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Trends in HIV testing and recording of HIV status in the UK primary care setting: a retrospective cohort study 1995-2005.

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Abstract

Objectives To provide nationally representative data on trends in HIV testing in primary care, and to estimate the proportion of diagnosed HIV positive individuals known to general practitioners (GPs).

Methods We undertook a retrospective cohort study between 1995-2005 of all general practices contributing data to the United Kingdom General Practice Research Database (GPRD), and data on persons accessing HIV care (Survey of Prevalent HIV Infections Diagnosed). We identified all practice-registered patients where an HIV test or HIV positive status is recorded in their general practice records. HIV testing in primary care, and prevalence of recorded HIV positive status in primary care were estimated.

Results Despite 11-fold increases in male testing, and 19-fold increases in non-pregnant female testing between 1995 and 2005, HIV testing rates remained low in 2005 at 71.3 and 61.2 tests per 100,000 person years for males and females respectively, peaking at 162.5 and 173.8 per 100,000 person years at 25-34 years of age. Inclusion of antenatal tests yielded a 129 fold increase in women over the 10 year period. In 2005, 50.7% of HIV positive individuals had their diagnosis recorded, with a lower proportion in London (41.8%) than outside the capital (60.1%).

Conclusion HIV testing rates in primary care remain low. Normalisation of HIV testing and recording in primary care in antenatal testing has not been accompanied by a step change in wider HIV testing practice. Recording of HIV positive status by general practitioners (GPs) remains low, and GPs may be unaware of HIV-related morbidity or potential drug interactions.

INTRODUCTION

HIV prevalence has increased in the UK over the last decade, with an estimated 73,000 individuals living with HIV by 2006, of whom 21,000 remained undiagnosed.(1) HIV patients' medical care has historically been managed by stand alone HIV specialist services, of which the larger provide some primary care services.(2) The number of HIV positive individuals requiring these services has increased three-fold since the mid-1990s as a consequence of new diagnoses and improved survival following the introduction of Highly Active Antiretroviral Therapy (HAART) around 1996.(1) While HIV services can ensure a high quality of HIV care for diagnosed individuals, GPs report anecdotally that overall clinical care may be compromised where a general practitioner is unaware of their patient's HIV status and other treatments.(3) There is evidence that close liaison between specialist HIV services and primary care can shorten admissions and improve the standard of health care in this group generally.(4)

Primary care remains a relatively under-utilised resource for the delivery of sexual health services other than contraception. England's National Strategy for Sexual Health and HIV proposes enhancement of sexual health services in general practice, including HIV testing, in order to reduce high mortality rates amongst individuals diagnosed late, and to reduce transmission associated with undiagnosed infection.(5) Universal offer of HIV testing to pregnant women began in 2000,(6) as it became clear that neonatal transmission is preventable, and uptake of antenatal testing practitioner-dependent.(7;8) While the success of this policy demonstrated the feasibility of HIV testing in a non-specialist setting,(9) no framework existed for delivering HIV testing in the wider population until recent recommendations for testing in primary care, and in other health settings.(10;11) Many patients diagnosed with acute(12) and established(13) HIV infection consult prior to diagnosis in primary care, often missing opportunities for earlier diagnosis.

In this study we aimed to provide the first nationally representative estimates of testing rates and recording of positive HIV status in primary care.

METHODS

Briefly, HIV testing rates and prevalence of recorded HIV in primary care were estimated using disaggregated data from a large primary care database (GPRD), broadly representative of the UK

population and containing 2.8 million current patients in 2005. Incidence of HIV testing in males, and females, with and without antenatal screening was estimated. The prevalence of recorded HIV positive status in the GPRD was compared with a denominator of all HIV positive individuals reported to the surveillance dataset SOPHID (Survey of Prevalent HIV Diagnosed). This allowed us to estimate the proportion of all HIV positive individuals whose status was coded in their general practice record.

Population and sampling

The General Practice Research Database (GPRD) is a large anonymised primary care database derived from computerised clinical records produced during consultations in primary care. It contains anonymised data on 4.7% (2.8 million in 2005) of the UK population. The Medicines and Healthcare Regulatory Agency (MHRA) holds the licence for the database and undertakes checks on the quality and completeness of data, which have been collected continuously since 1988. The GPRD is broadly demographically representative of the UK population, though there is a slight under-representation of inner London and Scotland. It has been used and validated for many pharmacoepidemiological, epidemiological and public health uses,⁽¹⁴⁾ with a denominator of 296,098 person years of observation available to us for 2005. GPs enter medical diagnoses and symptoms using Read codes⁽¹⁵⁾ or the similar but now superseded OXMIS (Oxford Medical Information Systems) codes. Read and Oxmis codes are alphanumeric hierarchical codes which have an associated text description, which are used to summarise information on diagnoses, symptoms, examination and referral in UK primary care in coded form. Their scope is more diverse than ICD-10 disease codes and some are ambiguous (e.g. “chlamydia”) or nonspecific (“unspecified chronic viral infection”). In addition investigations, prescription data, and consultation data, age, gender, and Strategic Health Authority (SHA) of residence are recorded for each registered individual.

Practice level quintiles of Index of Multiple Deprivation for 2004 (IMD 2004) score were used as a proxy for the level of deprivation but ethnicity data were not available. Individual level linkage to other datasets was not available.

We classified GPRD practices as rural or urban at super output area level (a small area geographic boundary) in England, Wales and Northern Ireland, and by NHS region in Scotland, using data from national statistics providers.

Definitions of HIV testing and recorded HIV positive status

33 codes were identified denoting a definite HIV test (Web Appendix 1) and 61 codes referring to HIV status, of which 56 codes denote a definite HIV positive status (see Web Appendix 2 for details). Individuals who had any medical code recorded in the GPRD denoting definite HIV positive status were subsequently defined as having recorded HIV positive status. An HIV test was considered to be “antenatal” if it occurred within six months of any medical code indicating a current pregnancy.

