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ORIGINAL RESEARCH

Accuracy of self-report of HIV viral load among people with HIV on antiretroviral treatment

J Sewell,[1] M Daskalopoulou,[1] F Nakagawa,[1] FC Lampe,[1] S Edwards,[2] N Perry,[3] E Wilkins,[4] R O'Connell,[5] M Jones,[6] S Collins,[7] A Speakman,[1] AN Phillips[1] and AJ Rodger[1] for the Antiretrovirals, Sexual Transmission Risk and Attitudes (ASTRA) Study Group*

[1]Research Department of Infection & Population Health, University College London, London, UK, [2]Mortimer Market Centre, Central and North West London NHS Foundation Trust, London, UK, [3]Brighton and Sussex University Hospitals NHS Trust, Brighton, UK, [4]Pennine Acute Hospitals NHS Trust, Manchester, UK, [5]Barts Health NHS Trust, London, UK, [6]East Sussex Healthcare NHS Trust, Eastbourne, UK and [7]HIV i-Base, London, UK

Objectives

The aim of the study was to assess, among people living with HIV, knowledge of their latest HIV viral load (VL) and CD4 count.

Methods

Agreement between self-report and clinic record was assessed among 2771 HIV-diagnosed individuals on antiretroviral treatment (ART) in the UK Antiretrovirals, Sexual Transmission Risk and Attitudes Study (2011–2012). A confidential self-completed questionnaire collected information on demographic, socioeconomic, HIV-related and health-related factors. Participants were asked to self-report their latest VL [undetectable (≤ 50 copies/mL), detectable (> 50 copies/mL) or "don't know"] and CD4 count (< 200, 200–350, 351–500 or > 500 cells/μL, or "don't know"). Latest clinic-recorded VL and CD4 count were documented.

Results

Of 2678 participants on ART, 434 (16.2%) did not accurately report whether their VL was undetectable. Of 2334 participants with clinic-recorded VL ≤ 50 copies/mL, 2061 (88.3%) correctly reported undetectable VL; 49 (2.1%) reported detectable VL; 224 (9.6%) did not know their VL. Of 344 participants with clinic-recorded VL > 50 copies/mL, 183 (53.2%) correctly reported detectable VL; 76 (22.1%) reported undetectable VL; 85 (24.7%) did not know their VL. Of 2137 participants who reported undetectable VL, clinic-recorded VL was ≤ 50 copies/mL for 2061 (96.4%) and <1000 copies/mL for 2122 (99.3%). In analyses adjusted for gender/sexual orientation, ethnicity, age and time since starting ART, factors strongly associated with inaccurate self-report of VL (including "don't know") included socioeconomic disadvantage [prevalence ratio (95% CI) for "not" *vs.* "always" having enough money for basic needs: 2.4 (1.9, 3.1)], poor English fluency [3.5 (2.4, 5.1) *vs.* UK born], nondisclosure of HIV status [1.7 (1.3, 2.1)], ART nonadherence [2.1 (1.7, 2.7) for three or more missed doses *vs.* none in the past 2 weeks] and depressive symptoms (PHQ-9 score ≥ 10) [1.9 (1.6, 2.2)]. Overall, 612 (22.9%) of 2667 participants on ART did not accurately self-report whether or not their CD4 count was ≤ 350 cells/μL.

Conclusions

There is a high level of accuracy of a self-report of undetectable VL in people on ART in the UK. Overall, accurate knowledge of personal VL level varied according to demographic, socioeconomic, HIV-related and health-related factors. Active identification of people who may benefit from increased levels of support and engagement in care is important.

Correspondence: Dr Janey Sewell, UCL Department of Infection and Population Health, Royal Free Hospital, London NW3 2PF, UK.
e-mail: j.sewell@ucl.ac.uk

*See Appendix.

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Introduction

Advances in antiretroviral therapy (ART) have resulted in greatly reduced mortality among people living with HIV [1,2], such that life expectancy for HIV-positive individuals with access to treatment now approaches that of the general population [3]. International [4–6] and UK [7] guidelines recommend that patients are involved in decision-making about HIV care and treatment. For this to be achieved, patients require adequate knowledge of their HIV-related health and treatment goals, and are dependent on health care professionals providing and discussing the relevant information.

Reviewing laboratory markers such as CD4 counts and HIV viral load (VL) in conjunction with a patient is now common practice amongst HIV health care providers. Previous studies have suggested that providing health-related knowledge to people with HIV infection may improve adherence and treatment outcomes, as well as benefitting the patient–health care provider relationship [8–10]. Furthermore, as increasing evidence shows that a suppressed HIV VL greatly reduces the risk of onward transmission of HIV to sexual partners [11–17], people with HIV infection may use their VL results to make decisions on condomless sex. Therefore, in this context, it is critical that individuals have correct self-knowledge of their latest VL result.

