

IMPROVING AIDS SURVEILLANCE

An apparent shortfall in predicted new AIDS cases for 1990 recently prompted a review of records among HIV/AIDS-treating facilities in NSW. The review at the Albion Street Centre in Sydney found 24 previously unreported cases of AIDS. This article discusses methods and presents suggestions for improving on-going AIDS surveillance.

There are about 15,000 records of past and present clients at the clinic. A computer database is maintained but does not record the date a person starts living with AIDS or the date of onset of complications such as opportunistic infections or secondary cancers. CD4 lymphocyte (T4 cell) count is recorded. On the basis that most clients progressing to AIDS have a low CD4 count in the later stages of their illness, a search of the database was made for any client whose CD4 count had gone below 200/mm³ at any time in the past three years. This time limit was set assuming that fewer unreported living people with AIDS would be found among those with low CD4 counts before this period.

About 700 clients were identified by this criterion. Each client's history, examinations and test results were reviewed to determine whether the current case definition for AIDS, as provided by the Centers for Disease Control (CDC) in MMWR (1987)¹ was ever satisfied (with the exception of 40 absent records). About 150 people were thereby found to have progressed to AIDS. These cases were then carefully matched by name code and date of birth with entries on the NSW AIDS database at the Epidemiology Branch in the Health Department, to identify cases already notified.

After matching with the NSW AIDS database, 24 of the original 150 cases of AIDS were found never to have been reported by the Albion Street AIDS Centre or any other institution or doctor.

Table 1 presents the AIDS-defining illnesses and numbers for these previously unreported cases:

TABLE 1	
AIDS-DEFINING ILLNESS FOR CASES NOT PREVIOUSLY NOTIFIED.	
AIDS-Defining illness	Number
Kaposi's sarcoma	6
HIV wasting disease	4
Pneumocystis Carinii Pneumonia (PCP)	4*
Multi-dermatomal herpes zoster	3
Oesophageal candidiasis	2
Chronic herpes simplex	1
Disseminated Mycobacterium Avium Intracellulare	1#
Lymphoma	1
Extra-pulmonary tuberculosis	1

*two of these were previously diagnosed overseas, and one was diagnosed and treated in a private hospital in Sydney
#diagnosed at Prince Henry Hospital

Most of the unreported cases were of recent onset. Fifteen occurred in 1990, five in 1989 and only four in 1988. There were eight different 'usual treating' doctors for the unreported cases. Differences between them in numbers of unreported AIDS cases were proportional to clinical workload.

Fourteen of the unreported cases had no record of attending a tertiary referral hospital since the onset

of their AIDS-defining illness. However, ten had been admitted to hospital subsequently for treatment.

Our review would have missed people whose CD4 count has never been below 200/mm³ (especially those with Kaposi's sarcoma), or who progressed to AIDS more than three years ago and have remained undetected since. The number of the latter such cases is likely to be small, as the median time of survival after diagnosis of AIDS in Australia has been estimated as 10.4 months² (although longer for those on azidothymidine).

Nevertheless, we identified a substantial number of AIDS cases not previously notified. It may be useful to consider, from the clinician's view of case notification, what features of the AIDS-defining illnesses of these cases may be relevant to their being unreported.

Kaposi's sarcoma is a cancer which may occur in otherwise well patients and for which no specific treatment is usually given in its early stages. The clinician's minor response to a single lesion may contribute to its omission from reporting as an AIDS case. HIV wasting disease, defined as more than 10% weight loss accompanied by chronic diarrhoea or weakness and fever (without known cause) is a diagnosis which becomes evident slowly, often with no abrupt event. The point at which the condition becomes an AIDS-defining illness may be missed unless the case definition is kept constantly in mind.

Pneumocystis infection is the most common AIDS-defining illness. However, notification may not be uppermost in the mind of a clinician concerned with urgent treatment or referral of a patient with severe symptoms. The early symptoms of oesophageal candidiasis are often relatively mild and of gradual onset. Multi-dermatomal herpes zoster and chronic (more than one month's duration) herpes simplex are both similar in that the onset of the AIDS-defining condition may occur gradually over time. Lymphoma and extra-pulmonary tuberculosis are among the less common AIDS-defining illnesses.

A common feature of many of these unreported cases is a gradual onset with no acute change in the patient's health.

Opportunities for missed notification also exist in the movement of patients between initial and referral centres. Tertiary referral centres may not report a case, believing it to have been already reported by the primary treatment centre, particularly if the onset of the AIDS-defining illness occurred some time previously. The primary centre may, however, leave reporting to the tertiary centre. The possibility of this occurring will increase as centres such as Albion Street treat patients progressively later into the course of their disease.

It is possible that other medical practices providing primary health care to people with HIV, particularly if staffed by a changing population of doctors, have omitted reporting similar types of AIDS cases.