Estimation of HIV testing rate in primary care

We estimated the incidence of HIV testing during the time period 1995-2005 for males and females, including and excluding antenatal tests, using the GPRD registered population as denominator for person years at risk. Survival analysis was used to calculate person-years-of-exposure at risk of HIV testing. Poisson regression was used to calculate 95% confidence intervals (CI) and incidence rate ratios (IRR). Testing rates (excluding antenatal tests) were estimated by age group, gender, SHA, IMD and rural/urban category, and area of residence (London vs outside London) for 2005.

We restricted counts of patients’ HIV test records to at most one test in any 90 day period. HIV test events are often duplicated in the GPRD due to the nature of data recording in general practice. For example, a patient may have an HIV test in general practice recorded in their medical records, while the corresponding laboratory test result may be recorded in their test records two weeks later. In addition, current surveillance from specialist clinics reports only one test in each 3 month period.⁽¹⁾ This approach also allows for one test only within the “window period” of 90 days after exposure to HIV, which can be regarded as a single episode of testing. We have therefore used the same definition of a 3 month period to allow for comparisons with other work. (Our data show that in 2005, 5.4% of all male and 2.2% of all female tests were recorded within this 90 day period, with little evidence of change over time).

Recorded HIV positive individuals were removed from the denominator for HIV testing incidence calculations, as they are no longer “at-risk” of HIV infection or testing.

Estimating the prevalence of HIV recorded in primary care

Prevalence of recorded HIV in primary care was calculated for the years 1995-2005 for males and females with a more detailed breakdown by age and demographic characteristics for 2005 only. The proportion of all diagnosed cases recorded in the GPRD was estimated by comparing recorded prevalence in the GPRD population as numerator, with age and sex-specific reports to the SOPHID surveillance system (see below) as denominator.

In the GPRD, prevalence of recorded HIV infections in general practice was calculated using the number of patients registered as at 30th June (mid-year) as denominator. HIV infection is most commonly diagnosed in genito-urinary medicine (GUM clinics) or elsewhere in secondary care settings, after which HIV positive patients may or may not inform their GP.(16) Practice software allows separate recording of the date of a diagnosis, and the date of a first consultation relating to that diagnosis. Therefore the GPRD patient record may in some cases give two different dates for first HIV diagnosis: an ‘event date’, (e.g. the date on which the diagnosis was made elsewhere) which could precede the ‘consultation date’ (e.g. date of first consultation in primary care when HIV was discussed and recorded by the GP). For this analysis we used the first date on which HIV positivity was recorded in the primary care record.

The Survey of Prevalent HIV Infections Diagnosed (SOPHID) is an annual survey of all persons attending at least once for HIV care in specialist services across the UK and represents the best available estimate of the diagnosed prevalence of HIV in the UK.(17) It was used as the denominator from which to estimate the proportion of HIV cases recorded in the primary care record. Individual anonymised data are collected and analysed by the Health Protection Agency. Mid-year population estimates were obtained from the UK’s Office of National Statistics (ONS) as the denominator for UK HIV prevalence estimates.

Other

For all analyses we defined the population of London as the five pre-2006 Strategic Health Authorities (SHAs), with all other UK regions classed as outside the capital, using data provided by the Office for National Statistics .

Data analysis was performed using STATA (version 9.0).

RESULTS

A total of 13.8 million person years of observation was available for males and 13.9 million for females. We identified 28,447 HIV tests in the GPRD during the study period 1995-2005. In 1995, 147 males and 45 females contributing data were recorded as HIV positive by the end of the year, and by 2005 this had risen to 776 and 413.

HIV testing in primary care

Figure 1 summarises trends in HIV testing during the study period, with rates for the age groups 16-44 and non-antenatal testing shown separately. The period 1995-2005 saw an 11-fold increase in HIV testing rates among males, and a 129-fold increase in all women, reaching 514.5 per 100,000 women in 2005. However when antenatal tests were excluded, the increase among females reduced to 19-fold, and annual testing rates remained lower in females (61.2 per 100,000 person-years) than in males (71.3 per 100,000 person-years) in 2005. Exact numbers are given in Web Table 1.

Tables 1a and 1b show HIV testing by age, sex and demographic characteristics. In 2005, testing incidence (excluding antenatal) among patients living in London was more than double the rate seen elsewhere in the UK in both sexes (IRR= 2.1 (95% CI 1.8, 2.4) and 2.2 (95% CI 1.9, 2.6) for males and females, respectively). Outside London, testing rates were highest among adults aged 25-34 in both sexes (156.2 and 162.3 per 100,000 person years respectively). However in London testing was higher among adults aged 35-44 among both males and females (263.9 and 271.9 per 100,000 person years respectively). Among females, testing varied by level of deprivation with more testing in deprived settings. Individuals in non-urban areas were less likely to test.

Prevalence of recorded HIV positive status in primary care, and how it compares with SOPHID data

Table 2 shows trends in the prevalence of recorded HIV positive status in the GPRD, separately and as a proportion of SOPHID cases. An estimated 50.7% (95% CI 47.9-53.7%) of HIV positive individuals had their status recorded in coded form in their primary care record in 2005, a proportion which changed little in the period between 1995 and 2005. Prevalence of HIV recorded in primary care increased in parallel with HIV diagnosed prevalence in SOPHID, but the proportion of diagnosed individuals having their HIV status recorded in primary care remained relatively constant. Throughout, recording remained lower in London than elsewhere, with the

proportion declining to 41.8% in 2005, by contrast with an increase to 60.1% outside the capital city.