Little is known about the accuracy of individuals' knowledge of their own HIV biomarker status, or whether socioeconomic and other factors impact on such knowledge. In particular, there have been no studies assessing the accuracy of self-report of VL status among people living with HIV in the UK. Despite access to free HIV care in the UK via the National Health Service, recent results from the Antiretrovirals, Sexual Transmission Risk and Attitudes (ASTRA) study indicated that socioeconomic disadvantage was associated with a substantially increased probability of virological nonsuppression and virological rebound among people on treatment for HIV infection in the UK [18]. In this study, we used data from ASTRA to investigate the ability of individuals on ART to correctly report their HIV VL level and CD4 count level, by comparing self-report with the clinic-recorded value. We also assessed the association of demographic, socioeconomic, HIV-related and health-related factors with inaccurate reporting of HIV VL level.

Methods

Study design and procedures

ASTRA is a cross-sectional questionnaire study that recruited people with diagnosed HIV infection from eight HIV out-patient clinics in the UK between February 2011 and December 2012 [19]. The time period allocated for recruitment in each clinic was of sufficient duration that infrequent clinic attendees would be included in those invited to participate. Exclusion criteria were as follows: age < 18 years; unable to understand the study questionnaire (available in English or French) because of language or cognitive difficulties; too ill or distressed to complete the questionnaire. Participants self-completed a confidential paper questionnaire that included items on demographics (gender/sexual orientation; age; ethnicity), socioeconomic factors (UK birth/English fluency; education; employment; housing; financial hardship; supportive network assessed by a modified version of the Duke Functional Social Support questionnaire[18,20]), HIV-related factors (stable partner and their HIV status; disclosure of HIV status; ART use; ART start date; ART adherence), health-related factors (symptoms of depression and anxiety as assessed by the Patient Health Questionnaire, 9 item scale [PHQ-9] [21] and the Generalized Anxiety Disorder 7 item scale [GAD-7] [22], respectively); treatment for depression.

Participants who reported that they had ever started ART were asked to report the value of their VL from the last time they received their test results, with three options: "50 copies/mL or less ('undetectable' or 'suppressed)"; "more than 50 copies/mL ('detectable' or 'raised')"; or "don't know". All participants were asked to report their last CD4 count result, with five options; "less than 200"; "200–350"; "351–500"; "more than 500"; or "don't know/can't remember". For all participants, the study recruiter documented, from clinic records, the latest VL and CD4 count laboratory results that were available to the participant at the time the questionnaire was issued. Therefore, information on VL and CD4 levels was available both from the participant self-report and from the clinic record.

Agreement between self-report and clinic record for VL and CD4 was assessed only among participants who

reported currently taking ART. Accurate self-report was defined as agreement between participant self-report and clinic record that the latest VL was either ≤ 50 copies/mL or > 50 copies/mL. Inaccurate self-report was defined as either disagreement between self-report and clinic record on the level of VL, or a response of "don't know" to the question on VL level. Participants who had no clinic-recorded VL, whose clinic-recorded VL was dated after the questionnaire issue date, or who gave no response to the question on VL level were excluded from the analysis. Similarly, accuracy of reporting CD4 count was defined as agreement between participant self-report and clinic record that the latest CD4 count was > 350 or ≤ 350 cells/μL. Inaccurate self-report was defined as indicating a different CD4 count category from that of the clinic-recorded CD4 count, or a response of "don't know". Analysis of factors associated with inaccurate self-report was carried out for VL only, as it was posited that, among those on ART, VL may be monitored more regularly than CD4 count. In addition, knowledge of VL level is of particular importance in relation to decision-making around sexual behaviour.

Statistical analysis

Agreement between participant self-report and clinic record for VL level and CD4 level was assessed among participants on ART. In order to examine the associations of demographic, socioeconomic, HIV-related and health-related factors with inaccurate self-report of VL level, modified Poisson regression models with robust standard errors were used to produce unadjusted and adjusted prevalence ratios (PRs) with 95% confidence intervals (CIs) [23]. In multivariable analyses, each factor was considered in a separate model and adjusted only for: gender/sexual orientation [men who have sex with men (MSM), heterosexual men and women], age group (< 30, 30–39, 40–49, 50–59, ≥ 60 years, and missing), ethnicity (white, black African, black other, and other/missing) and time since first starting ART group (≤ 6 months, 6 months to 1 year, 1–2 years, 2–5 years, 5–10 years, > 10 years, and missing). Results were similar when cases with missing values for age and time since starting ART were excluded from analysis. Further adjustment for (or stratification by) clinical centre had little effect on associations; associations unadjusted for clinical centre are presented. In a separate sensitivity analysis, participants who gave no response to the question on self-reported VL level were included in the "disagreement" category (inaccurate self-report) rather than being excluded.

