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Correspondence:
j.sewell@ucl.ac.uk

Accuracy of reporting undetectable HIV viral load among people with HIV on antiretroviral treatment in the UK

Janey SEWELL[1], Marina DASKALOPOULOU [1], Fumiyo NAKAGAWA[1], Fiona C LAMPE[1], Simon EDWARDS [2], Nicky PERRY[3], Ed WILKINS[4], Rebecca O'CONNELL[5], Martin JONES[6], Simon COLLINS [7], Andrew SPEAKMAN[1], Andrew N PHILLIPS[1], Alison J RODGER[1].

[1]UCL, Royal Free Campus, London, UK, [2] Central and North West London NHS Foundation Trust, London, UK, [3]Brighton and Sussex University Hospitals NHS Trust, Brighton, UK, [4]The Pennine Acute NHS Hospitals Trust, North Manchester, UK, *[5]Department of Sexual Health, Newham University NHS Hospital Trust, Barts Health, UK; [6] Eastbourne Sexual Health Centre, Eastbourne, UK, [7] HIV i-Base, London, UK*

Background

- In people with HIV, knowledge of current HIV viral load (VL) and CD4 count is important for supporting self-management and informing decisions on sexual behaviour and condom use
- Reviewing laboratory markers such as CD4 counts and HIV VL with a patient is now common practice amongst HIV healthcare providers, and patient involvement in decisions about care and treatment is recommended by UK guidelines
- Little is known about the accuracy of peoples' knowledge of their own HIV biomarkers, or whether socio-economic and other factors, impact on such knowledge

Aims

We aimed to investigate if HIV positive people on ART correctly report their HIV VL levels and CD4 count level (comparing self-report with the clinic-recorded value) and to assess associations with socio-economic and other factors with accurate reporting of HIV VL level

Methods

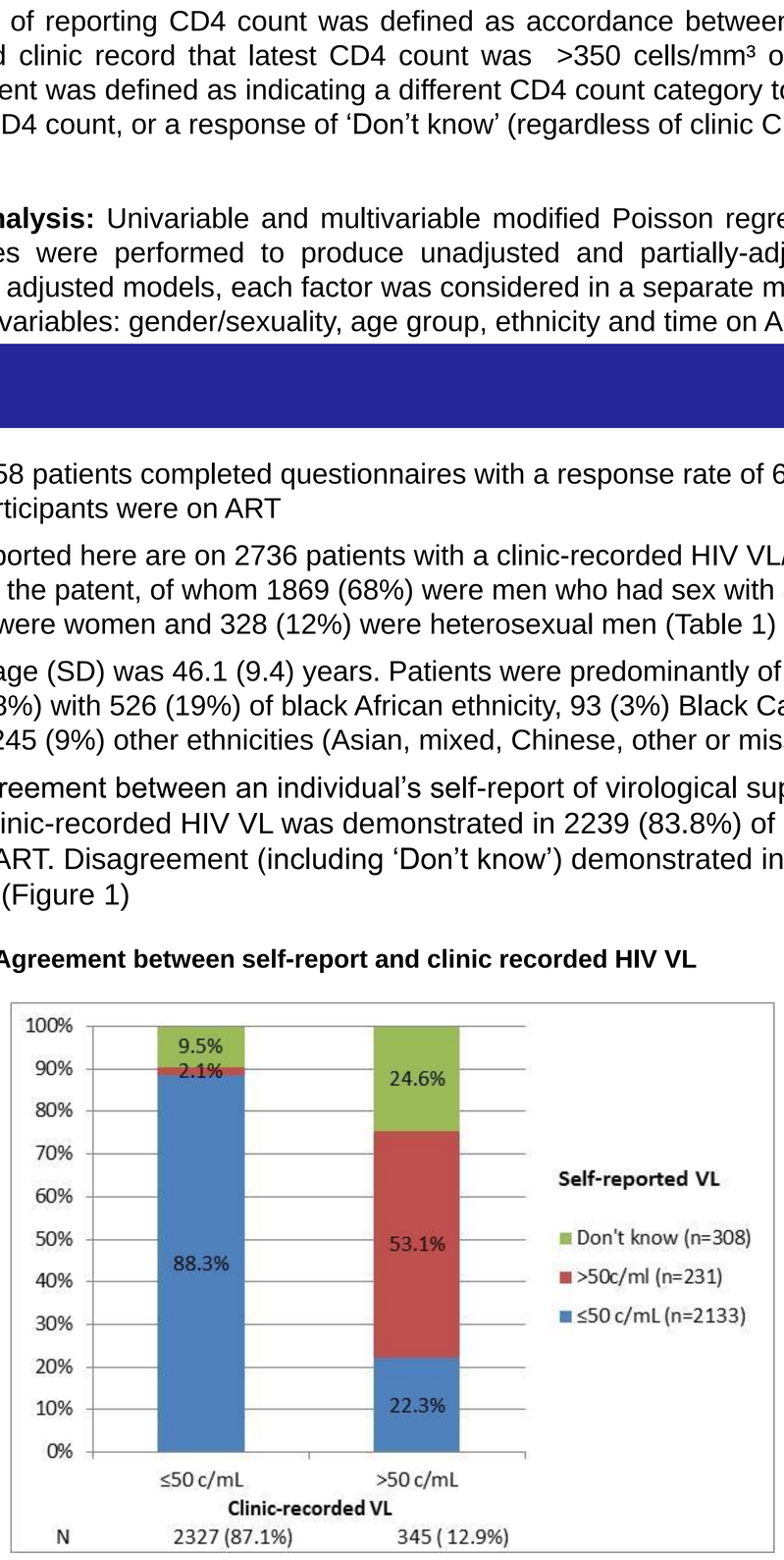
- We used data from the ASTRA study, a cross-sectional, clinic based study that recruited HIV positive people from 8 UK HIV out-patient clinics between Feb 2011-Dec 2012
- Participants self completed a confidential paper questionnaire that included items on demographics (gender/sexuality, age, ethnicity, UK born/English fluency), socio-economic factors (education, employment, housing, money for basic needs), HIV (disclosure of HIV status, partner's HIV-status, ART adherence), health and lifestyle factors (symptoms of depression [PHQ-9 >=10], alcohol and recreational drug use)
- Participants on ART were asked to;
  - (i) Categorise their most recent HIV VL into: '≤50 copies/mL ('undetectable' or 'suppressed')'; or '>50 copies/mL ('detectable' or 'raised')'; or 'Don't Know'
  - (ii) Categorise their most recent CD4 count into; '<200'; '200-350'; '351-500'; 'More than 500' or 'Don't know / can't remember'
- Clinic recorded HIV VL and CD4 count results that were available to the patient were documented
- HIV VL agreement was defined as accordance between participant self-report and clinic record. Disagreement was defined as either disagreement between self-report and clinic record on the level of HIV VL, or a response of 'Don't know' to the question on HIV VL level (regardless of clinic viral load value)
- Agreement of reporting CD4 count was defined as accordance between participant self-report and clinic record that latest CD4 count was >350 cells/mm³ or ≤350 cells/mm³. Disagreement was defined as indicating a different CD4 count category to that of the clinic-recorded CD4 count, or a response of 'Don't know' (regardless of clinic CD4 count value)

