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# Does community-based point of care HIV testing reduce late HIV diagnosis? A retrospective study in England and Wales

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## Abstract

The objective of this study was to investigate if patients diagnosed in community clinics have higher baseline CD4 cell counts than those diagnosed in Genitourinary medicine (GUM)/HIV clinics. We undertook a retrospective review of baseline CD4 cell counts for patients receiving a reactive HIV test in community-testing clinics. Eleven local HIV clinics were contacted to determine the baseline CD4 cell counts of these patients. Baseline CD4 cell counts of those diagnosed in the community were compared with mean local GUM/HIV clinic and median national baseline CD4 cell count for their year of diagnosis. Clients diagnosed in community settings had a mean baseline CD4 cell count of 481 cells/mm<sup>3</sup> (SD 236 cells/mm<sup>3</sup>) and median baseline of 483 cells/mm<sup>3</sup> (interquartile range 311–657 cells/mm<sup>3</sup>). This was significantly higher than those diagnosed in the GUM/HIV clinic local to the community-testing site (mean baseline CD4 397 cells/mm<sup>3</sup>,  $p = 0.014$ ) and the national median for that year (336 cells/mm<sup>3</sup>,  $p < 0.001$ ). HIV testing in community settings identifies patients at an earlier stage of infection than testing in clinical settings.

## Keywords

Screening, AIDS, HIV, diagnosis, Europe, baseline CD4 count

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## Introduction

Late diagnosis of HIV is an important predictor of morbidity, short-term mortality and HIV transmission.<sup>1</sup> In 2014, two fifths of HIV diagnoses in the UK were made 'late' (with a CD4 cell count  $< 350$  cells/mm<sup>3</sup> within three months of diagnosis).<sup>2</sup>

Most HIV tests in the UK are undertaken in clinical settings. These include primary care and antenatal clinics. Community HIV testing facilities are defined:

as those that are based outside pre-existing traditional healthcare settings. These include both stand-alone HIV testing services, provided separately from other clinical services, and venues primarily used for other purposes (such as social venues or community centres) where HIV testing is available as an additional service.<sup>3</sup>

Between 2006 and 2009 in the UK, by far the majority, 73%, of all HIV diagnoses were made in sexual

health clinics and less than 1% in non-clinical settings including prisons and the Blood Transfusion Service.<sup>4</sup>

However, people cite overcrowding, waiting times and the lack of anonymity as disincentives for attending sexual health clinics for HIV testing.<sup>5</sup> Black Africans in London cited further uncertainty about where to test and lack of time as barriers to testing.<sup>6</sup> While one UK study looking at the views of men who have sex with men (MSM) on STI testing in community settings found that the majority would prefer to test for HIV

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in 'National Health Service (NHS) specialist service' settings,<sup>7</sup> studies around the world show that HIV testing outside of clinical facilities is acceptable and that mobile community HIV testing can be cost effective in diagnosing new cases and effective at enrolling HIV-positive patients in care before they become ill.<sup>8–13</sup> A systematic review of 44 community HIV testing programmes in resource-rich countries found that 'community HIV testing strategies provide an acceptable alternative to HIV testing in healthcare settings and are feasible to implement'.<sup>3</sup>

Many of these studies were, however, undertaken in either developing world settings or the United States. Neither of these environments accurately reflects the state-funded and free-at-the-point-of-use healthcare system found in the UK. A US study found that clients testing in the community were older and more likely to be HIV-positive than those testing in clinical settings,<sup>14</sup> while a small UK study<sup>15</sup> and most developing world studies found the reverse.

Terrence Higgins Trust (THT) is the largest HIV and Sexual Health charity in the UK and has run community HIV testing programmes since 2004. THT community HIV testing clinics have performed more than 14,000 HIV tests since 2008 in England and Wales. These nurse-led or Healthcare Assistant-delivered clinics are located in easily accessible sites including high street offices, saunas, libraries and churches and often operate on evenings and weekends. A small study evaluating one such service found that the average baseline CD4 cell count was higher, although not significantly so, when compared to clients of the local Genitourinary medicine (GUM)/HIV clinic.<sup>15</sup> For the period 2008–2012 we used data from THT's community HIV testing clinics to determine whether people receiving a reactive HIV test at a community-testing site were identified at a different stage of HIV infection compared with those diagnosed in clinical settings and national averages. We refer to these clinical settings as GUM/HIV clinics due to the integrated nature of many UK sexual health services. Patients may present for HIV testing at a primary healthcare or GUM clinic but baseline CD4 data are recorded and provided by a hospital HIV clinic. We defined a patient's first recorded CD4 cell count as their baseline CD4 cell count.

