

Sexual Health Needs Assessment – HIV and AIDS

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HIV – defining the issue

First identified in the 1980s, Human Immunodeficiency Virus (HIV) targets the white blood cells, damaging the immune system and leaving the infected person susceptible to serious infections and certain types of cancer. At the point where a typical combination of defined illnesses has developed, the patient is said to have progressed to Acquired Immunodeficiency Syndrome (AIDS). Throughout this report, references to HIV also include patients with AIDS.

HIV is associated with serious morbidity, high costs of treatment and care, significant mortality and high number of potential years of life lost. Thousands of individuals are diagnosed with HIV each year. The infection is still frequently regarded as stigmatising and has a prolonged 'silent' period during which it often remains undiagnosed.

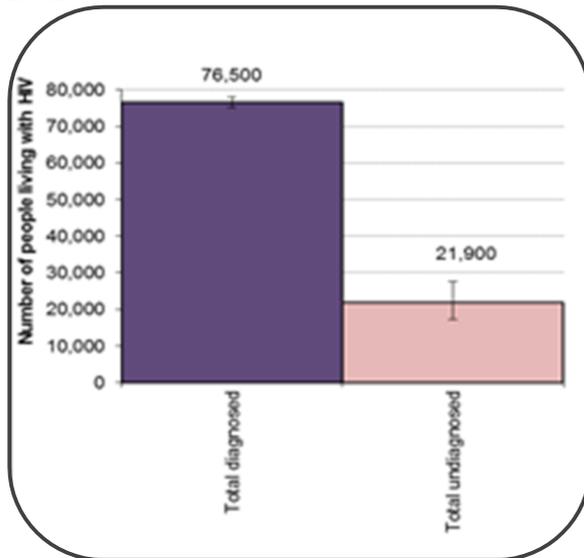
With the advent of highly active antiretroviral therapy (HAART) in the mid-1990s, the number of AIDS diagnoses and deaths declined rapidly from its peak. AIDS has remained at a low level since the end of that decade, transforming HIV into a chronic but manageable long-term illness.¹ Challenges remain however, with high rates of late HIV diagnoses and an ageing population. As we are reminded by the title of the recent House of Lords select committee report, the virus has "No vaccine, no cure".²

Why is this issue highlighted?

Burden of disease

As shown in figure 1 (below) an estimated 98,400 (93,500-104,300) people were living with HIV in the UK in 2012 and approximately 21,900 (22%) were unaware of their infection.³ The overall prevalence was 1.5 per 1,000 population (2.1 in men and 1.0 in women). According to the House of Lords Select Committee report, there is a widespread perception that HIV and AIDS is no longer a serious problem, but it states "nothing could be further from the truth." The numbers accessing care have trebled since the year 2000, and the report stresses that HIV/AIDS remains "one of the most serious public health issues confronting the government at the start of the 21st century."⁴

Figure 1: Estimated number of people living with HIV (diagnosed and undiagnosed) in the UK, 2012



Implications of HIV

Thanks to antiretroviral drugs, and in complete contrast to the situation in the 1980s, people treated for HIV can now expect a near-normal life expectancy, particularly if diagnosed promptly.^{5,6} A person diagnosed at age 20 can now expect to live on average to age 66.⁷

HIV has now been transformed into a serious long-term condition, with corresponding cost implications for the NHS.⁸ For the individual patient, the consequences of HIV can include:

- Mental health problems – HIV positive status is associated with very high levels of anxiety and depression, which in turn may make patients less likely to adhere to their drug regimes.⁹ A survey of people with HIV in the North West found that 70% had suffered anxiety and depression problems in the past 12 months.¹⁰
- Medical problems – HIV also carries an increased risk of cardiovascular and renal disease, and possible neurocognitive impairment in later life.¹¹
- Stigma and discrimination – this may also deter people from being tested, with serious implications for individual and public health, such as a reduced earning capacity, affecting accommodation and quality of life.^{12,13}
- Miscellaneous problems – a substantial proportion of HIV positive respondents to the survey reported problems with basic issues such as housing, sleeping and eating.¹⁴
- The Framework for Sexual Health Improvement points out that as people with HIV age, their health and social care needs are expected to increase.¹⁵

Treatment costs

Approximately 43% (£640m) of the £1.48bn spent by primary care trusts (PCTs) on infectious diseases in England in 2011/12 went on HIV/AIDS, up from £370m in 2006/07 (although there have been changes in accounting procedures since then).¹⁶ It is unclear how much of the cost of HIV testing is included in this figure and it does not include spending on prevention, or the amount spent by councils on social care for people with HIV.^{17,18}

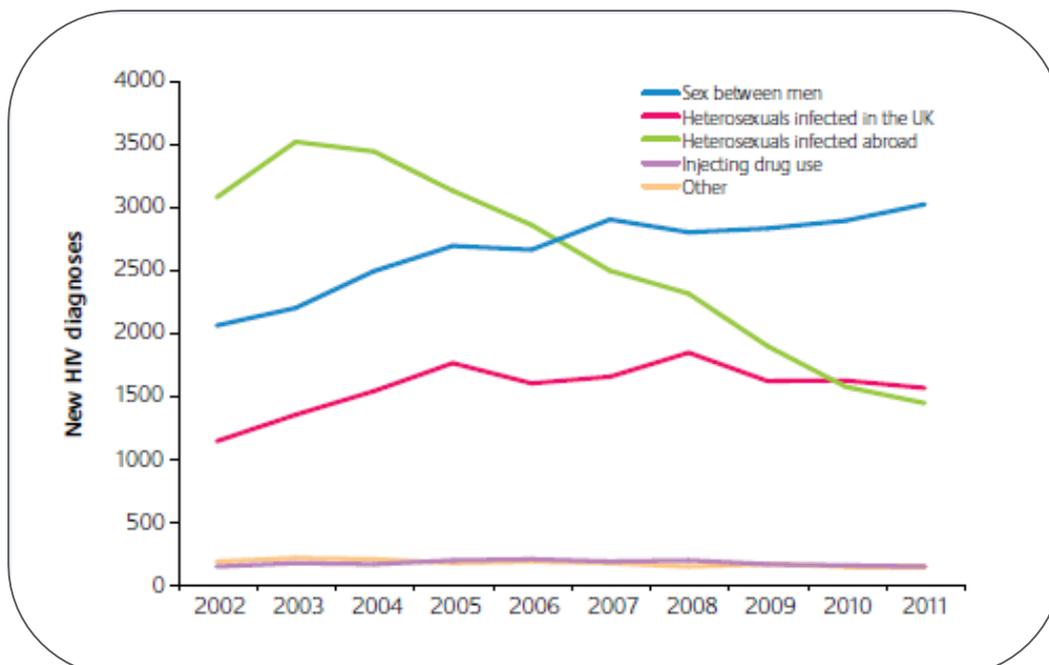
The lifetime cost of treating someone who is HIV positive is substantial – estimated to be between £280,000 and £360,000. If the 4,000 infections acquired in this country, diagnosed in 2011, had been prevented, this would have saved £1.9bn over the patients' lifetimes.¹⁹ Two-thirds of treatment and care cost is accounted for by drugs, with antiretroviral drugs alone costing £5,500 per person, per year. These costs can only be expected to continue to rise as life expectancy improves, making prevention all the more crucial.²⁰

HIV – who is at risk and why?

Routes of infection

The overwhelming majority (>95%) of HIV infections reported over the past 10 years in the United Kingdom were acquired through sexual transmission, whether heterosexual or among men who have sex with men (MSM).²¹

Figure 2: New HIV diagnoses by exposure group, UK, 2003/11



After adjusting for missing risk information, HIV infections acquired through heterosexual contact accounted for 41% (N=2,381) of the 5,846 diagnoses in England in 2012 whilst 46% (N=2,705) were among MSM (see table one below). Infections acquired through injecting drugs and through other routes have remained low over time, accounting for 187 of new diagnoses while 573 diagnoses did not have a confirmed exposure route.

Table 1: Probable exposure category (where reported) for new HIV diagnoses in England, and Cumbria and Lancashire, 2012

Probable exposure category	England	Cumbria and Lancashire
No. of new HIV diagnoses	5,846	82
Sex between men*	46%	54%
Heterosexual contact	41%	38%
Injecting drug use	2%	1%
Other	2%	0%
Not known	10%	7%
*includes men who also reported injecting drug use		

Source: Public Health England (PHE), HIV data, country and PHE region HIV data tables

Of the 5,846 new cases of HIV diagnosed in England, 4,162 (72%) were male and 1,649 were (28%) female.* Locally there were 82 new cases in the same period across Cumbria and Lancashire: 61 male (74%) and 21 female (26%).²² The breakdown of new cases across Cumbria and Lancashire is very similar to England as a whole. In the first half of 2013 there had been a further 25 cases diagnosed in Cumbria and Lancashire.† In Lancashire there were a total of 61 new cases in 2012 though the data does not allow a gender or exposure category breakdown.

Heterosexual contact

The estimated total number of people in England newly diagnosed with HIV transmitted through heterosexual contact has continued its steady decline to stand at 2,381 in 2012, including an allowance for probable late reporting.²³ Infections acquired abroad by this means have continued to fall, while those acquired in the UK appear to have plateaued (figure 2 above).

Men who have sex with men (MSM)

MSM remain the group most affected by HIV with 47 per 1,000 living with the infection. This is equivalent to an estimated 41,000 (37,300-46,000) MSM living with HIV in 2012, of whom 7,300 (18%; 3,700-12,300) were unaware of their infection. The

* Includes 35 cases where gender is not known

† Lancashire refers to the 12 districts in the county council area; Lancashire-14 incorporates the two unitary authorities of Blackburn with Darwen and Blackpool.

number of new diagnoses of HIV in MSM in the England, was at an all-time high of 2,705 in 2012 and by the end of June 2013 a further 998 had been diagnosed.²⁴

The Framework for Sexual Health Improvement cites evidence that gay men are four times more likely than average to have taken illegal drugs in the past year, and that drug and alcohol misuse increases their likelihood of engaging in risky sexual behaviour.²⁵

People who inject drugs

There were only 95 people who acquired HIV through injecting drug use diagnosed in England in 2012, a reduction from 111 diagnosed in 2011.²⁶ Early and effective interventions such as needle exchanges have kept this number low for many years. HIV prevalence among this group in the UK was only 1.5% in 2009, which compares very favourably with other countries.²⁷

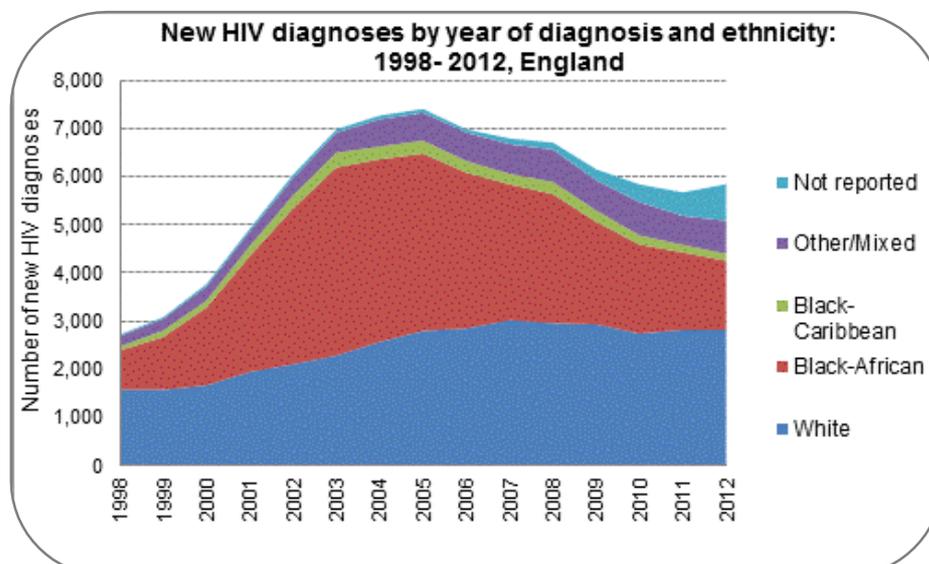
Other

The main other route of infection is mother-to-infant transmission, although there were only 71 such diagnoses in the UK in 2012, a reduction from 102 in 2011. By the end of June 2013 there were 27 new cases from mother-to-infant transmission. The number infected by receiving blood or tissue products has been below 20 each year, since 2008, and all such infections since 2002 have been acquired outside the UK.²⁸

