HIV and AIDS REPORTING IN DELAWARE

What you need to know!

DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health
Center for Health Information and Disease Prevention
HIV/AIDS Epidemiology
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FORWARD

This publication contains the procedure for the required reporting of HIV and AIDS cases to the Delaware Division of Public Health. It also provides answers to commonly asked questions and provides contact numbers for more information. HIV reporting provides supplementary data on HIV-infected Delawareans needed to enhance prevention efforts, improve resource allocation, and assist in evaluating public health interventions.

CONTENTS

Current Regulations ........................................ 2
How and where to report HIV/AIDS Cases ............... 2
No Identified Risk (NIR) case investigation ............... 3
Partner Notification ........................................ 3
Questions and Answers .................................... 4-5

APPENDICES

AIDS Case definition ........................................ A
Risk Factor Assessment Tool ............................... B

NOTE: Adult and Pediatric HIV/AIDS case report forms can be downloaded at

http://www.dhss.delaware.gov/dhss/dph/dpc/hivsurveillance.html
Current Delaware Regulations and Laws
Regarding HIV/AIDS Case Reporting

HIV/AIDS reporting is required under Delaware Code, Title 16, § 501 and § 502, and Delaware Regulations for the Control of Communicable and Other Disease Conditions, Chapter 42, para 7.4.1. It establishes the authority for Division of Public Health (DPH) to collect information on certain diseases, including HIV/AIDS patients. Reporting is required regardless of their state of residence; they must be reported if they are receiving care in Delaware.

Physicians, licensed health care professionals, and laboratory personnel who diagnose, suspect, or treat HIV are required to report cases to the DPH. When a patient is hospitalized, the hospital may file a report; however, the ultimate responsibility to report is that of the attending physician. Reports are to be made within 48 hours of diagnosis, suspicion or treatment.

How and Where to Report HIV/AIDS Cases

For your convenience, HIV or AIDS cases may be reported to the DPH at 302-744-1015. Filing a report by telephone takes an average of five minutes. To expedite the reporting process, please have the patient’s medical record available when you call.

If you prefer, you may complete a case report form and mail it to the address listed below. A copy of the Adult HIV/AIDS Confidential Case Report for patients 13 years of age or older at the time of diagnosis appears as Appendix A. The Pediatric HIV/AIDS Confidential Case Report for patients under the age of 13 is Appendix B. You may copy these forms for your use in filing a case report. By following these instructions, only authorized DPH staff will review the case report form.

Instructions:
Included with the HIV/AIDS Reporting in Delaware: What you need to know! packet, providers will receive envelopes to be used in a “double envelope” system. Please insert the completed case report form into the colorful envelope with security and confidentiality information on outside. This colorful envelope should then be placed inside the postage paid envelope (also contained in packet), sealed and mailed to the Surveillance Coordinator.

To report an HIV or AIDS case, or for help with completing a case report form, contact the following authorized Division of Public Health staff:

Surveillance Officer: 302-744-1015 / 302-744-1016
Mailing Address: HIV/AIDS Surveillance Office
417 Federal Street
Dover, DE 19901
No Identified Risk (NIR) Case Investigation

The national HIV/AIDS surveillance program is coordinated by the Centers for Disease Control and Prevention (CDC). Standard information has been collected nationwide on documented cases of AIDS since 1984. In order to meet standard reporting requirements, DPH staff will investigate all cases reported without risk. This investigation will assist Delaware in developing an accurate database. CDC recognizes the following risk exposures:

- Men having sex with men since 1977 (MSM)
- Injecting drug use since 1977 (IDU)
- Received clotting factor for hemophilia or coagulation disorder
- Received transplant of tissue/organs or artificial insemination
- Transfusion of blood or blood components between 1978 through March 1985
- Heterosexual contact with a person who fits any of the above risk exposure groups
- Worked in a health care or clinical laboratory setting

NIR case investigations include contacting the reporting source of the case report. There are multiple sources of case reporting; primary care physicians, infection control personnel, case managers, review of medical records, autopsy reports, death certificates, and sexually transmitted disease/Ryan White registries. Should these methods fail to identify the client’s risk exposure, authorized DPH personnel may also contact the client to request a confidential interview. NIR cases are considered open until a risk exposure is identified, the client is lost to follow up, or the client refuses to be interviewed. Closed cases may be reopened, however, with availability of new information.

