

A large, stylized orange graphic of a clipboard with a white sheet of paper. The clipboard has a circular hole at the top for a clip. The white sheet contains the title and subtitle. The background is white with orange decorative shapes: a large orange shape on the left and a large orange arrow pointing right on the right side.

Your Medical Record Rights in Illinois

(A Guide to Consumer Rights under HIPAA)

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Funded by Grant G13LM8312
The National Library of Medicine

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INTRODUCTION

Medical records are an important part of your health care. These records show the history of your health condition and treatment. They are used by health care providers to treat you.

A federal law called the HIPAA Privacy Rule gives you the right to get and amend (correct) your medical record. (HIPAA stands for the “Health Insurance Portability and Accountability Act.”) Illinois laws also give you rights in your medical record.

ABOUT THIS GUIDE

This guide is intended to help you understand how to see, get a copy of and amend (correct) medical records kept by Illinois health care providers. It is only about records kept by those Illinois providers who have to follow the HIPAA Privacy Rule. Section 6 lists some resources for obtaining information about getting your medical record from providers who do *not* have to follow the HIPAA Privacy Rule. You can read guides about getting medical records from health care providers in other states at <http://hpi.georgetown.edu/privacy/index.html>.

The rules explained in this guide only apply when you ask for your own record or when you ask for someone’s medical record as their personal representative. These rules do not apply when you request that your health care provider give your medical record to someone else (such as another doctor or a lawyer).

This guide was designed so that you can read just the parts that interest you. For example, if you are interested in how much your provider can charge you for copying your medical record, you may want to focus on that part of the guide. We urge you to read “Who Is Covered by These Rules?” so that you can be sure the guide applies to your provider. Because we expect most people to read only parts of the guide, we have repeated some basic information throughout the guide.

This guide does not discuss mental health records or records about drug and substance abuse treatment. Section 6 of this guide lists some resources where you can find some information about your right to get and amend these types of records.

Words to Know

Some of the words in this guide have a special meaning. In this guide “Health care providers” means *both* health care practitioners (such as medical doctors, dentists) and health care facilities (such as hospitals and nursing homes). Section 5 explains this phrase and other words that are helpful to know. The words explained in Section 5 are in **boldface** print the first time they appear in each section of the guide. Rather than use the awkward phrases “he, she, or it” and “his, her, or its” this guide uses “they” and “theirs” when referring to health care providers in a general way. Examples that use “he” or “she” are meant to refer to both genders.

DISCLAIMER

The author has made every attempt to assure that the information in this guide is accurate as of the date of publication. Many areas of the law can be interpreted more than one way. This guide has tried to interpret the law in a way that is consistent with protecting health care consumer rights. Others might interpret the law in another way. This guide is only a summary. The rights and procedures described in this guide can change depending on the circumstances. The information in this guide may not apply to your particular situation.

This guide should not be used as a substitute for legal or other expert professional advice. The author, Georgetown University, and the National Library of Medicine specifically disclaim any personal liability, loss, or risk incurred as a consequence of the use of any information in this guide.

ACKNOWLEDGMENTS

This work was funded by grant G13LM8312 from the National Library of Medicine.

In addition, sincere thanks to Teresa A. Lakin, RHIT, and Erin Sweeney, RHIA, for their comments and suggestions on this guide; and Jeffrey S. Crowley, MPH, Mila Kofman, JD and Kevin Lucia, JD for their input on early versions of the guide. Their help was invaluable. However, any mistakes are the author's own.

1. OVERVIEW

Both the *HIPAA Privacy Rule* and Illinois law give you rights to your medical record. The HIPAA Privacy Rule sets standards that apply to the records of *health care providers* across the nation. Illinois law sets standards for the records of doctors, hospitals and other health care providers within the state. Most health care providers have to follow both the HIPAA Privacy Rule and Illinois law. If the HIPAA Privacy Rule has a standard that is different from one in Illinois law, your health care provider must follow the law that is the most protective of your rights.

SUMMARY OF YOUR RIGHTS

In Illinois you have the right to:

- **See and get a copy of your medical record.**

Your health care provider usually must let you see your medical record or give you a copy of it within 30 days after they receive your request.

As of January 2007, your health care provider is allowed to charge you between 29¢ and 86¢ per page for paper copies, depending on the number of pages copied. They can charge you \$1.43 per page for copies made from microfilm. These amounts are adjusted annually. You can also be charged for postage.

