Title: Refusal of HIV testing among black Africans attending sexual health clinics in England, 2014

Running title: HIV test refusals in black Africans

Hamish Mohammed, Gavin Dabrera, Martina Furegato, Zheng Yin, Anthony Nardone and Gwenda Hughes

Public Health England, London, United Kingdom

Abstract

Objectives: Black Africans are one of the key risk groups for HIV in the UK and, among those living with HIV, 16% and 12% of black African heterosexual men and women, respectively, are undiagnosed and at risk of unknowingly transmitting HIV to their sex partners. Increased HIV test uptake is needed to address this, but there is limited information on how frequently HIV test refusal occurs among those attending sexual health clinics (SHCs). We identified factors associated with HIV test refusal among black African SHC attendees.

Methods: Data on all SHC attendances in England in 2014 were obtained from the genitourinary medicine clinic activity dataset (GUMCADv2), the mandatory surveillance system for sexually transmitted infections (STIs). Analyses were restricted to attendances by HIV-negative black Africans, and bivariate and multivariable associations between demographic and clinical characteristics and HIV test refusal were assessed. All associations were determined using generalised estimating equations logistic regression and adjusted odds ratios (aORs) with 95% confidence intervals (CIs) are reported.

Results: Black Africans made 80,743 attendances at SHCs in 2014 and refused an HIV test on 9,021 (11.2%) occasions. HIV test refusal was significantly more likely in women [aOR(95% CI): 1.54 (1.46-1.62) *vs*. heterosexual men], and those living in the most deprived areas [1.44 (1.24-1.67)], diagnosed with a new STI [1.26 (1.18-1.34)], or living in London [1.06 (1.01-1.12)]. Test refusal was significantly less likely with increasing age [0.99 (0.99-0.99)] and men who have sex with men [0.52 (0.43-0.63) *vs*. heterosexual men], and in those tested for HIV in the past year [0.85 (0.81-0.89)], born outside the UK [0.73 (0.69-0.77)], or those attending following partner notification [0.11 (0.03-0.38)].

Conclusion: Targeted interventions are needed to improve HIV testing uptake and reduce undiagnosed HIV infection among black Africans attending SHCs, especially heterosexuals residing in deprived areas.

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Key points

- Among black African heterosexuals living with HIV in the UK, 16% and 12% of men and women, respectively, are unaware of their HIV status.
- There is limited information on how frequently HIV test refusal occurs among black Africans attending sexual health clinics (SHCs).
- In 2014, an HIV test was refused at one in 10 attendances by black Africans at SHCs.
- Targeted interventions are needed to improve HIV testing uptake and reduce undiagnosed HIV infection among black Africans attending SHCs, especially heterosexuals in deprived areas.

Introduction

There were an estimated 103,700 people living with HIV in the UK in 2014 and the epidemic continues to primarily affect men who have sex with men (MSM) and black African heterosexuals [1]. The estimated proportion of undiagnosed infections among MSM is 14%, while 16% and 12% of black African heterosexual men and women, respectively, are undiagnosed and at risk of unknowingly transmitting HIV to their sex partners [1].

People with undiagnosed HIV are also more likely to be diagnosed late (after the point at which treatment should have been initiated: a CD4 count <350 cells/mm^3) which, in turn, increases the likelihood of HIV-related complications and deaths within one year of diagnosis [2]. Therefore improving early diagnosis of HIV infection by increasing the availability and uptake of testing has become crucial to the public health approach to HIV control in England [2].

Sexual health clinics (SHCs) provide a viable opportunity for HIV testing, with 32% and 22% of black African men and women (*vs.* 20% and 21% of men and women overall), respectively, reporting attending an SHC in the past five years on a national probability survey (Natsal-3; http://www.natsal.ac.uk/natsal-3.aspx). National guidance recommends improving the offer and uptake of HIV testing among black Africans in the SHC setting, yet acknowledges that there is limited information on how frequently refusal of HIV testing occurs among black African SHC attendees and if there are any demographic or clinical characteristics associated with test refusal [3]. In this analysis, we addressed this gap by using SHC surveillance data to assess the frequency and correlates of HIV test refusal at attendances by black Africans.

