

Notice to Patients about the Illinois Health Information Exchange (ILHIE) and the Right to Opt-Out

What is the ILHIE?

The ILHIE is a secure computer network set up to give healthcare providers (doctors, hospitals, clinics, labs, pharmacists, etc.) a fast and easy way to share health information about patients. That means that, instead of keeping patient health information on paper, those records will be kept and shared electronically. The ILHIE is protected by safety checks to make sure your health information is safe and private.

How does the ILHIE work?

Both you and your healthcare providers have a choice about whether to be a part of the ILHIE. Only healthcare providers who are part of the ILHIE can get patient records through the ILHIE. You will be a part of the ILHIE unless you choose not to *and* take steps to “opt out.” (See below) If you are part of the ILHIE, your healthcare providers who are also part of the ILHIE will be able to quickly get your health information, *except for certain sensitive health information*, from your other healthcare providers in the ILHIE, without needing to get your permission.

What are the possible benefits of the ILHIE?

Because the ILHIE allows for fast and easy sharing of health information your healthcare providers in the ILHIE will be able to get your most complete up-to-date health information on hand. As a result, there may be less chance for mistakes, for having tests or treatment that are not needed or for being given medications that do not work or could be harmful. In turn, this may result in better healthcare and improved patient safety for you with less cost. It will also save you and your healthcare providers in the ILHIE time and mean less paperwork to fill out.

What are the possible risks of the ILHIE?

Like the safety checks for any computer network, the safety checks for the ILHIE cannot ensure that health information passing through it will be 100% protected. That means someone who should not have patient health information could get it and use it for improper reasons, like identity theft. This could also happen with paper health records, but a breach of security of electronic records may affect more records. As with paper health records, if a healthcare provider in the ILHIE makes a mistake putting health information into a patient’s record that information will stay there until it is corrected and may be shared with other healthcare providers in the ILHIE who ask for those records. But incorrect health information sent electronically through the ILHIE may be spread more widely and quickly.

What is sensitive health information?

Under federal and Illinois law, the following health information is treated as sensitive and may be shared by healthcare providers in most cases only with the patient’s signed and written consent: 1) HIV testing and results; 2) sexually transmitted disease (STD); 3) alcohol and drug abuse treatment records; 4) genetic testing information; 5) sexual assault—rape kit evidence. Even if you choose to be a part of the ILHIE, this sensitive

health information cannot be shared by your healthcare providers through the ILHIE without getting your written permission.

Do I have to give written permission before my mental health records can be shared through the ILHIE?

No. There has been a recent and important change in Illinois law about mental health records. Before, mental health records generally could not be shared by your healthcare providers unless you signed and agreed in writing to share the records. A new Illinois law changed that. Now, if you choose to be a part of the ILHIE, your mental health records will be shared, along with your other health information, by your healthcare providers in the ILHIE without needing to get your written permission. If you do not want all of your healthcare providers in the ILHIE to be able to get your mental health records through the ILHIE, you must opt out of the ILHIE. In other words, you must choose not to be a part of the ILHIE.

What if I choose to opt out of the ILHIE?

It is your choice whether to be a part of the ILHIE; if you wish, you have the right to opt out. If you **do not** want your health records, including mental health records, to be shared through the ILHIE with all of your healthcare providers in the ILHIE, you must sign a form stating that you **“opt out”** of the ILHIE. (You can get this form from your healthcare provider or on the ILHIE website: _____) A healthcare provider cannot turn you away as a patient because you choose to opt out of the ILHIE.

What if I choose to be a part of the ILHIE?

If you **do** want your health records, including mental health records, to be shared through the ILHIE by all of your healthcare providers in the ILHIE, you do not have to do anything. You will automatically be a part of the ILHIE.

Can I share only some of my health information through the ILHIE?

Right now, you do not have the choice to share only some of your health records through the ILHIE. If you decide to opt out of the ILHIE, none of your healthcare providers will share your health records through the ILHIE and none of your healthcare providers will be able to get your health records through the ILHIE. But, there are other ways that some or all of your health records can be shared by your other healthcare providers, which you can talk about with any of your healthcare providers on your next visit.

Can I change my mind later about being a part of the ILHIE?

You can change your mind about whether to be part of the ILHIE at any time. This means you can revoke or take back a past choice to opt out. You can also choose to opt out even though you did not do so before. In either case, you will have to sign a form to make the change.

Have questions?

Talk to your healthcare provider or go to the ILHIE website at hie.illinois.gov to learn more about how the ILHIE works and to get audio, visual and written information on how to opt out.