Results

In total, 3258 patients completed a study questionnaire, of 5112 invited to participate (response rate of 64%). Of 3202 participants with ART information, 2771 (86.5%) were on ART, 366 were ART naïve, and 65 had previously taken ART but were not on ART at the time of the questionnaire. Of 2771 participants on ART, 1891 (68.2%) were MSM, 547 (19.7%) were women and 333 (12.0%) were heterosexual men (Table 1). The mean age was 46.1 [standard deviation (SD) 9.4] years. The sample was predominantly of white ethnicity (n = 1894; 68.4%), with 533 (19.2%) being of black African ethnicity, 94 (3.4%) of black Caribbean or black other ethnicity, and 250 (9.0%) of other or missing ethnicity. Forty-three per cent of participants (1155 of 2684) were not born in the UK, of whom just over a fifth (256; 22.2%) reported not being fluent in spoken English. Overall, 41.4% of participants (1115 of 2696) were educated to degree level or above and 55.9% (1509 of 2699) were in full or part-time employment. Less than half of participants (43.8%) reported "always" having enough money for basic needs. The majority of participants (1689 of 2681; 63.0%) had started ART 5 or more years ago; 6.2% started in the past 6 months and 30.8% started between 6 months and 5 years ago. In terms of self-reported non-adherence: 25.0% (688 of 2756) reported having missed at least one dose of ART in the previous 2 weeks, and 17.2% (474 of 2757) reported having missed two or more consecutive days of ART on at least one occasion in the past 3 months.

Agreement between self-reported and clinic-recorded VL

Among the 2771 participants on ART, the clinic-recorded VL was not documented for 18 participants, and was dated after the questionnaire issue for a further 11 participants. In addition, 64 individuals did not provide a response to the question on self-reported VL. Among the remaining 2678 participants, 2334 (87.2%) had clinic-recorded VL ≤ 50 copies/mL. Self-reported VL was as follows: 2137 (79.8%) participants reported VL ≤ 50 copies/mL, 232 (8.7%) reported VL > 50 copies/mL, and 309 (11.5%) responded "don't know" (Table 2a). In terms of agreement, of the 2334 participants with a clinic VL ≤ 50 copies/mL, a high proportion (88.3%; n = 2061) correctly self-reported undetectable VL; 49 (2.1%) incorrectly self-reported that their VL was detectable, while 224 (9.6%) did not know their latest VL. Of the 344 participants with clinic-recorded VL > 50 copies/mL, 183 (53.2%) correctly self-reported detectable VL; however,

Table 1 Demographic, socioeconomic, HIV-related and health-related factors, and associations with inaccurate self-report of clinic viral load level, among 2771 HIV-diagnosed participants on antiretroviral therapy (ART)

	Prevalence (N = 2771)*		Inaccurate self-report of clinic viral load† (n/N = 434/2678)‡		Unadjusted PR and 95% CI§			Adjusted PR and 95% CI§		
	N	%	*n*/*N*	Row %	PR	95% CI	*P*-value	PR	95% CI	*P*-value
Gender/sexual orientation (N = 2771)										
MSM¶	1891	68.2	225/1852	12.1	1			1		
Heterosexual men	333	12.0	91/312	29.2	2.4	1.9, 3.0		1.8	1.4, 2.4	
Women	547	19.7	118/514	23.0	1.9	1.5, 2.3	< 0.001	1.3	1.0, 1.8	< 0.001
Age at recruitment (N = 2713)										
< 30 years¶	103	3.8	29/99	29.3	1			1		
30–39 years	569	21.0	105/550	19.1	0.7	0.5, 0.9		0.8	0.6, 1.1	
40–49 years	1204	44.4	170/1157	14.7	0.5	0.4, 0.7		0.7	0.5, 0.9	
50–59 years	640	23.6	84/632	13.3	0.5	0.3, 0.7		0.7	0.5, 1.0	
≥ 60 years	197	7.3	31/189	16.4	0.6	0.4, 0.9	0.002 (*t*)	0.8	0.5, 1.2	0.16 (*t*)
Ethnicity (N = 2771)										
White¶	1894	68.4	231/1854	12.5	1			1		
Black African	533	19.2	134/498	26.9	2.2	1.8, 2.6		1.5	1.2, 2.0	
Black Caribbean or black other	94	3.4	20/89	22.5	1.8	1.2, 2.7		1.4	0.9, 2.1	
Other/missing	250	9.0	49/237	20.7	1.7	1.3, 2.2	< 0.001	1.4	1.0, 1.8	0.015
UK birth/fluency in spoken English (N = 2684)										
Born in the UK¶	1529	57.0	185/1491	12.4	1			1.0		
Non-UK born, fluent in spoken English	899	33.5	147/871	16.9	1.4	1.1, 1.7		1.0	0.8, 1.3	
Non-UK born, speaks English quite well	233	8.7	70/215	32.6	2.6	2.1, 3.3		1.7	1.3, 2.3	
Non-UK born, speaks English not at all well	23	0.9	17/23	73.9	6.0	4.5, 7.9	< 0.001 (*t*)	3.5	2.4, 5.1	< 0.001 (*t*)
Education (N = 2696)										
University education¶	1115	41.4	115/1084	10.6	1			1		
A levels/O levels or equivalent; other nonuniversity	1274	47.3	218/1237	17.6	1.7	1.3, 2.1		1.6	1.3, 2.0	
No educational qualifications	307	11.4	90/291	30.9	2.9	2.3, 3.7	< 0.001 (*t*)	2.7	2.1, 3.4	< 0.001 (*t*)
Employment status (N = 2699)										
Employed (full or part-time)¶	1509	55.9	182/1461	12.5	1			1		
Unemployed	496	18.4	118/477	24.7	2.0	1.6, 2.4		1.7	1.4, 2.1	
Not working because of sickness/disability	380	14.1	63/370	17.0	1.4	1.1, 1.8		1.6	1.3, 2.1	
Retired	180	6.7	25/174	14.4	1.2	0.8, 1.7		1.3	0.8, 2.0	
Other (looking after home/ family, carer, student or other)	134	5.0	32/131	24.4	2.0	1.4, 2.7	< 0.001	1.4	1.0, 2.0	< 0.001
Housing (N = 2720)										
Homeowner¶	959	35.3	91/938	9.7	1			1		
Renting (council or housing association)	1482	54.5	255/1431	17.8	1.8	1.5, 2.3		1.5	1.2, 1.9	
Unstable/other (temporary, staying with friends or homeless)	279	10.3	79/261	30.3	3.1	2.4, 4.1	< 0.001 (*t*)	2.1	1.6, 2.8	< 0.001 (*t*)
Money for basic needs, e.g. food and heating (N = 2717)										
Always¶	1189	43.8	121/1160	10.4	1			1		
Mostly	708	26.1	104/692	15.0	1.4	1.1, 1.8		1.4	1.1, 1.7	
Sometimes	483	17.8	103/461	22.3	2.1	1.7, 2.7		1.8	1.4, 2.3	
No	337	12.4	97/315	30.8	3.0	2.3, 3.7	< 0.001 (*t*)	2.4	1.9, 3.1	< 0.001 (*t*)
Low supportive network (score ≤ 12; modified Duke FSSQ) (N = 2731)										
No¶	2343	85.8	349/2268	15.4	1			1		
Yes	388	14.2	75/377	19.9	1.3	1.0, 1.6	0.041	1.4	1.1, 1.7	0.016
Partner status (N = 2752)										
HIV-positive stable partner¶	660	24.0	88/633	13.9	1			1		
HIV-negative or unknown status stable partner	905	32.9	128/878	14.6	1.0	0.8, 1.3		1.0	0.8, 1.3	

