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## **Routine surveillance data on AIDS and HIV infections in the UK: a description of the data available and their use for short-term planning**

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### SUMMARY

In the UK surveillance of AIDS and HIV infection is based on routine reporting systems. Whilst attempts are made to ensure that AIDS data are as complete as possible, numbers of reports fluctuate from month to month for reasons which are described. In 1986 there was an increase in death certificates naming AIDS as a cause of death in patients who were not identifiable in the surveillance data. More active surveillance is now undertaken in order to minimize this and other possible discrepancies.

It is probable that most cases of AIDS are reported and therefore these data can be used to describe trends in the epidemic by 'risk group'. Laboratory reports of HIV antibody-positive tests could give an earlier indication of trends because of the long incubation period of AIDS. But these laboratory data are difficult to interpret because they represent an incomplete and biased sample of all positive persons.

AIDS cases are still being reported at a rate which is increasing approximately exponentially. Short-term predictions are presented showing a growth in the epidemic which is consistent with previously published predictions. Most cases are in the homosexual risk group. New asymptomatic homosexual patients with HIV antibody are still being identified.

The epidemic of AIDS in haemophilia patients should be of finite size although new cases of AIDS are likely to continue to be diagnosed for several years. AIDS due to blood transfusion given in the UK before donor screening appears to be a much smaller epidemic. The epidemic in drug abusers is increasing. Heterosexually acquired AIDS and HIV infections are being reported in small but increasing numbers.

### INTRODUCTION

In 1982 a voluntary reporting scheme of AIDS cases fulfilling the CDC/WHO definition was set up at the Communicable Disease Surveillance Centre (CDSC) and the Communicable Diseases (Scotland) Unit (CD(S)U), and in 1984 a voluntary laboratory reporting scheme of newly identified patients with HIV antibody (Galbraith, McEvoy & Sibellas, 1986). Short-term predictions about the

course of the epidemic have been based on surveillance data in the UK (Tillett & McEvoy, 1986), although such statistical projections do not take into account changing epidemiological patterns of the disease. For medium- and long-term predictions more complex mathematical models are needed although, as yet, insufficient data are available for estimating parameters for many of the models.

Simple mathematical models which can be used immediately have been proposed by Bailey (1988), although he stresses that they must not be used in a rigid manner and that there should also be flexibility in the planning of health care facilities. Models have been proposed and discussed by Knox (1986) and Anderson *et al.* (1986). A more complex computerized simulation system has been developed (Koch & Welck, 1987), which will allow study of large numbers of variables and will readily accommodate new information. This system will allow assessments to be made of the robustness of simplified models.

Special studies are needed, and many are under way, to collect more data. The experience in other countries is being studied. In the meantime it may be helpful to demonstrate more fully the data which are already collected. This paper describes the information available in the UK from routine surveillance and tries to assess its quality.

## MATERIALS

### *Sources of data*

AIDS cases are reported to CDSC on a three-page surveillance form and request demographic, exposure and clinical data. Reports from Scotland come via the CD(S)U. All public health and other laboratories in England, Wales and Northern Ireland are invited to report HIV antibody-positive tests on new patients and also opportunistic infections associated with HIV infection to CDSC for the Communicable Disease Report (CDR). A third source of data are death entries (relating to deaths certified in England and Wales, where over 95% of UK AIDS cases are reported) on which AIDS, HIV infection or Kaposi's sarcoma are recorded as a cause of death. Copies of such entries are supplied by the Office of Population Censuses and Surveys (OPCS).

### *Problems with the data*

#### *Clinical AIDS surveillance*

The aim of the scheme is that these data should be as complete as possible, but some cases may fail to be reported because of misdiagnosis or because the physician concerned is not aware of the reporting scheme. Publicity for the scheme may therefore produce an increase in reporting. Some clinicians do not always have the manpower immediately available to complete the questionnaires, so that reporting may be spasmodic.

