IMPROVED TRACKING FOR HIV

Surveillance of Human Immunodeficiency Virus Infection, NSW, January 1984-June 1989

The Department of Health aims to collect accurate information on the number of people infected with the human immunodeficiency virus (HIV) and their characteristics to track the course of the condition in specific population subgroups and to assist in planning health services for HIV-related health conditions.

Since the introduction of specific HIV/AIDS notification and surveillance procedures in April 1986, both medical practitioners and HIV laboratories have been responsible for providing data concerning HIV to the NSW Department of Health. The lack of a standard HIV test request form hampered efforts to collect reliable epidemiological data from laboratories, and surveillance of HIV infection relied on reports received from medical practitioners. In 1987 the National Health and Medical Research Council Special Unit in AIDS Epidemiology and Clinical Research (now the National Centre in HIV Epidemiology and Clinical Research) and the Department of Health, NSW agreed that HIV surveillance be conducted by collecting reference laboratory data. This recommendation was endorsed by the NSW Ministerial Advisory Committee on AIDS which recommended procedures in October 1987.

The three HIV reference laboratories in NSW are the Serology Laboratory, Prince of Wales Hospital (POW); the AIDS Laboratory, Centre for Immunology, St Vincent's Hospital (SVH); and the HIV Laboratory, Institute for Clinical Pathology and Medical Research, Westmead Hospital (WMH). In addition to conducting screening tests, these laboratories receive all screen-positive and indeterminate samples from other laboratories for confirmatory testing. The only exception to this is the laboratory at Royal Prince Alfred Hospital which conducts its own confirmatory testing.

Doctors requesting HIV tests are now asked to complete a request form specific to the laboratory where the sample is to be processed and to provide the following information: patient identifier — either initials, name (for hospital inpatients), or a code generated by the medical practitioner or clinic attending the patient; sex, date of birth, postcode of residence, transmission category, clinical information, whether the patient has been previously tested for HIV infection and the result of any previous test. This last data item was introduced at the suggestion of the Ministerial Advisory Committee on AIDS to overcome the difficulties of double counting. As the request form promoted

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use of clinic codes rather than names and addresses, it was important to differentiate specimens belonging to patients who were newly diagnosed positive, from specimens belonging to patients who had previously been tested and returned a positive result.

For each reference laboratory data base we counted a group of specimens as a single 'case' if identifying codes matched. We did not use gender or date of birth for matching as these fields had not been completed on many test requests (Table 1). Because patient identifiers are not necessarily the same at different laboratories it was not possible to cross-match cases between laboratories, so those cases confirmed at more than a single laboratory have been counted at each. Similarly, patients attending more than a single clinic during the 5.5 year reporting period have been counted separately for each clinic patient identifier assigned to them.

We used only the well-known patient risk categories which could be unambiguously combined over time and data source (Table 2). Patient risk category information is collected differently by laboratories; indeed within laboratories over time. The detailed definitions used by each laboratory were therefore considered in judging which groups could be appropriately used in summarising the data. For example, it would have been of interest to collate data on needle stick incidents and the like. However, the most relevant risk group used at WMH during 1987 and 1988 is broadly defined to include needle stick injury, stood on syringe, bitten, blood splash in eyes, cut finger with contaminated scalpel, tattoos, whereas in 1985, 1986, and 1989 a similar group is defined as needle stick, mucosal splash only. At SVH there are codes for lab/hospital staff to cover routine testing, but for this very reason the code does not refer to a specific transmission category. Groups of this kind are listed as specified, not elsewhere classified in Table 2. Finally, some groups which were assigned separate codes at particular laboratories had to be merged because other laboratories did not make the same distinction. Examples are the inclusion of haemophilia within the transfusion group, and the use of a combined gay/bisexual group.

For the reporting period January 1984 to June 1989, a total of 9979 cases were identified: 293 (3%) from Prince of Wales, 8343 (84%) from St Vincent's, and 1343 (13%) from Westmead. Of these, we excluded 1670 (17%) because their request forms indicated a previous positive test result. Of the remaining 8309 cases, 6809 (82%) were from SVH, 1263 (15%) from WMH and 237 (3%) from POW. The number of new cases identified per quarter at each source and in total is shown in Figure 1.

