

Consumer and Provider Education Workgroup Report

Focus Group Findings, Educational
Materials and Recommendations



Workgroup Membership

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Workgroup Goal and Objectives

- **Goal: Develop communications strategies for patients and providers.**
- **Objectives:**
 - Plan for **educating Primary Care and Mental Health Providers about consumer options and methods for shared decision making** around mental health information sharing.
 - Plan for **consumer education about clinical information sharing** focused on mental health and the health information exchange (HIE).
 - **Educational materials to inform consumers about their choices** in sharing mental health data with the HIE.
 - **Educational materials for primary care and mental health providers** to use to inform consumers about options in sharing mental health data in the HIE.



How we visualized HealthInfoNet

Provider Medical Records



Patients & Families



Clinicians have several tools and information sources to help treat their patients. One of them is now HealthInfoNet.



Clinician's Toolbox

Diagnostic Equipment



About the Focus Groups

- **5 Consumer Focus groups** reviewed current communication tools, the HIE consent forms and consumer options for clinical information sharing.
- **1 Provider focus group** reviewed educational materials and consent forms for consumer information sharing.
- **Focus Group Types:** *(all must have visited a mental health provider in the past year)*
 - Guardians of persons with intellectual disabilities
 - Seniors (65+)
 - Veterans
 - Adults (25-65)
 - Youth (24 and younger)



Consumer Focus Group Results: Benefits of Sharing

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



Consumer Focus Group Results: 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 not included?
- Why would a provider want to see my information?
- What information is included?
- Who gets to see my information?



Consumer Focus Group Results: Common Concerns

- The patient loses control of the information
- Access is all or nothing, can't pick and choose which providers or what pieces of information are shared
- 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 brought up again.”



Provider Focus Group Results

- **Benefits of Sharing Information**

- Better treatment coordination
- Better coordination between providers

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

- **Common concerns**

- Confidentiality
- Loss of control over who has access to what record
- Discrimination
- Education and consent creates administrative burden for providers



Consumer & Provider Recommendations

- Simplify educational and consenting materials
- Define terms and give examples
- Use graphics and simple language to illustrate concepts and processes
- Emphasize patient benefits and use patient quotes
- Address consumers concerns about security and access
- Emphasize the availability of audit reports
- Create brief patient materials and provider talking points
- Provide a way for patients to access their data within HealthInfoNet



What did we do with the feedback?

- Developed a **printed consent form** for patients to “opt-in” mental health information.
- Developed **language specific to mental health information** and options for consent to insert into existing materials for patients and providers.
- **Modified all existing communications materials** to accommodate patient and provider feedback.
 - This included a 4-page brochure, one page brochure, talking points, provider education materials and external materials such as website text, press releases and patient newsletters.



HealthInfoNet Consent to Share Mental Health and HIV/AIDS Records

Please READ the HealthInfoNet educational materials before filling out this form

Check ONE of the boxes below

- 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 want to include both my mental health and HIV/AIDS information in my HealthInfoNet record.
- I would like to reverse my previous consent and remove the following information. Choose one.
- Mental Health HIV/AIDS 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 for that visit only. You will need to give permission each time you want them to have access in the future. To remove all your medical information from HealthInfoNet, even in an emergency, you need to fill out a separate opt-out form.

First Name Middle Name Last Name

Address City State Zip Code

Date of Birth Sex Daytime Telephone Email
(Month/Day/Year) (male/female)

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. 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>.

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 or notary signature and seal.


Signature Print Name Employer/Organization

Consent Form

- Patients choose mental health, HIV or both.
- Patients can use this form to revoke a previous consent.
- To verify identity, providers must witness or patients can come to HIN with photo ID.
- HIN will also provide a form that patients can have notarized.



Examples of Materials Changes



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.

Robert lives in northwestern Maine.

- Got flu vaccine from a pharmacist in Presque Isle
- Picks up his three prescriptions at his local pharmacy
- Sees a primary care doctor in Houlton
- Gall bladder removed in Bangor
- Had an allergic reaction to penicillin in Calais
- Sees cancer doctor in Lewiston
- Hospitalized for heart attack in Portland

Better. Easier. Safer.

125 Presumpscot Street, Box 8, Portland, ME 04103 • 866-592-4352 • 207-541-9250 • www.hinfor.net



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."

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 mental health, HIV, or both types of information.	Fill out consent form available from your participating provider or HealthInfoNet.	Available to all participating providers	Mental health, HIV or both types of information will be available to all participating providers.
Consent for individual providers to see your mental health information, HIV information, or both.	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 for that visit only. You will need to give permission each time you want them to have access in the future.
Opt-Out and remove all your medical information from HealthInfoNet.	Fill out an opt-out form available from HealthInfoNet, your provider, or online at www.hinfor.net/optout	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.

Further Workgroup Recommendations

- Provider organizations should work with HealthInfoNet to **find a way for patients to access their information in HealthInfoNet** through provider patient portals.
- A coordinated educational effort should be undertaken to **educate emergency medical providers to recognize and reduce this discrimination** felt by mental health patients when visiting the ER.



Further Workgroup Recommendations

- Based on individual clinical settings, workflows, and who the consumer/patient knows and trusts, **providers should carefully consider which positions within their organization/practice/setting are the most appropriate to educate patients about HealthInfoNet and consent options.**



Next Steps

- **Roll out the new communications materials** when appropriate based on technical implementation.
- HealthInfoNet initiate discussions with its provider participants to **investigate ways for patients to access information from their HealthInfoNet record** through their chosen provider's patient portal.
- Workgroup members will look into **opportunities to educate emergency medical providers** and staff.