Ethnicity

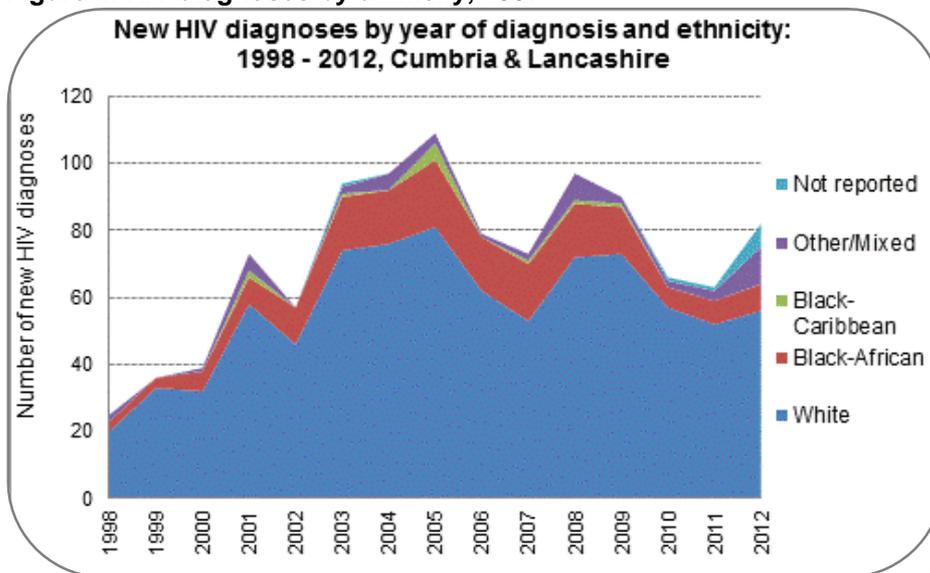
According to the 2011 Census, black African ethnic populations make up approximately 1.8% of England's population, though black Africans accounted for 24.5% (1,431) of new HIV diagnoses in 2012. However, as shown in figure 3, this represents a significant decline since 2005. The England population is over 85% white, but white people accounted for only 48% (2,825) of new HIV diagnoses in 2012.

Figure 3: HIV diagnoses by ethnicity, 1997-2012 England



Locally, black African ethnic populations make up less than 1% of Cumbria and Lancashire's population, however, black Africans accounted for 10% (8) of new HIV diagnoses in 2012. Nonetheless, as shown in figure 4 below, this represents a significant decline since 2005. Approximately 95% of Lancashire and Cumbria's population is white, and accounted for 68% (56) of new HIV diagnoses in 2012.^{29,30}

Figure 4: HIV diagnoses by ethnicity, 1997



Over a 15-year period from 1998 to 2012 there were just over 86,000 new HIV diagnoses across England and over 1,000 in Lancashire and Cumbria. Table 2 below shows the cumulative total of new HIV diagnoses by ethnicity. In Lancashire and Cumbria, black Africans accounted for approximately 14% of the cumulative total of new HIV diagnoses between 1998 and 2012. Overall there have been very few diagnoses in Cumbria and Lancashire in any ethnic group other than white or black African.

Table 2: Cumulative new HIV diagnoses (incidence), 1998-2012 by ethnicity

Ethnicity	England	Cumbria and Lancashire	
		No.	%
White	42.6%	845	78.7%
Black Caribbean	3.6%	11	1.0%
Black African	42.1%	167	14.3%
Other/mixed	11.7%	57	6.0%

Source: PHE, table 7: HIV-diagnosed persons resident in Cumbria and Lancashire, by ethnic group

The total number (prevalence) of HIV-diagnosed people was 71,351 in England in 2012 and 1,131 in Cumbria and Lancashire. Table 3 shows the proportion of HIV-diagnosed persons by ethnic group in 2003 and 2012 in England, and in Cumbria and

Lancashire. While the numbers of people living with HIV have generally doubled across all groups over the last nine years the proportions in each ethnic group have largely stayed the same.

White people form the largest percentage and black African people the second largest percentage of HIV-diagnosed persons both nationally and in Cumbria and Lancashire. The proportion of HIV diagnosed Indian/Pakistani/Bangladeshi residents is slightly greater in Cumbria and Lancashire than the national average but not significantly so.

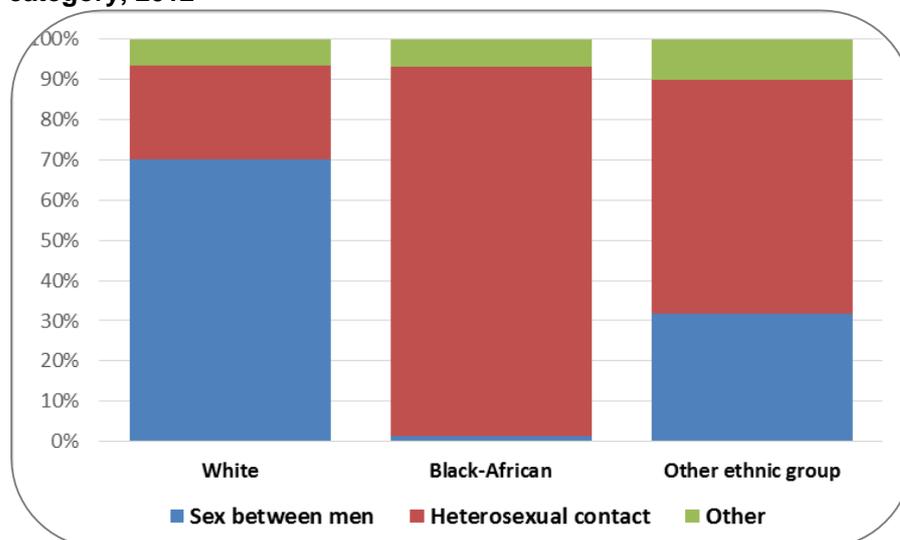
Table 3: Prevalence of HIV diagnosed persons by ethnic group, 2003-2012

Ethnic group	England				Cumbria & Lancashire			
	2003		2012		2003		2012	
White	17,441	52.6%	36,389	51.0%	461	84.9%	934	82.6%
Black African	11,745	35.4%	24,938	35.0%	54	9.9%	121	10.7%
Black Caribbean	1,021	3.1%	2,285	3.2%	5	0.9%	13	1.1%
Indian/Pakistani/Bangladeshi	390	1.2%	1,145	1.6%	9	1.7%	19	1.7%
All other	2,544	7.7%	6,594	9.2%	14	1.7%	44	2.0%
Total	33,141		71,351		543		1,131	

Source: PHE, HIV Data Tables, New HIV diagnoses by year of diagnosis and ethnicity and sex, 2003-2012

Ethnicity and exposure category are not unrelated and heterosexual contact is the usual route of transmission for black Africans (90%) and more black African women than men are diagnosed as having HIV.³¹ In the white population most of the new infections are accounted for by men who have sex with men (70%).³²

Figure 5: Proportion of new HIV diagnoses in North West England by ethnicity and exposure category, 2012



Age group

In terms of age at diagnosis, HIV has an older profile than many STIs. Although 56% of those diagnosed in England in 2012 with an STI other than HIV were under the age of 25 (or 44% if we exclude chlamydia), only 11.5% of UK diagnoses for HIV in 2012 were in this age group, while 47% were aged between 25 and 39.^{33,34} The often long delay between infection and diagnosis is suggested as the cause for this pattern.³⁵

There is a growing and steadily ageing population of people living with HIV, partly attributable to improved survival rates. In 2012, in Cumbria and Lancashire less than a fifth (19%) of those living with HIV were under-35.³⁶ This compares to 22% across England. The fastest rate of increase is among the over-50s, who now make up almost a quarter (24%) of people living with HIV across England and almost a third (32%) in Cumbria and Lancashire. (Figures 6 and 7 below).

Figure 6: People living with diagnosed HIV by age group, England, 2003-12

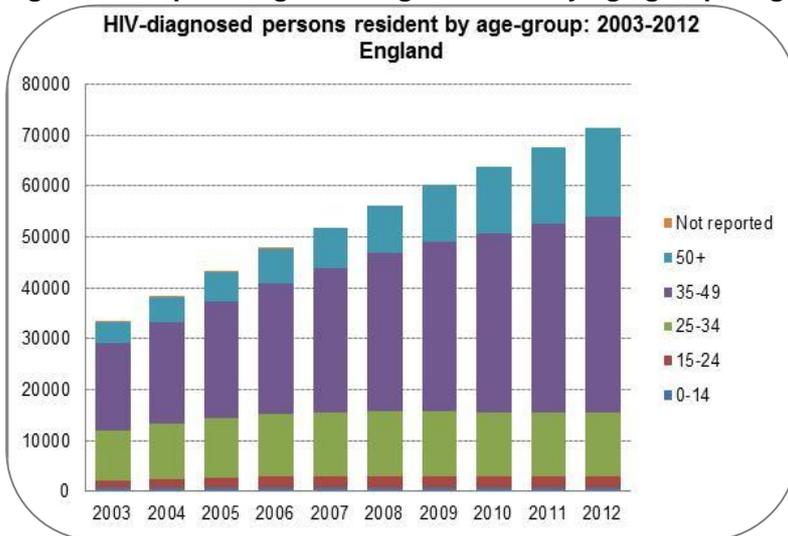
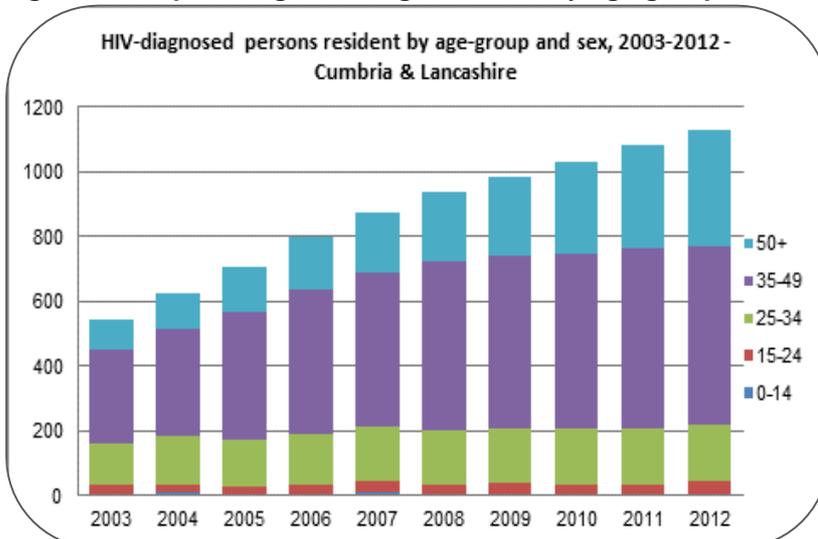
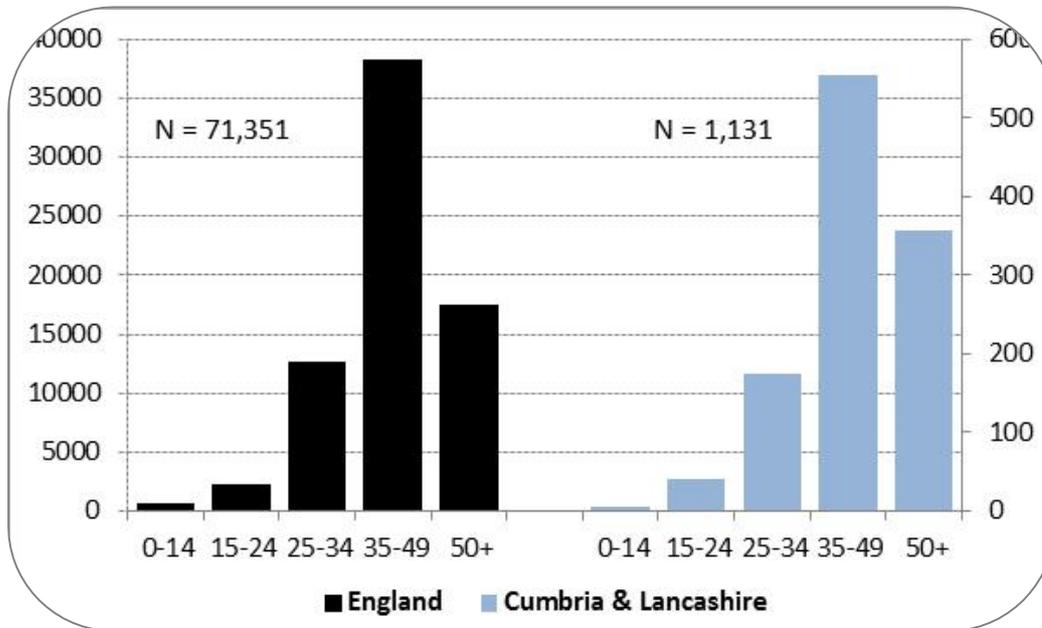