Table 3 shows estimates of recorded positive status by age, sex and demographic characteristics in 2005. Recording was less likely for men and women aged 25-34 (36.4% males and 40.0% females), than older adults (61.0% males and 73.2% females over 45) or children under 16 (Table 3).

Discussion

HIV testing increased substantially, 11 fold in males and 19 fold in non-pregnant females, in the primary care setting between 1995 and 2005. These increases were small in comparison with increased antenatal testing.

Only half of all HIV positive individuals are recorded as such in the primary care records. This proportion remained consistently lower in London than elsewhere, and did not change despite rising prevalence over the decade.

This study provides the first nationally representative estimates of testing rates and recording of positive HIV status in primary care. Only a small proportion of HIV tests have traditionally been taken in primary care. Chadborn and colleagues estimated that 6.6% of tests in London and 13.0% of tests outside London were taken in this setting, in the decade to 2000.(16) A number of studies have confirmed that many late presenters, who face increased mortality, have consulted in primary care in the 12 months prior to diagnosis.(18;19) Our data demonstrate that while a large number of antenatal HIV tests are routinely documented in primary care, expansion of antenatal testing has not been accompanied by a wider step change in testing patterns.

The steady rates of recording in primary care, during a period in which HAART has transformed prognosis and increased prevalence are surprising, particularly in London. Lower recording in London may relate to lower disclosure rates, to patients' difficulties in accessing primary care, or fear of disclosure among migrants who continue to form a high proportion of all HIV cases and are often resident in London.(1) However, earlier studies demonstrated high rates of GP registration and consultation even among these vulnerable groups,(20;21) and this does not fully explain the low recorded rates seen in the capital. No data are available on patterns of computerised coding practice for HIV in primary care, and these may have changed over time.

While benefitting from nationally representative data, our study has a number of limitations. We may be underestimating HIV testing and disclosure in primary care, particularly in earlier years before widespread implementation of electronically recorded laboratory results, which are more likely to lead to a recorded test code than paper results. Antenatal testing may also be underestimated, since women can be tested elsewhere (e.g. a hospital or community antenatal

visits) and negative results may not appear in the primary care record. We have not sought to match our estimates to antenatal HIV testing surveillance for this reason. Not all cases of HIV disclosed to GPs will be coded as such in the notes – “euphemism” codes such as “chronic viral illness” may be used, information may be hidden in non-coded free text, or not recorded at all. Recorded HIV diagnoses are a combination of HIV incidence and prevalence, with patients registering, presenting and disclosing to GPs, and then GPs entering this onto the clinical record. Anecdotal information sought from general practitioners during the study suggests that recording practice has been variable, but that precise coding is more likely in recent years.

We also cannot reliably determine a true “incident” date of HIV diagnosis, nor which cases were diagnosed in primary care. Initial HIV positive tests from a laboratory are normally notified to a GP by telephone for confirmatory testing (which may then be conducted in GUM settings). These do not automatically generate a coded entry, and so cannot be distinguished from cases diagnosed elsewhere.

The lack of ethnicity data in the GPRD means that we cannot reliably interpret the relationship between our findings and recent demographic changes in the UK HIV epidemic. We were not able to explore the extent to which non-recording is concentrated in different ethnic groups, and in particular among black Africans who may have concerns about migration and health care entitlements, which discourage disclosure to the GP. Sexual orientation may not be known to the GP and we are unable to estimate recording or testing rates among men who have sex with men from our data. Finally, biases introduced by under-representation of London practices cannot be accurately assessed.

It is increasingly recognised in UK policy that normalisation of HIV testing in primary care, on the scale already seen in the context of antenatal care, will be required in order to reduce the pool of undiagnosed prevalence,(22;23) and national guidelines aimed at achieving this have recently been published.(10) The CDC in the United States recommends opt out HIV testing for all adults attending any healthcare facility, aimed at decreasing late presentation with symptomatic HIV/AIDS and onward transmission.(24) Given that a third of HIV infected individuals are undiagnosed, and a third of all those newly diagnosed present late in the course of their infection,(1;25), there is a need to expand HIV testing in primary care as well as other healthcare settings.

Surveillance of HIV testing in the primary care setting is essential to measure uptake and to ensure its feasibility, acceptability and cost-effectiveness. Our data demonstrate the feasibility of using large primary care databases to monitor testing rates at national level. Further work is needed on the mechanisms required to deliver increased HIV testing in primary care. Detailed studies that explore barriers to the recording of positive HIV status in primary care and its relationship to the delivery of care to HIV positive individuals could contribute to the planning of services for this group.

Competing interest statement

All authors declare that the answer to the questions on your competing interest form are all No and therefore have nothing to declare.

Guarantor

Jackie A Cassell

Contributors.

JC had the original idea for the study, and developed a detailed proposal for funding alongside CM, GR, MGB, VD, AMJ, SS, GH, TW and IP. Code lists were developed and refined by all members of the team, particularly MH, MGB, GH and JC. HE undertook all analyses under the supervision of CM and JC, with input from all other members of the team. VD and TC led the provision, use, analysis and interpretation of SOPHID data. HE wrote the first draft and all authors contributed to and commented on subsequent versions.

Ethics approval

No study specific ethical approval was required. The protocol was submitted to the Independent Scientific Advisory Committee for the GPRD, who approved it under delegated authority.

