

Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK

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Objective: To identify opportunities for earlier HIV diagnosis within primary and secondary care settings in the UK in Africans with newly diagnosed HIV infection.

Methods: A survey of newly diagnosed HIV-positive Africans attending 15 HIV treatment centres across London was conducted between April 2004 and February 2006. The survey consisted of a confidential self-completed questionnaire linked to clinician-completed clinical records.

Results: A total of 263 questionnaires were completed, representing an uptake rate of 79.5% of patients approached and 49.8% (131/263) of participants presented with advanced HIV disease (CD4 cell count < 200 cells/ μ l at diagnosis). In the year prior to HIV diagnosis 76.4% (181/237) had seen their GP, 38.3% (98/256) had attended outpatient services, and 15.2% (39/257) inpatient services, representing missed opportunities for earlier HIV diagnosis. Of those attending GP services the issue of HIV and/or HIV testing was raised for 17.6% (31/176) and 37.1% (78/210) had a previous negative HIV test, 32.5% of these within the UK. Medical attention was sought for wide ranging reasons, often not obviously connected to underlying HIV status. Despite the population predominantly coming from countries of high HIV prevalence personal appreciation of risk was comparatively low and knowledge of benefits of testing lacking.

Conclusion: Africans are accessing health services but clinicians are failing to use these opportunities effectively for preventive and diagnostic purposes with regards to HIV infection. Comparatively low appreciation of personal risk and lack of perceived ill health within this community means clinicians need to be more proactive in addressing HIV.

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AIDS 2008, **22**:115–122

Keywords: Africans, healthcare access, HIV/AIDS, knowledge and attitudes, UK

Introduction

It is known that Africans with HIV infection in the UK access HIV services at a later stage of HIV disease than non-Africans [1–3], which denies them optimal therapeutic options and may hinder prevention efforts. The

extent of missed opportunities within primary and secondary healthcare settings for earlier diagnosis within Britain is not known. The term ‘secondary care’ refers to services provided by medical specialists who generally do not have first contact with patients (e.g., cardiologists, urologists, dermatologists). In the UK patients must first

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Received: 9 January 2007; revised: 4 July 2007; accepted: 11 July 2007.

seek care from primary care providers (general practitioners) and are then referred to secondary and/or tertiary providers, as needed.

In the UK there are now more heterosexually acquired HIV infections diagnosed than those acquired through sex between men. The majority of heterosexually acquired HIV is within the African communities [4]. Whereas the proportion of men who have sex with men who present late (CD4 cell count < 200 cells/ μ l) to HIV services has gradually reduced from approximately 30 to 20% over the past decade, there has been no such decline within the heterosexual community with between 40 and 50% continuing to present late [4]. HIV-infected individuals diagnosed late were approximately 8–10 times more likely to die within 1 year of diagnosis than those not diagnosed late [5,6]. Research in men who have sex with men suggests that earlier diagnosis could reduce short-term mortality by 56 to 84% and all mortality by 32% [5,6]. Late diagnosis not only denies an individual optimum therapy options, but also reflects missed opportunities to limit onward transmission. Work exploring missed opportunities for earlier diagnosis within the UK is extremely limited [7,8]. We sought to identify opportunities for earlier HIV diagnosis within primary and secondary care settings in the UK, and to identify factors related to these missed opportunities, in Africans with newly diagnosed HIV infection.

Methods

Participants

As part of the 'Study of newly diagnosed HIV infection among Africans in London' (the SONHIA study), a survey of newly diagnosed HIV-positive Africans attending 15 HIV treatment centres across London was conducted between April 2004 and February 2006. For the purposes of this study Africans were defined as persons born or raised in Africa, and as such included persons of all racial and ethnic groups. Participants had to be within 12 months of initial HIV diagnosis and aged 18 years or older. Patients diagnosed longer than 12 months but transferring to the study centre during the study period were excluded. Patients identified as eligible had their medical notes 'flagged' to alert clinicians to refer them at an 'appropriate time' to the study team for recruitment. Written informed consent was obtained from all those participating. If patients were not referred to the study team within the 12 months following diagnosis they were classified as not approached.

Study instruments

The survey consisted of a self-completed pen and paper questionnaire, available in English or French, linked to clinician-completed clinical records. The confidential questionnaire was designed to obtain quantitative data on demographic characteristics, utilization of health

services prior to HIV diagnosis; behavioural and social factors associated with delayed presentation to treatment services, sexual health and behaviour, HIV history, antiretroviral drug history, and to assess knowledge, attitudes and beliefs around HIV/AIDS. The questionnaire took approximately 40 min to complete and all respondents were provided a £10 token of appreciation.