Table 1 (*Continued*)

	Prevalence (N = 2771)*		Inaccurate self-report of clinic viral load† (n/N = 434/2678)‡		Unadjusted PR and 95% CI§			Adjusted PR and 95% CI§		
	N	%	*n/N*	Row %	PR	95% CI	*P*-value	PR	95% CI	*P*-value
No stable partner	1187	43.1	216/1150	18.8	1.4	1.1, 1.7	0.008	1.4	1.1, 1.8	0.001
Disclosed HIV status? (other than to health care staff) (N = 2754)										
Yes¶	2536	92.1	362/2464	14.7	1			1		
No	218	7.9	64/199	32.2	2.2	1.8, 2.7	< 0.001	1.7	1.3, 2.1	< 0.001
Time since clinic-recorded VL result (N = 2742)										
≤ 1 month¶	889	32.4	125/874	14.3	1			1		
1–6 months	1601	58.4	263/1564	16.8	1.2	1.0, 1.4		1.1	0.9, 1.4	
> 6 months	252	9.2	46/240	19.2	1.3	1.0, 1.8	0.039 (*t*)	1.3	1.0, 1.7	0.073 (*t*)
Time since started ART (N = 2681)										
≤ 6 months¶	166	6.2	51/159	32.1	1			1		
6 months to 1 year	104	3.9	20/102	19.6	0.6	0.4, 1.0		0.6	0.4, 1.0	
1–2 years	191	7.1	28/175	16.0	0.5	0.3, 0.8		0.5	0.3, 0.8	
2–5 years	531	19.8	89/521	17.1	0.5	0.4, 0.7		0.6	0.4, 0.7	
5–10 years	710	26.5	107/683	15.7	0.5	0.4, 0.6		0.5	0.4, 0.7	
> 10 years	979	36.5	107/958	11.2	0.3	0.3, 0.5	< 0.001 (*t*)	0.4	0.3, 0.6	< 0.001(*t*)
ART adherence: ART doses missed in past 2 weeks (N = 2756)										
None¶	2068	75.0	293/2006	14.6	1			1		
One	370	13.4	59/358	16.5	1.1	0.9, 1.5		1.2	0.9, 1.5	
Two	160	5.8	32/154	20.8	1.4	1.0, 2.0		1.5	1.1, 2.1	
Three or more	158	5.7	46/150	30.7	2.1	1.6, 2.7	< 0.001 (*t*)	2.1	1.7, 2.7	< 0.001 (*t*)
ART adherence: ever missed two consecutive days of ART in past 3 months? (N = 2757)										
No¶	2283	82.8	322/2209	14.6	1			1		
Yes, once	155	5.6	25/151	16.6	1.1	0.8, 1.6		1.1	0.8, 1.6	
Yes, two to three times	199	7.2	47/193	24.4	1.7	1.3, 2.2		1.5	1.2, 2.0	
Yes, more than three times	120	4.4	37/114	32.5	2.2	1.7, 3.0	< 0.001 (*t*)	2.2	1.6, 2.9	< 0.001 (*t*)
Depressive symptoms (PHQ-9 score ≥ 10) (N = 2771)										
No¶	2023	73.0	265/1955	13.6	1			1		
Yes	748	27.0	169/723	23.4	1.7	1.5, 2.1	< 0.001	1.9	1.6, 2.2	< 0.001
Anxiety symptoms (GAD-7 score ≥ 10) (N = 2771)										
No¶	2154	77.7	301/2082	14.5	1			1		
Yes	617	22.3	133/596	22.3	1.5	1.3, 1.9	< 0.001	1.6	1.3, 1.9	< 0.001
Treatment (medical or other) for depression (N = 2771)										
No¶	2206	79.6	334/2133	15.7	1			1		
Yes	565	20.4	100/545	18.3	1.2	1.0, 1.4	0.14	1.3	1.1, 1.6	0.013

