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**Access to HIV community services by vulnerable populations: Evidence from an enhanced HIV/AIDS surveillance system**

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## **Access to HIV community services by vulnerable populations: Evidence from an enhanced HIV/AIDS surveillance system**

HIV disproportionately affects vulnerable populations such as black and minority ethnic (BME) groups, men who have sex with men (MSM) and migrants, in many countries including those in the United Kingdom. Community organisations in the UK are charitable non-governmental organisations with a proportion of the workforce who volunteer, and provide invaluable additional support for people living with HIV. Information on their contribution to HIV care in vulnerable groups is relatively sparse. Data generated from an enhanced HIV surveillance system in North West England, UK, was utilised for this study. We aimed to determine the characteristics of individuals who chose to access community services in addition to clinical services (1,375 out of 4,195 records of people living with HIV in clinical services). Demographic information, risk factors including residency status, uniquely gathered in this region, and deprivation scores were examined. Multivariate logistic regression modelling was conducted to predict the relative effect of patient characteristics on attendance at community services. Attendance at community services was highest in those living in the most, compared with least, deprived areas ( $p < 0.001$ ), and was most evident in MSM and heterosexuals. Compared to white UK nationals attendance was significantly higher in non-UK nationals of uncertain residency status (Adjusted odds ratio [AOR]=21.91, 95% CI 10.48-45.83;  $p < 0.001$ ), refugees (AOR=5.75, 95% CI 3.3-10.03;  $p < 0.001$ ), migrant workers (AOR=5.48, 95% CI 2.22-13.51;  $p < 0.001$ ), and temporary visitors (AOR=3.44, 95% CI 1.68-7.05;  $p < 0.001$ ). Community services, initially established predominantly to support MSM, have responded to the changing demography of HIV and reach the most vulnerable members of society. Consequent to their support of migrant populations, community services are vital for the management of HIV in black and minority groups. Paradoxically, this coincides with increasing funding pressures on these services.

**Keywords:** HIV; community services; health services, deprivation; third sector; voluntary organisations.

## Introduction

As the global epidemiology of HIV changes and access to effective life prolonging antiretroviral drugs increases (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2009; ATCC 2008; Piot, Kazatchkine, Dybul & Lob-Levyt, 2009) the needs of people living with HIV (PLWHIV) change. In resource poor settings, where antiretroviral (ARV) drugs are now available, support services, which until recently had focused on prevention or palliative care, must now find ways to distribute life saving drugs to those in need. In countries where clinical care services are well established, and thus support services are not needed to provide ARV, they likewise need to adapt and develop new, more appropriate services. Support services that help with social issues such as immigration and poverty, and psychological issues, are needed. In the United Kingdom clinical care is provided free at the point of care to almost all people with HIV by the National Health Service (NHS) with additional support from the community services also being free, or nominal to users. Community organisations in the UK are charitable non-governmental organisations utilising a workforce partly made up of individuals who volunteer a proportion of their time. They may also receive funding from local and national government and the NHS. Such organisations have provided additional support to PLWHIV since the first gay men in London died from acquired immune deficiency syndrome (AIDS) related illnesses in the early 1980s

(NAM, 2006). The experience of community organisations enables them to offer a broad range of services tailored for HIV positive people.

While the demand on HIV services increases in parallel with the rising HIV prevalence, local government and NHS funding to community organisations has decreased or, at best, stabilised (Weatherburn et al., 2007). NHS and local government commissioners justify funding decisions on the basis of changes in need, restructuring to reduce duplication and substandard or unacceptable service provision (Weatherburn et al., 2007). A recent study found that of 13 different services or opportunities for support, HIV community services were ranked 2<sup>nd</sup> for a raft of support needs by 1,929 PLWHIV (Weatherburn et al 2009). It is therefore important to explore the role and impact of community services on the health and wellbeing of persons living with HIV. Few data exist on the systematic measurement on the value of such services.

The North West region of England, UK, comprises of five counties, with a population of 6.9 million people (Office for National Statistics, 2008). The largest city in the region, Manchester, has the highest prevalence of HIV in the UK outside London and the South East (HPA 2008). An enhanced HIV surveillance system in the region collects data from community as well as statutory clinical care services. The capture of such data provides a unique opportunity to examine the demographic characteristics of people living with HIV who access HIV treatment and care through these different services whilst still retaining confidentiality and anonymity. In this paper we explore characteristics of the population who chose to access community services as well as clinical services, to identify the role and

relative contribution of community organisations in the face of the changing epidemiology of HIV.