Whenever possible questions were taken from other large-scale surveys of health service utilization, and sexual attitudes and lifestyles; for example, The British National Survey of Sexual Attitudes & Lifestyles (Natsal 2000) [9] and the MAYISHA study [10], as these questionnaires have undergone thorough validation and reliability testing. An African Community Reference Group was set-up to approve, review and oversee all stages of the study to ensure that the content, construct and context were appropriate. Piloting was undertaken before embarking upon full-scale recruitment in order to test the feasibility of survey procedures and their acceptability to patients. The pilot explored patients' understanding of the questionnaire's items and constructs.

Statistical analysis

Data were entered onto a secure database and systematically checked for errors prior to statistical analysis. The principal outcome measure was late presentation, defined as a CD4 cell count of < 200 cells/ μ l on the first available sample following HIV diagnosis. For descriptive analyses standard bivariate statistical tests for example, the χ^2 test and *t*-test, were calculated unless numbers were small ($n < 25$) when Fishers exact test was used. Logistic regression modelling was used to obtain odds ratios. Statistical significance was defined at 0.05. Our power calculations assumed late presentation would have a population prevalence of 40%. To have 80% power to detect any significant associations of moderate strength a sample size of 250 was required. Analysis was performed using Intercooled STATA 8.0 (STATA Corp., College Station, Texas, USA) and SPSS12.0 (SPSS Inc., Chicago, Illinois, USA).

Ethics

The study was granted approval from the London Multicentre Research Ethics Committee (MREC/03/2/105).

Role of the funding source

The sponsor of the study had no role in study design; the collection, analysis or interpretation of the data; the writing of the report; or the decision to submit the paper for publication.

Results

Of 710 potentially eligible patients 109 (15.4%) were lost to follow-up and 17 (2.3%) had died before they could be

approached regarding the study. Sixty percent (352/584) of remaining patients were approached. The uptake rate was 79.5% (280/352) and 263 questionnaires were available for analysis. Patients not approached did not differ significantly from those participating in terms of gender or age. The median CD4 cell count of those participating was 200 cells/ μ l whereas for those not approached it was 260 cells/ μ l. The median time between HIV diagnosis and questionnaire completion was 3.5 months.

Approximately 50% (131/263) of participants presented with late stage disease. The median age was 34 years, 62.5% (159/263) were women, 71.1% came from countries with an HIV prevalence greater than 15%, and the median time in the UK prior to diagnosis was 3.9 years (Table 1). Primary care use was high with 84.6% (220/260) being registered with a general practitioner (GP) for a median of 3 years. In the year prior to HIV diagnosis 76.4% (181/237) had seen their GP, 38.3% (98/256) had attended outpatient services, and 15.2%

Table 1. Characteristics of Africans with newly diagnosed HIV infection.

