The changing epidemiology of prevalent diagnosed HIV infections in England, Wales, and Northern Ireland, 1997 to 2003

B D Rice, L J Payne, K Sinka, B Patel, B G Evans, V Delpech

Objective: To present the current epidemiology of prevalent diagnosed HIV infections in England, Wales, and Northern Ireland (E, W, & NI) and describe trends over time.

Methods: Descriptive analyses of the annual national Survey of Prevalent HIV Infections Diagnosed (SOPHID) for the period 1997 to 2003.

Results: In 2003, 34,251 adults (15 years of age or over) were seen for HIV related care in E, W, & NI, representing a 17% increase in the prevalence of diagnosed HIV infections compared with 2002 and a 132% increase compared with 1997. Between 1997 and 2003, as a proportion of total prevalent cases, adults who acquired their infection through heterosexual sex increased from 26% to 49%; black African adults increased from 13% to 35% and diagnosed adults resident in London fell from 62% to 55% of the total. The male to female ratio declined from 5:1 to 2:1. The proportion of adults receiving combination antiretroviral therapy increased from 53% in 1998 to 64% in 2003.

Conclusion: There has been a large increase in the number of adults with diagnosed HIV infection seen for care in E, W, & NI since 1997. Changes in the epidemiology of prevalent diagnosed HIV were seen by sex, route of infection, ethnicity, level of antiretroviral therapy, and areas of residence and treatment. In 2003, for the first time, prevalent diagnosed infections acquired through heterosexual sex overtook those acquired through sex between men. These increases have serious implications for the planning and financing of HIV services in the United Kingdom.

Individuals with diagnosed HIV infection may attend for HIV related care within England, Wales, and Northern Ireland (E, W, & NI) outside their area of residence. The result is that healthcare planners may lack the necessary information concerning their resident population needed to establish services to meet local healthcare needs and appropriately target prevention measures. In 1999 the annual cross sectional Survey of Prevalent HIV Infections Diagnosed (SOPHID) was established to satisfy this need for residence based and epidemiological data for individuals with diagnosed HIV infection.

The survey aims to include every individual in E, W, & NI with diagnosed HIV infection who has attended for HIV related care at National Health Service (NHS) sites of treatment within a calendar year. The data provide the only national measure of individuals with diagnosed HIV infection accessing HIV related care and provides public health professionals with aggregate information on individuals who are treated or resident within their local area. The data are also used by HIV commissioners to allocate residence based funding and estimate future resource needs. In this paper we present the epidemiology of prevalent diagnosed HIV infections in E, W, & NI for 2003 and describe trends for the period 1997 to 2003.

Methods

All individuals with diagnosed HIV infection, who access HIV related care within the survey period (full calendar year) at NHS sites of treatment in E, W, & NI are included in the survey. Sites include infectious disease units, genitourinary medicine (GUM) clinics, and community nurse services. Epidemiological, demographic, and clinical information is collected on individuals including patient residence, probable route of infection, ethnicity, sex, age, and level of antiretroviral therapy (ART) the patient was receiving when last seen in the survey period. Annual result tables and graphs, by these variables, at the government office region and strategic health authority (SHA) level, are made available on the Health Protection Agency website.

No names are collected or held on the SOPHID database; duplicate reports of the same individual are identified and removed within each annual survey, without compromising patient confidentiality, using sex, date of birth, and a four character coding of the surname (Surname code). Soundex code is not provided for children, therefore only records for adults (aged 15 years or above) were included in the analyses. Strict attention to confidentiality is maintained at every stage of data collection, analysis, and storage.

Records of adults from the 1997 to 2003 annual surveys were amalgamated to allow descriptive analyses of the survey data to show trends over time. Level of ART was excluded from analyses for 1997 because data were poorly reported as it was the first year of collection of this variable.

Rates shown are per 100,000 population, based on the Office for National Statistics (ONS) mid-2001 adult resident population estimates. Residence and treatment data are shown by strategic health authorities in England, health authorities in Wales, and by region for Northern Ireland. Collectively, areas of residence and treatment are referred to here as SHAs. Strategic health authorities of residence and treatment were mapped to all survey years, including surveys

Abbreviations: ART, antiretroviral therapy; E, W, & NI, England, Wales, and Northern Ireland; GUM, genitourinary medicine; IDU, injecting drug use; NHS, National Health Service; ONS, Office for National Statistics; SBM, sex between men; SHA, strategic health authority; SOPHID, Survey of Prevalent HIV Infections Diagnosed
In 2003, 34,251 adults were reported to have been seen for HIV-related care by 242 reporting sites in England, Wales, or Northern Ireland and reported to SOPHID (1997–2003); by sex, ethnicity, and probable route of infection.