Partner Notification

Regulations require physicians or health care professionals report the identity of patients’ sexual or needle-sharing partner(s) to DPH so the partner may be notified of risk of infection, provided:

- the patient is diagnosed with HIV or AIDS; and
- the provider knows of a partner who could be at risk of infection; and
- the provider believes there is significant risk of harm to partner; and
- the provider believes partner does not suspect he or she is at risk; and
- the patient is unlikely to notify the partner; and
- the provider has made reasonable efforts to inform patient of the intended disclosure and to give patient opportunity to express preference of who will notify partner.
Questions and Answers

Q: What is reportable in Delaware?
A: Patients diagnosed with a positive HIV test or meeting the case definition of AIDS, (CD4+ lymphocyte count <200 cells/µL or a CD4+ <14% of total lymphocytes), all viral load test results, and all perinatal exposures to HIV are reportable. Appendix C gives the details of case definition.

Q: Why is it important to report HIV and AIDS?
A: Information from HIV and AIDS case reporting is used to monitor the HIV and AIDS epidemic in Delaware and the United States. HIV reporting allows the surveillance office to obtain information on HIV incidence and prevalence, identify emerging trends and patterns of HIV infection, and characterize the people most recently infected with HIV. Data are used to target prevention programs and allocate funds for treatment services. HRSA Title II funds under the Ryan White CARE Act are distributed to Delaware through a formula grant based on the number of HIV/AIDS cases reported.

Q: Who is required to report?
A: The following are required to report cases:
- Physicians or health care professionals who diagnose, suspect or treat HIV/AIDS
- Administrator of a health facility or state, county, or city prison in which there is a case of HIV/AIDS
- Person in charge of clinical or hospital laboratory, blood bank, mobile unit or other facility in which a laboratory examination yields positive evidence of HIV/AIDS
- All facilities obtaining blood from human donors for purposes of transfusion or manufacture of blood products shall report HIV

Q: What can I do to help?
A: You can help by gathering and submitting complete case report information, including risk exposure. Explain to your client that in the vast majority of AIDS cases, the virus (HIV) was acquired through identified transmission routes. **Review the different risk exposures with your client using the Risk Factor Assessment tool provided as appendix D.** If your client is identifying an unusual transmission route for the virus, collect as much information as possible and share the information with an authorized DPH representative.

Q: What about anonymous testing? Is it still available to clients?
A: Anonymous counseling and testing remains available to all Delaware citizens. Test results from anonymous sites are reported to DPH, but names are not. For a list of current anonymous testing sites or to schedule an appointment, please contact the AIDS hotline at 1-800-422-0429.
Q: **What happens to data once reported?**

A: Once the case report is completed, it should be returned to DPH through previously described procedures (double envelope system, see page 2). Hard copies should **not** be made for the permanent medical record. You may wish to indicate on the medical record that the patient was reported to DPH (and the date of report). It is suggested that no record or case report form remain in the patient’s medical chart.

Please do not assume a patient has been reported. DPH will sort through duplicate reports. Also, when a patient moves from HIV positive to AIDS-defined, please inform DPH.

When DPH receives the case report form it will be handled by authorized DPH personnel only. Information from the case report form will be entered into the secure HIV/AIDS Reporting System (HARS). On a monthly basis, demographic information from HARS will be sent to CDC via a secure system (names will **NOT** be sent). Only authorized DPH staff may access the secure database or HIV/AIDS Reporting System (HARS).