Statistical Analysis: Univariable and multivariable modified Poisson regression with robust error variances were performed to produce unadjusted and partially-adjusted prevalence ratios (PR). In adjusted models, each factor was considered in a separate model and adjusted only for 'core' variables: gender/sexuality, age group, ethnicity and time on ART.

Results

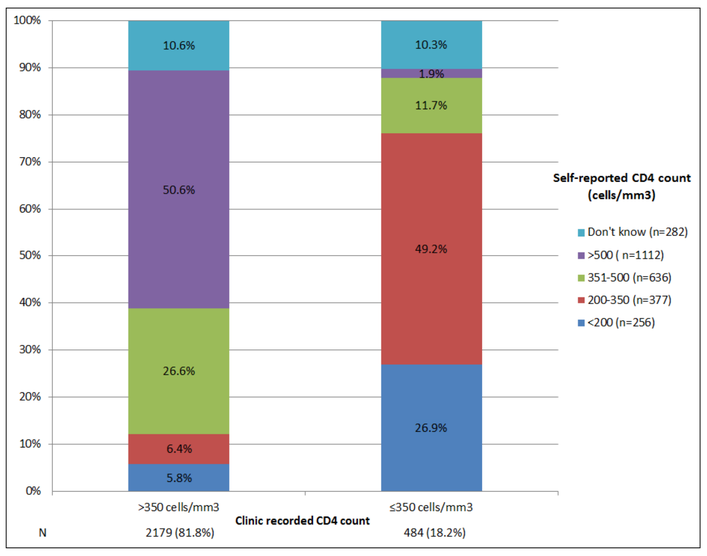
- Overall, 3258 patients completed questionnaires with a response rate of 64%, 2758 (86.5%) participants were on ART
- Results reported here are on 2736 patients with a clinic-recorded HIV VL/CD4 count available to the patent, of whom 1869 (68%) were men who had sex with a man (MSM), 539 (20%) were women and 328 (12%) were heterosexual men (Table 1)
- The mean age (SD) was 46.1 (9.4) years. Patients were predominantly of white ethnicity (n=1872, 68%) with 526 (19%) of black African ethnicity, 93 (3%) Black Caribbean or black other, and 245 (9%) other ethnicities (Asian, mixed, Chinese, other or missing ethnicity)
- Overall agreement between an individual's self-report of virological suppression on ART and clinic-recorded HIV VL was demonstrated in 2239 (83.8%) of HIV positive people on ART. Disagreement (including 'Don't know') demonstrated in 433 (16.2%) individuals (Figure 1)

