

Testing Your Blood for HIV, the Virus that Causes AIDS

As part of your protocol or during your medical care here, you may be asked to give a blood sample for HIV testing. You have the right to decide whether you want to be HIV tested. But before you decide, you should know why this test is being done, what the results might mean, and what you should do if the test is positive. If your doctor orders the HIV test, your doctor or a staff person such as the HIV Counseling Coordinator will inform you in advance. You will be told why the test is being done and asked for your consent to do the test. Your doctor will also notify you promptly of your test results.

What is HIV infection?

HIV infection is an illness caused by a virus (the Human Immunodeficiency Virus) that attacks the body's immune system. In some cases, untreated HIV infection leaves the body unable to fight off other infections.

How is it spread?

HIV is spread by sexual contact with an infected person, by exposure to infected blood (for example, through needle sharing) and by infected mothers to their unborn or new infants. HIV-infected people without symptoms can infect other people with HIV. HIV is not spread by casual, everyday contact.

What is AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome. It is caused by the Human Immunodeficiency Virus. As the HIV infection continues, it weakens the body's immune system. AIDS occurs when the body's immune system is so damaged by HIV infection that it becomes vulnerable to infections and some kinds of cancers.

What are the symptoms of HIV infection and AIDS?

Within a month after exposure to HIV, a person might have flu-like symptoms such as fever, swollen glands, muscle aches, diarrhea, fatigue, or rash. (But some people have no symptoms.) These symptoms usually go away, and the infected person may be symptom-free for months or even years. During this time, however, HIV damages the person's immune system. Without treatment, most HIV-infected persons develop AIDS and may die of infection or cancer. But with treatment, most people with HIV infection do not develop AIDS. There is no cure for HIV infection—life-long treatment is needed.

Why would my doctor order the HIV antibody test?

1. When your protocol requires all participants to be tested.

Protocols may require participants to be tested to safeguard their health. Your protocol may use treatments or drugs that affect the immune system. This might not be safe for HIV-infected people, so they might be excluded from the protocol. A protocol may also call for testing to make sure its results make sense. Each protocol is made to answer a question about a certain disease. To answer that question, people with this specific disease would be studied. Because people with this disease who are HIV-positive might be different from those who are HIV-negative, the researcher might need to know the HIV status of the participants to decide if they are eligible for the study. If the protocol requires HIV testing, those who refuse testing will not be eligible to take part.

2. When your particular health or social situation warrants testing.

If you have an unexplained illness that might occur with HIV infection, you will be asked for your permission to be tested. If you are in a risk group for getting HIV infection, you may be asked for your permission to be tested. These risk groups include:

- ▶ people who might have been exposed to HIV through sex with an infected person or
- ▶ through needle sharing
- ▶ pregnant and/or breastfeeding women
- ▶ people who have an illness that may occur with HIV infection, such as tuberculosis.

Testing may also be requested if an accident (such as a needle stick) exposed a health care worker to your blood or body fluid. Results of the blood test help doctors care for the injured health care worker. Treatment benefits people with HIV. It is important that they learn of their infection.

What is involved in an HIV test?

Two blood tests are used to look for antibodies that the body produces in response to infection with HIV: the ELISA (enzyme-linked immunosorbent assay) test, which is done first, and the Western Blot test. The Western Blot test confirms if a sample is positive or negative. Very rarely, a Western Blot result comes back as neither negative nor positive (“indeterminate”), meaning a person may have just started to develop antibodies to HIV because it is so close to the time of exposure to HIV. If this happens, the person will need to be re-tested in three months.

What does a negative test mean?

A negative HIV test means that no HIV antibodies were found in that blood sample. It is possible for an infected person to test negative, if tested too soon after HIV exposure because it takes a few weeks for the body to make these antibodies after HIV exposure.

If you are in a risk group for getting HIV infection, we recommend that you get regular testing. If you test negative for HIV and have not had recent or possible

HIV exposure, you are considered to be uninfected with HIV.

