminology.

- **Behavioral health stakeholders agree that better information sharing can lead to better outcomes for individuals and populations receiving behavioral health care.**
  - Most stakeholders agreed that all health information, including behavioral health data, should be shared in emergency situations.
  - The community generally agrees primary care and mental health providers should be provided with more robust access to data.
  - Participants agreed that the sharing of medication lists, although sensitive, would greatly reduce the possibility of negative drug interactions and other avoidable events. Most believed that this outweighed the potential privacy and confidentiality concerns.

- **Participants expressed they would have more comfort with information sharing if there were more choice about which information would be shared with whom. Current models of all-in or all-out information sharing does not seem to meet the needs of this community.**
  - Both consumers and providers are supportive of a more robust consent model where behavioral health information can be shared in a targeted way, whether it is by specific provider, by provider class (i.e. psychiatrist versus other specialist), by type of information, or by circumstances.
  - Lack of this tiered consent structure may limit information sharing as a whole, causing those with behavioral health issues to opt-out of information sharing completely. This creates a pressing need to develop a data segmentation policy, inclusive of the behavioral health community’s needs.
B. KEY RESULTS

PRINCIPAL CONCERNS

Although concerns regarding privacy and security were voiced throughout the community meetings, behavioral health consumer concerns about HIE do not seem to be any more or less significant than those expressed by the general consumer community. Many of these concerns can be addressed through better education regarding HIE.

The most prevalent concern falls outside the scope of electronic exchange but is related to information privacy in general (electronic or on paper). Participants were concerned with the social stigma and lack of understanding surrounding behavioral health diagnoses. There is a fear that this perception could affect their treatment by physical health professionals. Although this is not an issue HIE affects directly, streamlined information sharing may increase the likelihood of such occurrences. This greatly supports the need for better education on behavioral health issues, particularly among physical health providers. Also, some participants felt that providers may not use or review the information available, thereby reducing the impact of information sharing.

LIMITATIONS OF RESULTS

Every attempt was made to make the results of the community events as generalizable as possible. There is the potential of a selection bias, with community members only attending if they had strong feelings regarding information sharing; either very in favor, or very against sharing. This was mitigated through the following:

- A very wide distribution of the invitation by the mental health center / organizational staff.
- The selection of a convenient, protected environment by selecting facilities within each mental health center or behavioral health organization.
- The opportunity for stakeholders to provide further input by phone or email after the meeting, or for those unable to attend in person.

In addition, community meetings were all held at Community Mental Health Centers and other locally-based behavioral health organizations and centered on their clientele and providers. There is a community of consumers and providers independent of the integrated health centers that may not be represented in these meetings. Attempts to mitigate this include engagement of other behavioral health audiences such as the Colorado Mental Health Partnership as well as broad participation of other behavioral health stakeholders on the project Steering Committee. There is also a planned statewide review of key findings and recommendations, expanding the audience to any interested community members.
**SECTION FIVE**

**RECOMMENDATIONS/NEXT STEPS**

**PRIVACY AND SECURITY OF HEALTH INFORMATION ARE ESSENTIAL TO FOSTERING TRUST BETWEEN PROVIDERS AND PATIENTS.**

The purpose of the community outreach was to identify opportunities and concerns and develop recommendations to effectively and appropriately include the behavioral health community in the development of information exchange.

Analysis of Colorado laws and policies suggests that the exchange of behavioral health data can be supported now, in accordance with existing policies. All HIE participants must comply with strict federal laws, including, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and the Health Information Technology for Economic and Clinical Health (HITECH) Act, and Substance Abuse and Mental Health Services Administration (SAMHSA) regulation. In addition, personal health information is protected by state-of-the-art systems employing many security measures and physical and technical safeguards. These systems are subjected to regular third-party security audits. There are also severe criminal and civil penalties for misuse of information.

Because some consider behavioral health information to be particularly sensitive, privacy and confidentiality remain significant concerns for this community. Although all health information is rigorously protected, the behavioral health community has expressed a desire for particular protections and considerations to encourage behavioral health integration through HIE. Along with a call to action to integrate behavioral health information into statewide HIE, the following recommendations include a provision to continue to build HIE operational capabilities to enable further protection of patient health information.

Based on the input received to date, the following recommendations have been developed.