Figure 7: People living with diagnosed HIV by age group, Cumbria and Lancashire, 2003-12



In 2012, 35-49 year olds made up the highest proportion of the total HIV-diagnosed persons resident in both England (54%) and in Cumbria and Lancashire (49%). Figure 8 shows the total number of HIV-diagnosed people resident in England and in Cumbria and Lancashire in 2012 by age group.³⁷

Figure 8: The total number of HIV-diagnosed persons resident in England, and Cumbria and Lancashire by age group, 2012



Deprivation

London has by far the highest HIV rates in England, and within London this prevalence shows a strong deprivation gradient. Outside of London the relationship with deprivation is much less striking.³⁸ In Lancashire there is no significant relationship between district deprivation and the prevalence of diagnosed HIV (population aged 15-59 years) in 2012.

HIV – level of need in the population

Disclosure rules

Instead of the usual 'no number less than five' disclosure rule, HIV data is subject to a set of rules based on the size of the denominator population.³⁹

New cases of HIV in Lancashire

In 2012, there were a total of 61 new diagnoses of HIV in Lancashire. This is compared below with other local authorities in the North West, both as a number (figure 9) and as a rate (figure 10).

In 2012, Lancashire had the third highest number of new HIV diagnoses cases in the North West though when looked at as a rate it is almost half that of the North West. New HIV cases per 100,000 population (aged 15-59 years) in Lancashire was 8.7 compared to the North West rate of 16.5.⁴⁰

Figure 9: Total number of new HIV diagnoses, North West upper tier local authorities, 2012

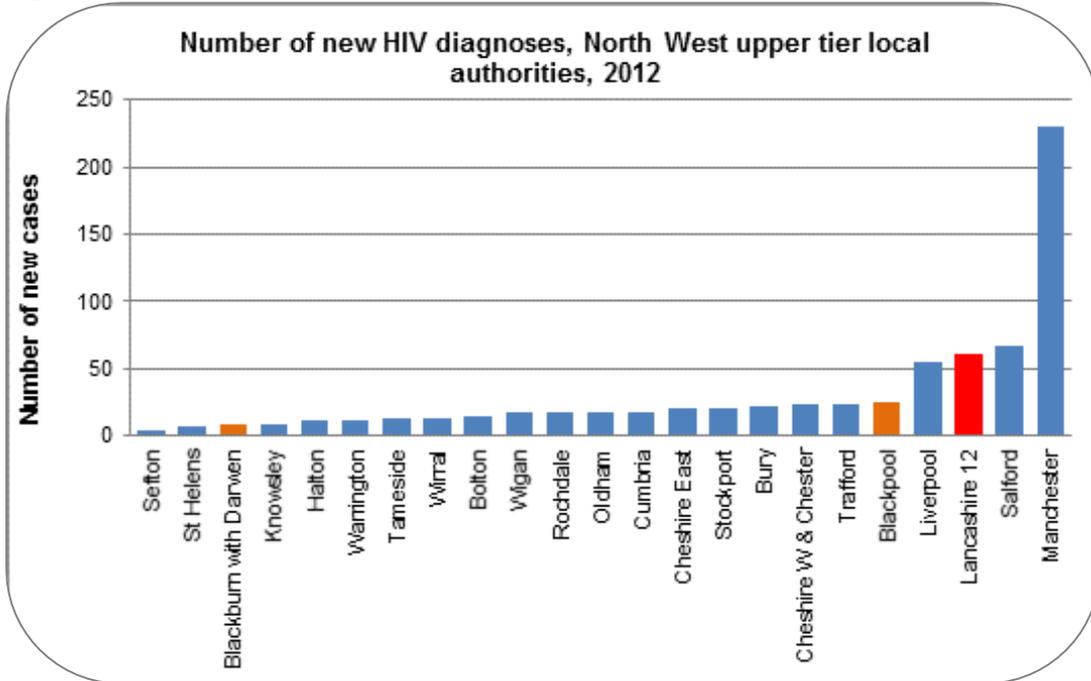


Figure 10: New HIV cases per 100,000 population aged 15-59 years, North West local authorities, 2012

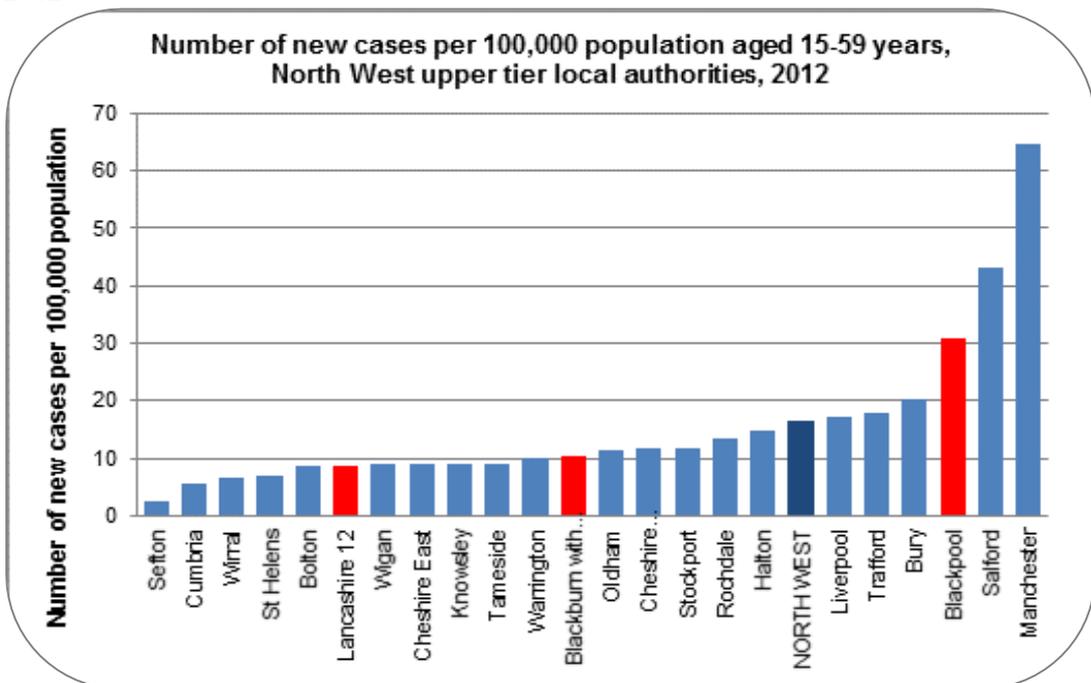
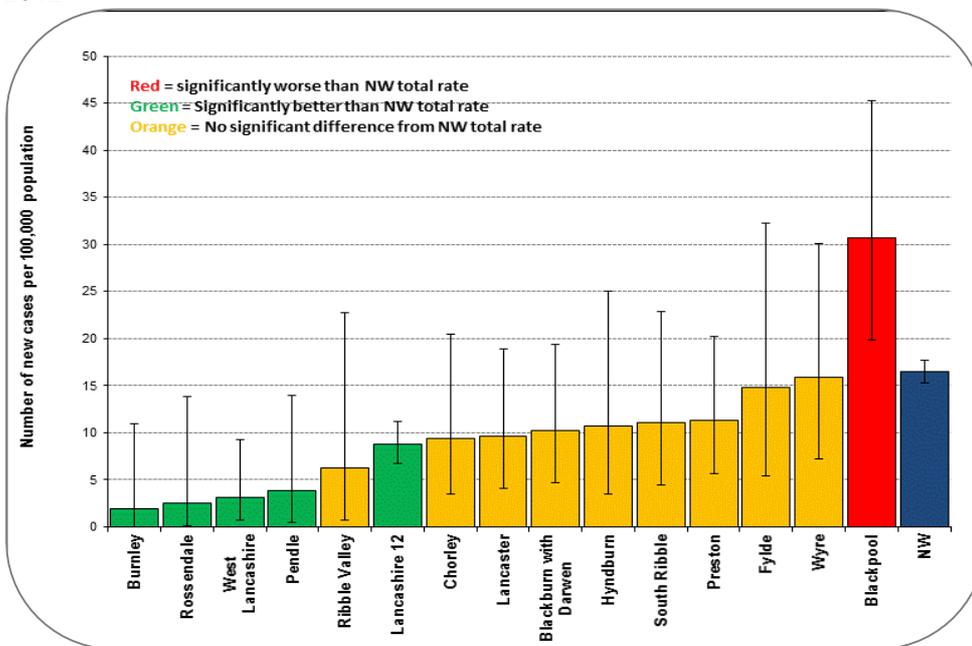


Figure 11 shows the breakdown of new HIV cases per 100,000 by the Lancashire districts. In 2012, within Lancashire, Fylde, Wyre and Preston had the highest rates of new HIV cases per 100,000 of 15-59 year olds, though none were higher than the North West average. Burnley, Rossendale, West Lancashire and Pendle had rates significantly lower than the North West average.

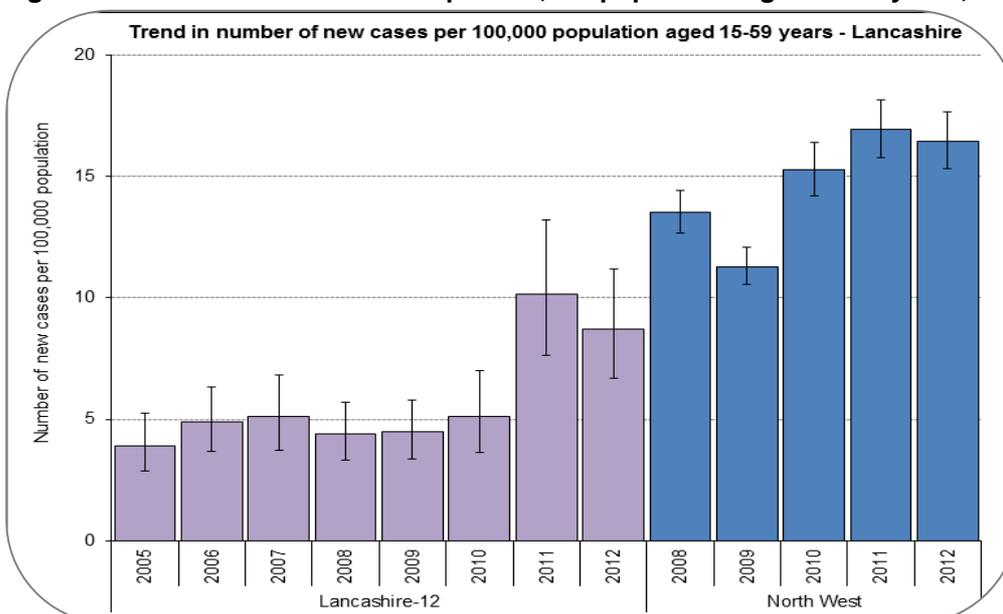
Figure 11: New HIV cases per 100,000 population aged 15-59 years Lancashire-14 local authorities, 2012



Trend over time

Lancashire's new HIV cases have fluctuated over the years from 3.9 per 100,000 in 2005 to 8.7 in 2012. The highest rate over the period was 10.2 in 2011. Similar to the North West, Lancashire incidence of HIV has increased significantly between 2008 and 2012 though it is still significantly lower than the North West average.

