

Ten Years of Monitoring HIV & AIDS
in the North West of England

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Foreword

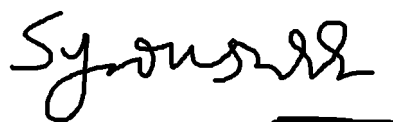
The emergence of HIV represented perhaps the first major challenge to the established modern epidemiological and health care systems of the developed world. Systems created in response to centuries of conditions such as cholera, syphilis and influenza were suddenly faced with an entirely new and fatal syndrome with initially no information about what was causing it or how it was transmitted. The challenge to health systems was all the more alarming as AIDS emerged after a period when medications (mainly antibiotics) had been declared to be the end of our battle against infectious diseases, yet AIDS did not respond to any known therapies. With no cure, research and monitoring systems were rapidly needed to inform prevention, identify which communities were most affected and ultimately the different ways and rates at which HIV spread between individuals. By the end of the 1980s, the picture of sexual, blood borne and mother to child transmission routes was fairly well described. However, with still no cure, throughout the 1990s research and monitoring systems were again central to understanding to who and how fast HIV was spreading, as well as whether interventions delivering information and addressing sexual behaviour were reducing rates of infection. Later, although cures for HIV still evaded bio-medical science, the emergence of treatments that reduced symptoms created a new role for monitoring. Data systems could now be used to examine who was or was not receiving the best treatments available and what affects such new interventions were having on everything from use of health care to life expectancy.

For the past ten years the North West HIV monitoring system has been part of all these processes. Its core aim has been to inform commissioning of HIV treatment, care and prevention services; yet as part of that process it has also added unique knowledge on local, national and international HIV issues including health inequalities, asylum seekers, the role of the voluntary sector, and the health economics of prevention, treatment and care. However, the stark statistics that comprise HIV epidemiology have impacted more broadly across society in general. Faced with regional, national and international data showing increasing levels of an incurable sexually transmitted infection has meant society has had to: start to reassess Victorian attitudes which have prohibited discussion of sex and sexuality; engage with gay and bisexual groups; and highlight the plight of other marginalised communities such as injecting drug users. This has also exposed the impoverished state that many genito-urinary medicine and sexual health services had found themselves in and, coming full circle, the need to understand much more about the whole range of sexually transmitted infections currently on the increase in the North West and across the UK. Therefore, as we enter a new decade of HIV monitoring, the North West has already begun to adopt similar systems for monitoring all sexually transmitted infections which will hopefully form the case for better interventions, targeted commissioning and general improvement in the region's sexual health.

Many of the issues relating to who continues to be affected by HIV in the North West, where inequalities in treatment need addressing, and how changes in treatment have affected the epidemiology of HIV are addressed in this report. We hope that you find it an interesting and useful summary of developments over the past ten years and that the learning from HIV not only means better HIV treatment and prevention in the next decade but also leaves us better prepared for the next new infectious disease.



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Executive Summary

In 1996 the World Health Organisation (WHO) predicted that globally there would be 26 million people living with HIV/AIDS by the year 2000. However, the reality far outstripped these predictions, and in 2000 there were an estimated 36.1 million people living with HIV and by 2005 that number rose to 40 million¹. In the UK alone, 78,938 people have been diagnosed with HIV since monitoring began in 1982 and it is estimated that there are currently 47,517 diagnosed people living with HIV/AIDS in the UK², considerably more than the prediction made in 1999 of 20,765³. The number of people accessing treatment and care slightly underestimates the number of people diagnosed as individuals can drop out of treatment for periods of time, however these data do show the increasing demand on services and the changing epidemiology of HIV. The number of people receiving treatment and care in the UK increased from 14,908 in 1996 to 47,517 in 2005⁴ and, as the North West consistently represents 7–9% of national cases, this increase was observed locally with an increase from 1,014 in 1996 to 4,195 in 2005 (see chapter 2). Overall by the end of 2005 the North West HIV/AIDS Monitoring Unit had recorded data on 4,959 unique individuals accessing HIV treatment and care in the North West since 1996, of whom 94 were children (see chapter 7) and 463 are known to have died in the last ten years (see chapter 9).