- **Amend your medical record by having information added to it.**

You have the right to have information added to your medical record to make it more complete or accurate. This right is called the *right to amend* your record.

- **File a complaint.**

You have the right to file a complaint with the Office for Civil Rights, U.S. Department of Health and Human Services if you believe your health care provider has violated your right to see, get a copy of, or amend your medical record. You can also file a complaint with the state agency that regulates your health care provider.

- **Sue in state court to get your medical record.**

Under Illinois law, you have the right to sue in Illinois Circuit Court to obtain your medical record.

You can learn more about these rights in the following sections of this guide.



WHO HAS TO FOLLOW THESE RULES?

Most Illinois health care providers (such as doctors and hospitals) must follow *both* the HIPAA Privacy Rule and state laws that give patients rights in their medical records.

There are some health care providers, however, that do *not* have to follow the HIPAA Privacy Rule. The HIPAA Privacy Rule only covers health care providers that use computers to send health information for certain administrative or financial purposes (such as filing claims for insurance).

Example

Sometimes Ashley goes to a doctor at a free clinic for medical treatment. The doctor does not accept private insurance, Medicaid, or Medicare. The doctor does not file any insurance claims. Ashley's doctor probably does not have to follow the HIPAA Privacy Rule. This is because the doctor does not appear to send health information for the types of administrative or financial purposes that would make her a covered health care provider under the HIPAA Privacy Rule.

If you have questions about whether your health care provider must follow the federal HIPAA Privacy Rule, you can contact the Office for Civil Rights, U.S. Department of Health and Human Services (OCR), the agency that is in charge of enforcing the HIPAA Privacy Rule. Section 4 of this guide lists contact information for OCR.

What if my provider does not have to follow HIPAA?

Even if your provider does not have to follow the HIPAA Privacy Rule, they still have to follow Illinois laws that give you rights to your medical record. Section 6 lists some resources that summarize these state laws.

This guide, however, only explains getting your medical record from Illinois providers who *have* to follow the HIPAA Privacy Rule.



WHAT RECORDS DO I HAVE THE RIGHT TO GET AND AMEND?

You have the right to see and get a copy of your medical record. You also have the right to amend your medical record by having information added to it to make it more complete or accurate. This right is called the

right to amend your record. (This guide will call these rights the right to “get and amend.”)

Your medical record includes such things as:

- Information that identifies you, such as your name and Social Security number.
- Information that you tell your doctor, such as:
 - o Your medical history.
 - o How you feel at the time of your visit.
 - o Your family health history.
- The results of your examination.
- Test results.
- Treatment received in a hospital.
- Medicine prescribed.
- Other information about things that can affect your health or health care.

Who owns my medical record?

Under Illinois law, your health care provider owns the actual medical record. For example, if your provider maintains paper medical records, they own and have the right to keep the original record. You only have the right to see and get a copy of it.

My provider makes personal notes about patients. Do I have a right to get these notes?

Probably. You have the right to get a provider’s personal notes about you if the notes are used to make decisions about you.

Example

Michael’s doctor writes notes about her personal impressions of patients in their medical records. She uses these notes to help her treat her patients. Michael’s doctor wrote a note in his medical record that says she suspects that Michael is exaggerating his complaints about his health and that his problems are “all in his head.” If Michael requests his entire medical record, the doctor must let him get a copy of this note.

What happens if my medical record has information in it that came from a different health care provider?

Generally, if a health care provider has the medical information that you request, they must give it to you. It does not matter who originally put the information in the record.

Your right to *amend* this information may be limited, though. For more information about how to amend information in your record you can read Section 3 of this guide.

My health care provider collected information about me because they think I might sue them. Do I have the right to get this information?

Not under these particular laws. You do not have the right under the HIPAA Privacy Rule to get information about you that has been gathered for potential use in a law suit or similar proceeding.

Example

Roberto complained to his hospital that he was very unhappy with his treatment. Believing that Roberto is going to sue, the hospital lawyer interviews doctors and nurses involved with Roberto's treatment to get their version of what happened. Roberto requests a copy of all medical information that the hospital has about his treatment. The hospital must give Roberto a copy of his medical record, including test results and entries made while Roberto was in the hospital. However, the hospital does not have to give Roberto a copy of the interview notes they took for potential use in the law suit.

There are other rules for getting information in law suits.

Do I have the right to get and amend records about my mental health treatment?