Table 1 demonstrates the data quality for specific variables which are relevant for epidemiological purposes. There is a general change in data quality during the period when specific test request forms were being introduced by screening laboratories and

TABLE 1

PERCENTAGE OF COMPLETED DATA ON HIV REQUEST FORMS BY VARIABLE, LABORATORY, AND TEST PERIOD

Period	Before Mid 87			Since Mid 87			Second Quarter 89		
Laboratory	POW	SVH	WMH	POW	SVH	WMH	POW	SVH	WMH
No of cases	106	5318	564	187	3025	779	29	352	114
Info provided:	%	%	%	%	%	%	%	%	%
Gender	99	53	74	95	97	90	83	97	91
Age/DoB	64	29	63	88	80	78	79	84	76
Risk Group	73	15	18	73	79	47	93	81	12
Postcode	N/A	1	20	N/A	26	38	N/A	62	41
Previous Test	14	3	3	33	54	12	86	86	41
Previous Test +	8	3	2	25	46	9	79	69	5

TABLE 2

HIV CASES BY RISK GROUP AND SEX, NSW, January 1984-June 1989

RISK GROUP	SEX			TOTAL
	F	M	U	
Sexual Contact	4	33	5	42
Gay/Bisexual	6	1679	124	1809
Heterosexual Contact	11	41	–	52
IVDU	21	81	15	117
Transfusion	17	68	2	87
Child-Mother Positive	4	6	1	11
Gay/Bisexual + IVDU	1	35	4	40
Heterosexual + IVDU	3	7	–	10
Gay/Bisexual + Transfusion	–	1	–	1
Specified, n.e.c.[1]	32	247	38	317
Unknown	194	3052	2577	5823
Total	293	5250	2766	8309

1. not elsewhere classified

reference laboratories. We chose the beginning of July 1987 as an appropriate dividing point between the previous and current systems. As the use of these forms steadily increased since then, we also show the most recent data available — for the second quarter of 1989. Postcode data were so rarely provided on request forms that they were not requested from laboratories when compiling the summary data reported here. Data were, however, provided from WMH, and estimates from an earlier analysis of the SVH data set are included for illustration. The last two fields deserve particular attention, since they indicate the effect of asking doctors to use their knowledge of the patient's clinical history to distinguish new cases from previously-known positives. Without this information we would have considerably over-

estimated the number of new positives at both POW and SVH in the second quarter of 1989, and at SVH for the whole period since July 1987.

For the 67% of cases with known sex, 95% were reportedly male and 5% female. This remained relatively stable over time, with the male percentage in the range 95-96% since 1986, as against 93% in 1985 and 91% in 1984. The age distribution at the time of confirmation also remained stable during the study period (Figure 2). Of those with known risk category, 73% were reportedly gay or bisexual and 5% were reported as intravenous drug users (Table 2). Fifty-two cases reported heterosexual contact as a risk factor and eleven HIV positive children were reported to have HIV positive mothers.

These data, the first estimates of HIV infected persons using data provided by reference laboratories in NSW, were reported to the National Centre in HIV Epidemiology and Clinical Research early in 1990[1].

It is likely that our figures do not accurately represent the true number of HIV infected persons in NSW. On the one hand there are several reasons why we may have over-estimated the true number. First, it is likely that persons were tested at the same laboratory with a different identifier or were tested at different laboratories with the same or different identifiers. In either case we would have double counted such persons.

Second, the absence of a field for previous HIV testing in earlier years, combined with the use of coded identifiers, makes the estimated numbers likely to contain duplicates. Relying on the coded identifier fields alone increased our estimate by 20 per cent. *Adequate data on previous history are essential to compensate for the difficulties introduced by inadequate patient identifiers.*

Third, because of incomplete data we were unable to make positive matches on date of birth and gender. Using these poorly-completed fields in the matching criteria yielded a new case for every person of unknown gender and/or date of birth.

On the other hand our figures may under-estimate the true number of cases. An unknown proportion of persons with HIV fail to get tested. Of persons presenting with AIDS at two of the major centres for AIDS management, 18-20% have not been previously tested (Dr Roger Garsia, and Dr Philip Jones, personal communications, May 3, 1990).

Changes in data quality over time (Table 1) result in corresponding changes in the ability to match cases, and thus to estimate the number of newly-identified cases in each time period. This in turn creates considerable uncertainty in projections of the future need for HIV-related services and the funding to provide them. Similarly, the high proportions of missing data in fields such as risk group and postcode, limit our ability to estimate the regional distribution of HIV infection or the groups likely to require services. The most common single subgroup in this data has "unknown" status on all demographic variables.

Fortunately, the more recent data suggest that substantial improvements in data quality can be achieved through relatively simple changes in procedure. To improve tracking HIV infection in NSW we propose to:

- Clarify legislation concerning reporting of persons with HIV infection and AIDS. The Department of Health is currently reviewing related regulations. Completion of all fields on an HIV test request form would be all that would be necessary to notify a case of HIV infection.