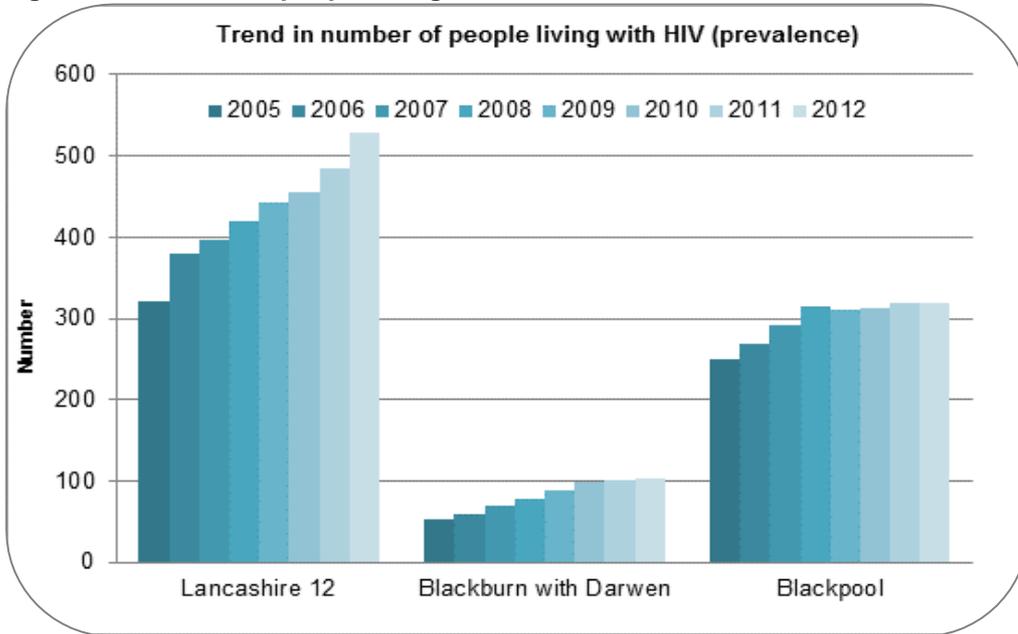
Figure 12: Trend in new HIV cases per 100,000 population aged 15-59 years, 2005 - 2012



All people living with HIV in Lancashire

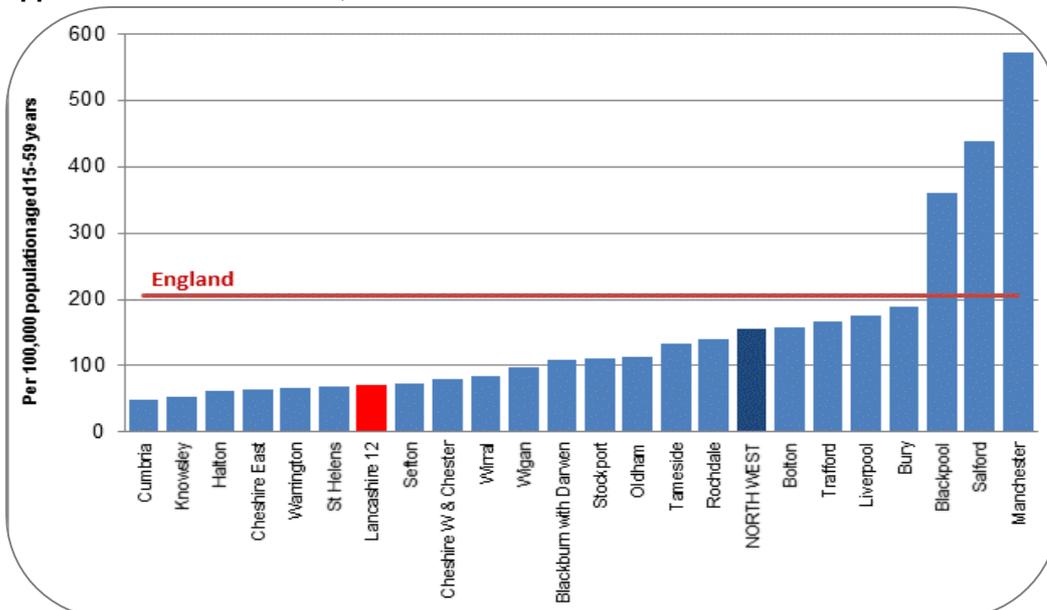
In 2012, there were 529 people (of all ages) living with diagnosed HIV in Lancashire and a further 423 people with diagnosed HIV in Blackpool, and Blackburn with Darwen. Figure 13 shows how this number has increased between 2005 and 2012.

Figure 13: Number of people living with HIV, 2005 – 2012



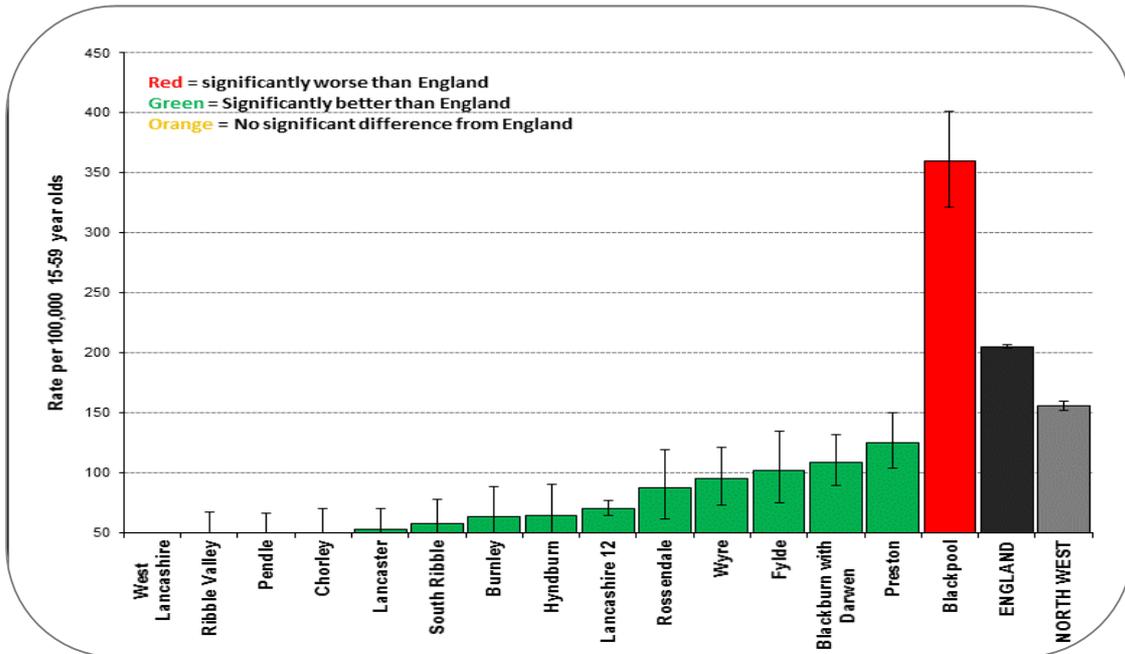
The majority of people living with HIV are aged 15-59, and it is conventional to focus on this age group when expressing the prevalence as a rate. Lancashire had 529 people aged 15-59 living with diagnosed HIV in 2012, which translates to a rate of 70.1 per 100,000. This is lower than most of the authorities in the North West. Figure 14 shows where Lancashire ranks against the other North West authorities.

Figure 14: People living with diagnosed HIV per 100,000 population aged 15-59 years, North West upper tier local authorities, 2012



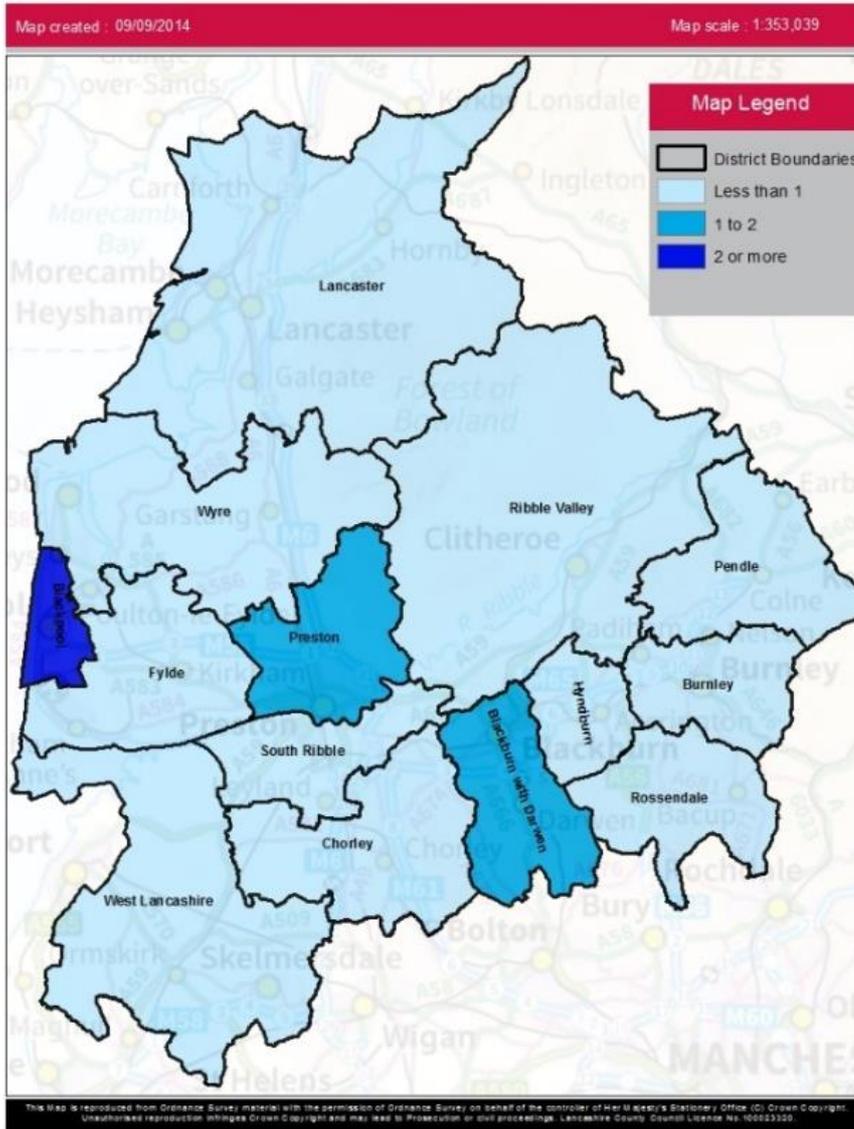
Within Lancashire, Preston has the highest number (118) of people living with diagnosed HIV (a rate of 125.1 per 100,000), although all of the districts are significantly lower than the England average. West Lancashire with 29 people living with HIV has the lowest prevalence rate at 34.8 per 100,000.

Figure 15: People living with diagnosed HIV per 100,000 population aged 15-19 years, Lancashire districts 2012



The Health Protection Agency (HPA) recommends that routine testing for HIV should be introduced in authorities with a HIV prevalence of 2 or more per 1,000 of 15-59 year-olds (or 200 per 100,000).⁴¹ The map of HIV prevalence across Lancashire districts (figure 16 below) shows only Blackpool out of the Lancashire-14 districts falls into this category.