#### *HIV antibody-positive reports*

Although over 100 laboratories report regularly, they can only report those patients who are tested, and overall this will be a very biased sample, the completeness of which will vary with risk group. The numbers tested may be influenced by national or local publicity campaigns. Laboratories report only new

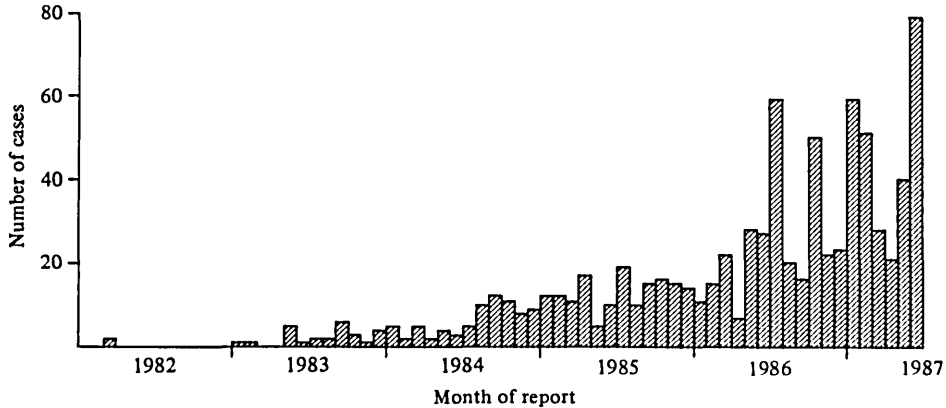


Fig. 1. AIDS cases in UK residents, by month of report.

positive patients, but the same individual may be tested at more than one laboratory or at the same laboratory with different identification and be reported more than once. Not all diagnostic laboratories report to the scheme and some may report incompletely, particularly when pressure of work is greatest.

#### *Death entries*

Because these are public property the physician may wish to avoid causing distress to relatives and give less specific causes of death. These deaths may therefore not be identifiable as AIDS- or HIV-related and so not made known to the surveillance scheme.

## RESULTS

### *AIDS in the total population (omitting non-residents)*

Up to the end of June 1987 there had been 870 cases reported in the UK for treatment. The 838 resident cases are shown in Fig. 1 by month of report. There are non-random fluctuations. For example, the high numbers in July 1986, January and June 1987 reflect batch reporting from single sources. From January 1987 AIDS was receiving considerable publicity through Government and media campaigns, also CDSC was piloting a new report form.

The monthly fluctuations may average out if aggregations are made. Table 1 shows cases by quarter and year of report and of diagnosis, where known. A cross-tabulation is given to demonstrate the time delays from diagnosis of AIDS to the report being received at CDSC (and accepted as fulfilling the case definition). The final column gives quarterly diagnoses – the figures in parentheses are numbers of patients for whom month of diagnosis is unknown but who were diagnosed in that year. The quarterly diagnoses show the true epidemic curve, but it is incomplete, especially for recent quarters. (The median interval from diagnosis to report is 2 months, with about 10% having a delay of 12+ months.) However, it is this true epidemic curve which is required by health care planners.

The bottom row of Table 1 shows quarterly cases by date of report. These data are complete and would reflect the true epidemic curve (shifted in time) if the



Table 2. Time of reporting for 774 cases for whom quarter of diagnosis is known

	Time of report								Total
	1982- 1984	1985	1986 1st	1986 2nd	1986 3rd	1986 4th	1987 1st	1987 2nd	
Diagnosed in same quarter	56 (57%)	63 (45%)	19 (42%)	26 (54%)	23 (27%)	25 (29%)	41 (31%)	57 (41%)	310 (40%)
Diagnosed previously	42	76	26	22	62	62	93	81	464
Total	98	139	45	48	85	87	134	138	774

$$\chi^2_7 = 33.3 (= 0.00002).$$

distribution of delay times to reporting were unchanging and if reporting was consistent in its completeness. Both these points will be considered.

Of the 838 cases the quarter of diagnosis is known for 774. These 774 cases are shown in Table 2, where the delay to reporting is summarized. Overall 310 (40%) of the 774 cases were diagnosed and reported in the same quarter-year. However, there have been significant fluctuations over time. The proportions were low in the second half of 1986, which could be due to current cases failing to be reported or to the receipt of a larger than usual number of late reports. The proportion was fairly low in the first quarter of 1987, when CDSC actively sought reports from centres which had not been able to report recently.