Maybe. The rules for when you can get and amend your records about mental health treatment can be different. For example, psychotherapy notes are treated differently than other records under the HIPAA Privacy Rule. Because the rules for mental health records can be different they are not discussed in this guide. You can find some resources that explain your rights in these types of records in Section 6.

WHO HAS THE RIGHT TO GET AND AMEND MY MEDICAL RECORD?

You have the right to see and get a copy of medical records that are about you. You also have the right to amend medical records that are about you by having information added to them. (This guide calls these rights the right to "get and amend" your medical record.) If there is someone who acts as your *personal representative*, they usually have the right to get and amend your record on your behalf. Generally, a personal representative is a person who has the right to make health care decisions on your behalf.



Do I have the right to get and amend my minor child's medical record?

Usually, yes. As a parent or guardian, you are generally considered to be the personal representative of your minor child. As a personal representative, you generally have the right to get and amend your child's medical record. In Illinois, parents have these rights when a child is younger than 18 years old.

As a parent, do I always have the right to get and amend my child's medical record?

No. A parent does not always have the right to get and amend a child's medical record. For example, a provider may reasonably believe that a parent is abusing or neglecting a minor child. When this is the case, the provider does not have to treat the parent as the personal representative of the minor child. This means the provider does not have to give the parent access to the child's medical record.

Some other situations where parents do not have the right to get and amend their child's medical records are discussed in the following questions and answers.

Who has the right to get and amend my child's medical record once she turns 18?

Once your child turns 18, your child has the right to see, get a copy of, and amend her own record. You usually no longer have the right to get and amend your adult child's record just because you are her parent.

I am under 18, but I'm considered emancipated under Illinois law. Who has the right to get and amend my medical record?

You do. If you are under 18, but are considered emancipated under Illinois law, you have the right to get and amend your own medical record. Your parents do not have the right to get your medical record.

I am a minor. I am not emancipated but I have the right to consent to certain kinds of medical treatment without my parents' permission. Who has the right to get and amend medical records related to this treatment?

It depends. In Illinois, even though you are a minor you can consent to certain kinds of medical treatment without the permission of your parents. When you consent to such treatment, you have the right to get and amend your own medical record related to that treatment. The HIPAA Privacy Rule lets state law determine whether your parents *also* have access rights to information about this treatment.

For example, in Illinois, a minor 12 years or older may consent to medical care for the diagnosis or treatment of sexually transmitted disease. The minor has the right to get and amend information related to this treatment. A health care provider may use their professional judgment to decide if the minor's parents also should be informed about the minor's treatment for sexually transmitted disease.

Example

Jason is 16 and believes he may have herpes, a sexually transmitted disease. Jason gets treatment for herpes. Jason's mother later asks for Jason's entire medical record. It is up to the doctor to decide whether to give Jason's mother the information about Jason's treatment for a sexually transmitted disease.

The rules may be different when you, as a minor, obtain treatment for other medical conditions without parental consent.

If you have questions or concerns about whether your parents will have access to your medical information, you should talk to your health care provider.

I have a health care power of attorney for my mother. Do I have the right to get and amend her medical records?

Yes. If you have your mother's health care power of attorney, you generally have the right to get and amend her medical records that are relevant to making health care decisions on her behalf. You have these rights while the power of attorney is in effect.

Example

Maria's mother signed a health care power of attorney form. If Maria's mother is not able to make decisions about her health care, this form gives Maria the power to make such decisions. Maria's mother was in a bad accident and is not able to make decisions about her health care. Maria now has the right to make decisions about her mother's health care. Maria also has the right to get and amend the medical records that are relevant to making decisions about her mother's health care.

Maria is curious about the time her mother had a miscarriage. Maria wants to look at these old medical records. Maria does *not* have the right to get and amend these old medical records because the records have nothing to do with her mother's current condition or treatment.

My father recently died. Do I have the right to see and get a copy of his medical record?

Maybe. You do not automatically have the right to see a deceased person's medical records, even if you are a close relative. In Illinois, you have the right to get and amend a deceased person's medical records if you are the executor, administrator, or other representative of their estate.



HOW LONG DOES MY PROVIDER HAVE TO KEEP MY MEDICAL RECORD?

Illinois law may require your health care provider to keep your record for a certain period of time. For example, under Illinois law, hospitals must keep medical records at least 10 years. There is no specific rule for how long doctors in Illinois must keep medical records.

You have the right to see, get a copy of, and amend your medical record for as long as your health care provider has it.

2. GETTING YOUR MEDICAL RECORD

SUMMARY

You have the right to see your medical record. You also have the right to get a copy of your medical record. These rights are often called the *right of access* to your medical record.