MSM, men who have sex with men; CI, confidence interval; FSSQ, Functional Social Support Questionnaire; PR, prevalence ratio; PHQ-9, Patient Health Questionnaire, 9 item scale; GAD-7, Generalized Anxiety Disorder 7 item scale; (*t*), test for linear trend across categories performed.
For explanatory variables with missing values for > 30 participants, the prevalence of inaccurate self-report among the subgroup with a missing value ranged from 16.7% (among those with missing education status) to 40.0% (among those with missing time since started ART).
*Prevalence among participants on ART at the time of the questionnaire.
†Disagreement between clinic-recorded and self-reported undetectable VL status, or "don't know" response for self-report.
‡Analysis excludes 93 of 2771 individuals on ART. Exclusions were: missing clinic-recorded viral load (n = 18); clinic-recorded viral load dated after questionnaire issue (n = 11); missing self-reported viral load (n = 64).
§Unadjusted and adjusted prevalence ratios and 95% confidence intervals using modified Poisson regression. For adjusted analyses, each factor is included in a separate model and adjusted for "gender/sexual orientation", "age group", "ethnicity" and "time since started ART group". Denominators are equivalent for unadjusted and adjusted analyses, as in multivariable models, "age group" and "time since started ART" were fitted using a "missing" category (n = 51 and n = 80 missing values, respectively). *P* values were obtained using the score statistic.
¶Reference category.

76 (22.1%) incorrectly self-reported that their VL was undetectable, and 85 (24.7%) did not know their VL. Of all 2137 individuals who self-reported an undetectable VL, the vast majority (2061; 96.4%) had clinic-recorded VL ≤ 50 copies/mL; among the remaining 76 individuals, clinic-recorded VL was 51–199 copies/mL for 48; 200–999 copies/mL for 13; ≥ 1000 copies/mL for 15. Therefore the prevalence of clinic-recorded VL<1000 copies/mL among those with self-reported undetectable VL was 99.3% (2122/2137). Overall, agreement between an individual's self-reported VL status and clinic-recorded VL was demonstrated in 2244 (83.8%) of HIV-positive people on ART, and disagreement (including "don't know") in 434 (16.2%) individuals.

Agreement between self-reported and clinic-recorded CD4 count

Among 2771 participants on ART, the clinic-recorded CD4 count was not documented for 19 participants, and was dated after questionnaire issue for a further 15. In addition, 70 individuals did not respond to the self-

Table 2 (a) Agreement between clinic-record and self-report for: (a) HIV viral load level among 2678 HIV-diagnosed participants on antiretroviral therapy (ART)* and (b) CD4 count level among 2667 HIV-diagnosed participants on ART†

(a)

All participants (*N* = 2678) Self-reported latest viral load	Clinic-recorded viral load (latest result available to participant)					
	≤ 50 copies/mL (*N* = 2334)			> 50 copies/mL (*N* = 344)		
	n	Column %	Row %	*n*	Column %	Row %
≤ 50 copies/mL‡ (*N* = 2137)	2061	88.3	96.4	76	22.1	3.6
> 50 copies/mL§ (*N* = 232)	49	2.1	21.1	183	53.2	78.9
Don't know (*N* = 309)	224	9.6	72.5	85	24.7	27.5
MSM (*N* = 1852) Self-reported latest viral load	**≤ 50 copies/mL (*N* = 1638)**			**> 50 copies/mL (*N* = 214)**		
	n	Column %	Row %	*n*	Column %	Row %
≤ 50 copies/mL‡ (*N* = 1555)	1500	91.6	96.5	55	25.7	3.5
> 50 copies/mL§ (*N* = 157)	30	1.8	19.1	127	59.3	80.9
Don't know (*N* = 140)	108	6.6	77.1	32	15.0	22.9
Heterosexual men and women (*N* = 826) Self-reported latest viral load	**≤ 50 copies/mL (*N* = 696)**			**> 50 copies/mL (*N* = 130)**		
	n	Column %	Row %	*n*	Column %	Row %
≤ 50 copies/mL‡ (*N* = 582)	561	80.6	96.4	21	16.2	3.6
> 50 copies/mL§ (*N* = 75)	19	2.7	25.3	56	43.1	74.7
Don't know (*N* = 169)	116	16.7	68.6	53	40.8	31.4