- **A.** Behavioral Health Information Sharing
- **B.** Broad Integration Agenda
- **C.** Education and Outreach
- **D.** Public Policy
- **E.** HIE Operations
A. INCLUDE THE BEHAVIORAL HEALTH COMMUNITY IN THE DEVELOPMENT OF STATEWIDE HEALTH INFORMATION EXCHANGE – STARTING TODAY

Providers and consumers in Colorado’s behavioral health community agreed that access to comprehensive patient health records is important to providing quality care and achieving desired health outcomes. The recent amendment to the Colorado Mental Health Practice Act (further discussed in recommendation D. Public Policy) resolved the most significant barrier for Colorado mental health providers to participate in HIE. Therefore, it is possible today to integrate patient health data across health care settings, including both physical and mental health providers.

Nevertheless, patient privacy and confidentiality concerns continue to be an issue in the behavioral health community. These concerns remain, and behavioral health providers should proceed cautiously with outbound information sharing. All providers should thoughtfully analyze the potential impact on their patient community before providing data to the HIE. As a result of this individual analysis, some behavioral health providers may choose only to receive data, and not provide outbound data to the HIE. As CORHIO continues to build additional functionality for granular consent (further discussed in recommendation E. HIE Operations), more providers may join in sharing health information across all care settings.

NEXT STEPS FOR A SHARING BEHAVIORAL HEALTH INFORMATION

▸ Encourage behavioral health providers and organizations to be integrated in the development of statewide HIE, as both recipients and sources of data.
SECTION FIVE

RECOMMENDATIONS/NEXT STEPS

B. ENDORSE A STATEWIDE INTEGRATION AGENDA TO PROMOTE BETTER COORDINATED CARE

Many new models support a coordinated, integrated care model across the health care continuum, such as Accountable Care Organizations and health home models. In order to achieve the desired outcomes of increased quality, lowered costs, and improved patient experience, these models must evolve to include behavioral health integration with primary and other medical care. Redefining behavioral health as a critical component of a patient’s overall health, and not a separate consideration, can also serve to lessen any associated social stigma. This may involve the development of new policies for the incorporation of non-traditional care providers, such as case managers, into CORHIO’s system. CORHIO will continue to support the community’s development of alternative care models. In addition, CORHIO could potentially serve a statewide convener for such issues, helping to develop consensus among stakeholders.

NEXT STEPS FOR A BROADER INTEGRATION AGENDA

- Continually evaluate types of HIE participants to determine gaps in types of users involved in treatment.
- Collaborate with communities, providers, government agencies, and other entities to further bring behavioral health into overall healthcare, identifying potential for improved care coordination and patient outcomes.
EDUCATION REGARDING HEALTH INFORMATION EXCHANGE

As evidenced by the community meetings, additional work is needed around education to providers and consumers. This will help alleviate the lack of awareness regarding information exchange opportunities, as well as HIE policies and privacy and security concerns. After obtaining a better understanding of HIE, participants were much more likely to identify positive benefits and be supportive of information sharing. For example, once it was explained that CORHIO can track access to a patient’s record, consumers’ concerns about privacy of electronic records seemed to decrease significantly. Education and outreach would also help alleviate any confusion surrounding the existing laws and regulations around sharing behavioral health information.

EDUCATION FOR CAREGIVERS IN PHYSICAL HEALTH SETTINGS - REDUCING SOCIAL STIGMA

A concern was echoed in each of the community meetings about the perceived social stigma surrounding behavioral health conditions. Consumers are more likely to want to restrict record access to physical health providers if they believe that they will receive different treatment because of the provider’s perception of their behavioral health status. Withholding important health information can lead to potentially fatal drug interactions, and at a minimum, inappropriate treatment. One consumer voiced the following concern: “I had a medical experience when I was under mental health care, and my problem was written off due to my mental health diagnosis. I ended up being hospitalized, and it was my gallbladder. I felt ignored.” Similar anecdotes were brought up in most meetings, but only a small number of consumers expressed a negative experience. In order for care integration efforts to succeed, there must be more and targeted education for personnel in physical health settings on how to understand and better work with the behavioral health community.