Methods

Data source

Data were obtained from the genitourinary medicine clinic activity dataset (GUMCADv2), the mandatory surveillance system for sexually transmitted infections (STIs) in England. Details on GUMCADv2 are provided elsewhere [4]; briefly, it is a patient-level dataset of all STI diagnoses and services from all 216 SHCs in England.

Inclusion and exclusion criteria

All SHC attendances in 2014 by HIV-negative black African patients aged 15-99 years were considered in the analysis. Patients of unknown gender or sexual orientation (6.9%) or who

were not residents of England (1.3%) were excluded, as were attendances which were coded ‘HIV test not appropriate’ (6.4%).

Independent and dependent variables

Ethnicity was defined by patient self-report and categorised using the standard ethnic groups used for the UK census by the Office for National Statistics. People of black African ethnicity include those born in the UK and those born in countries of the African continent or elsewhere.

Other independent variables included the demographic variables from GUMCADv2: age, gender, sexual orientation, residence (London/other) and country of birth (UK/other). Residential deprivation was determined using quintiles of the index of multiple deprivation, a measure of area-level socioeconomic status. Surveillance codes were used to determine whether patients were attending the clinic after partner notification (PN) for HIV, and whether a patient was diagnosed with a new STI or tested for HIV in the past year. No independent variables to distinguish patients by HIV risk were considered, as no behavioural data is collected through GUMCADv2.

HIV test refusal was defined as an attendance coded as ‘HIV test offered and refused’; SHCs have an opt-out HIV testing policy and an HIV test was assumed to be clinically appropriate unless an attendance was coded ‘HIV test not appropriate’.

Data analysis

Analyses were restricted to attendances by HIV-negative black Africans where an HIV test was assumed to be clinically appropriate. The frequencies of patients’ demographic and clinical characteristics were determined.

The outcome for analysis was the refusal of an HIV test at an SHC attendance. Unadjusted associations between the aforementioned demographic and clinical characteristics with HIV test refusal were determined, then all characteristics were entered into a multivariable model to determine adjusted associations. To account for the clustering of attendances by patient, generalised estimating equations (GEE) logistic regression was used.

Unadjusted and adjusted odds ratios (ORs and aORs, respectively) with 95% confidence intervals (CIs) are reported. All associations with *p*-values less than 5% were considered to be statistically significant and all analyses were performed using Stata v13.1 (StataCorp LP, College Station, TX, USA).

Results

There were 80,743 attendances by black Africans in 2014 that met the inclusion criteria and were considered in the analysis. Overall, 96.1% of patients were women or heterosexual men, 48.3% lived in the most deprived areas of England, 56.1% were London residents, and 75.6% were born outside the UK. Of those born outside the UK, the majority (84.9%) were born in Sub Saharan Africa.

The proportion of attendances where an HIV test was refused was 11.2%. On unadjusted analysis, refusal was more likely among women, those living in the most deprived areas or in London and those diagnosed with a new STI, but was less likely among those tested for HIV in the past year, those born outside the UK, MSM, older people and those attending the clinic through PN (table 1).

All variables were included in the final multivariable model (table 1). The adjusted odds of refusing an HIV test were higher in women [aOR (95% CI): 1.54 (1.46-1.62) *vs.* heterosexual men], those living in the most deprived areas [1.44 (1.24-1.67)], those diagnosed with a new STI [1.26 (1.18-1.34)] and those living in London [1.06 (1.01-1.12)]. The adjusted odds of refusing an HIV test decreased with age [0.99 (0.99-0.99)] and were lower in those tested for HIV in the past year [0.85 (0.81-0.89)], those born outside the UK [0.73 (0.69-0.77)], MSM [0.52 (0.43-0.63) *vs.* heterosexual men], and those attending the clinic through PN [0.11 (0.03-0.38)].

