

# Epidemiology

## Surveillance of AIDS in the United Kingdom

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### Abstract

The surveillance of cases of the acquired immune deficiency syndrome (AIDS) in the United Kingdom is described and a preliminary analysis made of the 1012 cases that were reported to the end of August 1987. Homosexuals were the largest risk group. For the first time it is possible to present cases by the date of diagnosis and by the regional health authority of residence. The rate of increase of new cases shows no sign of slowing down. One third of patients with AIDS lived in a different regional health authority from that in which their disease had been diagnosed. The geographical distribution varied with the risk group. The commonest presenting clinical feature at diagnosis was *Pneumocystis carinii* pneumonia. Kaposi's sarcoma was considerably more common among homosexuals than among people in other groups at risk.

### Introduction

Surveillance of the acquired immune deficiency syndrome (AIDS) is required to describe the epidemic by time, place, and the people who are infected to identify modes of transmission and to provide information both for health service planning and for evaluation of control measures.<sup>1</sup>

In 1982 the Public Health Laboratory Service Communicable Disease Surveillance Centre and the Communicable Diseases (Scotland) Unit set up a national AIDS surveillance system to which all doctors are now asked to report cases in strict confidence.<sup>2</sup> Reporting forms are provided by both centres and consist of three pages. The front page contains demographic data, the second questions on possible mode of transmission, and the third clinical features. A "no carbon required" copy of the front page can be detached for use in local surveillance of AIDS.

Previous publications have reported the results to December 1984<sup>3</sup> and December 1985.<sup>4</sup> This paper updates and revises these results to the end of August 1987 and presents some preliminary analyses and comment.

### Methods

Cases of clinical AIDS become known to both communicable disease centres in four different ways. Firstly, clinicians report cases under their care on the form designed for the purpose. Secondly, copies of entries of deaths for England and Wales that mention AIDS, infection with the human immunodeficiency virus (HIV), or Kaposi's sarcoma are sent to the Communicable Disease Surveillance Centre by the Office of Population Censuses and Surveys. Thirdly, microbiologists report both positive HIV antibody results and identifications of opportunistic infections through the laboratory reporting system to one of the two communicable disease centres.<sup>5</sup> If possible cases that have been identified from death entries or laboratory reports have not been reported to the clinical AIDS surveillance scheme the clinician is invited to do so. Fourthly, comparisons are made between the number of cases known to regional medical officers and to the Communicable Disease Surveillance Centre so that discrepancies may be studied, and clinicians are asked to complete a form for cases that have not been previously reported.

The definition of a case is based on the criteria of the Centers for Disease Control and the World Health Organisation for the diagnosis of AIDS, which have recently been revised.<sup>6</sup> A summary is printed on the back of the reporting form.

Either the patient's name or an alpha numeric (Soundex) code is required. The code does not allow reconstitution of the name, and instructions for its use can be obtained from either centre. This code and the date of birth provide sufficient information to check for duplicate reporting and to link with death entries.

The following dates are requested: the dates of infection if known, of first positive serology, of first clinical manifestation of immune deficiency, of when the criteria for definition were met, of the report, and of death. If the mode of transmission is not clear the reporting doctor is contacted, and if necessary the patient may be interviewed by a member of the surveillance team.

By December 1986 over 600 cases had been reported, and the data were reviewed. They were then entered, verified, and stored on a dedicated microcomputer using security software. The following analyses are based on reports of cases and deaths received up to 31 August 1987, excluding duplications detected by 21 September.

### Results

A total of 964 cases of AIDS in United Kingdom residents were reported to both centres, in 549 of which the patients were known to have died; an additional 48 cases in patients who were visitors from abroad were reported. Table I gives cases by sex and by risk group. The 48 cases from overseas (shown in parentheses) have been omitted from the following analysis.

### DISTRIBUTION OF CASES OVER TIME

Figure 1 shows quarterly cumulative case reports to the end of June 1987 and the number of known deaths. Table II gives the number of cases by year of diagnosis and year of report. The numbers of diagnoses for recent years are incomplete because there is often a delay between the diagnosis being made and the report (median interval two months, but for 9% of cases the delay was 12 months or more).