If you are HIV negative, take steps to stay that way—a negative HIV test does not mean that you cannot get HIV in the future. To lessen your chances of becoming infected, talk with your health care providers or with the HIV Counseling Coordinator. There is no vaccine to prevent HIV or cure AIDS. Avoiding exposure to the virus is the only way to prevent infection.

What does a positive test mean?

A positive test result means that both the ELISA and Western Blot found HIV antibodies in the blood sample. A positive HIV test does not mean that the person tested has AIDS—only that the person is HIV positive or HIV infected.

A person infected with HIV should talk to their health care provider about treatment. You and your doctor will discuss when would be the best time to start treatment. Keep in mind that a person who is HIV positive can pass the virus to others through sex or by sharing needles, or during pregnancy and breastfeeding, whether or not they are getting treatment.

If I have a positive test, what will I be told?

If your HIV antibody test is positive, your doctor will notify you of the results. You may also meet with the Clinical Center HIV Counseling Coordinator. This staff member will discuss how to prevent spreading HIV infection. You will receive information about

safer sex and your responsibility to inform certain people in your life. You should also protect others by:

- ▶ following safer sex guidelines
- ▶ not sharing needles
- ▶ not donating or selling your blood plasma or organs
- ▶ not donating sperm (males)
- ▶ not breastfeeding or donating breast milk (females)
- ▶ receiving appropriate medical care early in any pregnancy (females).

Patients with HIV infection are not isolated from other patients or staff. Health care workers in the Clinical Center practice universal precautions with every patient. This means that they do proper hand washing and use protective equipment such as gloves, gowns, and eyewear when they might be exposed to blood or other potentially infectious materials from any patient.

Learning that you are HIV infected can be scary. You might experience a range of emotions and wonder what's next. The Clinical Center HIV Counseling Coordinator can provide emotional support and information about living with HIV and where to go for additional help.

Who will know my HIV test results?

Clinical Center policy and laws about privacy and medical records, such as the Privacy Act, govern how your HIV test results are handled. Your test results are

confidential and become part of your Clinical Center medical record. Generally, only you and your NIH care givers can see your medical record. However, your referring physician and other healthcare providers may have access to your medical record if you sign a release of medical information.

Do I have other responsibilities if I test positive for HIV?

In keeping with public health policy, the Clinical Center requires you to inform your current needle-sharing or sexual partner(s) that they have been exposed to HIV. (Spouses are considered to be sexual partners.) They should be encouraged to be tested for HIV antibodies. If you are unable or unwilling to notify your partner(s), the Clinical Center will help with this process. Notification and counseling may also be done through local public health departments. Partners will be notified that they have been exposed to HIV— not who exposed them.

If I have a positive HIV test, will I be reported to the health department?

The Clinical Center may report certain communicable diseases, including HIV infection, to appropriate State and Federal government agencies. If you have any questions about HIV testing or this policy, you can discuss them with your caregivers in the Clinical Center or the Clinical Center HIV Counseling Coordinator.

The HIV Counseling Coordinator may be reached at 301-496-2381 or through the page operator at 301-496-1211.

What if I decide not to have the HIV antibody test?

You may choose not to have your blood tested. Generally, this decision will not affect your care at the Clinical Center. But if your research protocol requires that participants be HIV negative, then you may not be able to take part in the study unless your blood is tested and you are HIV negative. This will not affect your taking part in other protocols that do not require HIV testing.

What Clinical Center resources are available?

If you need information before your blood is tested, the HIV Counseling Coordinator can give you more information and answer your questions. The Coordinator can be reached at 301-496-2381 or through the page operator at 301-496-1211.

This information is prepared specifically for persons taking part in clinical research at the National Institutes of Health Clinical Center and may not apply to patients elsewhere. If you have questions about the information presented here, talk to a member of your health care team.

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Questions about the Clinical Center?
<http://www.cc.nih.gov/comments.shtml>

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