

HOW DOES HIV–AIDS SURVEILLANCE WORK IN NSW?

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The monitoring of epidemiological trends in HIV–AIDS in NSW and Australia has, since 1982, provided information critical for the prevention, care and treatment of HIV disease. National surveillance is done through several mechanisms described previously,¹ the notification of cases to the Department of Health by laboratories, medical practitioners and hospitals being an important part. Australia's HIV–AIDS surveillance is among the best in the world, with notification of AIDS in all states since 1982 and of HIV since 1989. Most countries do not collect public health data on all HIV diagnoses. For example, the United States and most European countries rely on other sources, such as sentinel sites, population surveys and AIDS notifications. However, because of the success of combination therapies and the reduction in AIDS incidence, there is new emphasis internationally on implementing HIV notification.²

The documentation required of clinicians for HIV–AIDS is considerable. Notification requirements plus research studies, drug trials, S100 drug forms, etc. result in a sometimes confusing array of forms that collect similar information. The aim of this article is to clarify the system of HIV–AIDS notification in NSW.

HIV

Under the *NSW Public Health Act (1991)* persons newly diagnosed with HIV infection are notifiable by laboratories that carry out confirmatory HIV testing (reference laboratories). There are currently seven reference labs in NSW. Following confirmation of diagnosis, the reference laboratory sends a notification form to the requesting doctor to collect information including the demographics, risk exposure, previous tests and clinical status of the patient. To protect patient confidentiality, a name code is used (first two letters of the surname and given name) instead of the patient's full name. By law, medical practitioners must complete the notification form and return it to the laboratory. The information is then entered on the NSW HIV database, forwarded to the National Centre in HIV Epidemiology and Clinical Research (NCHECR) for inclusion on the National HIV database, and to the World

Health Organisation (see Figure 4). Data summaries are published in the *NSW Public Health Bulletin*, the *National HIV Surveillance Report*, and in peer review journals.^{3–6}

Public Health Units (PHUs) follow up notifications that report risk exposures other than male-to-male sexual contact or mother-to-child transmission for more detailed assessment of risk exposure. PHU surveillance officers forward to the medical practitioner a detailed exposure assessment questionnaire which requests information on the patient's history of blood transfusions, injecting drug use and sexual exposures both in Australia and overseas. The questionnaire also enquires whether the patient would like the Department of Health to investigate the means of HIV infection. When this is requested, a comprehensive interview with the patient is carried out by appropriate staff and, where necessary, other investigations are performed. This mechanism of HIV risk exposure assessment is very important in tracking the emergence of new or unusual means of transmission, such as heterosexual contact, medical procedures or other rare exposures. Analyses of this data have been published on two occasions to date.^{7,8}

Completeness of HIV data, including risk exposure, increased dramatically from 1992 with the introduction of data collection by reference labs. However, the completeness of the data has deteriorated in recent years (see Figure 5), making the monitoring of the epidemic increasingly difficult. Paradoxically, this has also increased the paperwork load for clinicians. Where the risk exposure is not recorded, a form is forwarded to the clinician that seeks to record information describing sources of exposure (Exposure Assessment form). Most of these cases turn out to be due to male homosexual contact, and therefore the Exposure Assessment form would not have been required if the shorter laboratory notification form had been completed.

AIDS

Under the 1991 Act, AIDS is notifiable to PHUs by medical practitioners and hospital chief executive officers. The information requested is similar to that for HIV notification, with the addition of the AIDS-defining illness and the date of the last medical contact or death. As with HIV notification, a name code is used at all times. Notifications are entered on the Notifiable Disease Database at the PHU and forwarded to AIDB. AIDB forwards notifications to NCHECR for inclusion on the National AIDS Register (see Figure 6). The number of people notified as living with AIDS each year has been used as one determinant of AIDS care funding to the States by the Commonwealth Government. Therefore, a yearly audit is carried out by Area Health Services and AIDB to detect unnotified cases.