Q: **What happens if I don’t report?**

A: There are penalties for not reporting patients as required by the regulations. Penalties are also assessed for confidentiality breaches. If the authorized Public Health staff receives a lab report on an HIV+ patient, the staff will check the database for patient’s name. If, after a period of time, no case report is received, the authorized Public Health staff will contact the provider to request a complete case report and stress the importance of reporting within the established guidelines.

Q: **How is privacy protected?**

A: The double envelope system directs the recipient to deliver the color distinctive inner envelope to a specific person within DPH. Only authorized personnel will open the brightly colored envelope. The HIV/AIDS Reporting System (HARS) stores all information on the case report form in specialized software developed by CDC. The disks containing HARS data are stored in locked cabinets located within a locked room. Only authorized DPH personnel have access to the secured cabinets. The computer where HARS resides is **not** connected to a network or the internet.

Q: **What is a “name-based” system of reporting?**

A: Each patient name, received by the authorized DPH representative, will be entered into the HARS secure database. All demographic information, to include the patient’s name, will remain in the database. However, as stated previously, no names will be sent to CDC.

Q: **What is the connection between Partner Notification and HIV Reporting?**

A: Page two of the HIV/AIDS case report form contains the partner notification section. When the physician reports partners, only one person within DPH will review reports informing of the need for partner notification. The authorized DPH individual will complete a field record on the partner and provide it to a disease intervention specialist (DIS) within DPH. DIS professionals will make every effort to contact the partners and urge HIV testing.
Appendix A

What is the AIDS Case Definition?

An adult or adolescent (13 years or older) with documented human immunodeficiency virus (HIV) infection confirmed by a Western blot or other confirmatory test and who has one or more of the following conditions:

(♦ = Added in 1993 expansion of the AIDS surveillance case definition)

- CD4⁺ lymphocyte count <200 cells/µL or a CD4⁺ <14% of total lymphocytes ♦
- Candidiasis of bronchi, trachea, or lungs
- Candidiasis, esophageal
- Cervical cancer, invasive ♦
- Coccidioidomycosis, disseminated and extrapulmonary
- Cryptococcus, extrapulmonary
- Cryptosporidiosis, chronic intestinal (> 1 month duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes)
- Cytomegalovirus retinitis (with loss of vision)
- HIV encephalopathy
- Herpes simplex: chronic ulcer(s) (> 1 month duration); or bronchitis, pneumonitis, or esophagitis
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (> 1 month duration)
- Kaposi’s sarcoma
- Lymphoma, Burkitt’s (or equivalent term)
- Lymphoma, immunoblastic (or equivalent term)
- Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary
- Mycobacterium tuberculosis, any site (pulmonary ♦) or extrapulmonary
- Mycobacterium, other species or unidentified species, disseminated or extrapulmonary
- Pneumocystis carinii pneumonia
- Pneumonia, recurrent (2 or more episodes in a 12-month period) ♦
- Progressive multifocal leukoencephalopathy
- Toxoplasmosis of the brain
- Wasting syndrome due to HIV

The Pediatric AIDS Case Definition

Children under 13 years of age with documented human immunodeficiency virus (HIV) infection confirmed by a Western blot or other confirmatory test that have one or more of the conditions defining an adult/adolescent case but excepting the first and fourth conditions on appendix C.

Additional conditions that may define a pediatric case are:

- Bacterial infections, multiple or recurrent (including Salmonella septicemia)
- Lymphoid interstitial pneumonia and/or recurrent lymphoid hyperplasia
Appendix B

TALKING WITH YOUR PATIENTS ABOUT BEHAVIORAL RISK FACTORS FOR HIV AND AIDS

Patients may be uncomfortable disclosing personal risk factors and hesitant to respond to questions about sensitive issues such as sexual behaviors and illicit drug use. However, evidence suggests that when asked, patients will often discuss behaviors that increase their risk of acquiring HIV. Evidence also suggests that some patients have greater confidence in their clinician's ability to provide high-quality care when asked about sexual history during the initial visits. Of course, the more comfortable you are discussing these issues, the more comfortable your patients will be.

