

Understanding Massachusetts Sensitive Health Information Sharing

A Self-directed Consumer Tutorial on Privacy, Security, and Sensitive Health Information

A Massachusetts project of the
HISPC MULTISTATE EDUCATION &
CONSUMER ENGAGEMENT COLLABORATIVE

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Understanding Massachusetts Sensitive Health Information Sharing

What you will learn...

Your rights about legally “sensitive” health information

Questions to ask your doctor to learn more

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Understanding Massachusetts Sensitive Health Information Sharing

What is legally sensitive health information?



- Most people consider their personal health information to be private. Several laws exist to protect this privacy.
- “Sensitive” information is medical information that is protected by law. These laws were passed to help people to seek testing and treatment without fear of discrimination.



Understanding Massachusetts Sensitive Health Information Sharing

What does sensitive information include?



- [Mental health](#) (including records of psychiatrists, psychologists, and social workers)
- [Genetic test](#) results
- [HIV-AIDS test](#) results

Other sensitive information:...

- mammography test results
- substance abuse *treatment* (substance “use” information is not considered sensitive information)
- abortion for minors
- sexual abuse counseling



Understanding Massachusetts Sensitive Health Information Sharing

How is sensitive information protected?



The main way your sensitive information is protected is with a process called [informed consent](#)

- You always have the right to be provided with certain information (about what is going to be done and why) before health care services are rendered.
- Your consent may be needed each time your health information is sent from a health care provider at one office to a provider at another office.



Understanding Massachusetts Sensitive Health Information Sharing

What is consent?



“Consent” means permission. In health care, this is permission that is given by either you or a person authorized to use your health information.

Federal or state law may decide several details of the consent process.

Your doctor’s office or hospital may have other consent policies in addition to what is required by law.



Understanding Massachusetts Sensitive Health Information Sharing

What is consent?—*Example*



You just moved and found new doctors closer to your new home. Before your move, you had seen a psychiatrist. You went for monthly check-ups and to get your prescription medicines. You would like your new psychiatrist to have a copy of your old records. You sign a “release of information” form at your old psychiatrist’s office, giving permission to send your medical record to your new doctor.



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Understanding Massachusetts Sensitive Health Information Sharing

What is consent?—Quiz



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You just moved and found new doctors closer to your new home. Before your move, you had seen a psychiatrist. You went for monthly check-ups and to get your prescription medicines. You would like your new psychiatrist to have a copy of your old records. You sign a _____ **???** _____ form at your old psychiatrist's office, giving permission to send your medical record to your new doctor.



[See answer](#)



Understanding Massachusetts Sensitive Health Information Sharing

What is consent?—Answer



You just moved and found new doctors closer to your new home. Before your move, you had seen a psychiatrist. You went for monthly check-ups and to get your prescription medicines. You would like your new psychiatrist to have a copy of your old records. You sign a **“release of information”** form at your old psychiatrist’s office, giving permission to send your medical record to your new doctor.



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Understanding Massachusetts Sensitive Health Information Sharing

Consent Law Details



- The law says whether consent may be a signed written document, whether it may be given orally, or whether it is needed at all
- The law says that if a signed document is required, whether it must be on a particular form
- The law says whether the consent may apply to multiple uses or if it applies only to one use
- The law says whether other information must be provided to the person before the consent may be obtained
- The law says who may ask for the consent
- The law says that certain uses may be made without consent or even if the person objects



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What types of patient representatives are there?



- **Health care proxy** is someone you give the right (called “power of attorney”) to make decisions about your treatment if you are unable to do so yourself. Often this is a family member such as a spouse or child.
- **Parent or guardian of a minor child** is a caretaker who has the legal right to make decisions in the interest of someone else (such as a child) for a certain period of time.



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Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Definitions



- **Psychologist privilege**

Confidentiality and privacy of communications between psychologists and patients. This term also describes the sharing of this information.