Characteristic ^a	Total	with CD4 < 200 cells/ μ l at presentation ^b
Number of participants	263	131 (49.8)
Gender		<i>P</i> -value ^b = 0.420
Male	104 (39.5)	55 (52.9)
Female	159 (60.5)	76 (47.8)
Age (years):		<i>P</i> = 0.579
< 35	133 (50.6)	64 (48.1)
35+	130 (49.4)	67 (51.5)
Ethnicity:		<i>P</i> = 0.216
Black African	246 (93.5)	125 (50.8)
Other (e.g. black British, mixed, White, Asian, Arab)	17 (6.5)	6 (35.3)
Sexuality (n = 253):		<i>P</i> = 0.016
Heterosexual	234 (92.5)	121 (51.7)
Bi or Homosexual	19 (7.5)	6 (21.1)
HIV prevalence ^c of country of birth		<i>P</i> = 0.131
High (> 15%)	187 (71.1)	93 (49.7)
Moderate (5–15%)	61 (23.2)	27 (44.3)
Low (< 5%)	15 (6.7)	11 (73.3)
Time in UK before HIV diagnosis:		<i>P</i> = 0.798
3 or more years	166 (63.4)	82 (49.4)
< 3 years	96 (36.6)	49 (51.0)
Currently:		<i>P</i> = 0.445
Living in the UK	202 (76.8)	98 (48.5)
Other (e.g. studying, short term-work contract, visiting)	61 (23.2)	33 (54.1)
Residency status in the UK (n = 260)		<i>P</i> = 0.808
Indefinite right to remain (British citizen, EEC member, Permanent resident, refugee)	125 (48.1)	63 (50.4)
Other (e.g. visa entry, asylum seeker, applying for visa, illegal)	135 (51.9)	66 (48.9)
Registered with general practitioner (n = 260)		<i>P</i> = 0.530
No	40 (15.4)	18 (45.0)
Yes	220 (84.6)	111 (50.5)
General practitioner visits in year before HIV diagnosis (n = 237):		<i>P</i> = 0.023
None	79 (33.3)	35 (44.3)
1–2	80 (33.8)	33 (41.3)
3 or more	78 (32.9)	48 (61.5)
Median number of general practitioner visits (range)	2 (0–18)	
Attended general practitioner in 2 years before HIV diagnosis (n = 257)		<i>P</i> = 0.493
No	64 (24.9)	29 (45.3)
Yes	193 (75.1)	97 (50.3)
Inpatient in year prior to HIV diagnosis (n = 257)		<i>P</i> = 0.080
No	218 (84.8)	101 (46.3)
Yes	39 (15.2)	24 (61.5)
Outpatient in year prior to HIV diagnosis (n = 256)		<i>P</i> = 0.844
No	158 (61.7)	77 (48.7)
Yes	98 (38.3)	49 (50.0)
Illness or accident affecting health for at least 3 months in the last 5 years (excluding HIV) (n = 257)		<i>P</i> = 0.003
No	194 (75.5)	85 (43.8)
Yes	63 (24.5)	41 (65.1)
Attended antenatal care in UK in past 5 years (n = 259)		<i>P</i> = 0.922
No	232 (89.6)	114 (49.1)
Yes	27 (10.4)	13 (48.2)
Previous negative HIV test ^d (n = 210)		<i>P</i> = 0.035
No	132 (62.9)	74 (56.1)
Yes	78 (37.1)	32 (41.0)

continued

Table 1 (continued)

Characteristic ^a	Total	with CD4 < 200 cells/ μ l at presentation ^b
Last negative test in UK ($n = 77$)		$P = 0.897$
Yes	25 (32.5)	10 (40.0)
No	52 (67.5)	20 (38.5)
HIV testing mentioned by general practitioner in past year ^d ($n = 176$)		$P = 0.650$
No	145 (82.4)	73 (50.3)
Yes	31 (17.6)	17 (54.8)
CD4 cell count at diagnosis (cells/ μ l)		Not applicable
0–49	52 (19.8)	52 (19.8)
50–199	79 (30.0)	79 (30.0)
200–349	64 (24.3)	0
350+	68 (25.9)	0
Median (range)	200 (0–1333)	
HIV viral load at diagnosis (copies/ml) ($n = 247$)		$P < 0.001$
< 10 000	63 (25.5)	10 (15.9)
10 000 to < 100 000	109 (44.1)	50 (45.9)
100 000+	75 (30.4)	57 (76.0)
CDC classification at diagnosis ^e		$P < 0.001$
A (asymptomatic)	141 (53.8)	38 (27.0)
B (symptomatic)	63 (24.0)	48 (76.2)
C (AIDS defining illness)	58 (22.1)	44 (75.9)

Values are numbers (percentages) and $n = 263$ unless otherwise stated.

^aBase varies due to missing values and excludes those reporting 'don't know' unless otherwise stated.

^bComparing subcategories within each explanatory variable with late presentation.

^cHIV prevalence (%) adults aged 15–49 at end of 2003 according to UNAIDS.

^dExcludes those not attending but not those who were unsure how many visits they had made to the general practitioner in the past year.

^eCenters for Disease Control (CDC) disease stage.

(39/257) inpatient services. Of those attending GP services the issue of HIV and/or HIV testing was raised for 17.6% (31/176). Thirty seven percent (78/210) had a previous negative HIV test, and of these 32.5% (25/77) occurred within the UK.