(b)

All participants (*N* = 2667) Self-reported CD4 count (cells/μL)	Clinic-recorded CD4 count (cells/μL) (latest result available to participant)					
	≤ 350 (*N* = 484)			> 350 (*N* = 2183)		
	n	Column %	Row %	*n*	Column %	Row %
< 200 (*N* = 258)	132	27.3	51.2	126	5.8	49.8
200–350 (*N* = 378)	238	49.2	63.0	140	6.4	37.0
351–500 (*N* = 632)	56	11.6	8.9	576	26.4	91.1
> 500 (*N* = 1118)	9	1.9	0.8	1109	50.8	99.2
Don't know (*N* = 281)	49	10.1	17.4	232	10.6	82.6
MSM (*N* = 1840) Self-reported CD4 count (cells/μL)	**≤ 350 (*N* = 282)**			**> 350 (*N* = 1558)**		
	n	Column %	Row %	*n*	Column %	Row %
< 200 (*N* = 156)	80	28.4	51.3	76	4.9	48.7
200–350 (*N* = 257)	155	55.0	60.3	102	6.5	39.7
351–500 (*N* = 458)	29	10.3	6.3	429	27.5	93.7
> 500 (*N* = 845)	7	2.5	0.8	838	53.8	99.2
Don't know (*N* = 124)	11	3.9	8.9	113	7.3	91.1

reported CD4 question. Of the remaining 2667 participants, 2183 (81.9%) had a clinic-recorded CD4 count > 350 cells/μL (Table 2b). Of the 484 participants with a clinic CD4 count ≤ 350 cells/μL, 370 (76.4%) correctly self-reported a CD4 count ≤ 350 cells/μL, 65 (13.4%) incorrectly self-reported that their CD4 count was > 350 cells/μL, and 49 (10.1%) self-reported "don't know". Of 2183 participants with a CD4 count of > 350 cells/μL, 1685 (77.2%) correctly self-reported a CD4 count > 350 cells/μL; 266 (12.2%) incorrectly self-reported that their CD4 count was ≤ 350 cells/μL; 232 (10.6%) responded "don't know". Overall agreement between an individual's self-report and the clinical record of the level of CD4 count was demonstrated in 2055 (77.1%) of HIV-positive people on ART and disagreement (including "don't know") in 612 (22.9%).

Demographic and socioeconomic factors and accuracy of self-reported VL

In unadjusted analysis, demographic characteristics associated with inaccurate self-report of VL were:

Table 2 (*Continued*)

Heterosexual men and women (N = 827) Self-reported CD4 count (cells/μL)	Clinic-recorded CD4 count (cells/μL) (latest result available to participant)					
	≤ 350 (N = 202)			> 350 (N = 625)		
	n	Column %	Row %	*n*	Column %	Row %
< 200 (N = 102)	52	25.7	51.0	50	8.0	49.0
200–350 (N = 121)	83	41.1	68.6	38	6.1	31.4
351–500 (N = 174)	27	13.4	15.5	147	23.5	84.5
> 500 (N = 273)	2	1.0	0.7	271	43.4	99.3
Don't know (N = 157)	38	18.8	24.2	119	19.0	75.8

MSM, men who have sex with men.
*The analysis excludes 93 of 2771 individuals on ART. Exclusions were: missing clinic-recorded viral load (n = 18); clinic-recorded viral load dated after questionnaire issue (n = 11); missing self-reported viral load (n = 64).
†The analysis excludes 104 of 2771 individuals on ART. Exclusions were: missing clinic-recorded CD4 count (n = 19); clinic-recorded CD4 count dated after questionnaire issue (n = 15); missing self-reported CD4 count (n = 70).
‡50 copies/mL or less ('undetectable' or 'suppressed').
§More than 50 copies/mL ('detectable' or 'raised').

gender/sexual orientation (women and heterosexual men were more likely to have inaccurate self-report compared with MSM), younger age (those < 30 years old were more likely to have inaccurate self-report compared with all other age groups) and nonwhite ethnicity (Table 1). There were striking associations with socioeconomic factors: non-UK birth/low English fluency, nonuniversity education, nonemployment (other than retirement), being in rented or unstable housing, and greater financial hardship were strongly associated with a higher prevalence of inaccurate self-report. Low supportive network was also associated with inaccurate self-report. In analyses adjusted for gender/sexual orientation, age group, ethnicity, and time since started ART group, most associations were attenuated, but indicators of socioeconomic disadvantage remained strongly associated with inaccurate self-report (Table 1). For example, those who did not have enough money for basic needs had more than twice the prevalence of incorrectly self-reporting their VL status compared with those who always had enough money. Similarly, compared with those who owned their own home, those in unstable accommodation had twice the prevalence of incorrectly self-reporting their VL status. Those who were non-UK born and reported poor English fluency had more than three times the prevalence of incorrectly self-reporting their VL status compared with those born in the UK (which may in part reflect difficulties with comprehension of the question on the latest VL level). Gender/sexual orientation and ethnicity were independently associated with inaccurate self-report in the model including both factors together with age group and time since started ART group, but associations were attenuated.