## **Methods**

### ***North West HIV/AIDS Surveillance.***

The enhanced HIV surveillance data collected by the North West HIV/AIDS Monitoring Unit (Centre for Public Health, Liverpool John Moores University) measures the level of health services use, demographics including ethnicity and place of residence, and treatment variables such as route of infection and type of treatment obtained (Cook et al., 2009). Pseudo-anonymised identifiers are collected and a 'Soundex' (a one-way encryption of the surname that maintains anonymity) is recorded to prevent double counting of individuals attending more than one treatment centre or community service. Reporting is universal across the country from genito-urinary medicine (GUM) clinics, infectious disease departments, haematology units and a number of other specialist units and clinics (Health Protection Agency [HPA], 2006). Data are collected from these clinical services every six months, and include a summary of care from each clinic. A subset of the variables from the hospital dataset is submitted to the national HIV surveillance system at the HPA (2006). Data collection and storage conform to all relevant laws and guidance relating to security and confidentiality (Department of Health, 2003, The Data Protection Act, 1998, Department of Health, 1997). These govern the maintenance and development of the surveillance system and incorporate data extraction for monitoring and research purposes. For this study, data were extracted from the routinely collected data of all HIV positive persons accessing treatment

through clinical and community care settings between 1<sup>st</sup> January and 31<sup>st</sup> December 2005. The total was 4,195 records of individual people living with HIV.

***Community services.***

Community organisations in North West England have provided data to the surveillance system, without obligation, since monitoring began in 1996. Of the known community organisations in the region, eight out of the nine provided data in 2005. The missing organisation is a small service offering support to people in one county in the region. Key demographic variables are routinely gathered but, unlike clinical services, no clinical parameters or information on outcomes were documented. We restricted analysis to data records of HIV positive individuals with a valid Soundex, date of birth, and sex. Individuals only seen by community services were excluded from analysis (n=562) where reliable soundex and date of birth data were missing or could not be corroborated with the clinical records.

***Relationship with deprivation.***

Postal district of residence for all individuals reported by clinical services and community organisations were allocated an Index of Multiple Deprivation (IMD) score based on the lower super output area (LSOA - a small level geographical area consistent with a mean population of 1,500), supplied by the North West Public Health Observatory, England. The higher the IMD score, the more deprived an area. The case reports for people living with HIV were divided into three equal deprivation categories based on IMD score (Cook et al., 2009).

Valid LSOAs and IMD scores were obtained for 82% of case records. IMD scores were allocated to 75% of data records of persons attending only clinical services and to 95% of those also accessing community services. The higher proportion in the overlapping group reflects the greater likelihood of at least one service providing location of residence data. Community and clinical datasets were matched using identifying characteristics (soundex, date of birth and sex).

***Statistical analysis.***

All those accessing clinical services were categorised as having accessed additional services from community organisations (coded 1) or not (coded 0). The characteristics of those who did and did not attend community organisations were determined, and differences in the proportions assessed using Chi square tests. Multivariate backward logistic regression analysis was conducted to predict the odds of attendance at community services in addition to clinical services, based on characteristics including individuals' ascribed level of deprivation (based on postcode) and demographic indicators (age, sex, ethnicity/residency status and route of infection). Subgroups with the largest population were selected as the referent cell, apart from deprivation where 'least deprived' was selected. Missing demographic fields were coded as 'unknown' in these analyses. Data were analysed using SPSS version 15 with significance defined at the 5% level. Ninety five percent confidence intervals are reported.



## Results

A total of 4,195 individuals were recorded to have accessed clinical services in the study year: 2,820 (67%; 73% males) sought care from clinical services only, 1,375 individuals (33%; 76% males) attended both clinical and community services (table 1). Fifty three percent of all individuals were infected through sex between men (MSM) and 39% through heterosexual contact. Injecting drug use, blood/tissue and mother to child transmission was less common (2%, 1% and 2% respectively). The majority of individuals were aged between 25 and 44 years (69%). The profile of the subset attending only clinical services differed from those who also accessed community services ( $\chi^2 = 94$ ,  $df=5$ ,  $p<0.001$ ; table 1). While MSM formed 62% of all clients seen at community services, HIV infected heterosexuals represented only 38%, and those infected through blood products, 1%.