Figure 16: Prevalence of people living with diagnosed HIV (15-59) per 1,000 population, 2010-12



The [National AIDS Trust](#) (NAT) recommends that where in some lower prevalence areas (i.e. less than 2 per 1,000 diagnosed with HIV) late diagnosis rates may not be statistically significant (see the HPA Sexual Health Profiles Performance Map⁴²), it may be best in such cases to begin by focusing on the population groups and areas where prevalence and reported diagnoses of HIV are greatest. Focus can also be on addressing very late diagnosis (CD4 <200 cells/mm³) which often involves failures in local health services offering an HIV test at earlier presentations.⁴³

Figure 17 shows the rates per 1,000 of HIV prevalence within the Lancashire districts at a lower geographic level (mid super-output area). Preston is the only district in Lancashire with two areas where HIV prevalence is greater than 2 per 1,000 though there are areas across most of the other districts where rates vary between 1 and 2

per 1,000. Only Ribble Valley and West Lancashire do not have any areas with rates greater than 1.

Figure 17: Diagnosed HIV prevalence within Lancashire (MSOA level) per 1,000 population (age 15-59), 2012

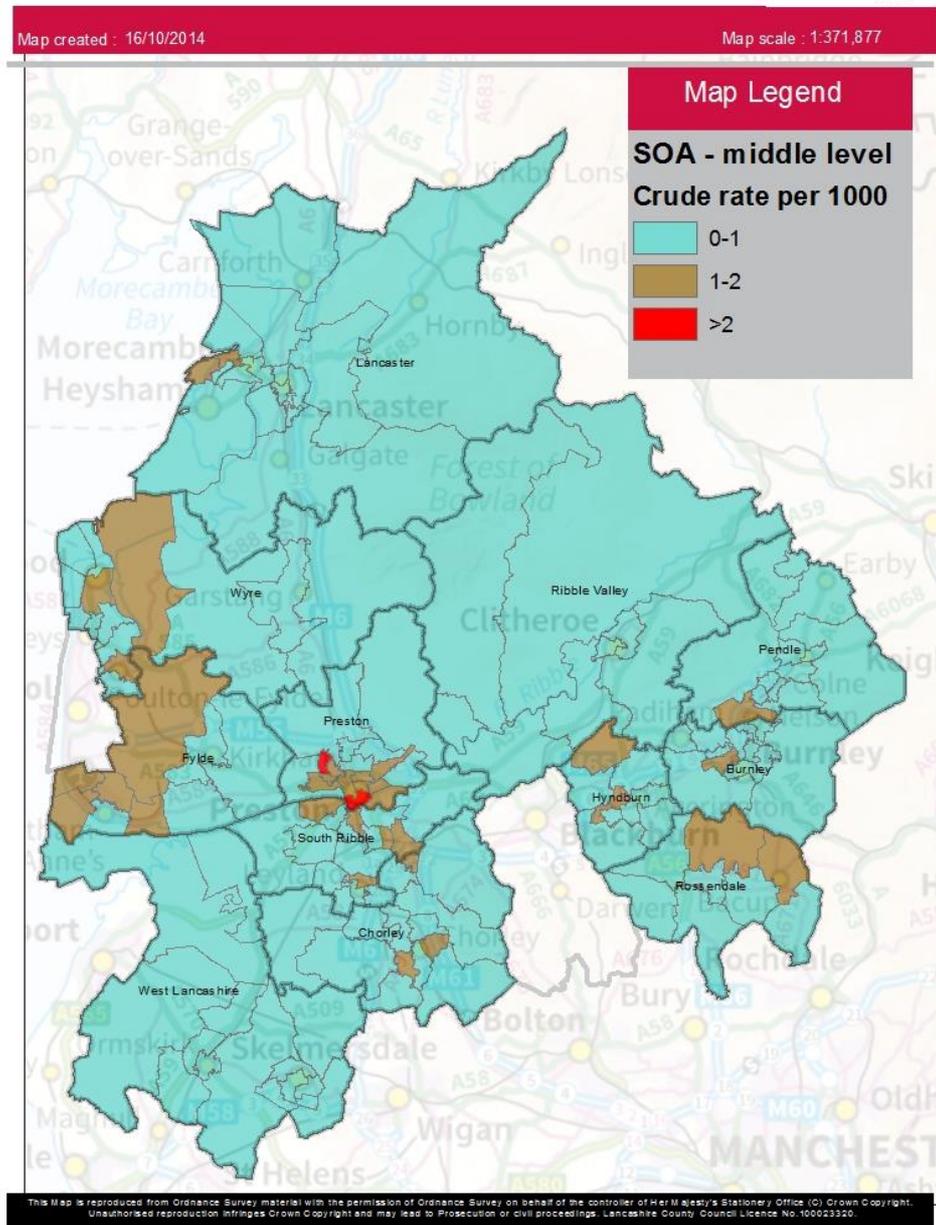
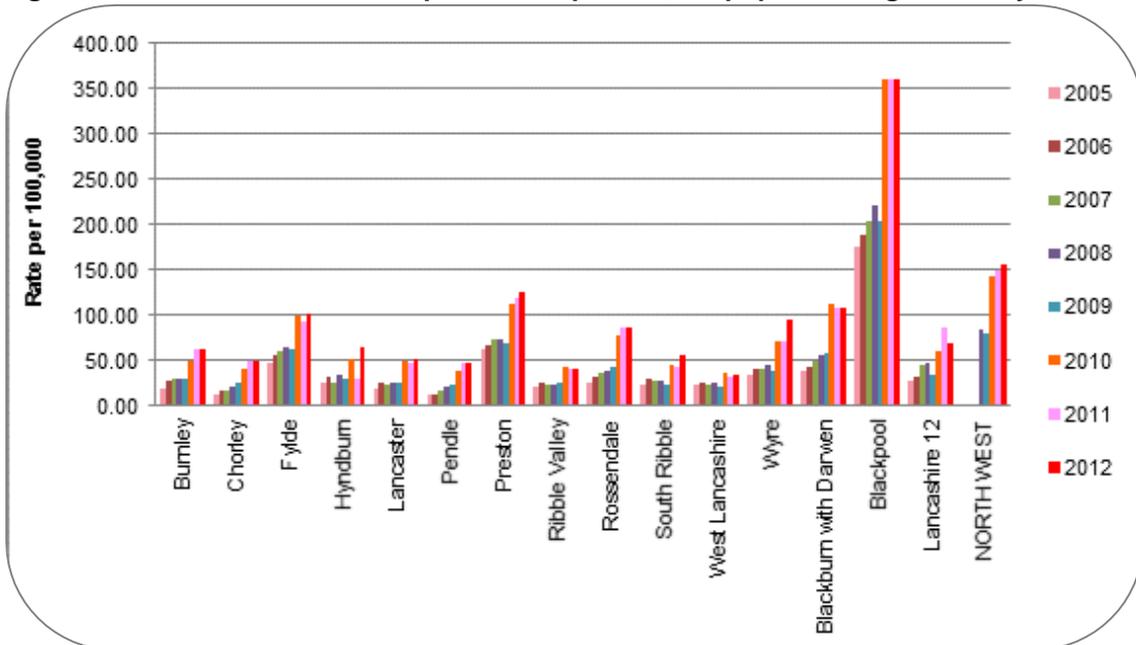


Figure 18 shows how the rate of diagnosed HIV prevalence has risen over the years in the districts. Between 2005 and 2012 Lancashire experienced a 150% increase in diagnosed HIV prevalence from 28.2 per 100,000 to 70.1. The districts with the highest rises in diagnosed prevalence were Burnley, Chorley, Pendle and Rossendale which had all seen more than a 200% increase. West Lancashire saw the lowest increase of less than 50%. These increases can probably be explained by increased testing for HIV and reducing late diagnoses.

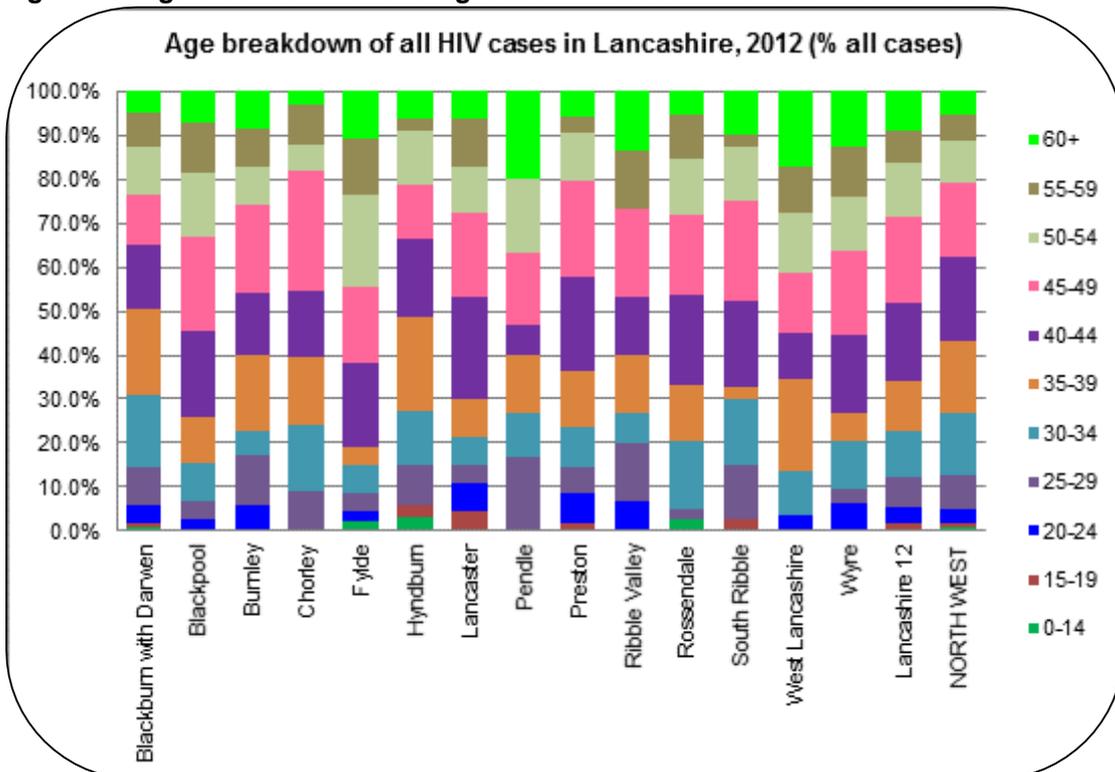
Figure 18: Trend in all HIV cases prevalence per 100,000 population aged 15-59 years



Note: North West total includes all those seen in the North West, including those residing out the region.

Figure 19 shows the age breakdown of all diagnosed HIV cases in Lancashire districts in 2012. Two-thirds (67%) of the diagnosed HIV cases in Lancashire are in people over the age of 40 years. Hyndburn appears to have the highest proportion of diagnosed HIV cases in the under-40's (almost 50%) while the majority of Fylde's cases (>80%) are aged over 40.

Figure 19: Age breakdown of all diagnosed HIV cases in Lancashire districts



Of the 529 people in Lancashire living with HIV in 2012, just over half, (54.6%) had acquired their infection via men who have sex with men (table 4). With the exception of Hyndburn, Lancaster and Ribble Valley all other Lancashire districts follow the same picture in that a higher proportion of people diagnosed with HIV had acquired the infection via MSM transmission. Only for Hyndburn is the rate of heterosexual transmission significantly higher than the Lancashire average, and Rossendale has a significantly higher proportion of MSM transmission.