Identification of an AIDS case, however, is not always simple. The 1987 MMWR case definition for AIDS is

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Improving AIDS surveillance

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FIGURE 3

**MYCOBACTERIA NOTIFICATIONS
NSW, 1982-1990**

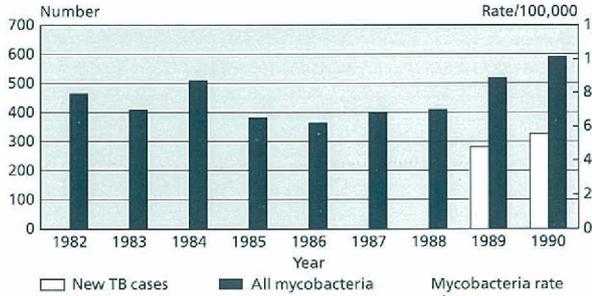


FIGURE 4

**TUBERCULOSIS
NEW CASES NOTIFIED BY AGE AND SEX
NSW, 1990**

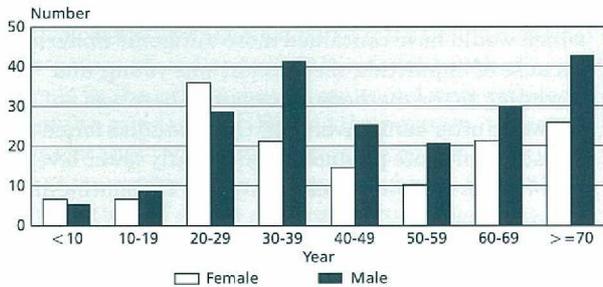


FIGURE 5

**TUBERCULOSIS
NEW CASES NOTIFIED
BY AREA/REGION, NSW, 1990**

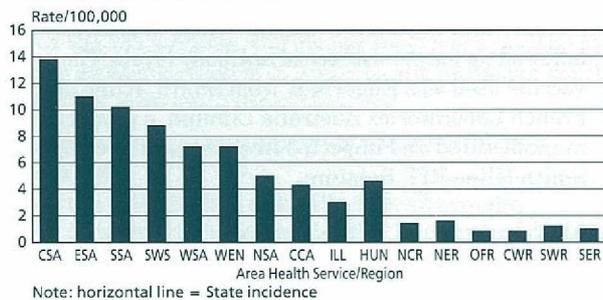
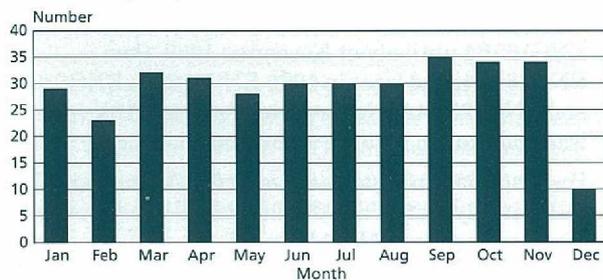


FIGURE 6

**TUBERCULOSIS
NEW CASES NOTIFIED
BY MONTH, NSW, 1990**



complex and at times vague and ambiguous. It also appears to be deficient; for example, HIV-related thrombocytopaenia, which may cause gastrointestinal haemorrhage and death, is not included in the definition as a specific entity. The case definition takes no account of immune system status, so a patient with a CD4 count of zero may never constitute a case. Additionally, prophylactic or other treatments may prevent or shorten or lessen the severity of attacks of illness so the threshold of AIDS diagnosis (for example, for PCP, 'chronic HSV' or oesophageal candidiasis) is never reached.

Funding formulas that rely on numbers of AIDS cases diagnosed, using the current definition, may therefore underestimate the resources required for dealing with HIV-related disease.

In conclusion, possible improvements to on-going AIDS surveillance noted during our review include the following:

1. Clinical services treating substantial numbers of HIV-positive people should maintain a computer database of clients, containing fields at least for seropositivity, CDC stage, significant diagnoses and whether notified, if a case.
2. A record should be kept in patients' files indicating whether they have been notified if they fulfil AIDS-defining criteria.
3. It would be valuable if one senior, motivated clinician were made responsible for correct and timely notification in all multiple-doctor centres. They could provide copies of the most recent CDC/MMWR case definition for AIDS, as well as material on the importance of notification, to all doctors in contact with clients/patients in their centre. Regular reminders may also be necessary.
4. There should be feedback to doctors after notification — a receipt for the notification has been suggested and may be instituted. The circulation of a regularly updated (confidential) list of cases notified by a centre to its practising doctors may be sufficient.
5. Depending on the size and type of institution, a regular review could be undertaken of records of HIV positive patients to look for missed notifications.
6. Clear guidelines on who is responsible for notification also need to be provided to all centres. Perhaps both referring and tertiary treatment centres should be asked to notify, with duplication detected and removed by the Epidemiology Branch.

Many of these facilities or procedures already exist in some centres, or are being implemented.

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1. Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome, *MMWR* 1987;36(1S): (whole supplement).
2. Whyte BM, Swanson CE, Cooper DA. Survival of patients with the acquired immunodeficiency syndrome in Australia. *Med J Aust* 1989;150:358-362.