Use of primary and secondary care services did not significantly differ in those presenting late in comparison with those not presenting late [primary care odds ratio (OR), 1.22; 95% confidence interval (CI), 0.69–2.15; inpatient use OR, 1.85; 95% CI, 0.92–3.72; outpatient use OR, 1.05; 95% CI, 0.64–1.74]. Similarly GPs mentioning HIV was not associated with late presentation (OR, 1.2; 95% CI, 0.55–2.61). People who had a prior negative HIV test were less likely to present late (OR 0.55; 95% CI, 0.31–0.96); this did not depend on whether the test was in the UK or abroad (OR, 0.94; 95% CI, 0.35–2.49). The median time between last negative HIV test and testing HIV positive was 2.8 years for those who been previously tested.

Whereas 89.6% (233/260) trusted the staff at their HIV clinics, 39.6% (97/245) trusted the staff at their GP surgery. The principal concerns were lack of confidentiality (54.1%), behaviour and attitudes of reception staff (53.2%), discrimination (33.0%) and lack of knowledge about HIV (30.3%). Thirty six percent (78/214) of respondents had disclosed their HIV status to their GP.

Neither the type of health service nor the number of different services attended was associated with either the

site of (e.g. in hospital), or reason for (e.g. advised to by doctor), their last HIV test. The reasons for seeking medical attention are presented in Table 2. No one reason for seeking medical care was found to be associated with late presentation. Although accessing of health services was high the majority [64.8% (169/261)] of participants rated their health status as excellent or very good 12 months prior to completion of the questionnaire. When asked to identify factors stopping earlier HIV testing the predominant factor identified was that they had not considered the possibility that they may be HIV positive [69.9% (179/256)] (Table 3). This was reflected in the fact that 64.4% (166/258) were not expecting a positive result at the time they tested HIV positive. A total of 59.1% (146/247) believed they would have tested earlier if someone had told them they were at risk of HIV (Table 3). Advice from a doctor (hospital, clinic or primary care-based) was the principal reason for having a HIV test for 40.2% (105/261) of respondents.

Discussion

Fifty percent of participants presented late to HIV services. High primary and secondary care use was found prior to HIV diagnosis representing missed opportunities for earlier HIV diagnosis. Primary care in particular was extremely well utilized by this high-risk population; however HIV testing was not broached by the GP for 82.4% (145/176) of Africans who subsequently tested HIV positive. Medical attention was sought for

Table 2. Summary of medical care prior to HIV diagnosis.

	Attended general practitioner in the 2 years prior to HIV diagnosis ^a	Attended outpatients in the year prior to HIV diagnosis ^a	Inpatient stay in the year prior to HIV diagnosis ^a
Total	193/257 (75.1)	98/256 (38.3)	39/257 (15.2)
Reason for seeking care ^b	<i>n</i> = 183	<i>n</i> = 92	<i>n</i> = 31
Dermatology	42 (23.0)	6 (6.5)	–
Gastroenterology	3 (1.6)	3 (3.3)	1 (3.2)
Hypertension and diabetes	6 (3.3)	6 (6.5)	–
Infectious causes			
Fever ?cause	3 (1.6)	–	4 (12.9)
Flu or chest infection ^c	84 (45.9)	17 (18.5)	2 (6.5)
Tuberculosis	–	0.5 (1)	–
Varicella zoster	3 (1.6)	1 (0.5)	1 (3.2)
Other (e.g. hepatitis, meningitis, sinusitis, syphilis)	3 (1.6)	11 (11.9)	3 (9.7)
Malaise	4 (2.2)	7 (7.6)	–
Neurological	7 (3.8)	1 (1.1)	–
Obstetrics, gynaecology and family planning	38 (20.8)	5 (5.4)	3 (9.7)
Psychiatric/depression	–	4 (4.3)	3 (9.7)
Surgical	3 (1.6)	6 (6.5)	9 (29.0)
Trauma/minor injury	12 (6.6)	4 (4.3)	–
Other	31 (16.9)	21 (22.8)	4 (12.9)

Values are numbers (percentages).

^aTotal greater than 100% as more than one reason could be listed.

^bPercentages are the proportion of those accessing that service with reason given.

^cIncluding pneumonia.

wide-ranging reasons, often not obviously connected to underlying HIV status. Despite the population predominantly coming from countries of high HIV prevalence personal appreciation of risk was comparatively low and knowledge lacking as to the benefits of HIV testing. Whereas people testing HIV positive after a previous negative test reflects failure in prevention messages, people who had previously tested for HIV (37.1%) were less likely to present to HIV services late. Confidentiality concerns meant trust and disclosure of HIV status to GPs was low.