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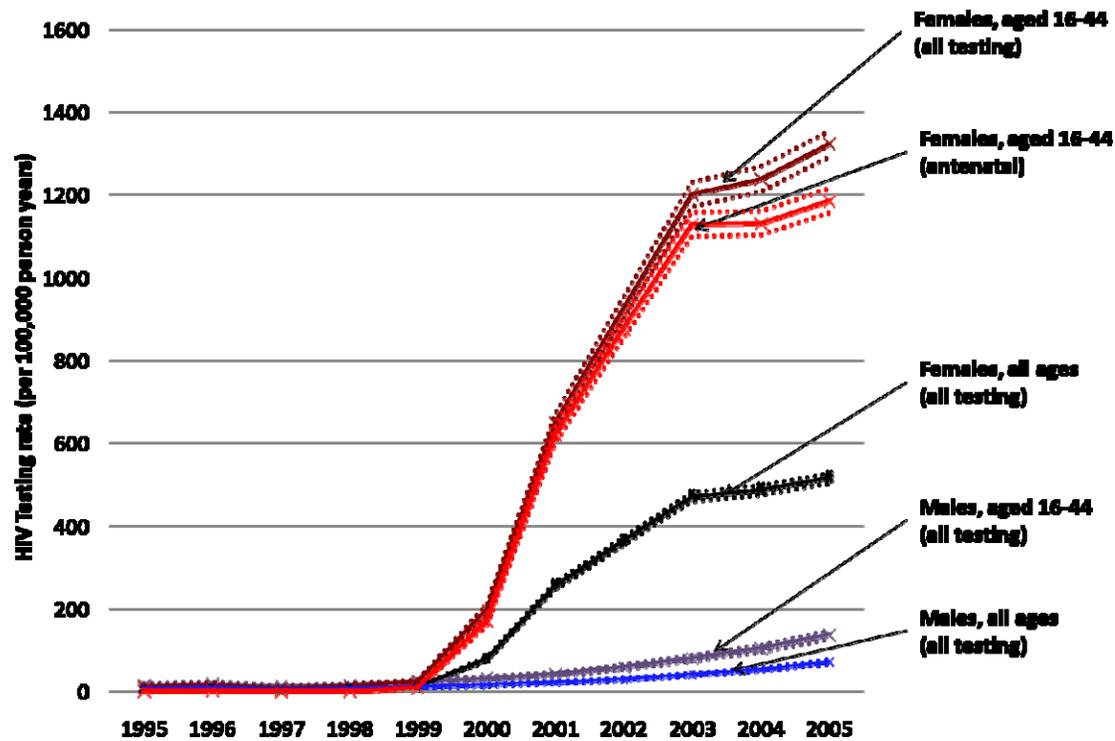
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Key points.

- Little is known about HIV testing in primary care, or the extent of disclosure of HIV positivity to GPs, despite the importance of early diagnosis.
- HIV testing rates in primary care increased slowly, but remained low in the decade to 2005, and were highest in young adults.
- GPs test for HIV more in London and other urban areas.
- Less than half of all HIV positive individuals are recorded as such by their GPs, and with a lower proportion in London where HIV is concentrated.

Figure 1: HIV testing in general practice, all ages and ages 16-44 years by gender ,and antenatal testing rates among females 16-44 between 1995-2005 with 95% CI.



Web Table 1: Rates (per 100,000 person-years) of HIV testing recorded in general practice among a) all males b) all females and c) non-antenatal testing (females only) 1995-2005.

	Year:	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
a) All males:												
Number of tests		55	74	52	79	137	211	315	435	594	777	1044
Rate		6.68	8.24	5.22	7.29	11.27	15.95	22.28	30.14	41.07	52.81	71.29
<i>95% CI lower bound</i>		<i>5.12</i>	<i>6.56</i>	<i>3.98</i>	<i>5.85</i>	<i>9.53</i>	<i>13.94</i>	<i>19.95</i>	<i>27.44</i>	<i>37.90</i>	<i>49.22</i>	<i>67.09</i>
<i>95% CI upper bound</i>		<i>8.69</i>	<i>10.35</i>	<i>6.85</i>	<i>9.09</i>	<i>13.32</i>	<i>18.25</i>	<i>24.88</i>	<i>33.11</i>	<i>44.51</i>	<i>56.66</i>	<i>75.75</i>
b) All females:												
Number of tests		34	55	27	61	129	1069	3705	5358	6932	7304	7699
Rate		3.99	5.92	2.62	5.46	10.29	78.53	255.45	363.08	469.69	486.55	514.46
<i>95% CI lower bound</i>		<i>2.85</i>	<i>4.55</i>	<i>1.80</i>	<i>4.25</i>	<i>8.66</i>	<i>73.96</i>	<i>247.35</i>	<i>353.48</i>	<i>458.76</i>	<i>475.52</i>	<i>503.10</i>
<i>95% CI upper bound</i>		<i>5.59</i>	<i>7.71</i>	<i>3.83</i>	<i>7.01</i>	<i>12.22</i>	<i>83.38</i>	<i>263.81</i>	<i>372.93</i>	<i>480.88</i>	<i>497.84</i>	<i>526.08</i>
c) Non-antenatal testing (females only):												
Number of tests		28	46	23	54	84	167	203	326	479	700	916
Rate		3.29	4.95	2.24	4.83	6.70	12.27	14.00	22.09	32.46	46.63	61.21
<i>95% CI lower bound</i>		<i>2.18</i>	<i>3.63</i>	<i>1.42</i>	<i>3.63</i>	<i>5.34</i>	<i>10.48</i>	<i>12.14</i>	<i>19.76</i>	<i>29.61</i>	<i>43.24</i>	<i>57.31</i>
<i>95% CI upper bound</i>		<i>4.75</i>	<i>6.61</i>	<i>3.36</i>	<i>6.30</i>	<i>8.29</i>	<i>14.28</i>	<i>16.06</i>	<i>24.62</i>	<i>35.50</i>	<i>50.22</i>	<i>65.30</i>

Table 1a): Rates (per 100,000 person-years) of HIV testing recorded in general practice in 2005 by age group, deprivation level and rural/urban indicators, stratified by London vs. outside of London-Males