- **Psychologist records**

Refers to the maintenance and review of patients' records

- **Providers included in this rule:**

- Psychologists and their colleagues
- People employed by the psychologist



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Definitions



- **Psychotherapist records/privilege**

Confidentiality of communications between psychotherapist and patients. This term also describes the sharing of this information.

- **Providers included in this rule:**

- A “**psychotherapist**” includes licensed individuals in the fields of psychiatry, psychology, and nursing.
- **Psychiatrists**, individuals licensed by the board of medicine to practice psychiatry.
- Licensed **psychologists**, as well as students supervised by licensed psychologists.
- Licensed **psychiatric nurses**.



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Benefits



1. **Better quality of care** (your doctor will be able to access your mental health information when making decisions about your care)
2. **Better safety of care** (your doctor will be able to know more about your medications, medical history, and problems)
3. **Better use of your time** (less time is needed to ask about your history)



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Mental Health: Risks



It is possible for your mental health information to get into the wrong hands—either intentionally or unintentionally

A specific concern might include the possibility of this information getting into the hands of your employer, causing discrimination at your workplace. However, in Massachusetts it is **ILLEGAL** for this information to be shared without your consent.



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Your Rights



- All patients have rights and protection over information shared with their psychotherapist.
- All communication and conversations will be kept confidential. For example, this information cannot be disclosed in a court proceeding without the patient's permission or a court order after a hearing. There are some exceptions and they are listed on the next page.
- All psychotherapists keep records for each of their patients. A record may include information regarding diagnosis and treatment as well as other personal information.



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Your Rights—*Exceptions*



- Your communications and information from your psychotherapist may be disclosed in a court proceeding **WITHOUT** your prior permission, when made in the following situations:
 - When your psychotherapist discloses the communication to admit you to the hospital for treatment for mental or emotional illness
 - When your psychotherapist discloses the communication following your threats to harm yourself or another person
 - During court-ordered evaluations to help explain your mental or emotional status



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Your Rights—*Exceptions*



- Your communications and information from your psychotherapist may be disclosed in a court proceeding **WITHOUT** your prior permission, when made in the following situations:
 - In court, if your lawyer uses your emotional condition as part of your defense
 - In court, relating to adoption or child custody, **to serve the best interests of your child**
 - In malpractice lawsuits against the psychotherapist, whereby disclosures are necessary in the therapist's defense



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Your Rights—*Examples*



Recently, you have been under a lot of stress at home and work. You are having thoughts of suicide and about overdosing on pills. You tell your psychologist about your fears about keeping yourself safe. You and your psychologist decide that you need to be hospitalized. Your psychologist makes a call to the hospital to arrange for your stay. He provides the admitting doctor at the hospital with a brief history of your present illness, and current thoughts of hurting yourself.



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Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Your Rights—Quiz



Recently, you have been under a lot of stress at home and work. You are having thoughts of suicide and about overdosing on pills. You tell your psychologist about your fears about keeping yourself safe. You and your psychologist decide that you need to be hospitalized. Your psychologist makes a call to the hospital to arrange for your stay. He provides the admitting doctor at the hospital with a brief history of your present illness, and ???.



[See answer](#)



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: Your Rights—Answer



Recently, you have been under a lot of stress at home and work. You are having thoughts of suicide and about overdosing on pills. You tell your psychologist about your fears about keeping yourself safe. You and your psychologist decide that you need to be hospitalized. Your psychologist makes a call to the hospital to arrange for your stay. He provides the admitting doctor at the hospital with a brief history of your present illness, and **current thoughts of hurting yourself.**



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Mental Health: Your Rights—*Examples*



Your mother has a long history of depression, and most recently required a hospital stay. The psychiatrist met with you and your mother in a family meeting to talk about different treatment options. Your mother has been on several medicines over the years. None of these medicines have worked very well. The psychiatrist wants your authorization to try your mother on a new drug that is very effective to treat depression. This new drug has some risky and serious side effects. You agree to this plan, but your mother refuses to take the new drug. In order for your mother to take the new drug, you and the psychiatrist must get approval from the court. In court, your mother's diagnosis and prior treatment were discussed.