## Objectives

1. To determine if newly diagnosed patients receiving a reactive point-of-care HIV test in a community setting have different baseline CD4 cell count when compared with patients diagnosed in clinical settings.

2. To explore the care pathway of people testing for HIV in community clinics, including what proportion of patients engages with subsequent clinical care.

## Methods

We received ethical approval from South East Coast – Kent NRES Committee as project 12/LO/1778. Following this, we searched THT's database and paper records to identify people who had received a reactive HIV test in a community clinic between 2008 and 2012. We contacted the hospital specified on each patient's care pathway to determine if they had accessed subsequent HIV care and, if so, to establish their baseline CD4 cell count. We provided an encrypted list of the patients' Soundex (scrambled surname and date of birth code) to Public Health England (PHE) to ascertain whether patients had sought HIV care elsewhere in England or Wales and, if so, what had been their baseline CD4 cell count. PHE were also able to identify whether patients had received a CD4 cell count pre-dating their visit to THT's community clinic.

### Study population

Figure 1 shows the flow chart of how we arrived at our final sample of 74 patients who were newly diagnosed with HIV in a community clinic and had a known baseline CD4 cell count.

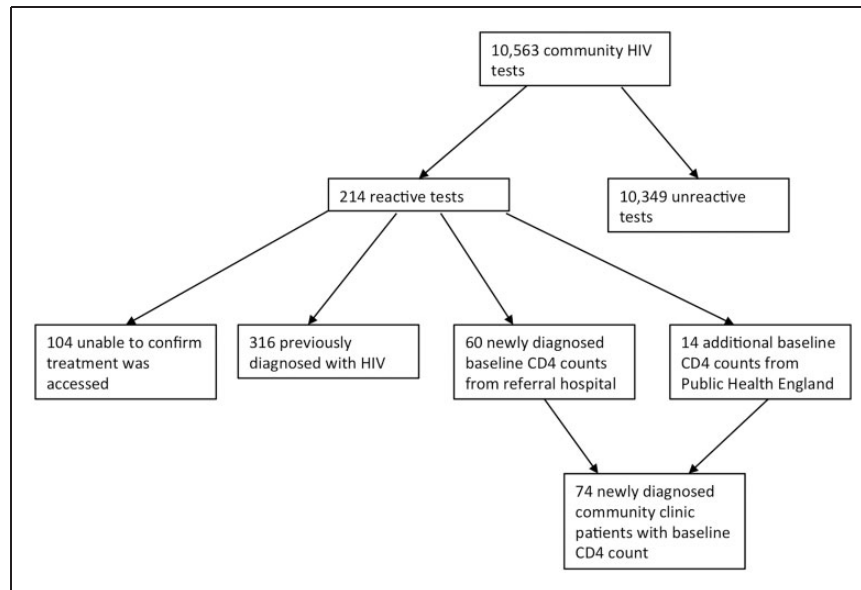
A demographic breakdown of the sample is given in Table 1.

### Statistical methods

Comparator CD4 cell counts were obtained from the hospital HIV clinics where THT community-testing patients went for confirmatory tests and care. These clinics provided annual mean averages of their patients' baseline CD4 cell counts from 2008 to 2012.

PHE provided national median CD4 cell counts from 2008 to 2011. The national median CD4 cell count for 2012 was not available at the time of data analysis. These, however, showed consistency between years, and clients who were tested in 2012 were assigned the PHE value from 2011. Medians are used instead of means here because extreme outliers are found at the national level and these skew the mean values. There were no significant outliers in the THT data we collected and so we compared means for this part of the study.