### Data completeness

The completeness of information across surveys was high. Ethnicity was known for 98% of records, route of infection for 98%, SHA of residence for 98%, and ART for 96% of records. Sex, age, and SHA of treatment had complete, or near complete ascertainment, as these fields were followed up where missing in survey returns. Proportions shown in the results exclude records with missing values.

### Route of infection

In 2003, 49% (16,169/33,307) of adults with diagnosed HIV infection were infected through heterosexual sex, 47% (15,652) through sex between men (SBM), 3% (956) through injecting drug use (IDU), and 1% (452) through receipt of blood products. Sex between men (SBM) was the most probable route of infection for all surveys between 1997 and 2002; however, in 2003, the number of infections acquired through heterosexual sex overtook those acquired through SBM (table 1). As a proportion of overall diagnosed infections, infections acquired through SBM has fallen each year from 64% (9238/14,190) in 1997 to 54% (18,103/33,513). In contrast, the proportion of diagnosed adults who were black African increased from 15% (2129) to 35% (11,832).

### Male to female ratio

The number of females with diagnosed HIV infection seen for HIV related care in England, Wales, & Northern Ireland increased by 316% between 1997 and 2003 (table 1). The male to female ratio declined from approximately 5:1 in 1997 to 2:1 in 2003. In 2003 females accounted for 32% (10,871) of all prevalent infections, compared to 18% (2615) in 1997.

### Age

Between 1997 and 2003 the median age of adults with diagnosed HIV infection seen for HIV related care in England, Wales, & Northern Ireland increased from 35 years to 37 years. The largest increase in median age was among individuals who acquired their infection through IDU, and blood/blood product recipients, from 35 years to 40 years and 33 years to 38 years, respectively.

In 2003 the median age of males was 39 years compared to 34 years for females. Men who acquired their infection through heterosexual sex were slightly younger than those infected through SBM (median age 38 years compared to 39 years), as were individuals of either black African or black Caribbean ethnicity compared to white individuals (median age 35 years compared to 39 years).

### Antiretroviral therapy

Of the 98% (33,649) of diagnosed individuals for whom level of ART was recorded in 2003, 64% (21,553) received combination therapy (three drugs or more), 2% (659) received mono/dual therapy, and 34% (11,437) were not.
Figure 1 shows infections acquired through SBM and heterosexual sex by sex and ethnicity.

Heterosexual sex was reported as the probable route of infection for 92% (3628) of males of black African ethnicity, 54% (139) of Indian/Pakistani/Bangladeshi, 44% (304) of black Caribbean, 31% (99) of black other, and 10% (1573) of males of white ethnicity. Heterosexual sex was the probable route of infection for at least 92% of females of all ethnicities, the exception being females of white ethnicity where heterosexual sex was reported for 83% (1485/1781) and IDU for 15% (263). Individuals of white ethnicity, both male and female, made up the majority of prevalent diagnosed infections acquired through IDU seen in the 2003 survey (86%, 826/956).

Overall, the largest increases in diagnosed prevalence between 1997 and 2003 were among black African females (497% (1266 to 7562), fig 1B), and black African males (431% (683 to 3628), fig 1C) with infections acquired through heterosexual sex. Of infections acquired through heterosexual sex in 2003, females represented 68% (7562/11 190) of black African, 55% (369/673) of black Caribbean, and 49% (1485/3058) of white individuals.

Strategic Health Authority of treatment or care

Of the total number of individuals with diagnosed HIV infection reported in 2003, 59% (20 127/34 251) were seen for treatment or care in London. This proportion has decreased from 67% (9818/14 755) in 1997. North West London SHA saw the greatest number of patients, representing 21% (7037/34 251) of the total treated population (table 2). The largest proportional increases in individuals seen for treatment between 1997 and 2003 were in SHAs outside of London, in particular Bedfordshire and Hertfordshire SHA, where the number of individuals seen for treatment increased ninefold (table 2).

Strategic Health Authority of residence

In 2003, of the total number of individuals with diagnosed HIV infection (where SHA of residence was known) 55% (18 420/33 649) were resident in London. This proportion has decreased from 62% (9064/14 548) in 1997.