Discussion

In this analysis we found that an HIV test was refused at one in every 10 SHC attendances by black Africans. Women were more likely to have refused an HIV test, but this may be due to a high uptake of testing in other settings such as general practice or antenatal care [5]. The increased likelihood of test refusal among those living in more deprived areas is consistent with evidence of poorer sexual health among this population subgroup. The reasons for this are unknown, but it may reflect a lack of knowledge about HIV [6]. As being newly diagnosed with an STI may be indicative of recent condomless sex, the increased odds of refusing an HIV test in this group is concerning, but is consistent with at least one other study [7].

There was a strong negative association between attending an SHC through HIV PN and test refusal and this demonstrates the importance of PN in HIV case-finding. Black African MSM were less likely to have refused an HIV test, which is consistent with the higher uptake of testing in MSM compared to heterosexuals [1], with no significant difference between black

African and white British MSM [8]. Similarly, it is interesting to note that black Africans born outside the UK were also less likely to refuse a test; a higher perceived risk of HIV has been documented among this group [9].

The data source used for this analysis has no behavioural data, so we are unable to assess reasons for having attended an SHC or refusing an HIV test, or HIV-related risk behaviours such as condomless sex or sharing injection drug equipment. However, this attendance-level analysis captured the likelihood of test refusal as it changed over time with recent sexual risk. Furthermore, while work is underway to change this, SHCs cannot (as of August 2016) report transgender status to PHE, thus there are no data on test refusal among transgender people. As patients can only be followed up within and not across SHCs, we may have overestimated the proportion refusing an HIV test. However, one of the strengths of this STI surveillance dataset is clinicians' ability to code an attendance as 'HIV test not appropriate' if one was recently performed elsewhere; this reduces the likelihood of misclassifying attendances by refusal status. In light of the opt-out testing policy and high uptake of HIV testing at SHCs [8], the likelihood of test refusal in the context of undisclosed HIV infection is assumed to be low. An additional strength of this analysis is that it considered data from all attendances to all SHCs in England in 2014, thus providing a comprehensive overview of HIV refusal patterns among black African attendees.

HIV testing is refused at a substantial proportion of SHC attendances by black Africans. We were unable to ascertain the reasons for refusal, which may be due to barriers to HIV testing shared with other migrant populations in high income countries; [10] in-depth interviews should be employed to better understand this in England. Raising awareness of the need for regular testing in specific subgroups, especially among heterosexuals residing in deprived areas, may increase test uptake. These findings can be used to inform economic analyses of initiatives to improve HIV testing within this population subgroup and decrease the proportion with undiagnosed HIV.

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Competing interests: We declare no competing interests.

Author contributions: GD conceived the analysis, and agreed the data analysis plan with MF and HM. HM performed the analysis and prepared the first draft of the manuscript with GD. All authors read, critically reviewed and approved the final version of the manuscript for publication.

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Ethics statement: As GUMCADv2 is a routine public health surveillance activity, no specific consent was required from the patients whose data were used in this analysis. PHE has permission to handle data obtained by GUMCADv2 under section 251 of the UK National Health Service Act of 2006 (previously section 60 of the Health and Social Care Act of 2001), which was renewed annually by the ethics and confidentiality committee of the National Information Governance Board until 2013. Since then the power of approval of public health surveillance activity has been granted directly to PHE.

Table 1 - Unadjusted and adjusted associations with refusal of an HIV test at attendances by HIV-negative black Africans at sexual health clinics in England, 2014