Here are some ideas for talking with your patients.

**PUT YOUR PATIENT AT EASE**

- Reassure them their responses will remain confidential.
- Let them know that you ask all your patients these types of questions.
- Tell them that the information they provide about their sexual and drug use behaviors will help you provide the best possible care.
- Respect a patient’s choice not to answer a question. Showing them respect increases the chance they will provide the information later.

**HONEST RESPONSES ARE MORE LIKELY IF THE QUESTION IS WORDED TO “NORMALIZE” THE BEHAVIOR**

- “Some people inject drugs. Have you ever done that?”
- “Some people have had anal intercourse. Have you ever done that?”
- “Some people exchange sex for drugs or money. Have you ever done that?”

**LABELS CAN BE MISLEADING**

- Some men do not consider themselves “gay” if they practice same sex anal insertive intercourse, but their receptive partners may be considered to be “gay”.
- The question, “Are you a homosexual?” may be answered with “no” by a person who has had only a few same sex encounters or considers him/herself to be bisexual.
- Describe behaviors instead of assigning labels to the behavior. Use terms like “drug user”, “men who have sex with men”, “women who have sex with women”, “sex worker”

**AT THE END OF THE SESSION**

- Summarize the patients responses to make sure you both understand what was said
- Encourage the patient to ask questions about any issues he or she did not understand

Source:
PATIENT QUESTIONNAIRE

In order to understand your risk factors for HIV, we have to ask you some very personal questions. You may be embarrassed but your answers are very important. Knowing your risk factors for HIV may help keep you and others you care about healthier. We encourage you to talk to the medical staff about your concerns and ask any questions you may have. All information is kept strictly confidential.

THE QUESTIONS IN THIS SECTION ARE ABOUT YOU BEFORE YOU FOUND OUT YOU WERE HIV POSITIVE

1. Did you have sex with a male?
2. Did you have sex with a female?
3. Did you use needles to inject heroin, cocaine, steroids or any other drug that was not prescribed by a doctor?
4. The following are currently unlikely ways to get HIV. We would like to know if you have had any of the following happen to you since February, 1985. Please check all that apply:
   - transfusion of blood or blood products
   - hemophilia or other bleeding disorder
   - organ/tissue transplant
   - artificial insemination
5. Did you work in a health care or laboratory setting where you might have been exposed to human blood or other body fluids? If yes, please state your occupation__________________________________________
6. How do you think you got infected with HIV? ____________________________________________

ANSWER THE QUESTIONS IN THIS SECTION IF YOU HAD A SEX PARTNER OF THE OPPOSITE SEX BEFORE YOU FOUND OUT YOU WERE HIV POSITIVE

7. Women only: Before you found out you were HIV positive, did any of your male sex partners have sex with other men?
8. Before you found out you were HIV positive, did any of your opposite sex partners use needles to inject heroin, cocaine, steroids, or any other drug that was not prescribed by a doctor?
9. Before you found out you were HIV positive, did any of your sex partners receive a transfusion of blood/blood products or organ/tissue transplant before they found out they had HIV or AIDS?
10. Before you found out you were HIV positive, did any of your opposite sex partners have hemophilia or any other bleeding disorder?
11. Before you found out you were HIV positive, did any of your opposite sex partners have HIV or AIDS?
12. Before you found out you were HIV positive, were any of your opposite sex partners born outside of the United States? If yes, where___________________________
13. Before you found out you were HIV positive, did any of your opposite sex partners live or work outside the U.S.? If yes, where________________________________
14. Before you found out you were HIV positive, did you have a Sexually Transmitted Disease (STD)?
15. Before you found out you were HIV positive, did you trade money, drugs, or gifts for sex?
16. Before you found out you were HIV positive, did you use crack, cocaine, or crystal meth?
17. Did you have more than one sex partner in the year before you found out you were HIV positive?