In E, W, & NI the overall rate of diagnosed HIV infection was 76 per 100 000 population (age >14). South East London SHA had the highest number (4683 (rate 841 per 100 000)) of resident individuals with diagnosed HIV infection in E, W, & NI in 2003, followed by North West London (4462 (275 per 100 000)). Outside of London, Surrey and Sussex (1790 (85 per 100 000)) had the highest numbers and rates of resident diagnosed individuals, whereas North Wales (104 (19 per 100 000)) and Mid and West Wales (150 (19 per 100 000)) had the lowest numbers and rates (fig 2).

The largest proportional increase in the number of resident individuals with diagnosed HIV was in Essex SHA where the diagnosed population increased fivefold (109 to 514) between 1997 and 2003. Bedfordshire and Hertfordshire SHA had a near fivefold increase (189 to 884), and Leicestershire, Northamptonshire, and Rutland SHA (161 to 667) and Thames Valley SHA (283 to 1071) both had fourfold increases.

HIV related treatment or care within SHA of residence

In 2003, 76% (25 418/33 649) of diagnosed individuals were seen for HIV related care or treatment in the SHA in which they reside, compared to 72% (10 407/14 548) in 1997. The SHAs that managed the highest proportion of their resident diagnosed population for treatment or care in 2003 were Northern Ireland (99%), Greater Manchester (97%), Northumberland, Tyne and Wear (96%), South East Wales...
Data from the 2003 SOPHID confirm that the number of diagnosed individuals accessing HIV care between 1997 and 2003 and epidemiological shifts that have come to redefine the HIV epidemic in E, W, & NI.

In western Europe as a whole a similar picture of increasing numbers of new HIV diagnoses, particularly among heterosexuals, and decreasing numbers of AIDS related deaths, as a result of the widespread use of combination therapy, has been seen. Of the total number of newly reported HIV cases in western Europe in 2002 (reports were not received from Spain, Italy, or France) 34% were reported from the United Kingdom. The 17% increase in diagnosed individuals accessing HIV related care or treatment between 2002 and 2003 is the second largest increase seen during the history of the SOPHID survey (1995 to 2003), the increase between 2001 and 2002 was the largest. The small drop in the rate of increase may be as a result of early signs of a slight decrease in the rate of new diagnoses and a modest increase between 2002 and 2003 in the number of deaths among diagnosed individuals. Also, with infections acquired in countries with a generalised epidemic making a growing contribution to prevalent diagnosed HIV in the United Kingdom, as in western Europe as a whole, it is reasonable to assume that there may be increased out-migration among individuals reported to the survey. At present it is not possible to quantify out-migration among diagnosed individuals.

### DISCUSSION

#### Increased prevalence of diagnosed HIV infections

Data from the 2003 SOPHID confirm that the number of individuals receiving HIV related care in E, W, & NI is continuing to increase, with a 17% rise between 2002 and 2003. This period covered by these analyses has seen two influential changes in the UK HIV epidemic. Firstly, the unprecedented increase in new HIV diagnoses and, secondly, the success of ART in reducing mortality rates.

In recent years there has been a rapid increase in the number of new diagnoses of HIV infection in E, W, & NI. In 2003 there were 6228 newly diagnosed individuals (aged 15 years or above) compared to 5684 in 2002, 4775 in 2001, and 3596 in 2000. Between 1998 and 2003 the proportion of diagnosed individuals receiving combination therapy (three drugs or more) increased. Over the same period the number of reported deaths in HIV diagnosed individuals fell from 656 to 420 (the figure for 2003 will rise as further reports are received). Both the rise in numbers of new diagnoses and the decrease in number of deaths have led to a large increase in the number of diagnosed individuals seen for HIV related care between 1997 and 2003 and epidemiological shifts that have come to redefine the HIV epidemic in E, W, & NI.

The 17% increase in diagnosed individuals accessing HIV related care or treatment between 2002 and 2003 is the second largest increase seen during the history of the SOPHID survey (1995 to 2003), the increase between 2001 and 2002 was the largest. The small drop in the rate of increase may be as a result of early signs of a slight decrease in the rate of new diagnoses and a modest increase between 2002 and 2003 in the number of deaths among diagnosed individuals. Also, with infections acquired in countries with a generalised epidemic making a growing contribution to prevalent diagnosed HIV in the United Kingdom, as in western Europe as a whole, it is reasonable to assume that there may be increased out-migration among individuals reported to the survey. At present it is not possible to quantify out-migration among diagnosed individuals.