HIV-related factors and accuracy of self-reported VL

In unadjusted analyses, not having a stable partner and nondisclosure of HIV status were associated with inaccurate self-report of VL. A shorter time since starting ART was strongly associated with inaccurate self-report, with a particularly high prevalence among those who had very recently started ART (when VL level is likely to be changing rapidly). Self-reported nonadherence to ART was also strongly associated with inaccurate self-report: for example, the prevalence was twice as high among those who missed three or more doses in the past 2 weeks compared with those who reported no missed doses. The prevalence of inaccurate self-report was also somewhat higher for those whose latest VL results were > 6 months ago compared with more recent. These associations were similar after adjustment for gender/sexual orientation, ethnicity, age group and time since started ART group (Table 1).

Mental health and accuracy of self-reported VL

Depression symptoms and anxiety symptoms were strongly associated with inaccurate self-report in unadjusted and adjusted analyses. For example, in the adjusted analysis, the prevalence of inaccurate self-report was increased approximately twofold for those with current depressive symptoms. Treatment for depression was also associated with inaccurate self-report in the adjusted analysis (Table 1).

Sensitivity analysis

When participants who did not provide an answer to the question on self-reported VL (n = 64) were included in

the "disagreement" category, the proportion of participants with inaccurate self-report of VL was 18.2% (498 of 2742). When 70 participants with missing self-report of CD4 count level were classified as "disagreement", the proportion of participants with inaccurate self-report of CD4 count level was 24.9% (682 of 2737). Associations of factors with inaccurate self-report of VL were very similar to those found in the main analysis (results not shown).

Discussion

We report on levels of agreement between self-report and clinic-recorded laboratory values of VL and CD4 count in people treated for HIV infection in the UK. A minority (16%) of HIV-positive individuals on ART did not correctly self-report whether their VL was undetectable. A quarter (25.0%) of HIV-positive individuals on ART did not correctly self-report their CD4 count within broad categories. Heterosexual male and female gender/sexual orientation, non-white ethnicity, lower socioeconomic status, poor English fluency, low supportive network, not having a stable partner, nondisclosure of HIV status, having recently started ART, ART nonadherence and poorer mental health were associated with inaccurate self-report of VL.

To our knowledge, this is the first European study to assess agreement between self-reported and clinic-recorded HIV VL and CD4 count. Our findings are comparable to those of several studies assessing accuracy of reporting of HIV biomarkers in people with HIV in the USA, most of which found overall moderate levels of agreement between self-report and medical record, and which found evidence that younger age, lower education, lower health literacy and socioeconomic disadvantage were associated with inaccurate self-report of VL and CD4 count [24–28]. Our results suggest that, even in a UK setting with free access to health care and treatment, socioeconomic disadvantage is strongly linked to lack of knowledge of HIV-related markers.

HIV is a life-long, chronic condition and proficient knowledge of HIV health markers among people with HIV infection supports self-management, which can impact on engagement and retention in care [29]. Reasons for lack of knowledge of personal VL level in those with disadvantaged socioeconomic circumstances are likely to be complex and multifaceted. Lower levels of knowledge could in part be a consequence of health ranking as a lower priority in the context of immediate pressures. For example, financial, housing, employment or family difficulties may result in prioritization of these issues above personal health. This may impact on attendance at, or engagement with, health services. For patients who are non-UK born with lower English fluency, this language barrier alone can result in anxiety and stress at clinic appointments, and make clinic interactions difficult and thus harder to engage with. Our study suggests that those with a lower level of education are also less likely to have accurate knowledge of their VL status, which may be linked to health literacy, and may also make HIV appointments stressful or confusing, and potentially reduce motivation to attend. Depression and other mental health problems may adversely impact on motivation and prioritization of HIV-related health.

The results could also be interpreted as showing that health providers are less successful in actively engaging HIV-positive people who have more complex needs in their own health care. Possible strategies to improve such engagement may include having clearer explanations after diagnosis about the importance of CD4 count and VL and what they mean for care, and having printed resources in languages other than English with involvement of peer advocates who speak the mother languages. In addition, greater training and resources on these issues for health professionals themselves may be needed. It is also important to note that lack of knowledge of personal VL level may be related to the approach taken by a doctor in discussing results with a patient. Specific values of laboratory test results may not always be given to all patients, a strategy that could be viewed as appropriate in some circumstances. In some cases, doctors may only communicate results if there is something to be concerned about. For example "undetectable viral load", or an exact value of the CD4 count, might not be directly explained by a doctor if they think their patient would prefer a more general summary of HIV health status. A doctor might choose instead perhaps to emphasize adherence and say that generally everything is okay. Insights into this level of patient–doctor communication are beyond the scope of this study.

Defining engagement in care is complex, and requires more than a single measure of appointment attendance [30–33]. One previous study from the USA used multiple markers including knowledge of personal CD4 count and antiretroviral treatment, medication adherence, and appointment attendance, to form a composite measure of engagement [30]. In our study, knowledge of personal VL level was strongly associated with ART adherence. Previous studies have found that greater engagement with care was associated with higher prevalence of viral suppression [30,33]. Further investigation of self-knowledge of VL as a predictor of engagement in care could help identify those patients at risk of becoming disengaged.