FIGURE 4

HIV NOTIFICATIONS FLOW CHART

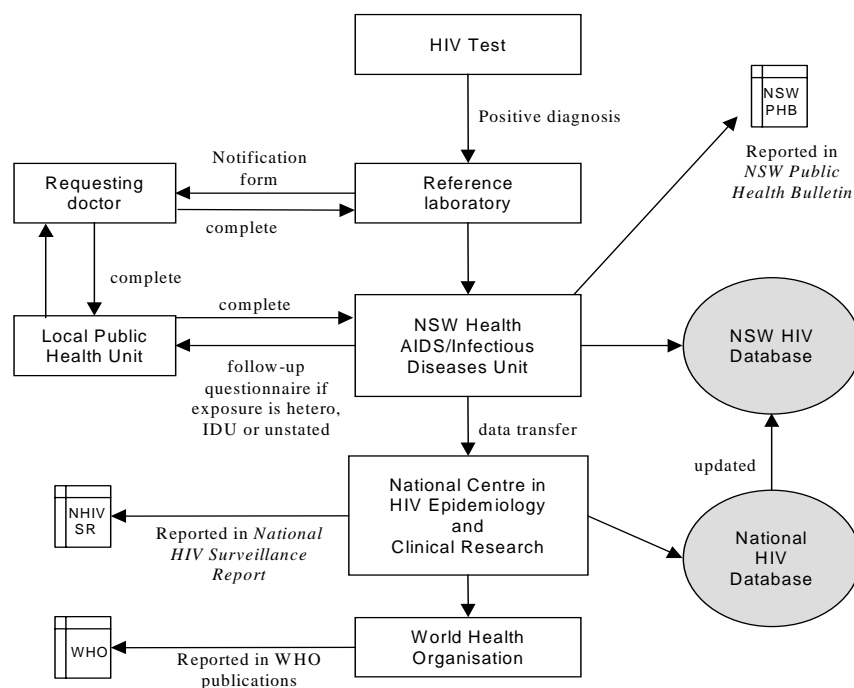
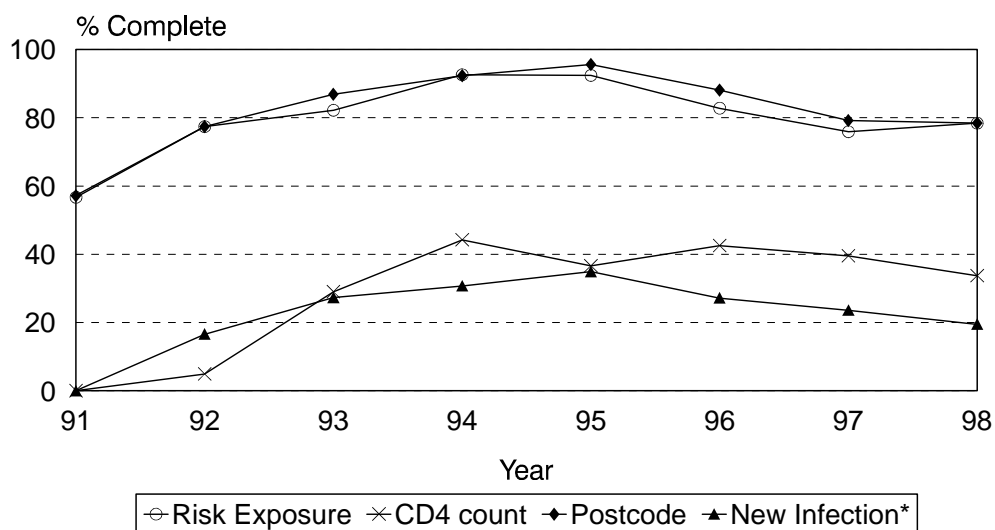


FIGURE 5

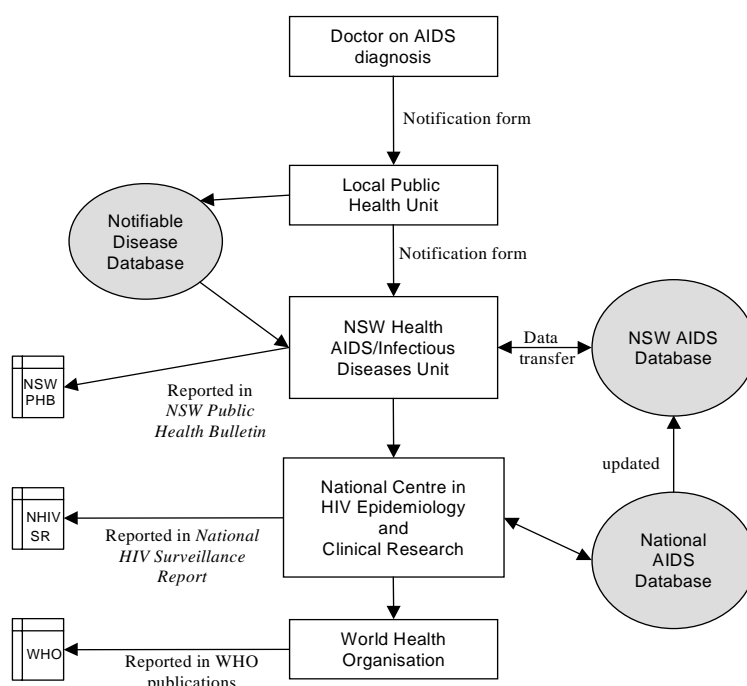
NSW HIV SURVEILLANCE DATA COMPLETENESS



* Defined as negative test within 12 months or documented seroconversion illness

FIGURE 6

AIDS NOTIFICATION FLOW CHART



The process includes cross checking the AIDS register with other data sources such as hospital inpatient data, clinic records and death registrations.

When a patient dies as a result of HIV disease, medical practitioners are requested to complete a specific notification form and forward it to their local PHU. Data on deaths are also updated using death certificates during the yearly audits.

The AIDS Register has provided a crucial means of monitoring the epidemic. Patients may be infected with HIV for many years before being diagnosed, and notified; therefore HIV notifications will underestimate the total prevalence of HIV. However, the development of AIDS almost always requires the patient to seek medical attention, which provides an opportunity for notification. As a result AIDS notifications have given the most reliable estimates of the population affected by HIV. However, as AIDS may develop many years after HIV infection this does not provide information on recent HIV transmission. In recent years, the successful introduction of combination therapies has delayed the development of AIDS in many patients indefinitely. This will result in AIDS data being used more as a measure of treatment failure than of the

natural clinical progression of HIV disease. Data from AIDS notifications are published in the *NSW Public Health Bulletin*, the *National HIV Surveillance Report* and peer reviewed journals.⁹⁻¹⁵

The AIDS case definition is outlined in the Australian National Council on AIDS Bulletin No. 18, which is available from PHUs. AIDS and AIDS death notification forms are also available from PHUs.

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