Usually, your health care provider must respond to your request for your record within 30 days of receiving your request.

Generally, your health care provider must give you a copy in the format that you request if they are able to do so.

You may have to pay a fee to get a copy of your record.



HOW DO I ASK FOR MY MEDICAL RECORD?

You should ask your health care provider about their specific procedures for getting your medical record. Often, your provider has a form for requesting your medical record. You should use this form if one is available. You should be able to find some information about getting your medical record in your health care provider's *notice of privacy practices*.



Can my provider make me to put my request for my medical record in writing?

Yes. Your health care provider can require that you put your request in writing (such as by sending a letter, an e-mail, or a fax). Your provider must let you know that they have such a requirement.

What information should I include in my request for my medical record?

If your health care provider does not have a form for requesting your medical record, you should check to see what information they require.

Generally, when you ask for your medical record, your request should include:

- Your name, address, telephone number, and other contact information.
- Your date of birth or your medical record number.
- Date(s) of service (such as dates when you were in the hospital).
- A description of the information that you want to see or copy. This might include:
 - Whether you want the entire record or just part of the record.
 - Medical condition for which you are asking information.
 - Specific test results.
 - Whether you want X-rays or records made by heart monitors or similar medical devices.

- Whether you want to see your medical record, want a copy of your record, or would like both.

Can my health care provider require that I include my Social Security number in my request for my medical record?

Yes. Because some health care providers use Social Security numbers as a way to identify medical records, they may need your Social Security number to locate your medical record. There is nothing in the HIPAA Privacy Rule or the Social Security Act that prohibits a private provider from engaging in this practice.

Do I have to choose between seeing my medical record and getting a copy of it?

No. You have the right to do both.



WHAT WILL HAPPEN IF MY REQUEST FOR MY MEDICAL RECORD IS ACCEPTED?

Your health care provider will inform you if they agree to give you your medical record. If you asked to *see* your records, your health care provider must arrange a convenient time and place for you to review the record. If you have requested a *copy* of your record, your health care provider should either send it to you or arrange for you to pick up a copy.



HOW LONG SHOULD IT TAKE TO GET MY MEDICAL RECORD?

Generally, within 30 days after they receive your request, your health care provider must either

- Let you see or give you a copy of your medical record *or*
- Tell you that they are denying your request for your record.

Can it ever take longer?

Yes. If your provider cannot respond in 30 days, they can get one 30-day extension. In order to get an extension, your provider must give you a written explanation for the delay and tell you the date they expect to respond. Your provider must give you this explanation during the original 30 day period. It should not take more than 60 days total to get your record.

My health care provider says that under the HIPAA Privacy Rule they can take up to 90 days to give me my medical record. Is that true?

Not really. Although there are times when the Health Privacy Rule would let a health care provider take up to 90 days to respond to a request for a medical record, Illinois law requires that providers respond within 30 days (or 60 days if they get an extension). Your health care provider must follow the shorter deadlines set by Illinois law.

Will I have to show some proof of who I am in order to see or get a copy of my medical record?

Maybe. If your health care provider does not know you well, they are supposed to make sure you are the person who has the right to get the medical record before they give it to you. Your provider can choose the method for verifying your identity. For example, your provider might ask for an identification card (such as a driver's license).

If you are acting under a health care power of attorney, your provider may require you to show them a copy of the power of attorney form. You also may be required to show that the power of attorney is in effect. For example, you may need a letter from the doctor treating the patient to show that the patient is unable to make health care decisions.



CAN I CONTROL WHERE MY MEDICAL RECORD IS SENT?

Yes. You can ask your health care provider to send the copy of your medical record to your regular address (such as your home) or to another address (such as to your office or to a friend's house). As long as your request is reasonable, your provider must send your record to the place that you identify.



CAN I GET A PAPER, E-MAIL, OR FAX COPY?

It depends. Generally, your health care provider must give you your medical record in the format that you request if it is not difficult to do so. For example, if you request a paper copy of your record, your provider generally must give you a paper copy.

Providers also must make sure that they send your records to you in a secure manner. Due to security concerns, many health care providers are reluctant to send copies of medical records by e-mail or fax.



CAN I GET A SUMMARY OR EXPLANATION OF MY MEDICAL RECORD?