### TABLE 1 AROUND HERE

While 46% of individuals infected through injecting drug use accessed community services, this was the case for only 18% of those infected through blood/tissue. Heterosexuals were significantly less likely to attend community services than MSM (27.1% vs 37.9%, Adjusted Odds Ratio [AOR]= 0.41, 95% CI = 0.31-0.54;  $p<0.001$  table 1).

Whilst a larger proportion of white UK nationals than black African UK nationals (35% and 12%) were seen in the community services, of all those attending a clinical service, non-UK nationals were more likely than white UK

nationals to also attend community services ( $P < 0.005$ ). Compared to the referent category of white UK nationals, attendance was greatest in refugees (71.8%; AOR=5.75, 95% CI 3.30-10.03;  $p < 0.001$ ), migrant workers (62.5%, AOR=5.48, 95% CI 2.22-13.51;  $p < 0.001$ ), and temporary visitors (50%, AOR=3.44, 95% CI 1.68-7.05;  $p = 0.001$ ) and those classified as 'other' which includes non-UK nationals with uncertain or ambiguous residency status (90.8%, AOR=21.91, 95% CI 10.48-45.83;  $p < 0.001$ , table 1).

Compared to those aged 35 to 44 years (the predominant age group of HIV positive persons in the study area), younger persons (those aged 25 to 34 years) were less likely to attend a community service (AOR=0.78, 95% CI 0.66-0.94;  $p < 0.001$ , table 1).

Attendance at community services was significantly higher in those living in the most deprived areas compared with those resident in the least deprived areas (48.3% vs 29.0%, AOR=2.40, 95% CI 1.99-2.91; ;  $p < 0.001$ , table 1). Figure 1 displays the proportion of HIV positive individuals visiting community services as well as statutory services, by level of deprivation for the two main infection routes; MSM and heterosexual sex. For both groups, the proportion of persons visiting community services rose with increasing deprivation. The subcategory with the highest attendance at community services was MSM in the most deprived areas (54%) followed by heterosexuals in the most deprived areas (44%).

FIGURE 1 AROUND HERE

## Discussion

We were able to explore a unique dataset that characterises HIV infected persons accessing HIV community services, in addition to clinical services, in a region of the UK representing a socio-economically and demographically diverse population.

Analysis of one year's figures, in this instance 2005, suggest community organisations in the study region specialise in care of MSM (61.8% of all clients seen), and are currently less involved with the care of HIV infected heterosexuals (31.9%) or persons infected through blood products (0.8%), especially when compared with those who solely visited clinical services (MSM: 49.4%; heterosexual: 41.8%; blood/tissue: 1.8%). This difference may be partly historical; highly specialist services were developed for haemophiliacs, for example Birchgrove (<http://www.birchgrovegroup.org>), while separate community services developed to support HIV positive gay men. Heterosexually infected individuals have tended to be mainly amongst black and minority ethnic groups (BME; HPA 2006) and can include asylum seekers or temporary visitors to the UK (Cook, Downing, Rimmer, & Bellis, 2006). Our data suggest the most vulnerable of these groups, such as refugees, migrant workers, and temporary visitors are now more likely than UK nationals to access community, as well as clinical, services. This increased attendance is despite stigma amongst the black African community (Dodds 2006), and the slow adaptation of services to the needs of BME groups. Despite the erosion of such barriers it is likely unmet need amongst the BME community continues.

Persons accessing community services as well as clinical services lived in more deprived areas than those only accessing clinical treatment centres. This may be explained by the effectiveness of the referral systems which encourage the most vulnerable to access these additional services, as well as by the attractiveness of the services to those most in need. Many community services have set up support groups for people from BME populations, and these populations tend to reside in relatively deprived areas of the UK.

The relationship between deprivation and ill-health has been well documented (Townsend & Davidson, 1982; Acheson, 1998). In terms of PLWHIV, international studies have shown a close correlation between socioeconomic status and antiretroviral use (Joy et al., 2008), and with longevity (McFarland, Chen, Hsu, Schwarcz, & Katz, 2003; Borrel et al., 2006). In the UK, HIV prevalence is higher in more deprived areas (Cook & Hargreaves, 2007) and those in the most deprived areas are more likely to be admitted to hospital for HIV-related care (Cook, Hargreaves, Tocque, & Bellis, 2004). Research into health inequalities reveals the most deprived areas have the highest levels of poor health indicators including binge drinking, smoking, births to lone mothers, mental health conditions, claimants of disability living allowance and mortality from all causes (Wood et al., 2006). Many socio-economic and cultural components collude towards this imbalance, such as unemployment, low wages, poor housing, xenophobia, and deserve more attention as an increasing proportion of new HIV infections are heterosexually acquired (Hargreaves et al 2009). The evidence that community organisations provide services for relatively more people from deprived areas highlights their ability, and the importance of, permeation of community

services to reach those who most need additional support. Our analysis provides evidence of a relationship between deprivation and community service attendance for both of the main groups of people (MSM and heterosexual) affected by HIV.