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Mental Health: Your Rights—Quiz



Your mother has a long history of depression, and most recently required a hospital stay. The psychiatrist met with you and your mother in a family meeting to talk about different treatment options. Your mother has been on several medicines over the years. None of these medicines have worked very well. The psychiatrist wants your authorization to try your mother on a new drug that is very effective to treat depression. This new drug has some risky and serious side effects. You agree to this plan, but your mother refuses to take the new drug. In order for your mother to take the new drug, you and the psychiatrist must **???** .



[See answer](#)



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Mental Health: Your Rights—Answer



Your mother has a long history of depression, and most recently required a hospital stay. The psychiatrist met with you and your mother in a family meeting to talk about different treatment options. Your mother has been on several medicines over the years. None of these medicines have worked very well. The psychiatrist wants your authorization to try your mother on a new drug that is very effective to treat depression. This new drug has some risky and serious side effects. You agree to this plan, but your mother refuses to take the new drug. In order for your mother to take the new drug, you and the psychiatrist must **get approval from the court.** **In court, your mother's diagnosis and prior treatment were discussed.**



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Mental Health: Questions to Ask Your Provider

1. How does he/she store your information?
2. Does he/she always ask your permission before sending your information anywhere?
3. What kinds of information does he/she share?



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Mental Health: Frequently Asked Questions (FAQs)



1 Can my employer see my sensitive mental health information?

ANSWER: **No**, your provider cannot disclose your mental health information to an employer without your written consent or authorization

2 Does my health plan/insurer have my sensitive mental health information?

ANSWER: **Yes**, your health plan has received your provider's claims that have to include enough information to know the claim is valid before it is processed, so diagnosis and provider specialty is given to health plans.



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: FAQs



3 Can I ask that my provider not add certain information to the electronic record?

ANSWER: You have a right to ask, but your doctor has the right to document as he or she feels is necessary to provide appropriate care.

4 I already signed consent when I registered at my physician's office—what did I agree to and did it include my sensitive information?

ANSWER: Typically you agreed to a consent to treat you for the symptoms that are present during the visit, and allow your doctor to share your health information with your health plan in order to receive reimbursement for the care.



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: FAQs



5 What if information on my record is inaccurate?

ANSWER: If mental health information on your record is inaccurate, write a letter to your provider about the error, and ask that it be amended. The provider is not allowed to delete the earlier information that you found to be inaccurate, but the provider will indicate receipt of your correction.

6 Can I take back my consent?

ANSWER: Yes, you can take back your consent in writing, but it becomes effective from the day of the revocation forward; you can not go back in time.



Understanding Massachusetts Sensitive Health Information Sharing

Mental Health: FAQs



7 How will I know if my health information has been breached or accidentally shared?

ANSWER: Once the entity holding your mental health information knows that there has been a problem or a breach they are required by law to notify you of the situation.

8 Where can I learn more?

ANSWER: We have prepared a more extensive FAQ that can be viewed [here](#).



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Genetic Tests: Types



Diagnostic Testing:

Many genetic disorders appear in adolescence or later. If you have signs and symptoms of an adult-onset genetic disorder, genetic testing may confirm the diagnosis.

If a hereditary cancer syndrome runs in your family, you can be tested for the genetic variations associated with the syndrome. If the test shows that your likelihood of eventually developing hereditary cancer is high, you can have the appropriate cancer-screening tests, such as a colonoscopy (to check the health of your intestine), more often than generally recommended, and starting at an earlier age.

[Reference: <http://www.mayoclinic.com/health/genetic-testing/FL00076>]



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Types



Carrier Testing:

Couples with family histories of certain (single-gene) disorders may undergo genetic testing and counseling before starting a family.