- Introduce standardised HIV test request forms throughout the State. All request forms should collect exactly the same information.

- Develop mechanisms for HIV reference laboratories to check new positive results with their existing positives data set. This would decrease the work load to obtain further information on those persons with a positive test and missing information on the request form. The data from POW have been improved by procedures for comparing identifiers for new positive results with the laboratory's historical list of positives and by allowing patients to be matched manually when automated matches fail. Similar labour-intensive procedures which are now being applied to the SVH and WMH data are expected to reduce our current estimate of the number of cases and to considerably improve the quality of demographic information.

- Provide clear information to medical practitioners to explain how the system works, and especially the relationship between provision of information on request forms and the ability of the Health Department to plan for appropriate provision of services.

- And finally, clarify the generation of patient code identifiers by standardising the use of the first two letters of first name and the first two letters of surname. ■

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Department of Health, NSW),
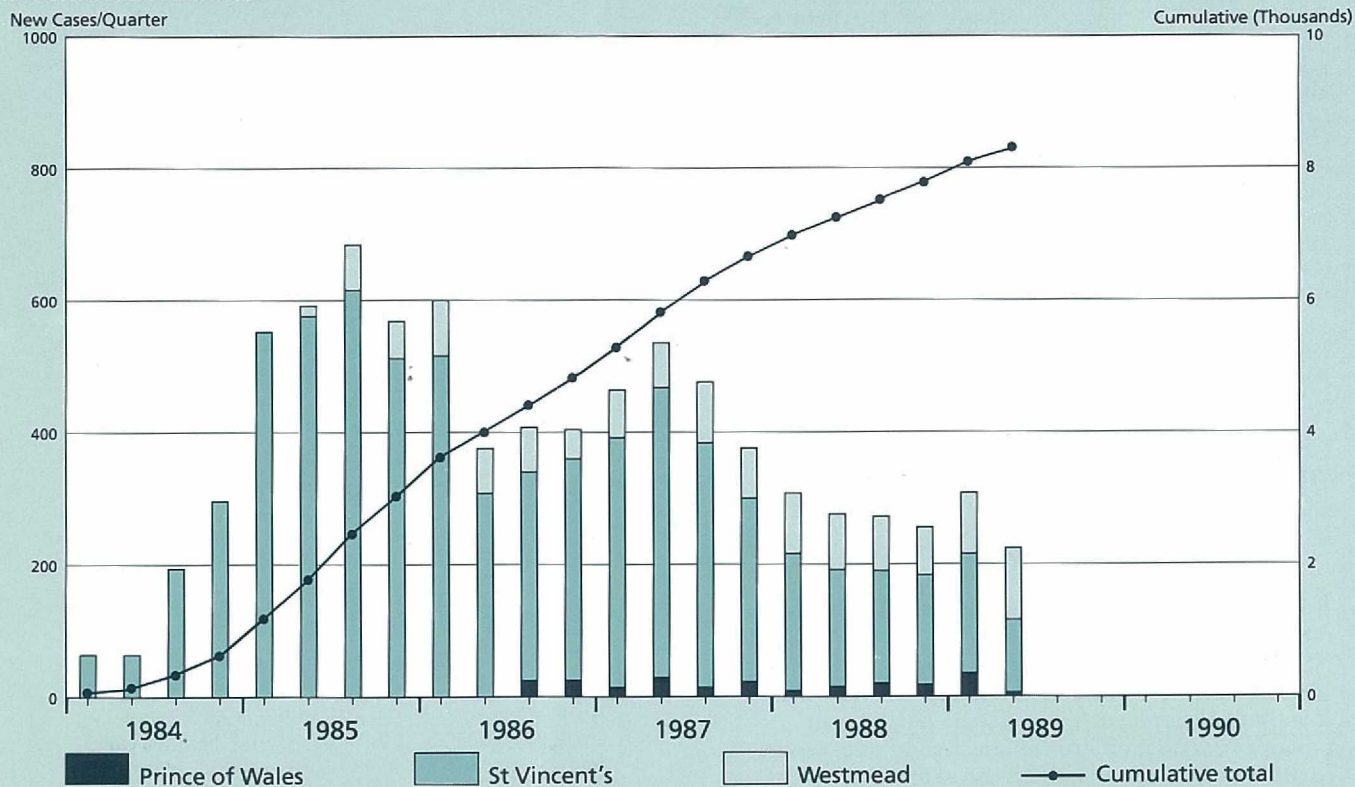*Matthew Blackmore MBA*
(AIDS Unit,
Department of Health, NSW)