T-tests were performed to compare the mean baseline CD4 cell count of the community-testing clients



**Figure 1.** Flow chart of how we arrived at our final sample of 74 patients who were newly diagnosed with HIV in a community clinic and had a known baseline CD4 cell count.

who presented for hospital HIV care to the mean baseline CD4 cell count for the HIV service to which they were referred, in the year they presented. PHE provided national median baseline CD4 cell counts. We performed Wilcoxon signed rank tests to compare community-tested clients to the national median from PHE for the year they were tested.

To control for confounders, we performed further tests where individuals were categorised by gender, sexuality and ethnicity and compared with clinic and national level medians for the same demographics. Due to very small sample sizes in the demographic-specific tests, we pooled these into a meta-analysis to estimate an overall effect.

We performed further t-tests to ascertain if community-testing clients were more likely to be diagnosed at a CD4 cell count  $>350$  or  $>500$  cells/mm<sup>3</sup> compared to those testing in clinical settings. These figures were chosen as they were the recommended CD4 cell counts at which patients were advised to start treatment in the UK and the US, respectively, at the time of testing. Finally, we performed a binary logistic analysis to examine which demographic factors predicted whether an individual presented for a follow-up appointment.

## Results

Two-hundred and fourteen people received a reactive HIV diagnosis in the study period (2.0%). Seventy-four (36%) fit the inclusion criteria of being newly diagnosed and subsequently confirmed as accessing HIV treatment in England or Wales. Thirty-six patients were

already aware they were HIV-positive at the time of their community clinic test and 104 patients could not be linked to a subsequent baseline CD4 cell count. The mean baseline CD4 cell count of patients who tested positive in a THT community clinic was 84 cells/mm<sup>3</sup> higher than that of patients diagnosed at the referral hospitals' GUM/HIV clinics ( $p=0.014$ ) (see Table 1).

Wilcoxon signed rank tests showed that community-tested patients were significantly more likely to have higher CD4 cell count than the national population. Fifty-nine community-tested patients had CD4 cell counts higher than the national median while 20 presented below. Clients diagnosed in community clinics were significantly more likely to be diagnosed at a baseline CD4  $>350$  cells/mm<sup>3</sup> than clients diagnosed in clinical settings. This effect was not replicated for baseline CD4 cell count  $>500$  cells/mm<sup>3</sup>.

T-tests controlling for sexuality, ethnicity and gender found that MSM, diagnosed in community settings, had significantly higher baseline CD4 cell counts than clients tested in clinical settings and were significantly more likely to be diagnosed at a baseline CD4  $>350$  cells/mm<sup>3</sup> (Figure 2).

Table 2 shows the results of a binary logistic regression analysis testing the demographic predictors of follow-up likelihood. The most important demographic predictor is being homosexual or bisexual (these categories were pooled in order to compare this group to heterosexual participants). MSM were almost four times more likely to present for follow-up after a reactive test in a community clinic. Being male and white was also associated with higher odds of

**Table 1.** Demographics of patients testing in HIV community clinics, those who received a reactive test, those who had received an HIV diagnosis prior to their community clinic test and those who were newly diagnosed in the community clinic and could be traced to a baseline CD4 cell count.

	Total patients tested in community clinics (n = 10,560) (%)	Total reactive population in community clinics (n = 214) (%)	Patients with new HIV diagnoses in community clinics (n = 36) (%)	Newly diagnosed patients with CD4 cell count originally tested in community clinics (n = 74) (%)
<b>Ethnicity</b>				
White UK	5102 (48)	89 (42)	6 (17)	49 (66)
White non-UK	562 (5)	16 (7)	2 (6)	9 (12)
Black African	2721 (26)	80 (37)	23 (64)	12 (16)
Other Black including mixed	957 (9)	11 (5)	2 (6)	3 (4)
Asian and mixed	795 (8)	7 (3)	1 (3)	1 (4)
Ethnicity unknown	426(4)	11 (5)	2 (6)	0 (0)
<b>Sexuality</b>				
Heterosexual	6840 (65)	96 (45)	26 (72)	16 (22)
Homosexual	2039 (19)	82 (38)	4 (11)	51 (69)
Bisexual	477 (5)	13 (13)	3 (8)	5 (7)
Sexuality unknown	1207 (11)	23 (23)	3 (8)	2 (3)
<b>Gender</b>				
Female	3059 (29)	66 (31)	19 (53)	10 (14)
Male	7504 (71)	148 (69)	17 (47)	64 (86)
Median age	29	32	36	35
Mean baseline CD4 cell count for patients diagnosed in community setting (cells/mm <sup>3</sup> )			481 (SD 236)	(versus mean baseline CD4 cell count for patients diagnosed in referral hospital p = 0.014)
Mean baseline CD4 cell count for patients diagnosed in referral hospital			397 (SD 34)	
Median baseline CD4 cell count for patients diagnosed in a community setting (IQR)			483 (311–657)	(versus Public Health England's national median baseline CD4 cell count p < 0.001)
Public Health England's national median baseline CD4 cell count (IQR not available)			336	
Median number of days between reactive community test and presenting to a hospital HIV clinic for a CD4 test in newly diagnosed patients (IQR)			3 (1–9)	
Median number of days between reactive community test and presenting to a hospital HIV clinic for a CD4 test in patients with identified pre-existing HIV diagnosis (IQR)			2 (1.5–3)	