For 86% of the 549 patients who were known to have died at the end of August both the month of diagnosis and the month of death were known.

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TABLE I—Number of cases of AIDS in UK residents by transmission characteristic or risk group by sex reported by end of August 1987. (Number from abroad treated in the UK in parentheses)

	Males	Females	Total
Homosexual/bisexual	833 (26)		833 (26)
Intravenous drug abuser	10	3	13
Homosexual and intravenous drug abuser	15		15
Haemophilic	55 (1)	1	56 (1)
Transfusion recipient	13 (2)	5 (3)	18 (5)
Heterosexual	10 (10)	12	22 (10)
Child of parent who is HIV positive	2 (2)	3 (4)	5 (6)
Other		1	1
Not determined	1		1
<b>Total</b>	<b>939 (41)</b>	<b>25 (7)</b>	<b>964 (48)</b>

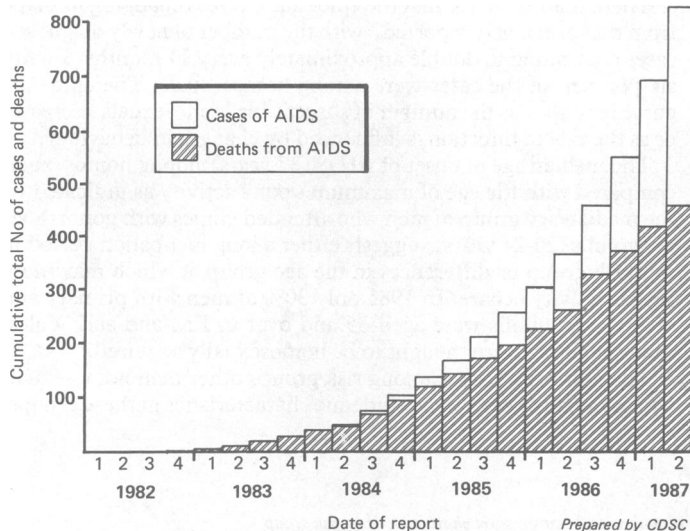


FIG 1—Cumulative number of cases of AIDS and known deaths by quarter year of report.

TABLE II—Number of cases of AIDS among UK residents, by quarter year of diagnosis and year of report

Year	Diagnosis	Reports
1979	1	
1980	0	
1981	3	
1982	11	2
1983	30	26
1984	97	76
1985	208	156
1986	358	301
1987 (to August)	226	403
Not known	30	
<b>Total</b>	<b>964</b>	<b>964</b>

The median length of survival was four months and varied from less than a month to three years. It would be necessary to try to trace patients who are not known to have died before an analysis of survival time could be done.

#### GEOGRAPHICAL DISTRIBUTION

A health district or less specific area of residence in the United Kingdom was identified from the reporting form for 895 (93%) of the 964 patients reported, but these included 35 for whom only "London" was stated, who could not be allocated to a health district or region. There was insufficient information to determine the district of residence for a further 18 cases, although the regional health authority was known. Of 842 patients who could be allocated to a health district, only 321 (38%) gave an address in the same district as the health care facility from which their case was reported.

An address in a different district within the same health authority was given by 244 (29%) patients, but 277 (33%) gave an address in a different health authority. Table III gives the numbers reported and numbers known to be resident in each region or country in the United Kingdom.

TABLE III—Number of cases of AIDS by place of report and residence

Country and region	No reported from region or country	Resident
<b>England:</b>		
Northern	25	24
Yorkshire	14	13
Trent	19	19
East Anglia	10	10
North West Thames	432	234
North East Thames	184	157
South East Thames	84	113
South West Thames	24	95
London, unspecified		35
Wessex	23	34
Oxford	19	25
South Western	15	16
West Midlands	18	19
Mersey	15	19
Northern Western	34	31
Wales	16	19
Scotland	30	31
Northern Ireland	2	1
No information		69
<b>Total</b>	<b>964</b>	<b>964</b>

For the first 389 patients who were known to have died there was a death entry for 146. The health authority of usual residence on the death entry was the same as that stated on the report form in 134 cases (92%).

