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Privacy and STI testing — Who will know my results? ^[1]

Dear Alice,

I have been thinking about getting tested for STIs for a while now but have been concerned with medical privacy policy. From the research I have done, I have not been able to find if I tested positive for an STI would I be referred to in name as a 'risk to public safety' or simply as a statistic. I know that this will be placed in my medical records and documented for the rest of my life. Will I have a label attached to my name for the rest of my life? Who will be notified if I do test positive for something like syphilis or herpes?

Thanks a lot,

— Nervous

Answer

Dear Nervous,

You're not the only one who has had this concern; many people have wondered about their level of privacy regarding their sexually transmitted infections (STI) test results. Will you be labeled as a "risk to public safety" if test results turn up positive? The short answer is no. It's good to know, however, that when it comes to how your information is handled and shared, there are a few distinctions to make. There are different local, state, and territory laws that determine what pieces of your personal health information are accessible beyond you, your health care provider, and anyone else you choose to tell (more on that later). With that being said though, your results are still protected under the Health Insurance Portability and Accountability Act of 1996 ^[2] (HIPAA), so who has access to that information and what they can share is still limited.

To start off, it might be helpful to take a closer look at under what conditions information about a positive STI diagnosis may be shared and what happens with that information. When it comes to the tracking of infectious disease, some are deemed "reportable", whereas some are "notifiable;" the list of each of these varies by state and time and there is some overlap. Diseases that are "reportable" must be reported at state levels when they are positive cases identified. This can be done by a health care provider, hospital, or the laboratory. When these positive cases are reported, personal identifiers are used so that states can establish when immediate disease

control and prevention is needed. Moreover, in the case of a “reportable” STI case, those personal identifiers may help state and local agencies might try to locate any sexual contacts (provided that they are given) to recommend testing or treatment if they have already been infected. It's also good to note that a lot of states have [laws](#) [3] that require people who test positive for HIV to share their status with certain people (such as a previous or current partner). On the other hand, “notifiable” diseases are those in which cases are voluntarily reported, without any personal identification, to the Centers for Disease Control and Prevention (CDC) so it can be used in nationwide monitoring and data aggregation. Some STIs that commonly appear on this list are chlamydia, gonorrhea, hepatitis B, and syphilis. In the case of a “notifiable” STI, your positive diagnosis will just enter the system as another data point!

There's an added layer of complexity with HIV and it involves different testing circumstances. Most states offer both confidential and anonymous HIV testing. However, some states only offer confidential testing services. Confidential testing means that your results are connected to your name — other identifying information will go into your medical record and may be shared with your health care provider and insurance company. However, you're still protected by state and federal privacy laws, so your name cannot be released to state or local agencies without your permission. Furthermore, an insurance company can't rescind your coverage for being tested or testing positive for HIV. If you test positive on a confidential test, it is reported to the state and local health department for the purposes of public health surveillance. At the state level, only public health personnel have access to this information to understand rates of HIV in the state. The state health department then removes personal information about you to share with the [CDC](#) [4], so they can track national public health trends. This information is not shared with anyone else. The other testing option, if you don't want the result to be connected to your name, is an anonymous test. When you take an anonymous HIV test, a unique identifier is assigned to the results so that you can access them, but your name isn't revealed. This result is reported just as a "notifiable" disease is reported — without any personal identification attached.

One other thing to keep in mind before you get tested is that test sites may have different privacy rules and some aren't bound by HIPAA regulations. It might be a good idea to check out what their rules and regulations are before selecting a test site. For more information regarding confidential versus anonymous HIV testing, check out Planned Parenthood's [Where to Get Tested for HIV](#) [5]. You can also contact your local health department or go to the CDC's [GetTested](#) [6] website to learn more about the confidential and anonymous STI test sites in your area.

Hope this helps you make a decision about getting tested!

Alice!

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Published date:

Aug 30, 2013

Last reviewed on:

Sep 09, 2016

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[2] <http://www.hhs.gov/ocr/privacy/>

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[5] <https://www.plannedparenthood.org/learn/stds-hiv-safer-sex/hiv-aids/should-i-get-tested-hiv>

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