It depends. You may want just a summary of your record. You may want your provider to explain some of the information in your record. Under the HIPAA Privacy Rule, your health care provider can give a summary or explanation of your medical record if you both agree *in advance*

- That it is all right for them to give you a summary or explanation, *and*
- To the fee, if any, they want to charge for writing the summary or explanation.

Your health care provider generally must give you the summary within 30 days from when you request the summary. If they are unable to produce the summary in this time they can get a 30 day extension.

Your provider can charge you a reasonable fee for the actual time they spend preparing the summary or explanation.

Example

Leon asks for a summary of his medical record. The record does not currently contain a summary and the doctor does not have the time or staff to prepare one. Leon's doctor is not required to prepare a summary in response to Leon's request. But the doctor must let Leon see or get a copy of his medical record.

I received a copy of my medical record, but I can't understand it. Doesn't my provider have to give me a copy that is in plain language that I can understand?

No. Health care providers often use technical words or a type of medical shorthand. Providers are not required to translate this information for you or give you your medical record in a form that you can understand. If you cannot understand what is written in your medical record you can request an explanation of your record. As described above, you can only get an explanation if your provider agrees. You can find some resources that explain medical terms in Section 6 of this guide.



WILL I HAVE TO PAY FOR MY MEDICAL RECORD?

Maybe. Your health care provider can charge you for copying your medical record. In Illinois, the maximum cost per page depends on how many pages your provider copies. As of January 2007, your health care provider may charge you a maximum of 86¢ per page to copy the first 25 pages of your record; 57¢ per page to copy pages 26 through 50; and 29¢ per page for pages 51 and above. The maximum charge for copies made from microfiche or microfilm is \$1.43 per page. The Illinois Comptroller's Office adjusts these fees every year based on the cost of living. You also can be charged for postage if you have the copy mailed to you.

Can I be charged if I just want to look at or read my medical record?

No. Under the HIPAA Privacy Rule, your health care provider cannot charge you a fee if you just look at or read your medical record.

Can I be charged a fee for someone processing my request?

No. You cannot be charged a fee for someone processing your request. This fee is often called a "*handling fee*." Although Illinois law permits handling fees, the Health Privacy Rule does not. Because the Health Privacy Rule is more protective of your rights in this area, your provider must follow the Health Privacy Rule. Your provider may not charge you a handling fee.



Can I be charged for copies of X-rays and similar records?

Yes. Your health care provider can charge you a reasonable fee for copying X-rays and similar records. This fee must be based on the actual cost of making the copy. You can also be charged postage if you ask that the records be mailed to you.

Can I be charged if I want a copy of my medical record sent to another health care provider or to a lawyer?

The procedures and fees for having a copy of your medical record sent to someone else (such as to another doctor or to a lawyer) are not covered by the HIPAA Privacy Rule. They are not discussed in this guide.



CAN MY PROVIDER DENY MY REQUEST FOR MY MEDICAL RECORD?

Yes. Your health care provider can deny your request to see or get a copy of your medical record, but only in a few cases. For example, if your provider believes that letting you see your record might physically endanger you or someone else, they can deny your request for your record.

How will I know if my request for my medical record has been denied?

Your health care provider must tell you in writing (by letter, fax, or e-mail) if they deny your request for your medical record. They must tell you why your request was denied. They also must tell you if you have a right to have their decision reviewed and how you can file a complaint.

Generally, your health care provider must give you this information within 30 days after receiving your request for your record. You can read a more about this time limit in the section of this guide titled "How Long Should It Take to Get My Medical Record."

Can my health care provider deny my request for my medical record just because they think I might get upset if I read it?

No. Your health care provider cannot deny you access to your record because they think the information in the record might upset you or that it might cause you mental harm. However, they can deny your request if they believe you will become upset enough to physically harm yourself or someone else.

Can my health care provider deny my request for records related to my mental health treatment?

Records about mental health treatment may be treated differently from other types of medical records. This guide does not discuss mental health records. Section 6 lists some resources for information about mental health records.



Can my health care provider deny my request for my medical record because I have not paid my medical bill?

No. Your provider cannot deny your request for your medical record because you have not paid your medical bill.

What happens if my provider doesn't have the medical record that I requested?

If your health care provider doesn't have the record that you requested, they don't have to locate it for you. But your provider must tell you where your medical record is kept if they know.

My medical record contains some information that my provider is allowed to deny me access to. Does this mean that I can't get any of my medical record?

No. Under the HIPAA Privacy Rule, your health care provider must give you as much of your medical record as possible. Your provider may remove only the information that they are allowed to refuse to give you access to.