#### CHARACTERISTICS OF TRANSMISSION GROUPS

**Homosexual/bisexual patients**—Homosexual/bisexual patients made up 86% (833) of the total of 964 cases, and the proportion had not changed appreciably over time. Of these 833 patients, 136 (16%) were reported to be bisexual. Of the 833 homosexual patients, 537 gave information on sexual activity abroad. Just over half (298 of the 537) stated that they had been exposed abroad, most of them in the United States or Caribbean. The proportion of patients who had had contact abroad declined from three quarters of cases diagnosed up to the end of 1983 to just over half of those diagnosed in the first half of 1987. The ages at the date of diagnosis ranged from 18 to 73 years. The median age, where known, was 37 years. This did not vary with time of report or according to whether the patient had had sexual partners abroad. Among homosexual patients 667 (80%) cases were reported from four Thames health authority regions. This proportion has decreased from 87% (78 of 90) of cases reported in 1982-4 to 78% (263 of 338) reported so far in 1987. Two thirds of those for whom information was given were residents of greater London.

**Intravenous drug abusers**—Twenty eight patients were known to be intravenous drug abusers, including 15 who were also homosexuals and who were not included in the 833 patients described above. Their ages ranged from 21 to 49 years (median 30 years). One was diagnosed in 1983, two in 1984, six in 1985, 10 in 1986, and eight in 1987 (one unknown). Nineteen were residents of the Thames regions; three were from Scotland.

**Haemophilic patients**—Of the 56 haemophilic patients, only 11 were reported from the Thames regions. The age at diagnosis was known for 54; three were children, and the oldest patient was 72. The median age was 35 years. Figure 2 shows the quarter year of diagnosis for 48 cases. For five cases the date was not reported, and the three patients who have been diagnosed since June are not included in the figures.

**Transfusion recipients**—Ten of the 18 transfusion recipients had had the transfusion abroad. Six of the eight patients who had had a transfusion in the United Kingdom had it before screening of donated blood was introduced in October 1985. The date of transfusion was not reported for the remaining two. Figure 2 also shows the quarter year of diagnosis for the 12 patients who were known to have been diagnosed by June 1987. Four more were diagnosed during July and August, and for two the date was not recorded.

**Heterosexual patients**—Twenty two patients were reported to have been infected by heterosexual transmission. One was diagnosed in 1982, four in 1983, three in 1984, four in 1985, six in 1986, and four so far in 1987. Twelve

of these patients were women and 10 were men. Fifteen had been sexually active abroad or had lived in high risk areas (12 in Africa), although many of these had also had partners in the United Kingdom. Seven gave a history of having been sexually active only in the United Kingdom, five of whom were women (a prostitute, the wife of a haemophiliac patient, one who had African partners, one whose partner was bisexual, and one whose partner was a drug abuser). Two were men, one of whom had had many partners. These seven cases were diagnosed in 1983, 1985 (two cases), 1986 (two cases), and 1987 (two cases so far). The age at diagnosis ranged from 23 to 66 years, median 37 years.

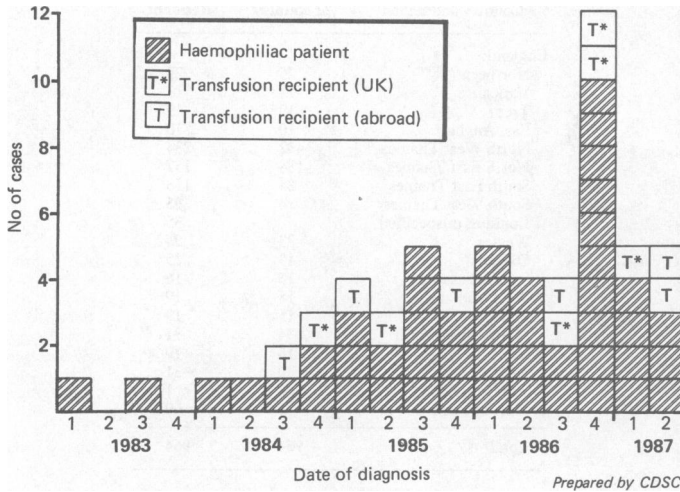


FIG 2—Patients with haemophilia and transfusion recipients by quarter year of diagnosis.