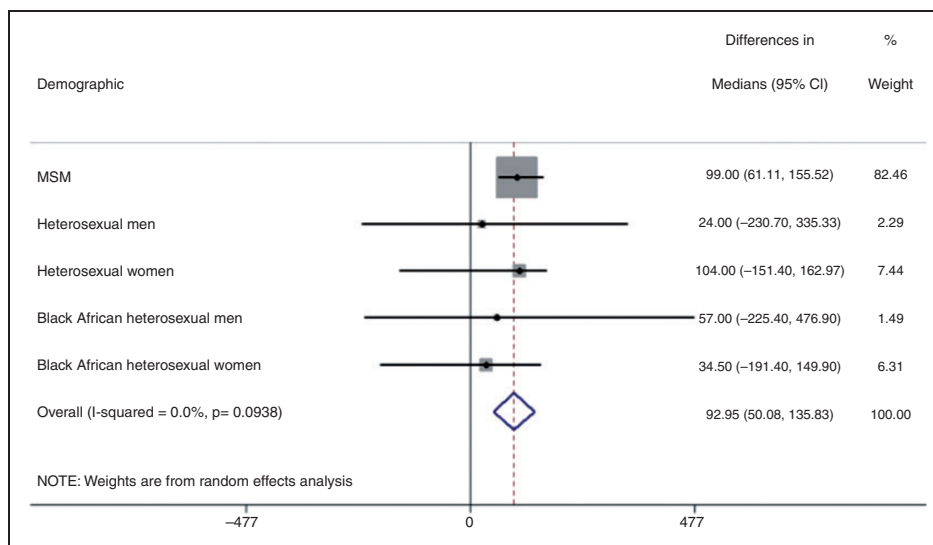
HIV: human immunodeficiency virus; IQR: interquartile range; SD: standard deviation.

presenting for follow-up although these results are not statistically significant. Age was not a predictor of likely follow-up.

### Previously diagnosed patients and re-engagement

Thirty-six people were already aware that they were HIV-positive when they took an HIV test at a community clinic. Of these, six patients were confirmed as subsequently accessing specialist HIV services having

never, or not within the last two years, received HIV care in the UK. They sought care a median of two days (IQR 1.5–3) following their community HIV test. Sixteen patients informed the nurse at the community clinic that they were aware of their positive HIV status. Notes in the patients' records showed that nurses counselled previously diagnosed patients about the importance of accessing HIV treatment and gave advice on how to access care. Twenty patients had a pre-existing baseline CD4 cell count, which was taken at a median



**Figure 2.** A forest plot showing the difference in the mean baseline CD4 cell count between those tested in a THT community clinic and the national median for each demographic group. CD4 cell count is given on the X-axis (cells/mm<sup>3</sup>).

**Table 2.** Results from binary logistic regression analysis of follow-up. Odds ratios, significance tests and 95% confidence intervals are presented for demographic indicators of the odds of presenting at follow-up after THT community testing. An odds ratio of higher than one denotes higher odds of follow-up.

Follow-up	Odds ratio	P-value	95% CI	
Male (ref female)	1.73	0.285	0.63	4.73
MSM (ref heterosexual)	3.84	0.015	1.29	11.40
White (ref. non-white)	1.97	0.208	0.69	5.65
Age at test	1.00	0.823	0.97	1.04

CI: confidence interval.

of 1010 days (IQR 431–1859) before their community clinic HIV test.