#### Table 2: Diagnosed HIV infected adults seen for care in England, Wales or Northern Ireland and reported to SOPHID (1997–2003), by Strategic Health Authority (SHA) of care or treatment

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(96%), and South Yorkshire (96%). The SHAs that managed the lowest proportion of their resident diagnosed population were South West London (56%), South East London (60%), North East London (65%), Essex (67%), and Bedfordshire and Hertfordshire SHA (68%). Of the 8231 individuals seen for treatment outside of their SHA of residence, 39% (3201) were seen in North West London and 26% (2175) in North Central London.
Epidemiological shifts in prevalent diagnosed HIV infections

Findings of this study indicate that the prevalent diagnosed HIV population seen for care has shifted from predominantly white individuals infected through SBM towards individuals infected heterosexually, of whom the majority are black African, particularly black African women. In 1999 new diagnoses of individuals with infections acquired through heterosexual sex overtook individuals with infections acquired through SBM for the first time. Since 2001 the largest number of new diagnoses have been among females with infections acquired through heterosexual sex. This relatively recent but marked change in newly diagnosed individuals entering the prevalent pool is the main factor behind the trends seen in SOPHID.

Extrapolations of the 1996 to 2001 SOPHID data using a negative binomial model (found to be the most appropriate to model the non-linear temporal trend data) predicted that...
prevalent diagnosed HIV infections would follow the pattern seen in new diagnoses, with the number of infections acquired through heterosexual sex exceeding those acquired through SBM in 2004.4 However, the large rise in new diagnoses of infections acquired through heterosexual sex has led to—in 2003 for the first time—a higher prevalence of individuals with infections acquired through heterosexual sex seen for care than individuals with infections acquired through SBM.

The prevalence of diagnosed infections among individuals who acquired their infection through IDU, or receipt of blood/blood products has remained remarkably steady. The ageing of these two prevalent groups can be explained by few new diagnoses and fewer deaths as a result of ART.1,7 Improved survival because of use of ART is also shown by the increased number of individuals infected through mother to child transmission surviving to adulthood.

The large increase in numbers of diagnosed HIV infections seen in heterosexual men and women, and the relatively steady increase in men who have sex with men, has led to the decrease in the male to female ratio. The introduction of the universal offer and recommendation of antenatal screening for HIV in England in 1999 may explain part of the rise in the number of females with HIV infection being diagnosed.8

A greater proportion of individuals were receiving combination therapy in 2003. It is of interest that taken separately, females, individuals with heterosexually acquired infection, and individuals of black Caribbean ethnicity were the least likely to be receiving combination therapy. Further exploration of these findings is warranted to assess whether real differences exist and to identify determinant factors. The results show the proportion of individuals receiving monotherapy or dual therapy to have significantly reduced in recent years, in line with UK guidelines.10

Geographical changes in prevalent diagnosed HIV infections

While London continues to be the focus of the epidemic, numbers of individuals both living and seen for care outside London are rising at a faster rate. Areas with traditionally low prevalence have seen the highest proportional increases and although often small in number when compared to main urban centres, these increases can have important implications for local healthcare services. That a growing percentage of individuals are seeking HIV care within their area of residence also of importance when considering future GUM clinic workload.

In 2003, the SHAs with the largest proportion of their resident diagnosed population seen for HIV care in their area tend to be those that have a single dominant urban centre—for example, Northern Ireland (Belfast), Greater Manchester, South East Wales (Cardiff), and South Yorkshire (Sheffield). The SHAs with the lowest proportion of residents seen for HIV care in their area are those that either border an SHA with a major urban centre—for example, Essex bordering North East London and Bedfordshire and Hertfordshire bordering both North Central and North West London, or are a London SHA that borders North West London. North West London SHA hosts two of the largest hospitals in terms of HIV caseloads.

Limitations of the data

The survey aims to provide an estimate of the prevalence of individuals with diagnosed HIV living in E, W, & NI. The figures presented however are likely to be an underestimate. A combined calculation for under-reporting (individuals who have accessed HIV related care services within the survey period but have not been reported) and non-attendance (individuals with diagnosed HIV infection who have not attended a participating site of treatment within the survey period) is used to adjust each annual survey total. For 2003 the combined adjustment added 13.2% to the total number reported, in 2002 it was 12.5%, and in 2001 it was 13.2%. The methods for calculating these adjustment factors have been described elsewhere.1,7 The results presented in this paper are based on unadjusted disaggregate data that allow trend analyses by epidemiological, geographical, and clinical factors.