WHAT CAN I DO IF MY HEALTH CARE PROVIDER DENIES MY REQUEST FOR MY MEDICAL RECORD?

If your health care provider denies your request for your medical record because they believe that seeing it might endanger you or someone else, you have the right to have another health care professional review their decision.

At the time your health care provider denies your request for your record, they must tell you in writing if you have a right to a review. They must also tell you how to ask for a review.

If you request a review, your provider must choose another licensed health care professional to review their decision. They cannot choose someone who was involved in the original decision. The reviewer makes the final decision whether you are allowed to get access to your medical record. Your provider must notify you in writing (such as by a letter, fax or e-mail) what the reviewer decides.

Can I choose the reviewer?

No. Your health care provider gets to choose the reviewer.

3. AMENDING (CORRECTING) YOUR MEDICAL RECORD

SUMMARY

When you read your medical record you may find something that you believe is not accurate. You might believe that important information is missing. You have the right to amend your medical record by having information added to your record to make it more complete or accurate. The *HIPAA Privacy Rule* calls this the *right to amend* your medical record.

If your *health care provider* accepts your request to amend your record, they must add the information to your record.

If your provider denies your request to amend, they must tell you. You then have the right to add a short statement to your record that explains your position.

As a minor, do I have the right to amend my medical record under the HIPAA Privacy Rule?

Sometimes. As a minor, you usually do not have the right to amend your medical record. The right to amend (like the right of access) usually belongs to your parents.

However, if you are an emancipated minor, you have the right to amend your own medical record. Similarly, when minors legally consent to certain kinds of medical treatment they have the right to amend medical records related to that treatment.



HOW DO I ASK MY HEALTH CARE PROVIDER TO AMEND MY MEDICAL RECORD?

Before you ask your health care provider to amend your medical record, you should:

- Identify the part of your medical record that you think is inaccurate or incomplete.
- Identify the health care provider that created the information or that first put the information into your record.

You should ask your provider about their specific procedures for requesting an amendment to your medical record. Your health care provider may have a form for requesting an amendment. You should use this form if one is available. You should be able to find some information about amending your medical record in your provider's *notice of privacy practices*.

Can my health care provider require that I put my request to amend my record in writing?

Yes. Your health care provider is allowed to require that you put your request to amend your record in writing, such as by a letter, fax, or e-mail. They are also allowed to require that you give them a reason why you want to amend your record.

What information must be included in my request to amend my medical record?

If your provider does not have a form for requesting your medical record, you should check to see what information your provider requires. Generally, your request to amend your medical record should include:

- Your name.
- Your address.
- Your telephone number.
- Your email address.
- Your date of birth or your medical record number.
- Dates related to the information (such as the date of treatment).
- A description of the information that you believe is inaccurate or incomplete.
- The information that you want them to add to your record.
- The reason why you want the information added.

Can my health care provider require that I include my Social Security number in my request to amend my medical record?

Yes. Because some health care providers use Social Security numbers as a way to identify medical records, they may need your Social Security number to locate your medical record so that they can amend it. There is nothing in the HIPAA Privacy Rule or the Social Security Act that prohibits a private provider from engaging in this practice.

Do I have the right to have information removed from my medical record?

No. You do not have the right to have information that is already in your record removed or altered. You only have the right to add more information.

I disagree with my provider's diagnosis. Can I make them change it?

No. The right to amend your record is not supposed to be a chance to dispute a diagnosis. It is meant to give you the chance to amend your record by adding information to it.





WHAT HAPPENS IF MY REQUEST TO AMEND MY RECORD IS ACCEPTED?

If your health care provider accepts your request to amend your medical record, they must add the new information to your record. They also must tell you in writing that your request to amend was accepted.

You might know people or organizations that should be told about the new information. You should give their names and contact information to your health care provider. Your provider must give the amended health information to the people and organizations you identify.



HOW LONG SHOULD IT TAKE TO AMEND MY MEDICAL RECORD?

Generally, within 60 days after they receive your request, your health care provider must either

- Add the information to your medical record as you requested *or*
- Deny your request in writing.

Can it ever take longer?

Yes. If your health care provider is unable to act within 60 days, they can get one 30-day extension to respond. In order to do this, they have to give you a written explanation for the delay and tell you the date they expect to respond. Even with an extension, they shouldn't take more than 90 days to respond to your request to amend your record.



CAN MY HEALTH CARE PROVIDER DENY MY REQUEST TO AMEND MY MEDICAL RECORD?