1. Australian HIV Surveillance Report. National Centre in HIV Epidemiology and Clinical Research, 23 March 1990, pp 7-8

FIGURE 1

**ESTIMATED NUMBER OF CONFIRMED
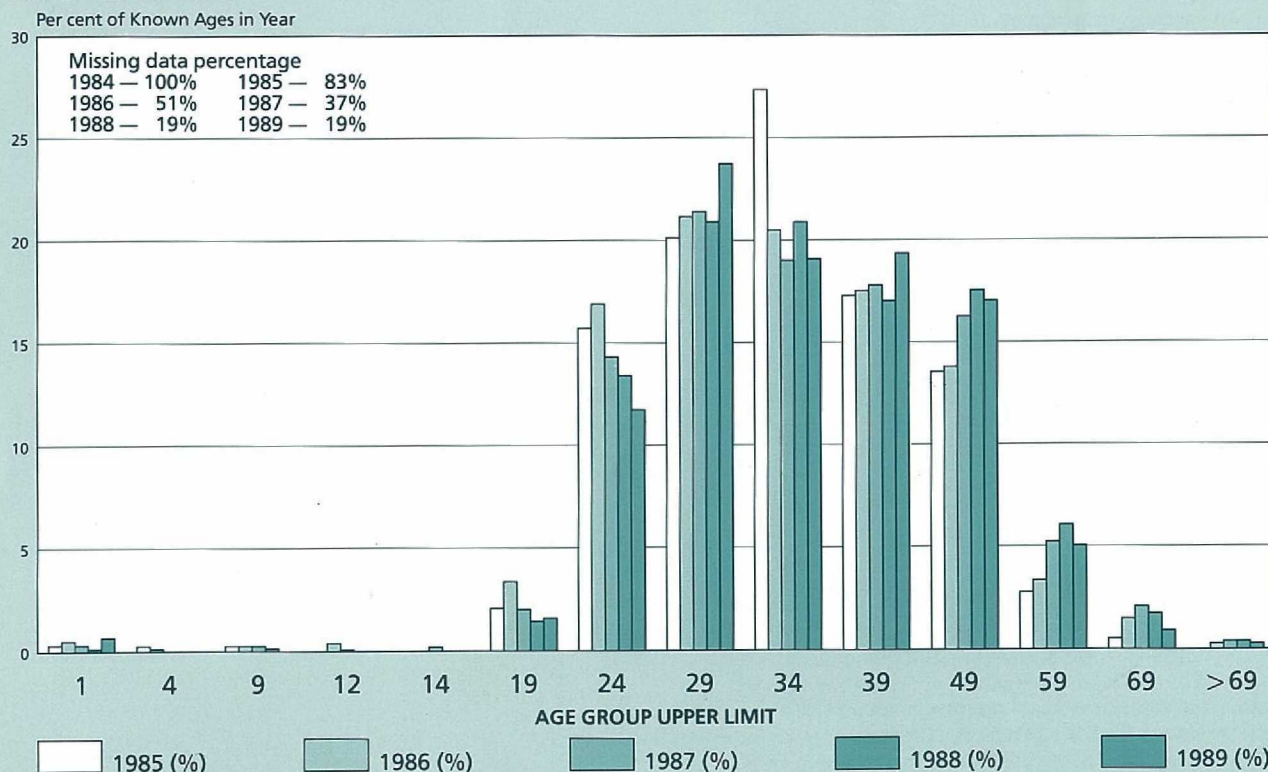HIV POSITIVE PERSONS IN NSW**

New Cases/Quarter
Cumulative (Thousands)

Prince of Wales   St Vincent's   Westmead   Cumulative total

Epidemiology & Health Services Evaluation Branch, Dept of Health, NSW Laboratory-based surveillance data to 30 June 1989

FIGURE 2

**AGE AT DIAGNOSIS OF CONFIRMED
HIV POSITIVE PERSONS IN NSW**

Per cent of Known Ages in Year

Missing data percentage
1984 — 100%   1985 — 83%
1986 — 51%   1987 — 37%
1988 — 19%   1989 — 19%

AGE GROUP UPPER LIMIT

1985 (%)   1986 (%)   1987 (%)   1988 (%)   1989 (%)

Epidemiology & Health Services Evaluation Branch, Dept of Health, NSW Laboratory-based surveillance data to 30 June 1989