	London			Outside Capital, UK		
	N	Rate (per 100,000 person-year)	IRR (95%CI)	N	Rate (per 100,000 person-year)	IRR (95%CI)
All	233	131.22		811	63.02	
Level of deprivation:						
Quintile 1 (Least deprived)	24	141.15	1 0.90	175	57.22	1 1.14
Quintiles 2-4	168	127.00	(0.59,1.38)	456	65.26	(0.96,1.36)
Quintile 5 (Most deprived)	41	144.95	1.03 (0.62,1.70)	179	63.41	1.11 (0.90,1.36)
			p=0.703			p=0.322
Rural\urban indicator:						
Urban	229	132.26	1 0.68	676	68.38	1 0.62
Intermediate	4	90.36	(0.25,1.84)	92	42.64	(0.50,0.77)
Rural	N\A*	N\A	N\A	42	50.90	0.74 (0.54,1.02)
						p<0.001
Age group:						
<16	12	31.40	1 1.61	68	21.05	1 2.75
16-19	6	86.39	(0.96,2.71)	18	33.97	(1.03,7.33)
20-24	15	159.41	4.54 (3.18,6.48)	55	95.53	5.08 (2.38,10.85)
25-34	58	189.38	7.45 (5.69,9.77)	228	156.20	6.03 (3.24,11.23)
35-44	87	263.91	6.32 (4.84,8.26)	258	133.10	8.41 (4.60,15.37)
45+	55	92.59	1.69 (1.28,2.24)	183	35.64	2.95 (1.58,5.51)
			p<0.001			p<0.001

* N/A signifies “not applicable”, since there are no areas in London classified as rural.

Table 1b): Rates (per 100,000 person-years) of HIV testing recorded in general practice in 2005 by age group, deprivation level and rural/urban indicators, stratified by London vs. outside of London - Females, excluding antenatal tests.

covariate	London				Outside Capital, UK			
	N	Rate (per 100,000 person-year)	IRR (95% CI)	p-value	N	Rate (per 100,000 person-year)	IRR (95% CI)	p-value
All	212	117.64 (102.82, 134.59)	--	--	704	53.48 (49.67, 57.58)	--	--
Level of deprivation:								
Quintile 1 (Least deprived)	21	114.81	1		135	43.15	1	
Quintiles 2-4	142	105.08	0.92 (0.58,1.45)		411	57.18	1.32 (1.09,1.61)	
Quintile 5 (Most deprived)	49	182.96	1.59 (0.96,2.66)	p=0.004	158	55.51	1.29 (1.02,1.62)	p=0.016
Rural\urban indicator:								
Urban	207	117.80	1		587	58.14	1	
Intermediate	5	111.45	0.95 (0.39,2.30)	p=0.903	90	40.60	0.70 (0.56,0.87)	
Rural	N\A	N\A	N\A		27	31.77	0.55 (0.37,0.80)	p<0.001
Age group:								
<16	6	16.44	1		64	21.40	1	
16-19	4	59.34	3.61 (1.02,12.79)		27	54.30	2.54 (1.62,3.98)	
20-24	27	246.27	14.98 (6.19,36.29)		70	118.05	5.52 (3.93,7.74)	
25-34	73	226.96	13.81 (6.01,31.74)		240	162.26	7.58 (5.76,9.99)	
35-44	81	271.90	16.54 (7.22,37.91)		200	105.13	4.91 (3.71,6.51)	

45+	21	32.79	1.99 (0.81,4.94)	p<0.001	103	18.07	0.84 (0.62,1.15)	p<0.001
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* N/A signifies “not applicable”, since there are no areas in London classified as rural.

Table 2: Prevalence of diagnosed HIV (SOPHID), HIV recorded in primary care (per 100,000 persons), and the proportion of HIV recorded in primary care, between 1995-2005 –a) London and b) outside London

	Year:	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
a) London												
Numbers in SOPHID		NA	8234	9252	10277	11531	12917	14505	16544	18824	20387	22228
Prevalence of diagnosed HIV (SOPHID) per 100,000 persons		NA	118.06	131.90	145.44	161.19	178.49	198.10	224.44	254.79	274.45	295.68
Numbers in GPRD		1	5	11	18	41	179	304	643	763	937	979
Prevalence of HIV recorded in primary care (GPRD) per 100,000 persons		43.12	42.24	47.92	52.50	60.10	84.56	78.66	88.04	101.40	113.48	123.43
	<i>95% CI, lower bound</i>	32.49	31.91	38.73	43.23	51.35	74.63	69.64	78.86	91.49	102.97	112.12
	<i>95% CI, upper bound</i>	56.13	54.86	58.64	63.17	69.91	95.44	88.53	97.99	112.10	124.77	135.58
% of HIV+ patients whose status is recorded in general practice		NA	35.78%	36.33%	36.10%	37.29%	47.37%	39.71%	39.23%	39.80%	41.35%	41.75%
	<i>95% CI, lower bound</i>	NA	27.03%	29.36%	29.72%	31.86%	41.81%	35.15%	35.14%	35.91%	37.52%	37.92%
	<i>95% CI, upper bound</i>	NA	46.47%	44.46%	43.44%	43.37%	53.47%	44.69%	43.66%	44.00%	45.46%	45.85%
b) Outside London												
Numbers in SOPHID		NA	6629	6818	7746	8856	10107	12096	15258	18274	21790	25116
Prevalence of diagnosed HIV (SOPHID) per 100,000 persons		NA	12.95	13.29	15.07	17.19	19.57	23.36	29.37	35.03	41.58	47.67
Numbers in GPRD		88	124	68	122	225	1101	3715	5146	6759	7137	7759
Prevalence of HIV recorded in primary care (GPRD) per 100,000 persons		8.90	8.99	9.43	9.36	10.81	10.66	12.57	14.79	18.43	23.06	28.65
	<i>95% CI, lower bound</i>	7.47	7.62	8.08	8.07	9.48	9.38	11.22	13.33	16.80	21.25	26.64
	<i>95% CI, upper bound</i>	10.52	10.55	10.94	10.81	12.28	12.06	14.03	16.36	20.17	24.98	30.77
% of HIV+ patients whose status is recorded in general practice		NA	69.44%	70.95%	62.14%	62.92%	54.46%	53.81%	50.35%	52.61%	55.46%	60.11%
	<i>95% CI, lower bound</i>	NA	58.81%	60.77%	53.53%	55.17%	47.94%	48.06%	45.39%	47.96%	51.10%	55.89%
	<i>95% CI, upper bound</i>	NA	81.44%	82.35%	71.75%	71.47%	61.61%	60.06%	55.70%	57.59%	60.09%	64.56%