Yes. There are times when your health care provider can deny your request to amend your medical record. Generally, your provider can deny your request when:

- They determine your record is accurate or complete.
- They did not create the information that you want to amend.

If your health care provider denies your request to amend your record, they must let you know in writing (for example by sending you a letter, a fax or an e-mail). Your provider also must tell you why they denied your request.

The provider that created the information that I want to amend isn't around any more. What can I do?

You can ask your current provider to amend your information. You should explain to them in as much detail as possible that the health care provider who first created the information that you want to amend is no longer available to act on your request. If

your explanation is reasonable, your current provider cannot deny your request just because they did not create the medical information that you want to amend.

Example

Brianna wants to amend information in her medical record that was originally put in her record by Dr. Smith. Dr. Smith has retired. Brianna asks Dr. Jones, her current doctor, to amend her medical record. She shows Dr. Jones the letter Dr. Smith sent to his patients announcing his retirement. Dr. Jones cannot refuse to amend Brianna's record just because he didn't create the information she wants to amend.

WHAT CAN I DO IF MY REQUEST TO AMEND MY MEDICAL RECORD IS DENIED?

If your request is denied, you have the right to give your health care provider a written statement that explains why you disagree with their decision. Your provider may reasonably limit the length of your statement. Your provider must make your statement part of your medical record. In the future, when your provider shares your medical information with others, your provider must also give them a copy of their denial of your request to amend and a copy of your statement of disagreement.

What if my health care provider disagrees with my statement of disagreement?

If your health care provider disagrees with your statement, they have the right to put a note in your record that says why they do not agree with you. They must give you a copy of this note.

Do I have the right to have someone else review my health care provider's denial of my request to amend my records?

No. If your health care provider denies your request to amend your medical record you do not have the right to have someone else review that decision.

4. ASKING QUESTIONS AND FILING COMPLAINTS

This guide is just a summary of your rights to see, get a copy of, and amend (correct) your medical record. If you have more questions or would like to file a complaint you can contact the people and organizations listed below. You can also contact professional help if necessary.



WHO CAN ANSWER MY QUESTIONS ABOUT GETTING AND AMENDING MY MEDICAL RECORD?

There are a number of resources available to answer your questions about getting and amending your medical record.

Your health care provider

Your health care provider should be able to answer many of your questions about getting and amending your medical record. Your provider's *notice of privacy practices* must contain a general description of your right to see, get a copy of, and amend your medical record. The notice also must list the name (or title) and the telephone number of a contact person who should be able to answer your questions about getting and amending your medical record. In addition, some providers have Web sites that list information on how to see, get a copy of and amend your medical record.

Office for Civil Rights, Department of Health and Human Services (OCR)

You may be able to get answers to your questions about your rights under the HIPAA Privacy Rule from OCR, the federal office in charge of enforcing the HIPAA Privacy Rule. OCR provides fact sheets for consumers and responses to frequently asked questions on its Website at <http://www.hhs.gov/ocr/hipaa/>.

If you do not find your question answered here you can call OCR at 866- 627-7748. This is a toll free number. OCR requests that you read their responses to frequently asked questions *before* you call this number.



WHAT CAN I DO IF I BELIEVE MY RIGHTS TO GET AND AMEND MY MEDICAL RECORDS HAVE BEEN VIOLATED?

Before taking any formal action, you should try to informally solve your problems getting and amending your medical record with your health care provider. If you are unable to resolve your issues informally, there are a number of possible actions you can take.

You can file a complaint with your health care provider.

You have the right, under the HIPAA Privacy Rule, to file a complaint with your health care provider. Your health care provider's notice of privacy practices must describe how to file your complaint.

You can file a complaint with the Office for Civil Rights, U.S. Department of Health and Human Services (OCR).

Complaints must be in writing. You can get detailed information about filing a complaint with OCR at <http://www.hhs.gov/ocr/privacyhowtofile.htm>.

You can call OCR at **1-800-368-1019** if you need help filing a complaint or have a question about the complaint form. This is a toll free call.

If you file a complaint with OCR, your health care provider cannot threaten you or do anything else to get even with you.

You can file a complaint about a licensed health care practitioner (such as a doctor or dentist) with the Department of Professional Regulation at:

Illinois Department of Professional Regulation

Complaint Intake Unit

100 W. Randolph Street #9-300

Chicago, IL 60601

312-814-6910 (Telephone)

You can file a complaint online at <http://www.dpr.state.il.us/filing/default.asp>.