Table 3 shows events in different time periods. Numbers in each row do not necessarily relate to the same patients. Annual deaths in patients reported to the scheme have been 6 deaths in 1982, 15 in 1983, 46 in 1984, 103 in 1985, 200 in 1986. Thus deaths in AIDS cases have been more than doubling each year up until 1986. Low numbers in recent time periods may reflect the delay in reporting of deaths or changes in survival times. Numbers of deaths in England and Wales in patients not known to the surveillance scheme (last column) increased from 16 in 1985 to 58 in 1986. It is possible that some of these were patients who died of HIV infection without fulfilling the case definition or that a few of them related to the 19 surveillance patients for whom neither the name code nor the date of birth was recorded. But under-reporting of AIDS may have been on the increase. In 1987 agreement was given from OPCS that the Director of CDSC could approach the consultant named on the death entry or the doctor who signed the death certificate of an unreported patient and ask for a surveillance form to be completed. This scheme is yielding new reports of cases which do fulfil the case definition.

#### *Predicting AIDS in the total resident population*

Short-term predictions for the UK had been made based upon the first presentation for medical advice (Tillett & McEvoy, 1986). The date of presentation was chosen to indicate when health care was required, but experience has shown that such an indicator is difficult to obtain routinely. Other countries adopted date of diagnosis (i.e. when the case definition is fulfilled) and so the following analysis aims to predict future numbers by the date of the patient's diagnosis. Because of

Table 3. *Numbers of reports, diagnosis and deaths in 6-month periods*

Period	Cases reported	Cases diagnosed	Deaths		
			In reported cases		Cases not reported, i.e. death entry only
			No death entry	Death entry	
1979-81	—	4	1	—	—
1982 Jan.-June	2	3	3	—	—
July-Dec.	—	5	3	—	—
1983 Jan.-June	8	5	2	1	—
July-Dec.	18	25	7	5	—
1984 Jan.-June	21	28	5	10	—
July-Dec.	55	66	11	20	—
1985 Jan.-June	67	76	20	33	6
July-Dec.	89	110	24	26	10
1986 Jan.-June	111	147	49	42	21
July-Dec.	190	168	64	45	37
1987 Jan.-June	277	137	59	34	Not applicable*
Total	838	774†	248‡	216	74

\* New follow-up scheme introduced. † Excluding 64, date not known. ‡ Excluding 10, date not known.

the time intervals between diagnosis and report, numbers for recent quarters are incomplete. Therefore we have used the complete data set of reported cases and made projections of numbers by date of report. These projections have then been adjusted for time delays between diagnosis and report to give estimates by date of diagnoses.

A log-linear regression was performed on quarterly reports from the second quarter of 1983 (Fig. 2). There is good fit ( $R^2 = 0.95$ ). The estimated new reports for the last two quarters of 1987 and for each quarter of 1988 are:

1987 (3)	1987 (4)	1988 (1)	1988 (2)	1988 (3)	1988 (4)
185	225	270	335	405	495

The doubling time from the regression equation remains at between 10 and 11 months.

Since the median delay to reporting has been 2 months the above estimates are lower than the new diagnoses to be expected in that quarter. It should be noted from Table 1 that a steady increase in reports or in diagnoses has not been observed – first and second then third and fourth quarters tending to have similar numbers.

As an approximate estimate of numbers diagnosed, the information from Tables 1 and 2 can be used. On average 40% of the reports in a quarter relate to diagnoses made in that quarter, 33% to diagnoses in the previous quarter, 11% in the one before that, 8% before that and 16% with longer intervals between diagnosis and report. For the purposes of this estimation these 16% have been assigned to the previous 6-month period.