Recorded cases of HIV in MSM are higher in poorer multicultural areas than in affluent areas (Cook & Hargreaves, 2007). Further, men from lower social classes and the poorly educated have been identified as being less accepting of homosexual behaviour (e.g. less likely to define their general opinion of sex between men as being 'not at all wrong'; Weatherburn Davies, Hickson, & Hartley, 1999). Those living in these poorer areas may experience negative responses and possible hostility to their sexuality. Those with HIV face further stigmatisation and barriers to disclosure of their status (Dodds, 2006). Many deprived areas in this study area are located near city centres, and those residing there may have easier access to services, as shown by analysis of distance travelled to clinical HIV services (Cook et al., 2009). Community organisations are also usually located close to city centres. Those living in more deprived areas, those who are unemployed and poorer are more likely to progress faster with HIV and have worse health (Delpierre et al 2008; Ezzy et al 1999; Cook, Hargreaves, Tocque, & Bellis, 2004). This poorer health may cause them to seek more additional support from community organisations. This greater need may explain why the gay men living in the most deprived areas in our sample were also the group most likely to access the social support offered through community organisations (54%, figure 1). Further research in the UK thus needs to examine the relationship between attendance at community services and other indicators of deprivation including unemployment, income and ill-health allowances (Delpierre et al., 2008; Ezzy et al., 1999; Wood et

al., 2006) to enhance understanding of how different social pressures affect attendance. Research into stigma, both internalised and external, and how it impacts on use of community services would contribute towards our ability to improve services and encourage uptake.

Community organisations in the UK provide a range of services to PLWHIV, including counselling, adherence support, information services, advocacy, financial assistance, support groups and help lines. These services offer a variety of specialist support services for women, gay men, persons originating from Africa, young people, asylum seekers and also provide care and support to the friends and family of those affected by HIV. Despite this contribution and preferential use by vulnerable groups, funding is already being diverted from community and non-governmental organisations to clinical services (Terrance Higgins Trust, 2004). Since the withdrawal of ring-fenced HIV funding in England in 2004 HIV charities have coped in an uncertain financial climate and with even fewer resources (Weatherburn et al., 2007), yet have managed to provide invaluable services to many more people. Current economic restraints will further compromise community service finances. Despite this, community organisations provide value for money (ie an estimated £2 of services are gained for every £1 purchased by the clinical sector because of the value of volunteering and non-statutory funding) (Cosgrove Lyons & Bellis, 2001).

### *Limitations of study data*

Of the known community organisations in the region eight out of the nine were able to provide data. While we could not assess any biases from this absence, the

population served was relatively small and would have thus contributed marginally to our regional dataset. This study depends on data reported without obligation and therefore restricts robust analyses of all characteristics; inclusion of 95% confidence intervals are provided where possible to help readers understand the distribution of data. Some caution is required when interpreting the overlap between the community and clinical datasets since inaccurate reporting of pseudo-anonymised unique identifiers can lead to some inaccuracies, preventing the complete matching between the two systems. This would result in an underestimate of the true overlap between community and clinical services. Bias may have been introduced as individuals with names that are unfamiliar to the English tongue (e.g. black Africans) are more likely to live in deprived areas (Tinsley & Jacobs, 2006), could thus be prone to miscoding. The higher rate of missing residence information of those seen only in the clinical sector (25% missing) would be expected to dilute the results and give weaker relationships. However, despite these caveats the relationship between service attended and deprivation was still highly significant ( $P < 0.001$ ). Thus, the finding that community services see people who, on average, live in more deprived areas appears robust despite possible non-matching and missing data. Comparison with other regions was not possible as such data are not collected at a national level. An ecological method was used for analyses by deprivation (i.e. socioeconomic characteristics are assumed based on an area of residence), and as such the data are subject to the 'ecological fallacy'. Clinical indicators could not be included in this model because the surveillance system lacks robust indicators of current stage of disease and has high levels of missing information for other clinical markers (e.g. viral load and CD4 counts). Evidence suggests BME groups and migrants are more likely to be diagnosed late with HIV