Notes for Tables 2 and 3:

The denominator used for the prevalence of diagnosed HIV (from SOPHID) was the estimated population mid-year provided by the Office of National Statistics.

The denominator used for the prevalence of HIV recorded (GPRD) was the number of patients registered mid-year.

Due to old geography codes and poor quality of the data in 1995, prevalence by region is not shown for this year.

Table 3: Prevalence of recorded diagnosed HIV in primary care (per 100,000 persons), and the estimated proportion of HIV recorded in primary care in 2005 –among a) males and b) females by age group.

	Age (years), grouped:	<16	16-24	25-34	35-44	45+
a) Males						
Number in SOPHID		631	878	6632	13588	9408
Prevalence of diagnosed HIV (SOPHID) per 100,000 persons		10.61	24.30	168.63	296.76	83.22
Number in GPRD		30	12	107	328	299
Prevalence of HIV recorded in primary care (GPRD) per 100,000 persons		8.39	9.54	61.38	143.94	50.85
	<i>95% CI, lower bound</i>	<i>5.66</i>	<i>4.93</i>	<i>50.31</i>	<i>128.78</i>	<i>45.25</i>
	<i>95% CI, upper bound</i>	<i>11.98</i>	<i>16.67</i>	<i>74.18</i>	<i>160.39</i>	<i>56.95</i>
% of HIV+ patients whose status is recorded in general practice		79.08%	39.26%	36.40%	48.50%	61.10%
	<i>95% CI, lower bound</i>	<i>53.35%</i>	<i>20.29%</i>	<i>29.83%</i>	<i>43.40%</i>	<i>54.37%</i>
	<i>95% CI, upper bound</i>	<i>112.89%</i>	<i>68.59%</i>	<i>43.99%</i>	<i>54.05%</i>	<i>68.43%</i>
b) Females						
Number in SOPHID		636	1189	5967	6147	2264
Prevalence of diagnosed HIV (SOPHID) per 100,000 persons		11.25	34.27	150.55	131.72	17.88
Number in GPRD		25	23	108	172	85
Prevalence of HIV recorded in primary care (GPRD) per 100,000 persons		7.53	18.42	60.21	77.51	13.08
	<i>95% CI, lower bound</i>	<i>4.87</i>	<i>11.68</i>	<i>49.40</i>	<i>66.36</i>	<i>10.45</i>
	<i>95% CI, upper bound</i>	<i>11.11</i>	<i>27.64</i>	<i>72.70</i>	<i>90.00</i>	<i>16.18</i>
% of HIV+ patients whose status is recorded in general practice		66.87%	53.76%	40.00%	58.85%	73.18%
	<i>95% CI, lower bound</i>	<i>43.28%</i>	<i>34.08%</i>	<i>32.81%</i>	<i>50.38%</i>	<i>58.46%</i>
	<i>95% CI, upper bound</i>	<i>98.72%</i>	<i>80.66%</i>	<i>48.29%</i>	<i>68.33%</i>	<i>90.49%</i>

Web Appendix 1: Read & OXMIS codes denoting an HIV test used to identify patients who have ever had a HIV test recorded in primary care.

Code	READ/ OXMIS	Code description	Certainty of HIV+ test
6827.11	READ	HIV screening	Definite
43C..00	READ	HTLV-3 antibody test	Definite
43C..11	READ	Aids antibody test	Definite
43C..12	READ	Human immunodeficient viral test	Definite
43C1.00	READ	Blood sent for HTLV-3 serology	Definite
43C2.00	READ	HTLV-3 antibody negative	Definite
43C2.11	READ	HIV negative	Definite
43CZ.00	READ	HTLV-3 antibody NOS	Definite
43d5.00	READ	HIV antibody/antigen (Duo)	Definite
43d6.00	READ	HTLV 1 antibody level	Ambiguous
43dc.00	READ	HTLV 2 antibody level	Ambiguous
43h2.00	READ	HIV 1 PCR	Definite
43j7.00	READ	HIV 1 nucleic acid detection	Definite
43V1.00	READ	Absolute CD4 count	Definite
43VE.00	READ	CD4/CD8 ratio	Definite
43VH.00	READ	Percentage CD4 count	Definite
43Vo.00	READ	Absolute CD4 (T4 cells) count	Definite
43Vp.00	READ	Percentage CD4 (T4 cells) count	Definite
43W7.00	READ	HIV1 antibody level	Definite
43W8.00	READ	HIV2 antibody level	Definite
43WK.00	READ	Human immunodeficiency virus antibody level	Definite
4J34.00	READ	HIV viral load	Definite
4J35.00	READ	HIV p24 antigen level	Definite
4JDT.00	READ	HIV serology	Definite
4JR7.00	READ	HIV screening test	Definite
62b..00	READ	Antenatal HIV screening	Definite
6827.00	READ	AIDS (HTLV-III) screening	Definite
R109.00	READ	[D]Laboratory evidence of human immunodeficiency virus [HIV]	Definite
ZV01800	READ	[V]Human immunodeficiency virus - negative	Definite
ZV73700	READ	[V]Special screening exam for human immunodeficiency virus	Definite
L1111PV	OXMIS	HIV ANTIBODY TEST POSITIVE	Definite
L 153P	OXMIS	HTVL-AIDS-III ANTIBODY TEST POSITIVE	Definite
L 153	OXMIS	HTVL-AIDS-III ANTIBODY TEST	Definite
L1111NE	OXMIS	HIV ANTIBODY TEST NEGATIVE	Definite
L 153N	OXMIS	HTVL-AIDS-III ANTIBODY TEST NEGATIVE	Definite
65VE.00	READ	Notification of AIDS	Ambiguous
43j8.00	READ	HTLV 1 nucleic acid detection	Ambiguous