Strong evidence now demonstrates that viral suppression as a result of ART substantially reduces infectiousness of HIV-positive people to sexual partners [11–17]. Further evidence indicates that some MSM may use viral suppression in decision-making about condomless sex [34–38]. In the ASTRA study, there was evidence that knowledge of suppressed VL impacted on condom use among MSM, although the effect was modest at the time of the study, and was not apparent for heterosexual men and women [38]. The accuracy of reporting an undetectable VL by HIV-positive individuals on ART is directly relevant for their HIV-negative sexual partners, if the HIV-positive partner's VL influences decision-making around condom use. The high level of accuracy of a self-reported undetectable VL found in this UK study is encouraging, as this implies that decisions to have condomless sex on this basis will generally be well informed. Of all participants who self-reported undetectable VL, < 4% did not have a VL ≤ 50 copies/mL. Furthermore, among this subset who incorrectly reported an undetectable VL, the majority had a clinic-recorded value < 1000 copies/mL, making HIV transmission very unlikely. However, it is important to recognize that the prevalence of VL suppression (both overall and among those with self-reported undetectable VL) and awareness of personal VL level may be overestimated in our study as it was conducted among HIV-positive individuals attending clinic and who agreed to participation, suggesting a degree of engagement in care. As ART use expands and knowledge about the protective effect of ART on HIV transmission is publicized and disseminated, further attention should be paid to ensure that all HIV-positive people on ART are able to correctly self-report whether their latest HIV VL is undetectable. The importance of ART adherence and regular VL testing for those with HIV-negative sexual partners should also be emphasized in this context.

A strength of the ASTRA study is that it included a large, unselected sample of people with diagnosed HIV infection in the UK, in contrast to similar studies on this topic from the USA that have mainly been conducted among low-income or hard-to-reach populations and had smaller sample sizes. [24–28]. Our study has some limitations. Knowledge of HIV biomarkers may have been overestimated if such knowledge was poorer among study nonresponders, those not eligible for the study because of language difficulties, those without the opportunity to be invited because of very infrequent clinic attendance, or the small number of participants who had missing data on ART status. Although study personnel were asked to record the latest clinic values of VL and CD4 that had been communicated to the participant, accuracy of self-report may be underestimated if cases of disagreement were attributable to participants recalling VL test results from a different date from the clinic-recorded test.

Our results demonstrate high accuracy of a self-report of undetectable VL among people receiving ART in the UK. Overall accuracy of self-report varied according to demographic, socioeconomic, HIV and health-related factors. Indicators of socioeconomic disadvantage, nondisclosure of HIV status, poorer ART adherence, and poorer mental health were strongly linked to inaccurate knowledge of VL. We identify a need for a stronger clinical focus on a specific group of patients, characterized by adverse socioeconomic circumstances, to improve their knowledge and experience of HIV care, as well as those with limited English who should be routinely offered access to interpreter services. Accurate knowledge of VL is important at both an individual and a public health level. Further consideration should be given to including it as part of a composite tool to measure engagement in care, together with a clinic plan for subsequent interventions to support people who are not engaged.

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Appendix: The ASTRA Study Group

ASTRA clinic teams: Royal Free Hospital: Alison Rodger, Margaret Johnson, Jeffrey McDonnell and Aderonke Adebiyi. Mortimer Market Centre: Richard Gilson, Simon Edwards, Lewis Haddow, Simon Gilson, Christina Broussard, Robert Pralat and Sonali Wayal. Brighton and Sussex University Hospital: Martin Fisher, Nicky Perry, Alex Pollard, Serge Fedele, Louise Kerr, Lisa Heald, Wendy Hadley, Kerry Hobbs, Julia Williams, Elaney Youssef, Celia Richardson and Sean Groth. North

Manchester General Hospital: Ed Wilkins, Yvonne Clowes, Jennifer Cullie, Cynthia Murphy, Christina Martin, Valerie George and Andrew Thompson. Homerton University Hospital: Jane Anderson, Sifiso Mguni, Damilola Awosika and Rosalind Scourse. East Sussex Sexual Health Clinic: Kazeem Aderogba, Caron Osborne, Sue Cross, Jacqueline Whinney and Martin Jones. Newham University Hospital: Rebecca O'Connell and Cheryl Tawana. Whipps Cross University Hospital: Monica Lascar, Zandile Maseko, Gemma Townsend, Vera Theodore and Jas Sagoo. *ASTRA core team:* Fiona Lampe, Alison Rodger, Andrew Speakman and Andrew Phillips. *ASTRA data management:* Andrew Speakman, Marina Daskalopoulou and Fiona Lampe. *ASTRA advisory group:* Lorraine Sherr, Simon Collins, Jonathan Elford, Alec Miners, Anne Johnson, Graham Hart, Anna-Maria Geretti and Bill Burman. *CAPRA grant advisory board:* Nick Partridge, Kay Orton, Anthony Nardone and Ann Sullivan.

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