Figure 1: Agreement between self-report and clinic recorded HIV VL



Results (continued)

Figure 2: Agreement between self-report and clinic recorded CD4 count



- For CD4 count, 2663 participants were included
- Overall agreement between an individual's self-report and clinical record of level of CD4 count was demonstrated in 2050 (77%) of HIV positive people on ART
- Disagreement (including 'Don't know') in 613 (23%) individuals
- In total, 50 participants incorrectly reported both HIV VL and CD4 count level

Socio-demographic factors and disagreement

- In unadjusted analysis, demographic characteristics significantly associated with lack of agreement between self-report and clinic HIV VL level were gender/sexuality (women and heterosexual men had higher levels of disagreement compared to MSM), younger age and non-white ethnicity
- There were striking associations between socio-economic factors and disagreement; disagreement was associated with non-UK birth and low English fluency, non-university education, unemployment, non-home ownership and greater financial hardship (Table 1)
- In partially adjusted analysis (for gender/sexuality, age, ethnicity, time on ART) lower socio-economic status remained strongly and significantly associated with disagreement of HIV VL

Table 1: Demographic, socio-economic, HIV-related and mental health factors and association with disagreement between self-report and clinic VL

	Prevalence in sample		Participants on ART with disagreement		Unadjusted analysis ◊			Partially adjusted analysis ◊		
	n	%	n/N	row %	PR	95% CI	p-value	PR	95% CI	p-value
Gender/sexuality group (N=2,736) ▪										
MSM	1,869	68.4	226/1850	12.2	1	ref		1	ref	
Heterosexual men	328	11.9	91/310	29.4	2.4	[1.9,3.0]		1.9	[1.4,2.5]	
Women	539	19.7	116/512	22.6	1.9	[1.5,2.3]	<0.001	1.3	[1.0,1.8]	<0.001
Age at recruitment, years (N=2,676) ▪										
<30	104	3.9	29/100	29	1	ref		1	ref	
30-39	556	20.8	103/546	18.9	0.7	[0.5,0.9]		0.8	[0.6,1.2]	
40-49	1186	44.3	171/1153	14.8	0.5	[0.4,0.7]		0.7	[0.5,1.0]	
50-59	635	23.7	83/628	13.2	0.5	[0.3,0.7]		0.7	[0.4,1.0]	
≥60	195	7.3	30/189	15.9	0.5	[0.3,0.9]	0.002(trend)	0.7	[0.4,1.2]	0.154(trend)
Ethnicity/race (N=2,736) ▪										
White	1,872	68.4	231/1852	12.5	1	ref		1	ref	
Black African	526	19.2	133/496	26.8	2.1	[1.8,2.6]		1.5	[1.1,2.0]	
Black Caribbean or black other	93	3.4	20/89	22.4	1.8	[1.2,2.7]		1.4	[0.9,2.3]	
Other (Asian, mixed, Chinese, missing)	245	9	51/237	21.5	1.7	[1.3,2.2]	<0.001	1.4	[1.0,1.9]	0.035
Fluency in English according to place of birth (N=2,647) ¡										
Born in the UK	1,506	56.9	186/1489	12.5	1	ref		1	ref	
Non-UK born, fluent	891	33.6	147/867	16.9	1.4	[1.1,1.7]		1.1	[0.9,1.4]	
Non-UK born, quite well	227	8.6	68/212	32.1	2.6	[2.0,3.3]		1.8	[1.3,2.4]	
Non-UK born, not at all well	23	0.9	17/23	73.9	5.9	[4.5,7.8]	<0.001	4.4	[3.2,6.0]	<0.001
Education (N=2,662)										
No qualifications or up to A levels	1,563	58.7	306/1525	72.5	1.9	[1.5,2.3]	<0.001	1.7	[1.4,2.1]	<0.001
University degree or above	1,099	41.3	116/1081	27.5	1	ref		1	ref	
Employment status (N=2,736)										
Employed	1,487	54.3	182/1460	12.5	1	ref		1	ref	
Unemployed or other(carer, student, reti	1,249	45.7	251/1212	20.7	1.7	[1.4,2.0]	<0.001	1.6	[1.3,1.9]	<0.001
Housing (N=2,736)										
Owner	949	34.7	91/938	9.7	1	ref		1	ref	
Renting	1463	53.5	254/1425	17.8	1.8	[1.5,2.3]		1.4	[1.1,1.8]	