Table 4: All people living with HIV in Lancashire by infection route, 2012

	Total cases	MSM*	Injecting drug user	Hetero-sexual	Blood/tissue	Mother to child	Other/not known
Blackburn with Darwen	103	30.1%	3.9%	59.2%	3.9%	1.9%	1.0%
Blackpool	320	78.1%	0.9%	18.1%	1.3%	0.3%	1.3%
Burnley	35	51.4%	0.0%	45.7%	2.9%	0.0%	0.0%
Chorley	33	51.5%	3.0%	39.4%	0.0%	0.0%	6.1%
Fylde	47	61.7%	2.1%	31.9%	0.0%	2.1%	2.1%
Hyndburn	33	24.2%	0.0%	69.7%	0.0%	3.0%	3.0%
Lancaster	47	46.8%	0.0%	46.8%	2.1%	2.1%	2.1%
Pendle	30	60.0%	6.7%	26.7%	3.3%	0.0%	3.3%
Preston	118	50.8%	0.8%	43.2%	0.0%	3.4%	1.7%
Ribble Valley	15	33.3%	0.0%	60.0%	6.7%	0.0%	0.0%
Rossendale	39	82.1%	2.6%	12.8%	0.0%	2.6%	0.0%
South Ribble	40	55.0%	5.0%	32.5%	0.0%	2.5%	5.0%
West Lancashire	29	51.7%	0.0%	37.9%	6.9%	0.0%	3.4%
Wyre	63	68.3%	0.0%	27.0%	1.6%	1.6%	1.6%
Lancashire	529	54.6%	1.5%	38.4%	1.3%	1.9%	2.3%
Total NW residents	7,021	51.9%	1.7%	42.2%	0.9%	1.8%	1.4%

*MSM – men who have sex with men

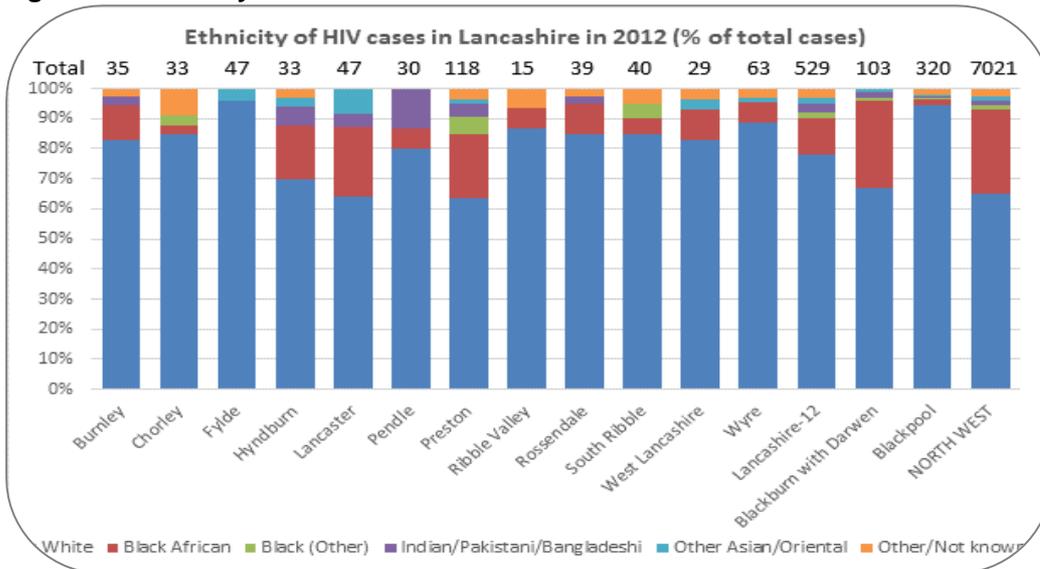
Significance for categories other than MSM and Heterosexual not calculated due to small numbers. Significantly **HIGHER / **LOWER** than the Lancashire average

Source: Centre for Public Health, LJMU.

HIV by ethnicity in Lancashire

Figure 20 shows the ethnic breakdown of people living with HIV in all Lancashire districts in 2012. Across Lancashire, the highest proportion of people living with HIV are of white ethnic origin and the second highest proportion are of black African ethnic origin. South Ribble has the same percentage of people of black African and black Caribbean ethnic origin living with HIV. Lancaster has the highest percentage of other Asian/oriental ethnic origin people living with HIV and Pendle has the highest percentage of South Asian people living with HIV.

Figure 20: Ethnicity breakdown of HIV cases in 2012

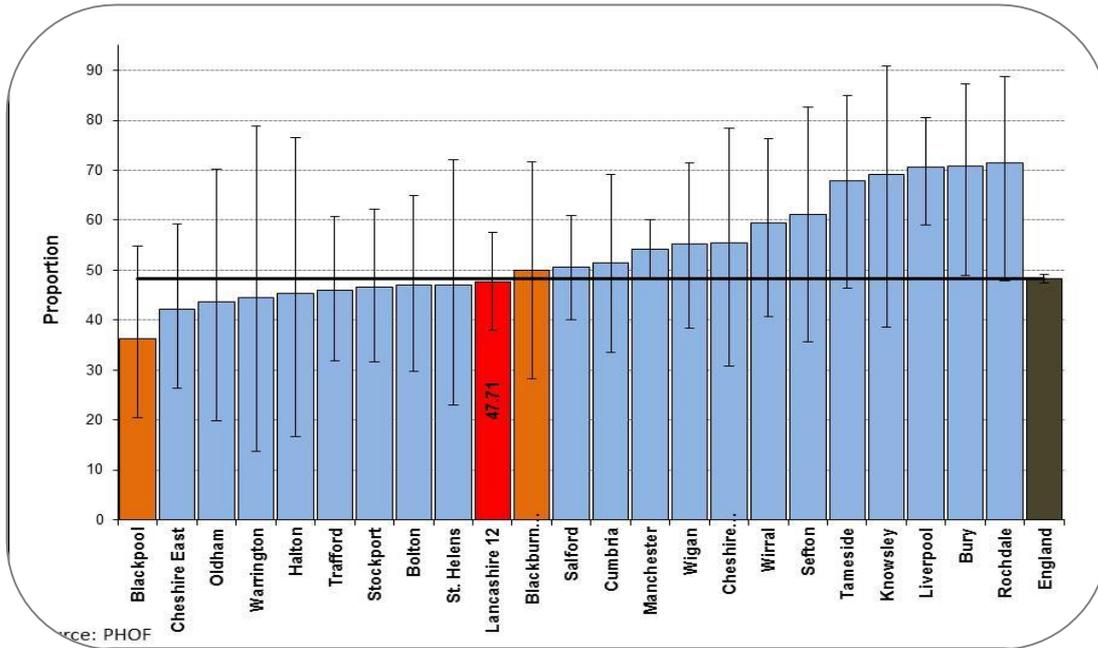


Late HIV diagnosis indicator

According to the British HIV Association ([BHIVA](#)) late diagnosis is “the most important factor associated with HIV-related morbidity and mortality in the UK” and it is essential to evaluate the success of expanded HIV testing.⁴⁴ In view of this, an indicator measuring the “proportion of persons presenting with HIV at a late stage of infection” has been included in the new Public Health Outcomes Framework (PHOF).⁴⁵

The indicator used to evaluate this is the number of adults (aged 15+) newly diagnosed with HIV infection with CD4 counts available within 91 days and indicating a count of less than 350 cells per mm³ as a percentage of number of adults (aged 15+) newly diagnosed with HIV infection with CD4 counts available within 91 days.

Figure 21: Percentage of late HIV diagnoses by North West local authorities, 2010/12



Many areas see relatively few HIV diagnoses each year, and even fewer late diagnoses. This means that the late diagnosis rate can fluctuate greatly from year to year due to chance alone. In recognition of this problem, the PHOF published the rate for 2010-12 combined (figure 21 above).

Across Lancashire, 52 of the 109 new diagnoses were classed as late, a rate of 48%, the same as the England average.⁴⁶ The proportion of late diagnoses is higher among heterosexual men and women than MSM, and in older (50+) rather than younger age-groups.

It is also of note that the current BHIVA Standards of Care for People Living with HIV 2013 guidance recommends within standard one (HIV testing and diagnosis) as one of its measurable and auditable outcomes that: 'All HIV services should undertake a review of all patients presenting to care with advance immunosuppression (CD4 <200 cells/mm³ or AIDS diagnosis), with a 'look-back' of previous engagement with health care services.'⁴⁷

It is a recommendation of this report that commissioners ensure this approach to look-back exercises is implemented.

HIV – current services/initiatives

Commissioning arrangements for HIV testing services

From April 2013 the revised responsibilities for the commissioning of HIV testing are shared amongst a number of different commissioning bodies and are as set out below.⁴⁸

Table 5: Commissioning responsibilities

Body	Level	Service	Commissioning responsibility
Local authorities	Local	Public health (including local sexual health/GU services and health promotion)	Testing in sexual health/GU clinics; testing in community settings; routine screening for public health purposes in primary and secondary care through local arrangements; testing in drug treatment services.
CCG	Local	Secondary care (apart from specialised commissioning, which includes HIV treatment – this is commissioned by NHS England)	Testing in all relevant secondary care specialities for clinical indicator conditions/as part of patient care; testing in termination of pregnancy (TOP) services.
NHS England	National	Primary care Specialised commissioning (including HIV treatment)	Testing in primary care as clinically indicated or when requested by patient; testing in SARC; testing in ante-natal care; testing in other NHS England commissioned services as part of patient care.

It is therefore particularly important that all relevant commissioners:

- recognise their role in commissioning HIV testing and reducing late HIV diagnosis;
- ensure commissioning is integrated and complementary across all commissioners at a local level, with clarity on responsibility for commissioning/payment and care pathways;
- work together to commission to a shared vision of need and a shared strategic approach to HIV testing; and
- include as partners key stakeholders from clinical, statutory, voluntary and community sectors.⁴⁹

Detailed guidance has recently been issued by Public Health England (PHE) on whole system commissioning for sexual health, reproductive health and HIV and it is a recommendation of this report that this guidance is followed when considering integrated commissioning approaches.⁵⁰

The case for ongoing development of effective HIV testing strategies

The position of an effective testing strategy for HIV needs to be seen in the context of a wider HIV prevention strategy which will typically encompass the following elements:

- a) promoting safer sexual practices;
- b) preventing mother-to-child transmission;
- c) preventing transmission among injecting drug users;
- d) risk reduction for people with diagnosed HIV;
- e) providing post-exposure prophylaxis (PEP);
- f) screening blood and treating blood products; and
- g) effective testing strategies.⁵¹

Effective testing strategies are particularly important for a wide range of reasons:

- Currently around a quarter of people with HIV in the UK don't know they have it and research estimates that it is this undiagnosed minority who are responsible for around 50% of new infections.^{52,53}
- People tend to adapt sexual behaviours to reduce risk following diagnosis, with some papers quoting the likelihood of unprotected sex being 68% lower.⁵⁴
- Effective treatment also significantly reduces transmission risk – if a HIV positive person adheres to an effective antiretroviral treatment regimen, the risk of transmitting the virus to an uninfected sexual partner is substantially less and one US study has indicated this can be reduced by 96%.⁵⁵
- Late diagnosis (CD4 cell count < 350mm²) leaves an individual ten times more likely to die within a year of diagnosis and is strongly linked to increased rates of morbidity, chronic illness and hospital admission.^{56,57}

There is particular value in diagnosing HIV at an early stage soon after infection, known as primary HIV infection when, in the majority of cases, temporary symptoms occur. At this stage the individual is highly infectious and it is thought a significant proportion of HIV transmissions take place during this period.

Late presentation of HIV therefore continues to carry significant risks of morbidity and mortality, reduced life expectancy, and increased rates of hospitalisation as well as impacting on a broader range of PHOF indicators including:

- employment for those with a long-term health condition (indicator 1.08 i);
- sickness absence (indicator 1.09);
- self-reported well-being (indicator 2.23);
- mortality from causes considered preventable (indicator 4.03);
- mortality from all cardiovascular diseases (indicator 4.04);
- mortality from cancer (indicator 4.05);

- mortality from liver disease (indicator 4.06); and
- mortality from respiratory diseases (indicator 4.07).⁵⁸

In spite of this overwhelming evidence, almost fifty per cent of people newly diagnosed with HIV in 2010 presented at a late stage of infection with a CD4 count below 350 cells/mm³ (after the recommended time to start therapy) and health care professionals in both primary and secondary care consistently miss and under-diagnose HIV even in people who are symptomatic which underlies the need for robust testing strategies and guidelines.^{59,60}

Development and expansion of HIV testing guidelines

HIV testing has been routinely offered and recommended to all patients attending antenatal clinics and sexually transmitted infection (STI) clinics since 1999 and 2001, respectively.^{61,62} However in order to address the problem of late diagnosis and undiagnosed HIV infection in the UK, the BHIVA issued national HIV testing guidelines in 2008 that recommended:

- increased levels of testing across a number of settings and in particular testing needs to move beyond antenatal and genitourinary medicine (GUM) settings;
- testing is done on a routine opt-out basis for certain services – this is felt to be different from the previous approach of testing offered to those felt to be at risk which was problematic as it singled out individuals; and
- frequent testing, particularly for those at high risk.