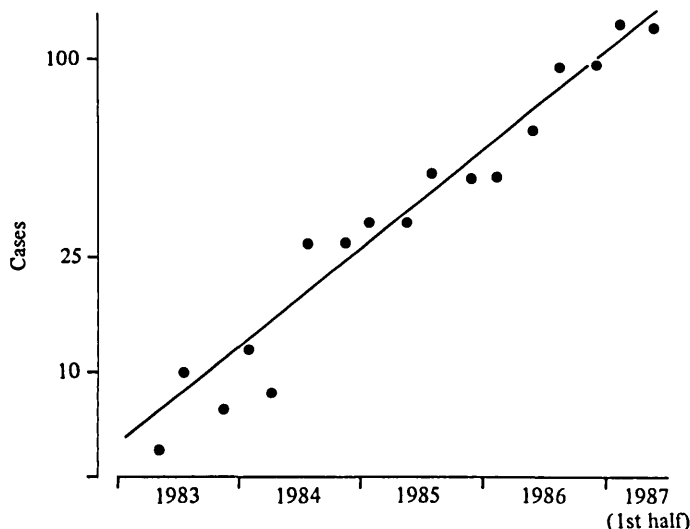


Fig. 2. Log-linear regression of AIDS cases by quarter year of report.

Table 4. *Observed and predicted numbers of new AIDS cases in UK residents (predictions based on numbers known by June 1987)*

	1987	1988
Observed reports	650†	n/a
Predicted reports	685	1500
Predicted diagnoses*	880	1900

\* N.B. It is anticipated that all these cases will be reported to the surveillance scheme, although not all reports will reach CDSC and CD(S)U in the calendar year of diagnosis.

† Provisional figure at mid-December.

Using observed reports in the first two quarters of 1987 and predicted ones thereafter, the estimated approximate diagnoses in each quarter of 1987 are 160, 190, 240 and 290. Thus about 880 new AIDS diagnoses may be expected in 1987 and, if the exponential phase continues so that the same doubling time pertains, about 1900 in 1988. These short-term predictions are summarized in Table 4.

In reality there is more than one epidemic taking place, there is spread within main risk groups and some spread between them. The main risk groups have been as follows.

#### *The epidemic in homo/bisexual men*

This is the largest and longest running epidemic in the UK, consistently accounting for 87% of reported cases. Figure 3 shows the cumulative epidemic curve for homosexuals resident in the UK, by quarter of diagnosis and of report. Data have been used for the 682 cases for whom date of diagnosis is recorded, the other 54 cases having been omitted from this graph. The curve for diagnoses looks as though it is slowing down, but this is because of incompleteness of recent quarters, where we may expect many more cases to be reported at a later date. The curve for reports has anomalies due to batch reporting and other problems previously described. Nevertheless this would be expected to slow down when the



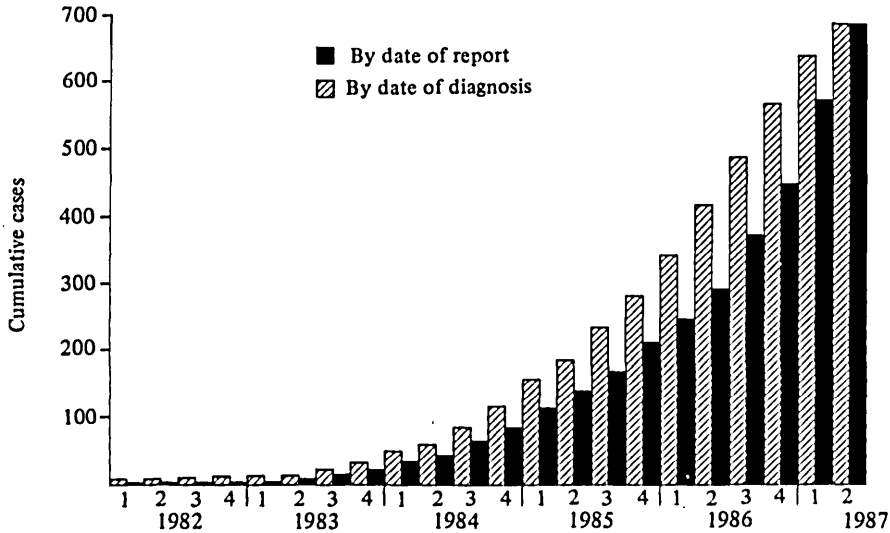


Fig. 3. Cumulative cases in homosexuals for whom date of diagnosis is known and who were reported by the end of June 1987 (682 cases).

exponential phase of the epidemic passes. Although the increase in cases in the second quarter of 1987 is no larger than that in the first quarter this is no indication of a slowing down, because this 'seasonal' pattern of similar quarterly numbers has been observed in previous years (Table 1).