Since 2000 there has been a 179% increase in heterosexual men and women seen for HIV care in the UK, the majority of whom are African [4]. High uptake of HIV

testing [11,12] and primary care services [13] by African communities have been known for some time, and Sullivan *et al.* [8] reported that 17% of newly diagnosed HIV-positive patients had sought medical care with symptoms suggestive of HIV in the 12 months preceding diagnosis. There has, however, been no other studies that have specifically explored the missed opportunities for earlier HIV diagnosis among Africans within primary and secondary care settings.

Our study had some limitations. The study design meant only those people already accessing care were eligible. This could introduce selection bias, it is possible that this population may be more favourably disposed to and eligible for medical services than those not accessing

Table 3. Factors influencing participants timing of HIV test^a.

	Factor	Main factor ^b
Factors stopping participants testing for HIV earlier	<i>n</i> = 256	<i>n</i> = 208
Had not considered possibility that may be HIV positive	69.9%	54.3%
Well so no need	51.2%	20.2%
Afraid of the result	28.1%	11.1%
Afraid of the stigma associated with HIV	28.9%	5.8%
Other ^c	33.1%	8.6%
Factors that would have made participants test for HIV earlier	<i>n</i> = 247	<i>n</i> = 213
If someone had told me that I was at risk	59.1%	49.3%
If felt would be supported if I tested HIV positive	31.2%	8.0%
If there was no stigma associated with HIV	36.8%	16.4%
If HIV was not so linked to sex	21.9%	6.6%
If knew medication for HIV was available	17.8%	6.6%
If knew it could reduce vertical transmission	11.7%	4.2%
Other factor	10.9%	8.9%

^aParticipants were asked to tick all factors that applied and to identify the single most important factor.

^bBase varies due to item non-response.

^cOther includes not wanting to go to a genitourinary medicine clinic, not knowing where to go, fear of losing a relationship, fear of influencing immigration process, the fact that some had previously tested for HIV so felt not applicable.

services. The 17 people who were potentially eligible but died before being approached may have differed in their opportunities for earlier diagnosis in comparison with the sampled population. As all of these patients died of advanced HIV-related diseases, if any missed opportunity for earlier diagnosis did exist this reflects a real failing on the part of our health services. If no such opportunity had existed then we must ask ourselves why someone who was likely to have been unwell had not been or felt able to seek medical care earlier. Similarly of concern is the substantial proportion (15.4%) of potentially eligible patients who became lost to clinic follow up. These people may also differ in comparison with the sampled population. Although getting people into HIV services earlier is the first step to improving clinical outcomes, this will only be achieved if people find services acceptable and are able to continue to access them. The study was limited to London and so was unable to assess if people moving away from their communities, as in the asylum dispersal scheme [14], had any impact on opportunities for earlier diagnosis.

As data were collected retrospectively recall bias may have occurred, especially for those in whom prior accessing of health services was associated with their HIV diagnosis. Any effect of this is, however, likely to have been small given that participants were surveyed within 12 months of HIV diagnosis (the median time between diagnosis and questionnaire completion was only 3.5 months) and questions around healthcare were deliberately restricted to a relatively narrow time frame. Finally the term 'African' comprises an aggregation of heterogeneous population subgroups. Although data were collected to explore the ethnic, cultural and temporal diversities of this population the study may have lacked power to fully explore their influences on missed opportunities for earlier diagnosis of HIV infection.

Despite these limitations, our findings add substantially to our understanding of health-seeking behaviours of Africans living in the UK. Our data suggest that rather than having poor access to health services, as reported for many migrant groups, Africans report higher rates of primary and secondary care attendance and HIV testing than the general population (F. Burns and C. Mercer, pers. comm. 2007). That Africans continue to present to HIV services with advanced disease despite accessing health services prior to diagnosis suggests HIV is often missed as a differential diagnosis, or that clinicians are either reluctant to address HIV or are doing so ineffectively. Similarly, that many Africans test HIV positive after a previous negative test, suggests these HIV prevention opportunities are not being used effectively.