The recommended range of settings was significantly expanded as outlined below:

A. Universal HIV testing is recommended in all of the following settings:

1. GUM or sexual health clinics;
2. antenatal services;
3. termination of pregnancy services;
4. drug dependency programmes; and
5. health care services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma.

B. A HIV test should be considered in the following settings where diagnosed HIV prevalence in the local population (PCT/LA) exceeds 2 in 1,000 population:

1. all men and women registering in general practice; and
2. all general medical admissions.

C. HIV testing should be also routinely offered and recommended to the following patients:

1. all patients presenting for healthcare where HIV, including primary HIV infection, enters the differential diagnosis (see table of indicator diseases and section on primary HIV infection);
2. all patients diagnosed with a STI;
3. all sexual partners of men and women known to be HIV positive;
4. all men who have disclosed sexual contact with other men;
5. all female sexual contacts of men who have sex with men;
6. all patients reporting a history of injecting drug use;
7. all men and women known to be from a country of high HIV prevalence; and
8. all men and women who report sexual contact abroad or in the UK with individuals from countries of high HIV prevalence

Source: [British HIV Association](#). UK national guidelines for HIV testing (2008).

Importantly, they advocated expanding HIV testing beyond specialised sexual health services to people admitted to a general hospital ward and new registrants to general practice in areas with a diagnosed HIV prevalence of ≥ 2 per 1,000 population aged 15-59 years. Subsequently the [National Institute for Health and Care Excellence](#) (NICE) also issued guidance documents which detail recommendations to extend the accessibility of HIV testing for black African (PH33) and MSM (PH34) groups, currently the highest risk groups in the UK. These guidance documents clearly state the need to promote, offer and to test in high-risk groups, as well as providing outreach and other measures to improve access to testing.

It is of note that the 2008 BHIVA guidelines outline not only the range of settings that should be included when undertaking HIV testing but also outline a wider range of issues including, for example, the frequency of testing for various population groups as well as the type of tests that should be used and under what circumstances.

Despite the existence of these recommendations, in the UK the majority of diagnostic HIV testing still occurs within antenatal clinics and STI clinics. For example, of all samples tested at one hospital laboratory in Leeds, 39% of tests were conducted as part of antenatal care and 38% were conducted at STI clinics. Only 3.8% of tests were conducted in GP surgeries and 0.4% in general medical and general surgical departments.⁶³ Indeed the extent to which these guidelines have been implemented nationally in general healthcare settings remains largely unknown. Responses from 17 medical royal colleges, faculties and professional organisations to a 2010 HPA survey showed that although 11 organisations reported awareness of the guidelines, only four

knew of any work being conducted within their specialty to address HIV testing and only five had included HIV testing in any of their own clinical guidelines.⁶⁴

As part of this debate the government subsequently funded pilot studies to examine the case for expansion in line with these HIV testing guidelines – these pilots were judged to be successful and available evidence to date have shown these approaches to be feasible, acceptable and cost effective according to international standards.⁶⁵ Research from the United States has described HIV testing as cost effective if one diagnosed person is found for every 1,000 tests performed although this economic modelling did not include secondary savings from reduced onward transmission.^{66,67,68} Indeed most of the UK pilots that have been done in novel settings have picked up HIV at a higher rate than this figure.⁶⁹

Clearly cost effectiveness must be an important consideration in expansion at a time of restricted public spending and as a result the focus must be on high prevalence areas.⁷⁰ However even if a given local authority has an area of lower HIV prevalence overall, it may still contain middle super output areas (MSOA) of high HIV prevalence within it. It is highly desirable therefore that a detailed local breakdown of prevalence is obtained to best inform prevention and testing strategies in a given area and there may be a case in a particular locality, for example, to agree routine HIV testing of new registrants with some GP practices. It is also important to always consider the robustness of patient pathways for those diagnosed by expanded testing in order to ensure immediate access to treatment and support.⁷¹

Notwithstanding the specific issue of testing new registrants within general practice settings, HIV testing in primary care still needs to be widely promoted as there are still a number of other key circumstances in which it is appropriate to conduct an HIV test in primary care including:

- at a patient's request;
- opportunistic testing – when an HIV test is offered to someone who might be at risk;
- diagnostic testing – when an HIV test is done because someone has an indicator condition, or symptoms or signs of HIV infection; and
- screening – for example antenatal screening, or routine offering of the test to someone who has had a diagnosis of an STI.⁷²

It is a recommendation of this report that the extent to which the HIV testing guidelines above are adhered to within Lancashire are assessed and appropriate steps put in place to ensure they are being appropriately implemented.

Potential role for home testing and/or self-testing approaches

Technologies that enable rapid and accurate HIV testing are increasingly becoming available. Yet there are still lower levels of HIV testing in the UK than in many other countries. In the UK, it is estimated that about 22% of people with HIV are undiagnosed and almost half of newly diagnosed HIV-infected adults are diagnosed late.^{73,74}

Barriers to testing include privacy concerns, stigma, transport costs, long waiting times and restricted clinic opening hours. Although home testing (also referred to as home sampling) and self-testing incorporate different approaches, they both have the potential to increase uptake and early diagnosis, and reduce the proportion of late diagnosis for HIV.⁷⁵

Two national pilots for home sampling, supported by PHE, have been extremely successful, demonstrating the feasibility, acceptability and effectiveness of such services. Since their inception, to summer 2014, they have together delivered nationally some 15,000 kits with a 62% return rate (9,700) and a 1.9% positivity rate.

Although there are a number of challenges associated with self-testing approaches, following a recent change in legislation, as from April 2014, it is now legal for [HIV self-test kits](#) to be sold in the UK, whether online or in the shops. This change in legislation was driven by a number of factors including:

- increased access to HIV testing, treatment and care;
- regulation of self-test quality; and
- public opinion on self-testing for HIV.

Recognising the need to monitor the introduction of self-testing in the UK, it has been announced that PHE, in collaboration with both the [British Association for Sexual Health and HIV](#) (BASHH) and the BHIVA, will monitor the outcome of reactive HIV self-tests. Clinicians who provide sexual health services, and who care for people with HIV infection, will be asked to report the confirmed HIV status of patients who have presented for further laboratory tests following a reactive self-test for HIV.⁷⁶

Given ongoing developments in respect of both these approaches, it is a recommendation of this report that commissioners continue to monitor the emerging evidence base both nationally and regionally and consider what their future position should be in relation to the implementation of both these approaches.

Barriers to implementation of expansion of HIV testing

The importance of professional engagement in ensuring more widespread testing is widely acknowledged and the following areas have been highlighted:

- incorrect perception that pre-test counselling is required;
- misunderstanding of the time it takes to conduct tests;
- stigmatisation by healthcare professionals;
- raising awareness amongst all clinicians of clinical indicators of HIV;
- the availability of training to support non-specialist healthcare professionals in offering HIV testing such as the sexual health in practice programme; and
- the need for royal colleges and other professional associations such as the British Medical Association (BMA) to better engage with this agenda.

Locally within Lancashire, the Sexual Health in Practice (SHiP) programme has recently been run and subsequently well evaluated.

It is a recommendation of this report that efforts continue to increase levels of professional engagement with HIV through the identification of clinical champions, promotion of existing national guidance as well as provision of accredited training courses such as the SHiP programme, on an equitable basis across Lancashire.

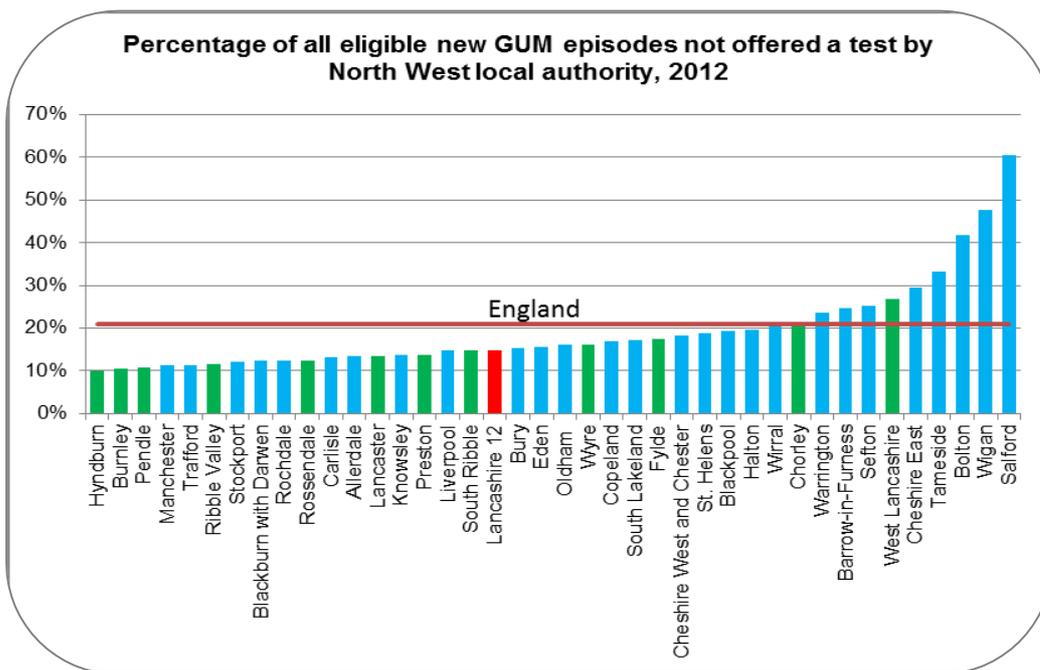
Improving uptake of HIV testing in sexual health clinics

Guidelines published by BHIVA and NICE recommend each new or re-booking patient within every sexual health clinic should receive a routine offer of a HIV test ('opt-out HIV test').⁷⁷

In 2011 only 77% of relevant sexual health clinic visits in the UK included the offer of an HIV test, meaning 70% of attendees were tested for HIV as the take-up rate when offered was 93%. It is important to note HIV test uptake data represent the number of HIV tests reported and not the number of people tested for HIV. The following year in 2012, a test was offered at 79% of all eligible GUM episodes in England, of which 81% were accepted.⁷⁸

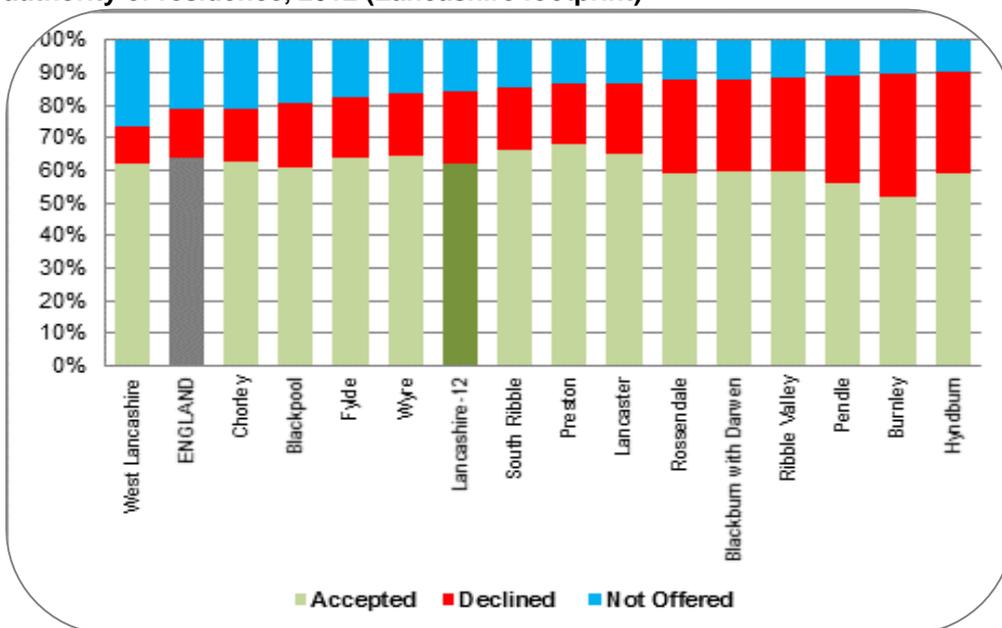
In Lancashire there were 25,740 eligible GUM episodes involving residents of Lancashire during 2012. The test was offered in 85% of cases (totalling 21,853 episodes), and accepted in 16,023 cases, equating to a 73% uptake (out of the 21,853 episodes in which it was offered). There were only 3,887 episodes where the test was not offered.⁷⁹ Figure 22 shows the percentage of all eligible GUM episodes not offered a test.