These AIDS data reflect infections which occurred years ago. For current spread it is necessary to study new HIV infections. Ideally a cohort should be studied, and such studies in the USA and West Germany provide valuable information. At CDC routine laboratory reports from England, Wales and Northern Ireland are available, and these are shown in Table 5 by time period of report and by presence or absence of symptoms. For many patients information on risk group or on symptoms was not available. This problem and the fact that reporting may be incomplete and that, in some risk groups, most infected patients are never tested in the early years of their infection mean that this Table has to be interpreted with caution.

Numbers of reported infected homosexuals increased rapidly through 1985 as more laboratories acquired diagnostic facilities. Numbers then steadied with an increase in the first part of 1987, coinciding with the national publicity campaigns. Numbers tested in every risk group rose sharply at this time, although most were antibody-negative. This agrees with the finding reported elsewhere that the 'worried well' are easily affected by publicity.

Table 5 shows that, among homosexuals, those found antibody-positive in the early quarters were more likely to be symptomatic. The majority of patients did not have AIDS at the time of testing. The main clinical feature was reported to be lymphadenopathy for half the symptomatic patients. For recent quarters more patients were asymptomatic than were reported symptomatic.

Table 5. Laboratory reports of patients with HIV antibody: England, Wales and Northern Ireland, up to week 26, 1987

Risk group and symptoms	Years and quarters										
	1985				1986				1987		Total
	(1st)	(2nd)	(3rd)	(4th)	(1st)	(2nd)	(3rd)	(4th)	(1st)	(2nd)	
Homosexual											
No	9	12	17	144	149	138	116	127	232	171	1115
Yes	15	43	52	189	151	117	116	102	175	138	1098
NK	10	44	70	109	126	39	24	77	58	45	602
Total	34	99	139	442	426	294	256	306	465	354	2815
Haemophilia											
No	12	21	29	150	28	14	7	15	4	7	287
Yes	2	4	7	12	5	5	2	4	4	1	46
NK	51	93	65	67	168	48	64	55	17	10	638
Total	65	118	101	229	201	67	73	74	25	18	971
IVDA											
No	—	1	3	10	24	12	13	26	38	43	170
Yes	—	2	2	9	10	9	8	11	16	23	90
NK	—	3	4	6	16	18	13	20	16	16	112
Total	0	6	9	25	50	39	34	57	70	82	372
Other/multiple											
No	1	2	2	4	13	8	9	13	33	30	115
Yes	—	2	1	8	7	15	12	24	24	28	121
NK	—	—	1	1	13	2	9	10	19	17	72
Total	1	4	4	13	33	25	30	47	76	75	308
Not known											
No	1	14	61	13	6	3	4	4	8	15	129
Yes	22	34	57	38	24	13	15	10	9	17	239
NK	20	32	48	50	36	25	17	24	22	16	290
Total	43	80	166	101	66	41	36	38	39	48	658
Total											
New patients	143	307	419	810	776	466	429	522	675	577	5124

*Haemophilia and transfusion-recipient patients*

These are considered together because both groups were infected by transfusion of blood products, and control measures have been introduced. Factor VIII, given to UK haemophiliacs, has been heat-treated since mid-1985. Blood for transfusion in the UK has been screened for HIV antibody since October 1985 and there is also a high degree of self-exclusion from donating blood if the donor may be in a risk group.

AIDS cases are shown in Table 6. The epidemic in haemophilia patients is increasing quite fast. There are fewer cases in blood transfusion recipients transfused in the UK.

Many haemophilia patients who have received Factor VIII are being monitored for HIV infection. Table 5 shows that 971 had been reported to CDSC infected but without AIDS by the end of week 26, 1987 (approximately the end of June). Few new infections are now being reported.

In the 'other/multiple' risk group in Table 5, 44 patients had multiple risk factors, and of the remainder only 48 were reported as transfusion recipients, of whom 13 were stated to have no symptoms. The country of transfusion is not always stated.