Individuals who only attend private healthcare facilities for HIV care will not be represented in the survey. The national strategy for sexual health and HIV, published by the Department of Health in 2001, states NHS commissioners should “make sure that there are clear open access arrangements [to local services and prevention], including for people who seek care from GUM services outside their own area.”11 It is likely, therefore, that the number of diagnosed individuals only accessing private healthcare facilities within a calendar year will be small. Only 15 of 225 attendees with diagnosed HIV at two London NHS GUM clinics held private health insurance.12

Implications for HIV care

Between 2001 and 2002 the estimated prevalence of overall HIV infections (diagnosed and undiagnosed) among adults in the United Kingdom, rose from 41 700 to 49 500.7 Across the world HIV continues to be a health priority, being associated with high morbidity, mortality, and socioeconomic costs. UNAIDS estimates that at the end of 2003 a total of 37 million adults worldwide were living with HIV/AIDS.13 With rising HIV prevalence in areas of the world with traditional links to the United Kingdom, increasing overseas travel and population movement, and continuing sexual transmission of HIV within the United Kingdom, especially through SBM, large annual increases in prevalent diagnosed HIV infections are likely to continue. Demand on available HIV care and treatment resources will therefore continue to increase.

The data suggest that future increases in diagnosed HIV infection will be proportionally greater outside London and be increasingly among females and individuals of black African ethnicity. It is important to note that there is great variability with regard to these trends between areas.

Annual SOPHID data, presented at the SHA and local level (primary care trusts in England, local health boards in Wales and health and social services boards in Northern Ireland), are provided to all areas in E, W, & NI. The data enable public health professionals to understand the epidemiological breakdown of their local treated and resident diagnosed populations, and monitor trends over time to ensure local needs are being met. Examples of how data, both residence and treatment based, are used at the local level include expanding family services where mother to child transmissions are shown to be increasing or targeting prevention outreach services to specific ethnicity or exposure groups where necessary—for example, introducing prevention and care services for individuals of black African ethnicity, where this group has been shown to represent an increasing proportion of the local prevalent population, or concentrating, or expanding, services for men who have sex with men where they continue to be the core diagnosed group.

For health providers to meet the Department of Health aim of local sexual health and HIV services responding to the different needs of different populations,11 the delivery of local services will need to continue adapting to the epidemiological and demographic changes in their area. In addition, those areas shown to be experiencing the largest increases in treated and resident diagnosed populations (both proportionally or in terms of absolute numbers) may need to
Key messages

(1) The number of people living with diagnosed HIV infection in England, Wales, and Northern Ireland rose by 132% between 1997 and 2003.

(2) The epidemiology of diagnosed HIV infection in England, Wales, and Northern Ireland has changed from predominately white men who have sex with men towards individuals infected heterosexually, of whom the majority are black African, particularly black African women. For the first time in 2003, the number of individuals with diagnosed HIV infection acquired through heterosexual sex exceeded that of individuals infected through sex between men.

(3) Between 1997 and 2003 an increasing proportion of adults with diagnosed HIV infection were resident and treated outside London. Areas with traditionally low prevalence have seen the highest proportional increases and although often small in number when compared to main urban centres, these increases can have serious implications for local care services.

(4) The trends presented in this paper are of public health concern and should continue to be reviewed for the planning and financing of HIV/AIDS services and appropriate targeting of prevention programmes for England, Wales, and Northern Ireland.

expand services so that future demand is provided for. The trends presented in this paper are of public health concern and should continue to be reviewed for the planning and financing of HIV/AIDS services and appropriate targeting of prevention programmes for England, Wales, and Northern Ireland.

ACKNOWLEDGEMENTS

We thank the SOPHID advisory group and all the SOPHID facilitators across England, Wales, and Northern Ireland for their continuing help and support with the survey. The authors also thank Janet Mortimer, Kevin Fenton, and Katharine Sadler for their helpful comments on this paper. The SOPHID survey is funded by the Department of Health. The views expressed in the paper are those of the authors and not necessarily those of the Department of Health.

CONTRIBUTORS

BDR, SOPHID coordinator and first author; LJP, previous SOPHID coordinator and second author, collected data shown in results and provided guidance as to the structure of the paper; BG, deputy director of CDSC, lead consultant for the SOPHID survey when the paper was conceived, provided guidance as to the structure of the paper; VG, lead consultant for SOPHID, provided guidance as to the grammatical and physical structure of the paper, and data analyses.

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No conflict of interest to declare.

Statement: The Survey of Prevalent Diagnosed HIV Infections was established in 1995 as an annual cross sectional survey of all providers of statutory medical HIV related treatment and care in England, Wales, and Northern Ireland. Since 1995 it has monitored the annual caseload of patients by district of residence and the district where care was provided. The decision whether to forward data collected for the survey via a local survey facilitator or directly to CDSC rests with the clinician providing treatment and care for the HIV infected patients concerned.

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Sex Transm Infect 2005 81: 223-229
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