## Discussion

Our results show that patients receiving an HIV diagnosis through community-testing are, on average, diagnosed at an earlier stage of infection when compared with patients testing in clinical settings. They are also significantly more likely to be diagnosed at a baseline CD4 above 350 cells/mm<sup>3</sup>. These associations are significant for the aggregated patient group and for MSM patients. It is not significant for Black African or heterosexual clients, but the average CD4 cell count at baseline was still higher when tested in community settings, compared with clinical settings. In our study, only a small number of Black African and heterosexual clients could be linked to a baseline CD4 cell count, and the small sample size is likely to contribute to this

lack of statistical significance. Those that presented to a hospital for confirmatory testing and care presented a median of three days after their community HIV test. This falls within BHIVA's 2013 Standard of Care guidelines that indicate that all patients should be offered a full baseline assessment, including a CD4 cell count test, within two weeks of diagnosis with HIV.<sup>16</sup> It is possible that people diagnosed in community settings are more likely to access care sooner after diagnosis than those in clinical settings and will therefore appear to have a higher baseline CD4 cell count. A 2014 study found that adults who received their HIV diagnosis in primary care or a community setting were significantly *less* likely to have presented for HIV care within one month, compared to those who were diagnosed in an integrated GUM/HIV clinic 76% versus 91%,  $p < 0.001$ .<sup>17</sup>

## Access to care

One hundred and four (49%) clients could not be confirmed as having accessed HIV care, therefore we were unable to link them to a baseline CD4 cell count. This could reflect some patients using false names or dates of birth when testing in community clinics in addition to those patients who have yet to seek HIV care. It may also represent some clients with false-reactive HIV point-of-care tests that were not subsequently confirmed as HIV-positive and therefore did not have a baseline CD4 cell count. Binary logistic regression analysis found that being male and white increased the likelihood of being linked to follow-up; however, these results are not statistically significant, and there was no effect of age. MSM clients were almost four

times more likely to be linked to follow-up care compared with heterosexual clients. Most of the heterosexual men who had reactive tests identified themselves as of African descent although we are unable to ascertain when they had migrated to the UK.

Difficulty in maintaining referral pathways is an established challenge in community testing.<sup>18</sup> This is possibly because while community testing removes barriers to HIV testing, these barriers remain in place when it is necessary for the patient to access hospital-based HIV care. Community testing may allow clients to test earlier than they otherwise would have done, but this does not mean they will be ready to accept their HIV diagnosis any sooner. The barriers a person needs to overcome to access clinic-based testing may mean they are more motivated to test and will be more prepared to proceed to seeking care.

In previous studies on community HIV testing, a similar proportion of reactive patients were confirmed to have accessed HIV care.<sup>19</sup> Studies in the United States found that 48% of the patients who received a reactive HIV test result in South Carolina and 77% in New York City linked to care within three months of their test.<sup>20,21</sup> A systematic review on HIV testing in community setting found only three studies collected data on the proportion of HIV diagnosed patients who transferred to care, and that these rates were 75–100% of all diagnosed patients.<sup>3</sup> All three studies were based in saunas and provided community HIV testing to MSM only.<sup>15,22,23</sup>

Other studies have demonstrated that access to and retention in HIV care varies between demographic groups. A South London HIV clinic investigated the loss to follow-up among its patients. It found that while more than a quarter of the heterosexual male black African (26.2%) and Caribbean (29.3%) patients were lost to all UK HIV care and follow-up, this occurred with less than 18% of white and black MSM and white heterosexual male and female patients.<sup>24</sup>

A study of Black Africans in the UK found that ‘fear of stigmatisation, deportation and expectations of HIV as incurable or as a “death sentence” continue to deter respondents from taking an HIV test’<sup>6</sup>. Black African workshop participants requested that community HIV testing staff should have training on, ‘1) dealing with questions about immigration status and entitlement to HIV treatment; [and] 2) discussing prevention of mother-to-child-transmission...’<sup>25</sup> These examples suggest that HIV-positive black African patients may have different needs and health-seeking behaviours than MSM patients, despite often being combined into the same discussion on the utility and outcomes of community HIV-testing programmes.