Figure 22: Percentage of all eligible GUM episodes not offered a test by local authority of residence, 2012 (North West footprint)



In Lancashire the percentage of cases not offered the test ranges from 10% in Hyndburn to 27% in West Lancashire. The Lancashire average was 15% and the England average was 21%. Of those offered the test the proportion accepting was 73% in Lancashire in 2012 compared to 81% in England. The variation within Lancashire ranges from 85% uptake in West Lancashire to 58% in Burnley. Figure 23 illustrates the proportion of HIV tests not offered, accepted and declined in the Lancashire area.

Figure 23: Proportion of HIV tests not offered, accepted and declined at GUM clinics by local authority of residence, 2012 (Lancashire footprint)



It is worth noting that the PHE sexual health profiles also disaggregate local HIV test uptake in sexual health clinics by key groups and it is important that local targets are also set for the rates of offer and uptake for this test; the ultimate ambition should be that no patient leaves a sexual health clinic unaware of his or her HIV status.⁸⁰

Sexual health clinics may be able to improve HIV testing and diagnosis rates through innovation to improve accessibility and acceptability of services. Setting, design of clinic, opening hours (outside core working hours or at weekends for example), timeliness – both of response to calls and of appointment booking – may all be effective and should be critically assessed and monitored. It is important that the test is offered on a routine or opt-out basis as evidence suggests it makes offering the test easier as it is perceived as non-judgemental and it is more likely to be accepted. For those clinics where locally set targets are not being met it may be worth discussing with the clinic their understanding of the term 'opt out'. The HIV test should not be recommended differently from other STI tests undertaken, but simply presented as one of the routine and recommended tests to be performed unless the individual refuses consent.⁸¹

It is a recommendation of this report that commissioners work with service providers to ensure that opportunities to further improve HIV testing within sexual health clinics are identified.

The role of partner notification

Partner notification for HIV and/or other STIs is an important public health strategy, facilitating early diagnosis among known sexual partners. Further HIV infections can be minimised by ensuring sexual partners are aware of the presence of HIV within the relationship, and are able to access risk reduction counselling and antiretroviral medication, either as prophylaxis if negative (in the form of PEPSE),[‡] or treatment if HIV positive. People living with HIV must be able to access appropriate support and guidance throughout this process and may require specific help when telling past and present sexual and/or injecting partners about being HIV positive. The need for testing of the children of HIV-positive parents, irrespective of their age and health status also need to be robustly undertaken.⁸²

The NAT has highlighted the fact that, despite the role of partner notification as a highly effective component of HIV prevention, its role often remains under resourced, unperformed or unacknowledged.⁸³

[‡] PEPSE - post exposure prophylaxis for HIV following sexual exposure

The BHIVA standards referred to above highlight the need for services to operate partner notification for patients who want to use them and it is a recommendation of this report that commissioners work together to ensure that the appropriate standards and outcomes pertinent to partner notification are adopted and monitored within local services.

Technical and laboratory considerations

There are two methods in routine practice for testing for HIV involving either venepuncture or a screening assay[§] where blood is sent to a laboratory for testing, or a rapid point of care test (POCT). The recommended first-line assay is one which tests for HIV antibody and p24 antigen simultaneously.⁸⁴ These are termed fourth generation assays, and have the advantage of reducing the time between infection and testing HIV positive to one month which is one to two weeks earlier than with sensitive third generation (antibody only detection) assays.⁸⁵ It is reasonable to expect universal provision of these assays.

Point of care tests for HIV using finger-prick blood samples can produce results within a matter of minutes. These have been shown to have a high level of acceptability in certain settings since they allow results to be delivered in the same consultation as the test is taken.⁸⁶ However, the lower specificity of these tests means that they are more likely to give false positive results than laboratory testing. In low prevalence settings this may mean that only a minority of reactive test results are true positives, e.g. where the undiagnosed prevalence is 1 per 1,000 then a point of care test with a specificity of 99.7% would have a positive predictive value of only 25%. When employing POCT, it is therefore important to report their result as reactive rather than positive, emphasise the likelihood of a false reactive result and ensure clear clinical pathways for confirmatory laboratory testing before a diagnosis is made.⁸⁷

When POCT is used it is vital that clinicians are able to communicate results to patients appropriately and arrange a confirmatory serological test in a local laboratory setting. BHIVA guidelines state that all individuals testing HIV positive should be immediately referred into specialist HIV services and preferably seen by an HIV specialist care worker or advisor within 48 hours of the test result. Further guidance on this is available nationally together with relevant standards from BHIVA which have recently been published.⁸⁸

It is a recommendation of this report that commissioners ensure that the full range of technical and laboratory considerations pertinent to HIV testing are included in

[§] An assay is an investigative (analytic) procedure

commissioning arrangements, particularly when new services/technologies are being considered.

Important of adherence to national standards

In 2013 BHIVA, in collaboration with other interested organisations, reviewed and updated their standards for the clinical care for adults with HIV infection in the NHS.⁸⁹ This was to ensure that they appropriately reflected the current health care needs of people with HIV and were relevant to all health services that provided their care. This was important given the significant changes in the field of HIV as well as in the associated commissioning and financial environment since their original publication in 2007. In the revised document there is a series of 12 quality standards, which are specific, concise statements about the care that any adult living with HIV in the UK should expect to receive together with a series of measureable and auditable outcomes applicable to each standard.

The scope of these standards of care are wide ranging from acquisition of infection to end of life. Crucially they now includes people with HIV who are as yet unaware of their HIV infection and therefore diagnostic testing for HIV is the key entry point for care in terms of both treatment and prevention services.

It is of note that MEDFASH (Medical Foundation for HIV and Sexual Health) and BASHH in 2014 also produced national standards for the management of STIs and within this document are also specific standards pertinent to HIV prevention that should also be considered when commissioning such services.⁹⁰

It is a recommendation of this report that commissioners and all service providers adhere to these national standards with a requirement that any relevant outcomes are routinely measured and audited.

Current provision of HIV testing services within Lancashire

Currently HIV testing is offered in a variety of locations across Lancashire, including primary and secondary health care services and specialist sexual health services. Although there are routinely available data outlining the provision of HIV tests across our GUM clinics unfortunately the number of tests carried out and the positivity rate per location of test is not readily known for all other testing locations. Testing in primary care would appear not to be routine and as a result there are likely to be wide variations in testing between practices. Likewise we have limited intelligence about the scale of HIV testing in other settings commissioned by other parts of the system such as in secondary care.

It is a recommendation of this report that systems are put in place to allow for an accurate assessment of our current position in respect of HIV testing across the range of different service providers across Lancashire.

The role of the voluntary sector

The House of Lords 2011 select committee report recommended that the role of the voluntary sector needed to be strengthened and recognised by both government and local authorities.⁹¹

Within Lancashire, Renaissance at Drugline Lancashire (a registered charity) operates a service, Healthier Living with HIV, offering support to those living with and affected by HIV. The service aims to enable each person to manage their diagnosis and to reach their goals – whether that is securing employment, housing, further education or emotional wellbeing. The Healthier Living service also offers support for the partners, family and friends of those living with HIV and provides advice and information as well as a safe space to speak to someone confidentially. Additionally the Healthier Living service provides access to groups of people facing similar problems to allow people to gain peer support. The service is also committed to raising HIV and sexual health awareness and support access to condoms, counselling and volunteering opportunities.

The collaboration with local clinical services has been particularly important and has involved building strong relationships with clinical staff across Lancashire, including Blackburn with Darwen. It has included attending GUM services in Preston, Lancaster, Blackburn and Burnley on a weekly basis, working collaboratively to ensure that all clients are provided with the support which they require. Volunteers and peers play an important role with the service and provide group support, befriending, and support by means of organising transport, home visits, taking medication to service users, accompanying service users to appointments, as well as providing counseling and complementary therapy.

It is a recommendation of this report that the service continues to be evaluated and that the position and role of the voluntary sector within HIV services is strategically considered in any future commissioning plans.

Importance of evaluating local HIV testing services

The recent Commissioning HIV Testing Services in England guide published by the NAT has highlighted the importance of not only reviewing current provision/practice of HIV testing services but also developing an appropriate range of measureable outcomes and systematically evaluating the provision of local HIV testing services on

an ongoing basis.⁹² The framework it proposes is wide ranging and outlines a number of dimensions for evaluation including:

- effectiveness;
- efficiency; and
- quality.

As would be expected many of the individual indicators that NAT proposes have strong resonance with documents such as national HIV guidelines referred to earlier, the PHOF as well as the various documents that outline national standards of care appropriate to HIV prevention.

It is a recommendation of the report that service commissioners incorporate this approach within any future commissioning arrangements.

Summary of recommendations

System integration

- Commissioning of HIV testing and treatment services must take place in an integrated manner across Lancashire.
- Given the significant personal and social consequences of a HIV positive diagnosis – which may take place in any setting where HIV diagnostic testing is being carried out – arrangements must be in place for appropriate onward treatment, care and support as required.
- The role of the voluntary sector (including the role of peer support networks) needs to continue to be evaluated and strategically considered as part of any future commissioning plans.
- A collaborative approach should be taken with commissioners of other services that impact on HIV prevention (for example with substance misuse services to ensure that investment in high-quality needle exchange services continue).

Surveillance and monitoring

- HIV prevalence needs to be routinely assessed at a number of geographical levels (including MSOA) to ensure that local need can be appropriately matched to local service provision in accordance with national guidance for testing strategies in those areas that have HIV prevalence rates greater than 2/1000 (15-59 years).
- Monitoring of the offer and/or uptake of HIV testing needs to be undertaken across a broad range of providers offering HIV testing services.

- All relevant providers of clinical services should engage with 'look back' where patients present to care with advanced immunosuppression (CD4 count < 200 cells/mm³ or AIDS diagnosis).

Expansion of HIV testing provision

Recognising the need to increase levels of testing across a number of settings in line with national guidance, local authority commissioners need to work collaboratively with NHS England, local clinical commissioning groups and local providers to ensure:

- Uptake of HIV testing within sexual health clinics is monitored and opportunities explored to improve local HIV testing rates.
- Support is offered to the commissioners of testing in other settings such as termination of pregnancy services, antenatal services, and services for TB, lymphoma and hepatitis B and C.
- HIV testing within all general practice settings take place in line with national guidance, including those with relevant risk factors, clinical indicator conditions and/or symptoms consistent with primary HIV infection.
- For those relatively few MSOA areas within Lancashire where the prevalence of HIV is consistently greater than 2/1,000 then consideration should be given for testing to be expanded to include new registrations in general practice.
- The emerging evidence base for approaches such as home testing and self-testing continue to be assessed and considered in any future commissioning plans.

Quality and performance

- The late diagnosis indicator in the PHOF must be routinely reported to the health and wellbeing board in conjunction with other indicators relevant to sexual health.
- All providers must demonstrate full compliance with nationally published standards of care including reporting on the measurable and auditable outcomes aligned to each relevant standard.
- Services should be routinely evaluated across a broad number of dimensions (such as effectiveness, efficiency and quality) in order to inform future service development/provision.

Expenditure

- The allocation of spending for individual programmes of work related to HIV prevention (such as provision of testing services, training, social marketing approaches) should be scoped out and if appropriate readjusted to reflect local need.

Professional engagement

- Further work needs to be undertaken to increase levels of professional engagement with HIV particularly as this is a major obstacle to more widespread testing.
- A range of approaches should be considered including the identification of clinical champions, promotion of existing national guidance as well as the equitable provision of accredited training courses.

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