Web Appendix 2: Read & OXMIS codes denoting HIV positive status used to identify HIV positive patients who have their HIV positive status recorded in primary care.

Code	Read/OXMIS	Code description	Certainty of HIV+ status
65QA.00	READ	AIDS carrier	Definite
A789700	READ	HIV disease resulting other ypes of non-Hodgkin's lymphoma	Definite
A789800	READ	HIV disease resulting in multiple malignant neoplasms	Definite
A788.00	READ	Acquired immune deficiency syndrome	Definite
A788500	READ	Human immunodeficiency virus with secondary infection	Definite
A788X00	READ	HIV disease resulting/unspcf infectious+parasitic disease	Definite
A789200	READ	HIV disease resulting in candidiasis	Definite
A789500	READ	HIV disease resulting in Kaposi's sarcoma	Definite
AyuC100	READ	[X]HIV disease resulting in other viral infections	Definite
AyuC700	READ	[X]HIV dis reslt/oth mal neopl/lymph,h'matopoetc+reltd tissu	Definite
A788000	READ	Acute human immunodeficiency virus infection	Definite
A788100	READ	Asymptomatic human immunodeficiency virus infection	Definite
A789300	READ	HIV disease resulting in Pneumocystis carinii pneumonia	Definite
A789600	READ	HIV disease resulting in Burkitt's lymphoma	Definite
A798.00	READ	Retrovirus infection	Definite
AyuC200	READ	[X]HIV disease resulting in other mycoses	Definite
AyuCA00	READ	[X]HIV disease resulting in multiple diseases CE	Definite
A788U00	READ	HIV disease result/haematological+immunologic abnorms,NEC	Definite
A789.00	READ	Human immunodef virus resulting in other disease	Definite
AyuC000	READ	[X]HIV disease resulting in other bacterial infections	Definite
AyuC800	READ	[X]HIV disease resulting in other malignant neoplasms	Definite
43C3.11	READ	HIV positive	Definite
A788y00	READ	Human immunodeficiency virus with other clinical findings	Definite
Eu02400	READ	[X]Dementia in human immunodef virus [HIV] disease	Definite
ZV01A00	READ	[V]Asymptomatic human immunodeficiency virus infection status	Definite
A789400	READ	HIV disease resulting in multiple infections	Definite
AyuC500	READ	[X]HIV disease resulting/unspcf infectious+parasitic disease	Definite
AyuC900	READ	[X]HIV disease resulting in unspecified malignant neoplasm	Definite
AyuCC00	READ	[X]HIV disease resulting in other specified conditions	Definite
43C3.00	READ	HTLV-3 antibody positive	Definite
A788W00	READ	HIV disease resulting in unspecified malignant neoplasm	Definite
A789X00	READ	HIV dis reslt/oth mal neopl/lymph,h'matopoetc+	Definite
AyuC300	READ	[X]HIV disease resulting in multiple infections	Definite
AyuC400	READ	[X]HIV disease resulting/other infectious+parasitic diseases	Definite
AyuC600	READ	[X]HIV disease resulting in other non-Hodgkin's lymphoma	Definite
A788600	READ	Human immunodeficiency virus with secondary cancers	Definite
A788z00	READ	Acquired human immunodeficiency virus infection syndrome NOS	Definite
A789A00	READ	HIV disease resulting in wasting syndrome	Definite
65VE.00	READ	Notification of AIDS	Definite
A788.11	READ	Human immunodeficiency virus infection	Definite
A788200	READ	HIV infection with persistent generalised lymphadenopathy	Definite
A788300	READ	Human immunodeficiency virus with constitutional disease	Definite
A788400	READ	Human immunodeficiency virus with neurological disease	Definite

Web Appendix 2 (CONT'D): Read & OXMIS codes denoting HIV positive status used to identify HIV positive patients who have their HIV positive status recorded in primary care.

Code	Read/ OXMIS	Code description	Certainty of HIV+ status
A788V00	READ	HIV disease resulting in multiple diseases CE	Definite
A789100	READ	HIV disease resulting in cytomegaloviral disease	Definite
AyuC.00	READ	[X]Human immunodeficiency virus disease	Definite
AyuCD00	READ	[X]Unspecified human immunodeficiency virus [HIV] disease	Definite
A789000	READ	HIV disease resulting in mycobacterial infection	Definite
A789900	READ	HIV disease resulting in lymphoid interstitial pneumonitis	Definite
AyuCB00	READ	[X]HIV disease result/haematological+immunologic abnorms,NEC	Definite
R109.00	READ	[D]Laboratory evidence of human immunodeficiency virus [HIV]	Definite
ZV01A00	READ	[V]Asymptomatic human immunodeficiency virus infection status	Definite
799MD	OXMIS	AIDS	Definite
799CA	OXMIS	AIDS CARRIER	Definite
L1111PV	OXMIS	HIV ANTIBODY TEST POSITIVE	Definite
L7990A	OXMIS	ACQUIRED IMMUNE DEFICIENCY SYNDROME	Definite
L 153P	OXMIS	HTVL-AIDS-III ANTIBODY TEST POSITIVE	Definite
43V1.00	READ	Absolute CD4 count	Ambiguous
AyuD800	READ	[X]Retrovirus infections, not elsewhere classified	Ambiguous
AyuKM00	READ	[X]Retrovirus/cause of diseases classified to other chapters	Ambiguous
43VE.00	READ	CD4/CD8 ratio	Ambiguous
A7y0100	READ	Retrovirus as cause of diseases classified to other chapters	Ambiguous
43VH.00	READ	Percentage CD4 count	Ambiguous
4J34.00	READ	HIV viral load	Ambiguous
4J35.00	READ	HIV p24 antigen level	Ambiguous
43h2.00	READ	HIV 1 PCR	Ambiguous
43j7.00	READ	HIV 1 nucleic acid detection	Ambiguous
43Vo.00	READ	Absolute CD4 (T4 cells) count	Ambiguous
43Vp.00	READ	Percentage CD4 (T4 cells) count	Ambiguous