Table 6. *AIDS cases in recipients of blood and blood products*

Year	Haemophilia patients		Transfusion recipients			
	Reports	Diagnosis	(i) in UK		(ii) abroad	
			Reports	Diagnoses	Reports	Diagnoses
1983	2	2	—	—	—	—
1984	1	5	—	1	—	1
1985	6	8	3	2	2	1
1986	16	14	1	3	3	2
1987 (first half)	14	6	2	—	1	1
(Year NK)	—	(4)	—	—	—	(1)
Total	39	39	6	6	6	6

*Intravenous drug abusers (IVDAs)*

The number of reported AIDS cases is increasing – one was diagnosed in 1983, 2 in 1984, 6 in 1985, 9 in 1986 and 6 by June in 1987. For one the year of diagnosis is not known. Twelve of these 25 patients were also homosexuals. In laboratory reports of HIV positivity IVDAs are the only known risk group where numbers were higher for the second than for the first quarter of 1987. Just under 10% of total antibody positive reports are from female patients, but half these females are reported to be IVDAs.

*Heterosexually spread epidemic*

There were 20 AIDS cases out of the 838 in which the patient's infection was thought to have been acquired heterosexually. Seven of these were reported to have been due to sexual contact in the UK and three of the seven were contacts of high-risk partners (one haemophiliac and two IVDAs). One was diagnosed in 1983, two in 1985, two in 1986 and two diagnosed by June in 1987. In the 'other' risk groups of Table 5 the majority of patients were reported as probably having acquired their infection through heterosexual contact. For many patients information on place of exposure is incomplete, but where travel of contact abroad was mentioned, Africa was commonly cited.

Six reported AIDS cases were not in the above risk groups, four of them were children born to infected mothers who had acquired their infection through blood transfusion, drug abuse or heterosexually.

## DISCUSSION

It appears that a high proportion of persons infected with HIV are likely to develop AIDS; as the length of cohort studies increases so does the progression rate to AIDS. For example, in San Francisco a cohort study of homosexuals shows only 24% to be asymptomatic after 6 years of infection, and after 8 years about 40% have AIDS (Hessol *et al.* 1987). There is no evidence of the progression rate slowing down.

At the December 1986 European Community meeting in Bilthoven on AIDS prediction (proceedings to be published) it was apparent that all countries with an AIDS epidemic experience an exponential phase for the first years. Very short-term predictions can be made using this epidemic curve, whether using log-linear

regression or a generalized linear mode. The two methods give similar results with UK data (Healy & Tillett, 1988). Statistical confidence limits are questionable for a single country's predictions when there is such similarity between countries. In Greece this observation has led them to use a Bayesian approach. Furthermore, the accuracy of extrapolation is affected by the quality of the surveillance data used.

In the UK the quality of the surveillance data make formal statistical extrapolations and confidence intervals hard to interpret. Various factors (publicity, extra staff at the surveillance centre, scrutiny of death certificates) may have resulted in more complete reporting of AIDS in 1987. If so, this is not reflected in an obvious acceleration of the epidemic curve. This could be interpreted as either that the true epidemic curve is slowing down or that the increase of effort in maintaining the surveillance is only matching the increase of the epidemic itself. The completeness of reporting, and particularly the consistency of that completeness, affect the confidence with which this epidemic curve can be extrapolated.

In practice, a logarithmic plot of quarterly reports shows a remarkably steady linear trend, which would seem to justify short-term extrapolations. A statistical regression was used for this purpose although an arbitrary decision was made to omit the first few observations where numbers were small and the rate of increase is affected by a positive 'transient' (Gonzalez & Koch, 1987), which is an anomaly due to the long incubation period whereby the rate of increase in cases at the beginning of the epidemic is artificially greater than had been the true spread of infection. These surveillance data are being used to make tentative projections without confidence limits for the reasons discussed. They suggested that about another 410 AIDS cases will be reported finally in 1987, bringing the annual total to about 685, with about 1500 new reports expected in 1988. At the time of going to press (mid-December) the actual total reports for 1987 are 650.