NEXT STEPS FOR EDUCATION AND OUTREACH

- Disseminate information regarding CORHIO’s policies and operations to target communities, creating and implementing a behavioral health-specific communication plan.
- Support behavioral health community partner education and outreach efforts with physical health providers.
Over the last year, CORHIO has assessed the policy and regulatory barriers to sharing behavioral health information in the state. CORHIO collaborated in behavioral health community efforts to update the “Disclosure of Confidential Communications” clause of the Colorado Mental Health Practice Act through Senate Bill 11-187. This clause required certain mental health professionals to secure specific consent every time they needed to share patient information, even among other treating providers. A coalition of provider and consumer groups came together to amend this clause and to align Colorado statute with federal law, clarifying that those health care providers who are covered under HIPAA are subject to federal standards instead of this limiting section. This revision allowed mental health professionals to follow the information sharing best practices utilized by their colleagues in the medical profession, and removed ambiguity from their privacy practices and requirements. CORHIO will continue to assist in identifying and addressing the legal, regulatory and policy issues at the federal and/or state levels to sharing health information to support better treatment, improve patient experiences, and ensure efficient and secure exchange of health data.

SUPPORT EFFORTS TO APPLY FEDERAL RULE 42 C.F.R. PART 2

One identified barrier in the current policy framework falls under the interpretation of the federal confidentiality rule title 42 C.F.R. Part 2, Confidentiality of Alcohol and Drug Abuse Patient Records. This rule limits the sharing of any information which would identify an individual as a patient of any federally assisted drug abuse or alcohol abuse programs. It considers any record of the identity, diagnosis, prognosis, or treatment of a substance abuse patient as confidential and subject to very tight limitations. Information held by one of these programs may be released only:

- If the patient grants very specific written consent for every disclosure of the records. This consent must include detailed information (listed below)
  - Patient name, signature, and date
  - The specific name of the person or program permitted to make the disclosure
  - The specific name of the person or organization receiving the disclosure
  - Purpose of release
  - How much and what kind of information is being released
  - This release must be accompanied by a written statement clarifying that under federal law, the recipient may not re-release the information

- There are a few exceptions to this rule:
  - If necessary in a medical emergency and documented by both accessing and disclosing providers.
  - By court order, but only if the public interest outweighs the harm done to the individual and with discretion as to which parts of the record can be released.
  - De-identified data can be made available for research purposes.
  - Information for specific administrative purposes can be made available to a Qualified Service Organization (QSO).

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In this model, once patient information is released in a particular emergency situation, the substance use treatment record is considered a part of the patient’s general health record, removing the 42 C.F.R Part 2 protections. In addition, if a patient seeks substance use treatment from a general practitioner, psychologist, or any drug abuse program that does not receive federal assistance, the rule does not apply. This unique barrier on federally assisted programs creates an avoidable information sharing silo. To solve this problem, many health organizations have created a single consent form, with patients authorizing the disclosure of information to multiple providers within a network. Unfortunately, the way the rule is currently interpreted, this consent form requires an actual list of the names of each person or organization to which disclosures are authorized. If a new provider is added to an existing network after a consent form is completed, the provider and patient must execute a new consent form. This is very difficult to operationalize for providers participating in an HIE.

Without inclusion of substance use treatment information in the HIE, there will be critical gaps in patient records, leading to fragmented care. According to the federal rule, this information can already be available in an emergency situation. Having this information available would be useful for emergency room physicians caring for a critically ill patient. Other treating providers could benefit from access to this information by ensuring treatment plans and medications are compatible with the patient’s substance use treatment program.

Additionally, the behavioral health community in Colorado has made significant progress in integrating mental health care and substance use disorder treatment. While most in the community agree this is a positive and much-needed development, it also has the effect of broadening the scope of programs, providers, and organizations required to comply with 42 CFR Part 2. A mental health center that has integrated substance use treatment programs to better serve patients in need of both types of services is likely to be required to follow these limiting federal regulations as a result of such integration.

After receiving guidance from the project Steering Committee and statewide stakeholders, CORHIO is supports continued work to enable exchange that is compliant with 42 CFR Part 2. This will allow for information sharing among all treating providers. To do this, CORHIO would collaborate with behavioral health stakeholders statewide to investigate the most effective means of applying this provision to an HIE framework. One option is for SAMHSA to reinterpret the requirement that a consent form contain “(2) The name or title of the individual or the name of the organization to which disclosure is to be made” to add the patient’s option to consent to information sharing for a named provider network, health information exchange network, or other care coordination network. Therefore, the revised option could read as follows, “(2) The name or title of the individual, the name of the organization, or the name of the network to which disclosure is to be made.”