In these situations, genetic testing determines whether either parent also carries a copy of the altered gene and is, as a result, at risk of having a child with the condition. Among the most common of these disorders are sickle cell anemia (affecting one in 400 African-Americans in the United States) and cystic fibrosis (affecting one in 2,500 descendants of Northern Europeans).

[Reference: <http://www.mayoclinic.com/health/genetic-testing/FL00076>]



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Genetic Tests: Types



Prenatal Genetic Testing:

Genetic testing is also an option when other prenatal screening tests suggest a genetic disorder, or when one or both parents have a family history of a single-gene disorder. For more than 25 years, doctors have been able to diagnose chromosomal abnormalities, such as Down syndrome, by doing prenatal genetic testing on fetal cells, which are obtained through diagnostic tests such as amniocentesis.

[Reference: <http://www.mayoclinic.com/health/genetic-testing/FL00076>]



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Types



Newborn Genetic Screening:

Some babies are born with gene abnormalities causing specific diseases. With relatively inexpensive technology, it's now possible to test all newborns for many genetic conditions, some of which can be corrected with ongoing treatment started early in life.

[Reference: <http://www.mayoclinic.com/health/genetic-testing/FL00076>]



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Types



Genomic Scanning:

Another type of genetic testing detects DNA variations at a more minute level, known as a single nucleotide polymorphism (SNP, pronounced "snip"). In a SNP, one nucleotide is out of sequence among the billions of base pairs in your genome. Although many SNPs are unimportant, some have powerful effects on disease risk and sensitivity to disease-causing agents. In clinical settings, for example, single tests for specific SNPs are sometimes used to predict how you'll respond to certain drugs or whether there's a chance you'll have a serious reaction to a particular drug.

[Reference: <http://www.mayoclinic.com/health/genetic-testing/FL00076>]



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Genetic Tests: Benefits



1. **Better quality of care** (your doctor will be able to access your health information when making decisions about your care)
2. **Better safety of care** (your doctor will be able to know more about your medications, health care history, and problems)



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Risks



It is possible for your genetic testing information to get into the wrong hands—either intentionally or unintentionally

- A specific concern might include the possibility of this information getting into the hands of your employer, causing possible discrimination at your **workplace**
- You might also be concerned about the possibility of this information getting into the hands of your **insurer**, causing your premium to rise

Both types of discrimination are **prohibited by law**



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Privacy and Insurance



- When you apply for health, disability, or life insurance you may have to disclose genetic test results, or risk losing your benefits if anything you omit comes to light. It is possible that genetic testing results held in your medical record may be available to your current insurer without your disclosure as well if they have paid for the test.
- A recently signed federal law, the Genetic Information Nondiscrimination Act (GINA), prohibits health insurers from discriminating against healthy individuals who are genetically predisposed to develop diseases. Under GINA, employment discrimination based on genetic risk also is illegal.
[Reference: <http://www.genome.gov/24519851>]



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Your Rights



- It is your right to limit access to your genetic information
- Health care providers cannot provide genetic testing without proper consent
- Health care providers can only share genetic test results with the patient or other members of the care team directly caring for the patient. This information will be kept confidential.



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Your Rights—*Example*



You and your husband are ready to have a baby. Before getting pregnant, you want to find out if you or your husband are at risk of having a child with a genetic disease. You and your husband speak with your doctor, and sign a consent form to have genetic testing. This consent form gives the doctors permission to test you.



[Test your understanding](#)



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Your Rights—Quiz



You and your husband are ready to have a baby. Before getting pregnant, you want to find out if you or your husband are at risk of having a child with a genetic disease. You and your husband speak with your doctor, and ??? to have genetic testing. This ??? gives the doctors permission to test you.