Unstable /Other (temporary, staying with	324	11.8	88/309	28.5	2.9	[2.3,3.8]	<0.001	2	[1.5,2.7]	<0.001
Money for basic needs (N=2,682)										
Always	1,175	43.8	121/1160	10.4	1	ref		1	ref	
Mostly	699	26.1	104/690	15.1	1.4	[1.1,1.8]		1.3	[1.0,1.7]	
Sometimes	476	17.7	101/458	22.1	2.1	[1.7,2.7]		1.5	[1.2,2.0]	
No	332	12.4	98/314	31.2	3	[2.4,3.8]	<0.001(trend)	2.4	[1.9,3.1]	<0.001(trend)
Disclosure of HIV status* (N=2,719)										
Yes	2,504	92.1	361/2459	14.7	1	ref		1	ref	
No	215	7.9	64/198	32.3	2.2	[1.8,2.8]	<0.001	1.8	[1.4,2.4]	<0.001
Time on ART (N=2,646) ▪										
≤6 months	162	6.1	52/158	32.9	3	[2.2,3.9]		2.5	[1.8,3.4]	
6 months-2 years	291	10.9	48/276	17.4	1.6	[1.1,2.1]		1.3	[0.9,1.9]	
2-5 years	529	19.9	89/523	17	1.5	[1.2,2.0]		1.3	[1.0,1.7]	
5-10 years	694	26.4	105/677	15.5	1.4	[1.1,1.8]		1.2	[0.9,1.5]	
>10 years	970	36.7	107/958	11.2	1		<0.001(trend)	1		<0.001(trend)
Adherence to ART (N=2726) ‡										
Adherent	1,850	67.8	252/1810	13.9	1	ref		1	ref	
Non-adherent	876	32.2	179/855	20.9	1.5	[1.3,1.8]	<0.001	1.4	[1.2,1.7]	<0.001
Depression symptoms† (N=2,736)										
No	1,998	73.1	264/1950	13.5	1	ref		1	ref	
Yes	738	26.9	169/722	23.4	1.7	[1.5,2.1]	<0.001	1.8	[1.5,2.1]	<0.001
Treatment for depression or other mental health issue (N=2,711)										
No	2,523	93.1	380/2467	15.4	1	ref		1	ref	
Yes - for depression	38	1.4	Dec-37	32.4	2.1	[1.3,3.4]		2.2	[1.4,3.5]	
Yes - for other mental health issue	150	5.5	33/148	22.3	1.4	[1.1,2.0]	<0.001	1.6	[1.2,2.2]	<0.001

* Disclosed HIV status to friends, family, and where applicable; stable partner, work colleague † Depression symptoms defined as PHQ-9 score >=10. ‡ Non-adherence defined as missing ≥1 doses of ART in the previous 2 weeks or missed ≥2 consecutive days of ART on more than one occasion in the previous 3 months. ◊ PR= Prevalence Ratio; CI=Confidence Interval. P-values by Wald test ▪ Partially adjusted for: gender/sexuality, age, ethnicity, and time on ART. All other factors were partially adjusted separately for gender/sexuality, age group (≤40, >40 years), ethnicity (white, all other), and time on ART (up to 5, 5-10, >10 years). ¡ Specific multivariable model excludes ethnicity as it was highly correlated (ρ≥0.5) with fluency, and thus was adjusted for gender/sexuality group, age group, and time on ART.

Discussion

- We report a high level of agreement between self-report and laboratory values of HIV VL and CD4 count in HIV positive people on ART in the UK though a minority (16.2%) were unable to correctly self-report the degree of virological suppression, and 22.3% thought their HIV VL was undetectable, but had a clinic-recorded detectable HIV VL
- Lower socio-economic status was strongly associated with inaccurate knowledge of HIV VL, as were factors linked with engagement in care, including non-disclosure of HIV status, poor English fluency, poor ART adherence and poorer mental health
- We identify a potential need for clinical services to focus efforts to improve engagement in care on patients at socio-economic disadvantage or who have limited English, which should include routinely offered access to interpreter services to those who require it
- Consideration should also be given to including patient self knowledge of HIV VL as part of a composite tool to measure engagement in care, with subsequent intervention

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