Reference List

- (1) The UK Collaborative Group for HIV and STI Surveillance. Testing Times. HIV and other Sexually Transmitted Infections in the United Kingdom:2007. London: Health Protection Agency, Centre for Infections.; 2007.
- (2) Cartledge JD, Weller IV. Shared care in HIV and AIDS: shifting care or shifting costs? *Journal of the Royal College of Physicians of London* 1998 Jul;32(4):376-9.
- (3) Singh S. Personal Communication. 2009.
- (4) Smith S, Robinson J, Hollyer J, Bhatt R, Ash S, Shaunak S. Combining specialist and primary health care teams for HIV positive patients: retrospective and prospective studies. *BMJ* 1996 Feb 17;312(7028):416-20.
- (5) Chadborn TR, Delpech VC, Sabin CA, Sinka K, Evans BG. The late diagnosis and consequent short-term mortality of HIV-infected heterosexuals (England and Wales, 2000-2004). *AIDS* 2006 Nov 28;20(18):2371-9.
- (6) NHS Executive. Reducing mother to baby transmission of HIV. London: Department of Health; 2008. Report No.: HSC 1999/183.
- (7) Mercey D. Antenatal HIV testing. *BMJ* 1998 Jan 24;316(7127):241-2.
- (8) Jones S, Sadler T, Low N, Blott M, Welch J. Does uptake of antenatal HIV testing depend on the individual midwife? Cross sectional study. *BMJ* 1998 Jan 24;316(7127):272-3.
- (9) Townsend CL, Cliffe S, Tookey PA. Uptake of antenatal HIV testing in the United Kingdom: 2000-2003. *J Public Health* 2006 Sep;28(3):248-52.
- (10) British Association for HIV, British Association for Sexual Health and HIV, British Infection Society. UK National Guidelines for HIV Testing 2008. 2008 Sep.
- (11) Chief Medical Officer Letter. Improving the detection and diagnosis of HIV on non-HIV specialities including primary care. Gateway reference no: 8519. 13th Sept 2007. 2007. London, Department of Health.
- (12) Sudarshi D, Pao D, Murphy G, Parry J, Dean G, Fisher M. Missed opportunities for diagnosing primary HIV infection. *Sexually Transmitted Infections* 2008 Feb 1;84(1):14-6.
- (13) Sullivan AK, Curtis H, Sabin CA, Johnson MA. Newly diagnosed HIV infections: review in UK and Ireland. *BMJ* 2005 Jun 4;330(7503):1301-2.

- (14) Majeed A. Sources, uses, strengths and limitations of data collected in primary care in England. *Health Statistics Quarterly* (21):5-14, 2004.
- (15) Department of Health NCfCaC. Read/ICD-10 joint training project: Read codes in use. 1997.
- (16) Chadborn TR, McGarrigle CA, Waight PA, Fenton KA. Trends in, and determinants of, HIV testing at genitourinary medicine clinics and general practice in England, 1990-2000. *Sexually Transmitted Infections* 2004 Apr 1;80(2):145-50.
- (17) Health Protection Agency. Numbers Accessing HIV Care. Health Protection Agency 2007 [accessed 2007 Oct 12]; Available from: URL: http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/Stats/HIV/Care/default.htm
- (18) Sullivan AK, Curtis H, Sabin CA, Johnson MA. Newly diagnosed HIV infections: review in UK and Ireland. *BMJ* 2005 Jun 4;330(7503):1301-2.
- (19) Gilbert VL, Dougan S, Sinka K, Evans BG. Late diagnosis of HIV infection among individuals with low, unrecognised or unacknowledged risks in England, Wales and Northern Ireland. *AIDS Care* 2006 Feb;18(2):133-9.
- (20) Anderson J, Doyal L. Women from Africa living with HIV in London: a descriptive study. *AIDS Care* 2004 Jan;16(1):95-105.
- (21) Madge S, Olaitan A, Mocroft A, Phillips A, Johnson M. Access to medical care one year prior to diagnosis in 100 HIV-positive women. *Fam Pract* 1997 Jun;14(3):255-7.
- (22) Department of Health. The national strategy for sexual health and HIV. London: Department of Health; 2001 Jul.
- (23) Donaldson L. Improving the detection and diagnosis of HIV in non-HIV specialties including primary care. London: Department of Health; 2007.
- (24) Branson B, Handsfield HH, Lampe MA, Janssen RS, Taylor A, Lyss S, et al. Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings. *MMWR* 2006;55((RR14)):1-17.
- (25) Sullivan AK, Curtis H, Sabin CA, Johnson MA. Newly diagnosed HIV infections: review in UK and Ireland. *BMJ* 2005 Jun 4;330(7503):1301-2.