		Did not refuse an HIV test		Refused an HIV test		Unadjusted			Adjusted		
Patient characteristics	N	n	%	n	%	OR	(95% CI)	*p*-value	aOR	(95% CI)	*p*-value
Overall	80,743	71,722	88.8	9,021	11.2	-	-	-	-	-	-
Age group (years)†											
15-19	7,233	5,962	82.4	1,271	17.6	-	-	-	-	-	-
20-24	18,597	16,419	88.3	2,178	11.7	-	-	-	-	-	-
25-34	29,946	26,788	89.5	3,158	10.6	-	-	-	-	-	-
35-44	16,794	15,138	90.1	1,656	9.9	-	-	-	-	-	-
45-64	7,806	7,070	90.6	736	9.4	-	-	-	-	-	-
65-99	367	345	94.0	22	6.0	-	-	-	-	-	-
Age (years) †	80,743	-	-	-	-	0.99	(0.99,0.99)	<0.001	0.99	(0.99,0.99)	<0.001
Gender/sexual orientation											
Heterosexual men	34,709	31,567	91.0	3,142	9.1	Ref	-	-	Ref	-	-
Men who have sex with men*	3,174	3,027	95.4	147	4.6	0.54	(0.45,0.65)	<0.001	0.52	(0.43,0.63)	<0.001
Women	42,860	37,128	86.6	5,732	13.4	1.55	(1.47,1.63)	<0.001	1.54	(1.46,1.62)	<0.001
Residence											
Not London	35,479	31,854	89.8	3,625	10.2	Ref	-	-	Ref	-	-
London	45,264	39,868	88.1	5,396	11.9	1.13	(1.07,1.18)	<0.001	1.06	(1.01,1.12)	0.017

IMD quintile of LSOA of residence (Q)‡											
IMD Q1 - Least deprived	2,953	2,710	91.8	243	8.2	Ref	-	-	Ref	-	-
IMD Q2	4,763	4,273	89.7	490	10.3	1.28	(1.07,1.52)	0.006	1.24	(1.04,1.48)	0.016
IMD Q3	10,485	9,423	89.9	1,062	10.1	1.25	(1.07,1.46)	0.006	1.20	(1.03,1.41)	0.023
IMD Q4	23,546	21,011	89.2	2,535	10.8	1.32	(1.14,1.54)	<0.001	1.27	(1.09,1.48)	0.002
IMD Q5 - Most deprived	38,996	34,305	88.0	4,691	12.0	1.48	(1.28,1.72)	<0.001	1.44	(1.24,1.67)	<0.001
Country of birth											
UK	19,716	16,896	85.7	2,820	14.3	Ref	-	-	Ref	-	-
Not UK	61,027	54,826	89.8	6,201	10.2	0.71	(0.67,0.74)	<0.001	0.73	(0.69,0.77)	<0.001
Attending the clinic after partner notification (PN) for HIV											
No	80,530	71,510	88.8	9,020	11.2	Ref	-	-	Ref	-	-
Yes – PN contact	213	212	99.5	1	0.5	0.11	(0.04,0.34)	<0.001	0.11	(0.03,0.38)	<0.001
Diagnosed with a new STI*											
No	71,459	63,636	89.1	7,823	11.0	Ref	-	-	Ref	-	-
Yes - new STI	9,284	8,086	87.1	1,198	12.9	1.22	(1.15,1.30)	<0.001	1.26	(1.18,1.34)	<0.001
Tested for HIV in the past year											
No	49,319	43,006	87.2	6,313	12.8	Ref	-	-	Ref	-	-
Yes - tested for HIV	31,424	28,716	91.4	2,708	8.6	0.85	(0.81,0.89)	<0.001	0.85	(0.81,0.89)	<0.001

Acronyms: OR – Odds ratio; aOR – Adjusted odds ratio; Ref – Reference category; IMD – Index of Multiple Deprivation (a measure of local area-level socioeconomic status†); LSOA – lower super output area (a census output area with an average population of 1,620 people); Q – Quartile; UK – United Kingdom; STI – Sexually Transmitted Infection

†Only the continuous age variable was considered in the logistic regression analyses. In both the unadjusted and adjusted models, the lower and upper bounds of the 95% confidence intervals for age differed by at least 0.005.

‡Department for Communities and Local Government (https://www.gov.uk/government/statistics/english-indices-of-deprivation-2010).

** Men who have sex with men were defined as men whose self-reported sexual orientation was gay or bisexual.*

*** New STIs include chlamydia, anogenital warts (first episode), non-specific genital infection, anogenital herpes (first episode), gonorrhoea, syphilis (primary, secondary & early latent), chancroid/LGV/donovanosis, pelvic inflammatory disease and epididymitis, and trichomoniasis.*

P-*values are from generalised estimating equations logistic regression.*

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