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This can be done through an affirmative consent/opt-in process, which must be renewed by the patient on some regular interval (the rule requires a consent be active no longer than reasonably necessary). Through this model, a patient can choose to have health information accessible through the HIE, and not be required to grant consent for every exchange. Policies would need to be developed to better define the provider types that would have access to this information. If this rule is not reinterpreted, it will be difficult, possibly prohibitively so, to include federally assisted drug abuse or alcohol abuse programs and their patients along with the rest of the health care community in the development of statewide HIE.

**NEXT STEPS FOR PUBLIC POLICY**

- Continue to partner with behavioral health stakeholders to amend public policy as needed, conducting regular reviews of policies and practices to ensure federal and state policy frameworks evolve with new health care delivery and payment systems and advances in treatment models.

- Advocate for a reinterpretation of 42 CRF Part 2 to support an operational policy framework for HIE. This will enable substance use treatment facility and providers to provide more integrated care.
The highest priority in revising HIE operations is the development of an operationally feasible method for exchanging behavioral health information through a granular consent model. Currently, patient information is exchanged through the HIE, unless they specifically request their information not be shared. This patient decision applies to all information relating to that patient – so all records are available for exchange until and unless a patient decides to “opt out” and have none shared. Although CORHIO does not currently have the technical capabilities to segment data, there is a possibility that the necessary infrastructure can be built. This is the most pressing concern among community members, who would prefer a tiered consent model. There are a variety of options for modeling consent, some of which are listed below. CORHIO can use one or more of these models to effectively address the behavioral health community’s concerns. Due to the current state of technology, the first two approaches are most feasible in the near-term.

1. **Informed Consent for Sensitive Health Information**
   Patient would have to “opt-in” or sign specific consent to share sensitive information in the HIE. Sensitive information can include mental health and substance use treatment information, as well as physical health diagnoses such as sexually transmitted diseases. This could also help navigate the 42 CFR Part 2 requirements.

Some barriers will exist, as separating information considered particularly sensitive from the rest of a patient health record could create significant gaps in patient health information for treating providers. Having specific consent for sensitive information could also create a substantial administrative burden for providers required to manage and track consent. Electronic consent forms are being developed at the national level, and could be utilized in the long term.

2. **Tiered Consent by Provider Type**
   Sensitive health information, including behavioral health information could be segregated by provider. For example, specifically flagged data elements (i.e. sensitive health information) would only be made available to specific provider types (i.e. ER doctor, primary care physician) and would be limited to other types of providers (i.e. specialists). This type of model could also orchestrate sharing behavioral health information only among behavioral health providers.

Detailed policies would have to be developed and significant time and input would be needed to determine what type of data should be segmented, and what providers should have access to each type. This would also require a technical build for both providers and CORHIO to appropriately flag data. This scenario creates potential information gaps for treating providers, but helps maintain a trust environment for consumers.
3. "Facebook Model" or Patient-Monitored Information Sharing

Patients actively select who has access to what information at a very granular level, giving the patient the ultimate control over information.

A great deal of technical work would be needed to make this feasible. There would be a need to create a personal health record for all patients in the state. At this time, patients do not interact directly with the HIE. Although this could empower patients, it shifts responsibility to them. This model also creates the most significant gaps in information, which may have negative treatment consequences by leaving out important pieces of information regarding a patient’s medications or conditions.

CONSUMER ACCESS TO DATA

There is a growing demand throughout the healthcare community to share HIE data with consumers. This will be particularly helpful for patients with co-occurring diseases or who visit multiple providers throughout disparate networks. The majority of behavioral health consumers were interested in obtaining access to their records (87%).

The remaining 13% would prefer this information be shared only among providers, or not shared at all. Providers would like to share this information directly with patients, as long as they are able to ensure information released will not negatively impact a patient’s recovery or well-being.

NEXT STEPS FOR MODIFICATIONS TO HIE OPERATIONS

- Conduct a thorough analysis of the options for more granular choices regarding consumer consent for information sharing through HIE, including input from consumer and participating provider communities to understand how consent models would be operationalized and the impact on consumer experience as well as provider workflows.

- Develop a strategy to allow providers to electronically send consumers a summary of visits and medication lists upon request. This will give consumers secure, timely access to their personal health information, while maintaining the trusted relationship between patients and providers.