The age and country of origin of participants alone should guide health practitioners to the possibility of HIV infection irrespective of health status. Although some of

the reasons for attending medical services may relate to HIV, many do not. Our findings suggest a proactive approach to HIV testing, as found in the antenatal setting, is required to minimize these missed opportunities for earlier diagnosis. A total of 37.1% of respondents reported a previous negative HIV test, and although the majority of these occurred in Africa, 32.5% had occurred in the UK. HIV infection risks are ongoing, with acquisition within the UK a real phenomenon for resident Africans. The continuing care relationship inherent in general practice provides an ideal context for ongoing HIV prevention messages. Similarly the majority of people came from countries with a high HIV prevalence but there was a comparatively low appreciation of personal risk, as reflected in the factors preventing earlier testing. Again primary care may be well placed to address these issues as it provides a setting for personalized and targeted health information. Advice from doctors, either primary or secondary care based, is influential with 40.2% primarily testing for HIV because of clinician recommendation.

Much of the failure to address the issue of HIV for this population may be the legacy of the HIV exceptionalism largely generated by HIV services over the past two decades. The whole process of HIV testing needs to be further normalized. Normalization refers to the process of treating HIV more like other infectious diseases for which early diagnosis is essential for appropriate therapeutic and preventive measures [15]. It encapsulates the notion that all doctors should be confident and competent at HIV testing and diagnosis. It also still incorporates the need for confidentiality and informed consent. The Centres for Disease Control and Prevention (CDC) now recommends that HIV screening be performed routinely in all health-care settings for 13–64 year olds [16]. GP's should be the first port of call for all health issues, including HIV. The ongoing care relationship provided by primary care services should lend itself to the provision of personalized ongoing HIV information and repeat screening opportunities. Work to address the concerns of service users around HIV and primary care is also required.

The National Strategy for Sexual Health and HIV [17] in 2001 set clear targets for HIV testing and reducing undiagnosed infection. In practice these recommendations have yet to be realized, probably because the low priority attributed to sexual health in most primary care trusts has resulted in lack of funds. Proposals to exclude overseas visitors from eligibility to free NHS primary medical service [18], designed to align primary care with hospital care, will further reduce opportunities for earlier diagnosis. A more positive approach would be to ensure that health services that are currently well utilized by this high-risk population have both the resources and incentives to effectively address HIV.

The key messages that are a result of the present study are listed here.

- (1) Late diagnosis of HIV increases HIV-associated morbidity and mortality and hinders prevention measures to limit onward transmission.
- (2) Africans in the UK access HIV services at a later stage of disease than non-Africans; missed opportunities for prevention messages and earlier HIV diagnosis within primary and secondary healthcare settings have not been fully identified for this population.
- (3) A total of 37.1% of newly diagnosed HIV-positive Africans had a previous negative HIV test, 32.5% of these within the UK.
- (4) Africans are accessing health services but clinicians are failing to use these opportunities effectively for preventive and diagnostic purposes with regard to HIV infection.
- (5) Primary care in particular is extremely well utilized by this high-risk population; however HIV testing was not broached for 82.4% of Africans who accessed GP services in the year prior to HIV diagnosis.

Acknowledgements

The authors would like to thank all those who participated in the study: C.M. Mercer and A. Copas for statistical support; the African HIV Research Forum steering committee; and staff at all participating centres: Archway Sexual Health Clinic: Denise Thorburn, Jo Baruah; Central Middlesex Hospital: Dr Gary Brook; Charing Cross Hospital: Dr John Wright, Dr Anil Rajkumar; Chelsea & Westminster Hospital: Dr Anton Pozniak; Homerton University Hospital: Nicky Hicky; Mortimer Market Centre: Dr Patrick French, Liz Kirkpatrick; Newham University Hospital: Cheryl Tawana; North Middlesex Hospital: Anele Waters, Fiona Young; St. Bartholomew's & the Royal London Hospitals: Are Isaksen; St. George's Hospital: Simone Ghosh, Ade Adebisi; St. Mary's Hospital: Dr Harpal Lamba, Julie Fowler; University College Hospital: Dr Rob Miller, Peter McKenzie; Victoria Clinic for Sexual Health: Tony Kerley; Watford District General Hospital: Dr Pat Munday; Whittington Hospital: Patricia Whyte.

Contributors: F.B. helped design the study, was responsible for study coordination, data collection, statistical analysis and was the lead writer of this paper. A.J., J.N. and K.F. on participated in the design of this study and preparation of this manuscript. The SONHIA collaboration group were responsible for managing the study, data collection, and preparation of this manuscript. All authors have seen and approved the final version of this manuscript.

The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication. The guarantor of the study is Dr Fiona Burns.

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Sponsorship: Dr Fiona Burns is supported by a Wellcome Training Fellowship (Grant 066866).

There are no conflicts of interest.

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