(Burns, Ade, & French et al., 2001) and delayed diagnosis is often associated with worse prognosis (Chadborn Delpech, Sinka et al., 2005). A relationship between faster disease progression and increased poverty has also been shown (Delpierre et al., 2008; Ezzy et al., 1999) so those from more deprived areas may require additional support from community organisations. Therefore, we may have underestimated the support needed by these individuals

## **Conclusions**

Data from North West England demonstrates that community services appeal to and reach disadvantaged people living with HIV, regardless of ethnicity, sexuality or gender. Attendance was highest in those living in the most deprived areas, as well as in migrants and those of uncertain immigration status. Consequent to their support of such populations, community services are critical for the management of HIV in BME groups. The British HIV Association recognises that community organisations are experts in providing patient education and support (British HIV Association, 2007). While the UK Government anticipates an increasing role for the community and independent sectors in HIV and sexual health care services (Department of Health, 2006) such views paradoxically coincide with increasing funding pressures on these services.



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Table 1. Univariate and Multivariate predictors of attendance at community services, for all those attending statutory services.

	Univariate					Multivariate	
	n	Number seen in community services (%)	Chi-square	df	P	Adj OR (95% CI)	P
sex			3.87	1	0.49		0.007
Male	3102	1043 (33.6%)				ref	
Female	1093	332 (30.4%)				1.43 (1.10-1.85)	0.007
Route			94.29	5	<0.001		
MSM	2242	850 (37.9%)				ref	<0.001
Injecting drug use	101	46 (45.5%)				1.50 (0.97-2.31)	0.066
Heterosexual	1618	438 (27.1%)				0.41 (0.31-0.54)	<0.001
Blood/tissue	62	11 (17.7%)				0.37 (0.19-0.73)	0.004
Mother to child	68	22 (32.4%)				0.08 (0.01-1.20)	0.068
Other/not known	104	8 (7.7%)				0.20 (0.09-0.42)	<0.001
Ethnicity/Residency			402.99	10	<0.001		<0.001
White UK National	2691	953 (35.4%)				ref	
Black African UK National	274	34 (12.4%)				0.37 (0.24-0.56)	<0.001
Other UK National	202	43 (21.3%)				0.64 (0.44-0.93)	0.020
Asylum Seeker	391	120 (30.7%)				1.31 (0.95-1.81)	0.096
Overseas Student	100	27 (27%)				0.81 (0.49-1.34)	0.420
Migrant Worker	24	15 (62.5%)				5.48 (2.22-13.51)	<0.001
Temp Visitor	38	19 (50.0%)				3.44 (1.68-7.05)	0.001
Refugee	78	56 (71.8%)				5.75 (3.30-10.03)	<0.001
Dependent	9	6 (66.7%)				4.30 (0.95-19.56)	0.059
Other non UK national <sup>1</sup>	98	89 (90.8%)				21.91 (10.48-45.83)	<0.001
Unknown	290	13 (4.5%)				0.10 (0.06-0.18)	<0.001
Age Group			32.44	5	<0.001		
0-14	64	22 (34.4%)				5.90 (0.40-86.65)	0.195
15-24	208	58 (27.9%)				0.71 (0.5-1.02)	0.067
25-34	1228	369 (30%)				0.78 (0.66-0.94)	0.008
35-44	1682	606 (36%)				ref	
45-54	725	257 (35.4%)				0.99 (0.81-1.21)	0.923
55+	288	63 (21.9%)				0.60 (0.43-0.83)	0.002
Deprivation			344.18	3	<0.001		<0.001
Least deprived	1144	332 (29.0%)				ref	
Average	1144	424 (37.1%)				1.48 (1.22-1.78)	<0.001
Most deprived	1144	553 (48.3%)				2.40 (1.99-2.91)	<0.001
No postcode <sup>2</sup>	763	66 (8.7%)				0.26 (0.19-0.34)	<0.001
<b>Total</b>	<b>4195</b>	<b>1375 (32.8%)</b>					

<sup>1</sup> Including those of uncertain residency status, failed asylum seekers and who do not fit into another category. <sup>2</sup> Analysis repeated excluding those without postcode – odds ratios were similar and significance levels did not change

Figure 1. Percentage of HIV positive persons seen in statutory services in 2005 who attend community services, by deprivation category.