[See answer](#)



Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Your Rights—Answer



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Understanding Massachusetts Sensitive Health Information Sharing

Genetic Tests: Questions to Ask Your Provider



1. How does the provider store your information?
2. Does the provider always ask your permission before sending your information anywhere?
3. What kinds of information does he/she share?
4. If a test reveals that I am at high risk for a condition, how will this information affect my treatment or help future planning and life decisions?
5. What is the risk if I don't take this test?



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HIV-AIDS: Benefits



1. **Better quality of care** (your doctor will be able to access your health information when making decisions about your care)
2. **Better safety of care** (your doctor will be able to know more about your medications, medical history, and problems)
3. **Better use of your time** (less time is needed to ask about your history)



Understanding Massachusetts Sensitive Health Information Sharing

HIV-AIDS: Risks



It is possible for your HIV-AIDS health information to get into the wrong hands—either intentionally or unintentionally

- A specific concern might include the possibility of this information getting into the hands of your employer, causing possible discrimination at your **workplace**
- You might also be concerned about the possibility of this information getting into the hands of your **insurer**, causing your premium to rise

Both types of discrimination are **prohibited by law**



Understanding Massachusetts Sensitive Health Information Sharing

HIV-AIDS: Your Rights



- No physician (also includes members of the physician's health care team) or health care provider can disclose the results of an HIV/AIDS test to any person other than the subject of the test, or identify the subject of the test to any person, without first obtaining the subject's written consent.
- No insurer, insurance producer, or employee can communicate information regarding an AIDS-related test, the results of any such test, or any other AIDS-related information to any person, unless made with the written authorization of the individual to whom the information relates, or as otherwise required by law.



Understanding Massachusetts Sensitive Health Information Sharing

HIV-AIDS: Your Rights—*Example*



You were hired at a company that asks your physician to provide your medical history to date. You are HIV+ and do not want this information to be given to your new employer. At your written request, your physician will provide the medical history, without including your HIV+ test results. Because HIV+/AIDS test results are ALWAYS protected, your employer WILL NOT know that your medical record was changed.



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Understanding Massachusetts Sensitive Health Information Sharing

HIV-AIDS: Your Rights—Quiz



You were hired at a company that asks your physician to provide your medical history to date. You are HIV+ and do not want this information to be given to your new employer. At your written request, your physician will provide the medical history, without including your HIV+ test results. Because HIV+/AIDS test results are ??? protected, your employer ??? know that your medical record was changed.



[See answer](#)



Understanding Massachusetts Sensitive Health Information Sharing

HIV-AIDS: Your Rights—Answer



You were hired at a company that asks your physician to provide your medical history to date. You are HIV+ and do not want this information to be given to your new employer. At your written request, your physician will provide the medical history, without including your HIV+ test results. Because HIV+/AIDS test results are **ALWAYS** protected, your employer **WILL NOT** know that your medical record was changed.



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Understanding Massachusetts Sensitive Health Information Sharing

HIV-AIDS: Questions to Ask Your Provider



1. How is this information protected from my employer?
2. Besides test results, is there other information in my medical record that indicates that I may have HIV/AIDS? Is that information protected?
3. What are the laws or protections for my information that may be in an electronic health record? How is my information protected in a electronic health record?
4. Does your office have rules to protect my privacy?



Understanding Massachusetts Sensitive Health Information Sharing

About Health Information Security & Privacy Collaboration (HISPC) Projects



- There is nationwide acknowledgment that a balance has to be found between privacy protections and information access.
- Beginning 2006, the federal government organized the nationwide Health Information Security and Privacy Collaboration (HISPC) effort, a contract managed by the Office of the National Coordinator for Health IT (ONC). ONC is leading efforts to address the challenges presented by electronic health information exchange. The aim is to develop and implement solutions to those challenges while preserving privacy and security protections.
- Patients like you are an essential part of this process. HISPC funding has supported the development of consumer and provider educational tools to get the word out about the benefits and risks of health information sharing.

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