For the purposes of planning it is preferable to express numbers by date of diagnosis rather than report. This has to be done by applying the average lag times observed previously. These lag times have fluctuated significantly, and so this averaging introduces another approximation into the forecasting. The observations suggest that just under 900 new AIDS cases will be diagnosed during 1987 and 1900 in 1988. These numbers are lower than those predicted in November 1986 (Tillett & McEvoy) of 1300 in 1987 and 3000 in 1988, but these latter were by date of first presentation for medical advice, which is often several months before diagnosis and would therefore be expected to be much larger. Many patients first presented at the time of onset of early HIV-related symptoms. The doubling time remains similar, and so these revised predictions are compatible with the earlier published figures, the differences being due to using a different date in the patients' illnesses.

The UK epidemic is currently dominated by AIDS cases in the homosexual risk group. The future course of this epidemic is likely to follow the features of those in the USA. The San Francisco epidemic is particularly well documented and has provided data for modelling (e.g. van Druten, 1986; Bailey, 1988). In the UK, as elsewhere, the AIDS cases are reflecting the spread of HIV several years ago. As the numbers of susceptibles diminish the exponential phase of the epidemic must

end, and a slowing down in the rate of increase of new cases will be seen. Changes in the 'high risk' sexual behaviour are also likely to slow the spread and there was extensive health education in this community, from an early date, organized by voluntary groups and later by government campaigns. A third cause of slowing down is the negative 'transient', which compensates for the positive 'transient' seen at the beginning of the AIDS epidemic.

When log-linearity ends and there is inflexion in the AIDS epidemic curve it will be possible to add one more parameter to short-term statistical projections. In the meantime projections beyond 1988 have to be very tentative. The doubling time of new AIDS cases of 10 to 11 months cannot continue indefinitely among the current main risk group, the homosexual population. But a doubling every 12 or even 24 months still implies large numbers of new cases annually.

As yet among homosexuals there is little evidence from clinical surveillance data that the AIDS epidemic is slowing down in the UK. It will be important to see whether the numbers reported in the next quarters are higher or lower than expected (being 160 and 195 for the third and fourth quarters of 1987 – calculated as 87% of total predicted residential cases by date of report) and whether about 40% of those (65 and 75) will have been diagnosed in that same quarter, although the significance of departures from expected is open to debate. Statistical probabilities cannot be assigned. At the time of going to press the numbers of new homosexual resident cases reported in the third quarter of 1987 were 149, of whom 55 were diagnosed during that quarter.

Current laboratory reports of newly diagnosed HIV infections include many asymptomatic homosexuals. Such patients are more likely to have been recently infected than those with symptoms (excluding those symptoms associated with seroconversion). New HIV infections in this risk group have not stopped, but it seems common sense to assume that they are no longer increasing exponentially.

The AIDS epidemic in recipients of blood and blood products given in the UK is perhaps more predictable. Intervention to prevent both epidemics was made in 1985. Progression rates to AIDS could be postulated for cohorts infected before intervention. It is likely that both epidemic curves will be of similar shape and timing, although the magnitude of the transfusion-associated epidemic looks to be much smaller than that among haemophilia patients. Few new infections are being reported in haemophiliacs now through the laboratory reporting scheme, although about a thousand had been previously. These laboratory data together with the AIDS surveillance data suggest that the transfusion epidemic will be small. By mid-1987 there had been six UK transfusion-associated cases reported, compared with 39 AIDS cases in haemophiliacs. A very few transfusion cases could still arise from screened blood which is infective but not detected by the tests used. AIDS due to transfusion abroad is far more unpredictable.

AIDS cases and laboratory reports of HIV antibody are increasing among intravenous drug abusers. Many are known to be infected in Scotland (Robertson, 1985) and many must be infected in the rest of the UK but never tested because they are asymptomatic. This epidemic is hard to predict and is likely to increase exponentially for several years, being in its early stages.

In the USA the heterosexual epidemic is following the same pattern as that for the homosexual epidemic, but following a few years behind (Robertson, White &

Bargmann, 1988). If the same were to occur in the UK this would affect AIDS projections substantially. Any indication of heterosexual spread from high-risk groups and then between heterosexuals must be sought. Studies can be targeted. At the third international conference on AIDS, Washington 1987, papers were presented which supported the hypotheses that heterosexual spread is more likely if the patients have genital ulcers (Katzenstein *et al.* 1987) or if the index case has an HIV infection which has already progressed to pre-AIDS symptoms (Goedert, Eyster & Biggar, 1987).

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