THT has a long history of working with gay men and is well accepted within the UK MSM community. It is

possible that THT’s community clinics are well designed for the MSM community but need to better understand the needs of the Black African community to increase progression from HIV testing into treatment.

### *Pre-diagnosed patients*

Thirty-six patients were aware of their positive HIV status before their reactive community clinic test. Nearly 41% of these patients told the THT staff of their positive HIV status. Community testing can be used to identify undiagnosed patients and to provide a supportive opportunity to re-engage patients with specialist HIV care.

This study’s findings were consistent across all five years, all demographic groups and all referral clinics. Participants came from a range of urban and peri-urban settings in England and Wales. It is therefore likely that these findings are generalisable to other developed world settings with free-at-point-of-use healthcare systems. Further research is needed to understand how to improve the number of confirmed patients seeking care following a reactive HIV test in a community clinic. This is particularly necessary for Black African patients. In recent years, THT’s community clinics have strengthened their referral pathways into local HIV services and now ensure that all patients with a reactive result are followed up at two weeks to ensure access to care. It would be useful to understand how community clinics are used to provide entry or re-engagement points into the medical system, as well as in counselling existing patients, normalising HIV testing and providing health promotion opportunities for HIV-negative patients.

### **Strengths and limitations**

The number of patients who had a reactive HIV test in the community, had never previously been diagnosed with HIV and for whom we were able to establish a baseline CD4 cell count is a small proportion of the total number of reactive community HIV tests. The impact of the missing data on the validity of the study findings makes it difficult to conclusively state that increasing the availability of community testing would increase the national average baseline CD4 cell count at diagnosis.

This study was dependent on patients providing the community-testing site with the same information they used if they sought HIV care. If they provided different information we were unable to link their baseline CD4 cell count. Patients who provided inconsistent information between HIV services may differ from those who provided consistent information. Hospitals listed on the local THT care pathway are geographically near to

the community clinic. Patients more fearful of stigma may have been more likely to seek HIV care away from their local area and not attend the referral hospital. We ameliorated this limitation by collaborating with PHE to obtain baseline CD4 cell counts from HIV clinics across the UK. Due to incomplete and delayed reporting, PHE did not have all the clinic baseline CD4 cell counts that we had obtained. There may be other patients receiving HIV care but are missing from PHE's national baseline CD4 database. This would be a source of bias as it excludes some of the clients who sought HIV care away from their local area. We did not have national data for 2012 and used national data from 2011 as a proxy as we did not expect there to be much change in the median national baseline CD4 cell count between 2011 and 2012.

This study does not investigate why patients appear to be testing at community clinics at an earlier stage of HIV infection than those testing in clinical settings. It may be that patients prefer the same-day test results offered in community clinics, compared to having to wait for results when testing in a primary or hospital-based setting. It may be that community clinics avoid having to provide the documentation that is required to register with a GP or that could be linked to other personal records. A minority of patients testing in clinical settings are being tested in accident and emergency or as part of a medical admission. Their hospital attendance may be because they are symptomatic with an HIV-related condition and these patients may never have tested for HIV until the point at which they became unwell. We suggest that all of these could be areas for further research.

Nevertheless, this study is the first to test whether HIV-positive community-tested patients are diagnosed at a higher baseline CD4 cell count than those who are tested in clinical settings. Although this study needs to be replicated with more data, our results suggest that this is indeed the case.

## Conclusion

Our findings suggest that increasing the scale of community-based HIV testing would serve the varying health needs of certain populations at high risk of HIV and contribute to reducing the proportion of late HIV diagnoses in the UK. In every category, we found that community-tested patients had higher CD4 cell counts than those who first tested in a hospital. Early diagnosis is crucial for the greatest benefits of treatment to be achieved. It is futile, however, to give someone an HIV diagnosis without providing them with the support they need to access treatment and this should be central to all community-testing programmes.

## Key messages

- Community HIV testing identifies patients at a significantly higher CD4 count than testing in conventional settings.
- Community HIV testing provides useful services to those already diagnosed with HIV who may not be accessing care.
- Clients diagnosed with HIV in a community setting need culturally appropriate support to ensure they access HIV care.

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