## Discussion

Although the surveillance of AIDS has generally been successful, there have been some problems. During the review of reports received up to December 1986 some duplicates were identified, giving rise to results that differed from those previously reported. When data are inadequate or inaccurate it is sometimes difficult to match clinical reports with laboratory reports and death entries, and comparing reports with copies of death entries that mention AIDS suggests some underreporting and is the subject of a separate paper.

The incubation period between infection and the development of AIDS is long and variable. Thus surveillance of clinical AIDS, though it provides information about the epidemiology of the syndrome, only shows the spread of the virus several years previously.

There is no evidence that the epidemic curve is changing in shape from that previously reported,<sup>8</sup> with the number of newly diagnosed cases continuing to double approximately every 11 months. Eighty six per cent of the cases were among homosexuals. The epidemic curve may alter as the number of susceptible homosexuals decreases or as the rate of infection is influenced by changes in behaviour.<sup>9</sup>

The median age of onset of AIDS (37 years) among homosexuals compared with the age of maximum sexual activity as indicated by the median age group of men who attended clinics with gonorrhoea or syphilis (20-24 years) suggests either a long incubation period in this risk group or differences in the age group at which maximum sexual activity occurs. In 1985 only 30% of men with primary and secondary syphilis were aged 35 and over in England and Wales. Many such cases are thought to be homosexually acquired.<sup>10</sup>

The number of cases among risk groups other than homosexuals was too small to determine epidemic characteristics in these groups.

TABLE IV—Total number of cases of AIDS by clinical presentation at diagnosis and transmission characteristic or risk group

	Kaposi's sarcoma	<i>Pneumocystis carinii</i> pneumonia	Kaposi's sarcoma and <i>Pneumocystis carinii</i> pneumonia	Other opportunistic infection	Non-Hodgkin's lymphoma	Other	Total
Homosexual	198	389	42	178	18	8	833
All intravenous drug abusers	3	15		9	1		28
Haemophiliac	2	35		13	3	3	56
Transfusion recipient		8	1	8	1		18
Heterosexual	2	11	2	6		1	22
Child of HIV positive parent				5			5
Other		1					1
Not determined		1					1
<b>Total</b>	<b>205</b>	<b>460</b>	<b>45</b>	<b>219</b>	<b>23</b>	<b>12</b>	<b>964</b>

*Children born to mothers who were HIV antibody positive*—Five children were reported. Three were children of transfusion recipients. One was born to a mother who was thought to have acquired her infection heterosexually in the United Kingdom, and the fifth was born to a mother who was positive for HIV and whose risk group was not determined. Their ages at diagnosis were 6, 21, 47, 48, and 92 months.

## CLINICAL FEATURES

Table IV lists the clinical features at the time of diagnosis by risk group. Of the 26 patients who presented with lymphoma alone, three had cerebral lymphoma and 23 non-Hodgkin's lymphoma. The clinical features of homosexual patients differed from those in other risk groups, as has been described in the USA.<sup>7</sup> Of the 833 homosexual patients, 240 (29%) had Kaposi's sarcoma compared with only 10 (8%) of the 131 other patients ( $p < 0.00001$ ). No difference was detected in the relative occurrence of other opportunistic disease. About half of the homosexual patients were reported to have had a sexually transmissible disease on at least two occasions compared with just over 6% of patients who were not homosexual.