You can file a complaint about your hospital with the Department of Health at:

Illinois Department of Health

Office of Health Care Regulation

525 W. Jefferson St., 5th Floor

Springfield, IL 62761-001

You can call the Department of Health's hotline for filing complaints at **1-800-252-4343**. This is a toll free call.

Can I sue my health care provider for violating my rights to get and amend my medical record?

Under Illinois law, you have the right to sue in Illinois Circuit Court to get your medical record if your health care provider does not give you your records within the deadlines set by state law (generally 30 days, 60 days if the provider has notified you that they need an extension). If the court orders your health care provider to give you your records, your provider may have to pay your expenses and reasonable attorney's fees.

You do *not* have the right to sue your health care provider in federal court (United States District Court) for violating your right to get and amend your medical record under the HIPAA Privacy Rule.

5. WORDS TO KNOW

Correct. This guide uses the word “correct” to mean adding information to your medical record to make it more accurate or complete.

Handling Fee. A fee for the administrative time spent processing your request for your medical record.

Health care provider. In this guide, the term “health care provider” means health care practitioners and health care facilities providing health care in Illinois. The term includes doctors, dentists, podiatrists, advanced practice nurses, physician assistants, medical offices, health care clinics, hospitals, nursing homes and others.

HIPAA Privacy Rule. A set of legal rules written by the United States Department of Health and Human Services under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). These rules set national standards that give patients the right to see, copy, and amend their own health information. They also set standards protecting the privacy of health information. The HIPAA Privacy Rule applies to health care providers (such as doctors and hospitals) and health plans (such as health insurers and Medicare). Other people (such as employers) generally do not have to follow the HIPAA Privacy Rule.

HIPAA. Health Insurance Portability and Accountability Act of 1996. This federal law directed the United States Department of Health and Human Services to write rules protecting the privacy of health information. The federal law leaves in place state laws that have privacy protections that are equal to or greater than the federal law.

Notice of Privacy Practices. A notice that health care providers must give their patients that explains the patients’ rights under the HIPAA Privacy Rule. This notice must also explain how a provider can use health information and share it with others.

Personal representative. This guide uses the term “personal representative” to refer to someone who has the legal right to make health care decisions on behalf of another person.

Right of Access. The right to see and get a copy of your medical record.

Right to Amend. The right to amend your health information by adding information to it. The right to amend does not mean a right to have information erased or removed.

6. WHERE TO FIND MORE INFORMATION

This guide only discusses how to get and amend (correct) your medical records from health care providers who have to follow the *HIPAA Privacy Rule*. The guide mentions some related topics without discussing them in detail. Here are some places where you can find information about these related topics.

Alcohol and Drug Treatment Records

Records related to alcohol and drug treatment may be subject to other privacy rules. You can get more information about these records at:

<http://hipaa.samhsa.gov/Part2ComparisonCleared.htm>

Illinois Medical Record Access Laws

Some health care providers do *not* have to follow the HIPAA Privacy Rule. These providers must still follow Illinois laws that give you the right to see and get a copy of your medical record. You can read the state statutes that address how to get your medical records on the Web site of the Illinois General Assembly at <http://www.ilga.gov/>. Look under "Illinois Compiled Statutes," Chapter 735, Code of Civil Procedure, Article VIII, Part 20, Sections 8-2001 through 8-2003.

Medical Records in General

You can read general information on your medical record rights, the flow of medical information, and how to create a personal medical record at <http://www.myphr.com/> a Website operated by the American Health Information Management Association, an association of professionals who manage medical records and information.

Medical Terms

You can find out the meaning of many medical terms and medical shorthand from the Medical Library Association's Website at:

http://www.mlanet.org/resources/consumr_index.html

Your library might also have books or brochures that explain medical terms.

Mental Health Treatment Records

You can get information about your rights in your mental health records under Illinois law from Illinois Legal Aid Online at <http://www.illinoislegalaid.org/>. Information on access to mental health records is contained in the document titled "Rights to Confidentiality for People with Mental and Developmental Disabilities" which can be found using the search term "mental health record."

The HIPAA Privacy Rule treats most mental health treatment records like other medical records. However, psychotherapy notes (as defined by the HIPAA Privacy Rule) are treated differently. You can find what types of records are included in psychotherapy notes and how these notes are treated in the *Summary of the Privacy Rule* written by the Office for Civil Rights, HHS at

<http://www.hhs.gov/ocr/hipaa/>