The heterosexual spread of infection in the next few years may also depend on changes in behaviour, which will perhaps be influenced by health education programmes. In Edinburgh about 500 women<sup>11</sup> and half of the intravenous drug abusers<sup>12</sup> have antibodies to HIV, but few of these have been reported to have developed clinical AIDS. Although transfused blood and blood products should no longer be a source of infection, there are over 1000 recipients in England and Wales who are known to be HIV antibody positive, over 90% of whom are haemophiliacs. The date of infection by blood transfusion is usually known and the incubation period can be calculated,<sup>13</sup> but this may differ from that in other risk groups. In the four cases reported to the Communicable Disease Surveillance Centre for which the date of transfusion was stated, the interval between infection and diagnosis ranged from seven months to approximately two years, but it is expected that intervals will be much longer for cases reported in future. For other risk groups exposure to infection may have continued over a period of time, and it is more difficult to estimate the interval between infection and clinical onset (N A Hessel *et al*, third international conference on



AIDS, Washington 1987). Little is known about the influence of genetic factors, but these may affect the rate of development of AIDS in people with HIV antibodies.<sup>14</sup>

It is important to know where patients receive health care to plan resources. Most of the patients were homosexuals living in London. Cases among other risk groups were more evenly distributed around the United Kingdom. In some countries a large proportion of cases have been reported among intravenous drug abusers.<sup>15</sup> In the United Kingdom HIV antibody has been found among drug abusers in well defined geographical areas.<sup>16</sup>

The clinical features at the time of reporting were similar to those described in other Western countries.<sup>7</sup> It is not yet clear, however, what clinical features may be predominant in patients who develop AIDS after long incubation periods. New types of opportunistic diseases may appear with a longer duration of incubation. It is not known whether some people may be HIV positive for many years and develop an AIDS syndrome in later life.

The surveillance system depends on prompt reporting of new cases. Efficient verification and documentation then permits rapid feedback of information through monthly press releases.

We thank all those clinicians who have reported cases to CDSC and CD(S)U; Dr Spence Galbraith and Dr Dan Reid, who developed the CDSC and CD(S)U AIDS reporting programmes; and Dr Galbraith for his continued support and encouragement. Dr S Young, Dr A Ellam, Dr G Marasca, Mrs K Porter, Miss E Overton, and the PHLS computer services staff have all helped to make computerisation of the data possible.

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## Letter from . . . Chicago

### Neuromeanderings

GEORGE DUNEA

In the hierarchy of medical specialists the neurologists traditionally ranked highest. Greatly admired for their elegance and skill, they frequently transcended the bounds of conventional neurological disease, their interests leading them to study the highest functions of the brain in health as well as in disease. For almost a century a series of clinical giants held the spotlight on the diagnostic stage, astounding the world with their unflinching ability to localise the offending lesion—which, alas, they could but rarely cure.

But now times have changed. No longer do neurologists remain wholly true to the traditional stereotype of “the doctor full of phrase and fame shaking his sapient head and giving the ill he cannot cure a name.” They may have lost much of their mystique, but they make up for it with a whole array of new tests and treatments. Yet despite their impressive armamentarium they occasionally suffer diagnostic Waterloos that would have made the great Charcot turn hysterically in his grave.

Such was the case reported in the *Chicago Tribune* of a man who had complained for some time of cramps, weight loss, and weakness of the arms, particularly about the wrists. His wife, who also became ill at the same time, was diagnosed as having porphyria, while he was told that he had a prolapsed intervertebral disc and also that he needed carpal tunnel surgery. Unconvinced by these diagnoses, wondering why both he and his wife should be anaemic, he turned to the medical textbooks to seek an answer and ended up by asking his doctors to order tests for heavy metals. So the mystery was solved: the diagnosis was lead poisoning, the source a 150 piece set of ceramic tableware shipped back from southern Italy at no little trouble and expense. The treatment, with edetic acid, led to great symptomatic improvement, also to an abiding interest in the problems of lead poisoning. The conclusions are: (1) as many as five million pieces of improperly glazed pottery in the United States are leaching excessive amounts of lead; (2) the price of health is constant vigilance; (3) think of buying a kit to test for lead in the home; (4) ask if the ceramic you are buying has been tested for lead; (5) beware of “vibrantly” coloured pots, especially from China or Mexico; (6) avoid storing foods or liquids in containers of unknown safety; (7) do not eat every day from the same plate or drink from the same cup; (8) expect the Food and Drug Administration to tighten standards and inspection procedures for lead, but do not hold your breath for this to happen soon.