The length and changing dynamics of the epidemic raises questions that a surveillance system can help to answer. Furthermore, analysing data over time or focusing analysis on one specific topic reveals more about the impacts of successful prevention interventions and highlights areas for future attention. Analyses, such as those included in this special ten year HIV report, also show the usefulness of integrating datasets and highlight areas for improvement. Most importantly, detailed investigation into longitudinal data reveal further issues specific to the North West HIV positive population that may help to inform policy, practice, commissioning, service provision, and monitoring.

This report encompasses many of the current issues relevant to HIV and also highlights others that may not have previously been recognised. The current epidemiology shows that the number of new cases has risen annually since 1998 with heterosexual sex representing the major route of infection in 2005 (chapter 2; table 2.1). New HIV cases have increased most dramatically in the black African population within the North West (2380% increase from 1998 to 2005; chapter 2, table 2.7). Projected data show a continued increase in the number of HIV cases accessing treatment and care in the North West. They also show that although an increase in HIV positive black Africans is likely, those of white ethnicity will continue to represent the majority of cases (chapter 2; figure 2.7). However, increases in the number of women infected with HIV should be expected (chapter 2; figure 2.5). Importantly, projected data show that if current trends continue, we could expect the number of heterosexual cases to almost equal cases infected via MSM by 2008 (chapter 2; figure 2.6). Themes relating to deprivation, residency status, health status, antiretroviral therapy and inpatient care are raised throughout this report.

Inequalities in HIV

The link between deprivation and HIV has previously been established⁵, and throughout this report further evidence is provided to consolidate this evidence and show how intrinsic deprivation is to the population prevalence and the individual's experience of HIV. Chapter 4 analysed three years' of HIV data by Indices of Multiple Deprivation (IMD) and showed the stark difference in prevalence of HIV between the most wealthy and least wealthy areas of the North West. The increase across deprivation category had a steeper gradient than any health condition yet investigated in the North West⁶. HIV prevalence was also analysed using a geodemographic lifestyle classification system similar to that used by commercial companies to target their marketing activities. The categories are strongly related to income deprivation, but in addition provide a range of detailed descriptive information about the target groups. The system chosen was P² People and Places categories (see appendix 1 for definitions). HIV prevalence was higher among 'Qualified Metropolitans' and 'New Starters' than would be expected on the basis of the relative deprivation of these groups. Prevalence was very high in 'Multicultural Centres' and 'Urban Challenge' as expected from the high deprivation of areas in these classifications. However, not all populations in deprived areas were at such great risk of HIV, with 'Disadvantaged Households' having a lower than expected prevalence of HIV. Elsewhere in the report deprivation was also linked to the willingness or ability of patients to choose their hospital for HIV services (chapter 11). Those residing in disadvantaged areas primarily accessed care at their nearest treatment centre and travelled fewer miles in a year compared to those who resided in less deprived areas. Findings from chapter 8 show that asylum seekers and other non-UK nationals were more likely to live in the most deprived areas compared to UK nationals. Deprivation was also linked to use of voluntary services (chapter 10), with those presenting only to voluntary organisations in 2005 having resided in areas of higher deprivation compared to any other group. HIV health status and deprivation was examined and evidence shows that those living in more deprived areas are more likely to have at least one inpatient stay in hospital (chapter 4), they are also more likely to have a low CD4 count and a high viral load count, which could lead to ill-health (chapter 5). However, the effect of deprivation on health is not straightforward, since people from deprived areas who were new to treatment centres in 2005 were less likely to be admitted to hospital (chapter 8), and also deprivation was not a predictor for mortality (chapter 9). These findings indicate that there needs to be more focus upon, for example, the housing, social care and nutrition for HIV positive individuals in order to alleviate the negative impact of poverty on their health choices and health status.

Health indicators: CD4 count and viral load

Health status is commonly measured by CD4 count and viral load. Typically a CD4 count less than 200 cells/mm³ indicates poor health as does a viral load greater than 10,000 copies/ml. Health status at diagnosis has increased slightly over time since 2002 with individuals currently being diagnosed with a median CD4 count of 341.5 cells/mm³. However, 29% of newly diagnosed individuals had a CD4 count of less than 200 cells/mm³ showing that individuals are being diagnosed late in their HIV infection (chapter 3), which can influence how well they respond to treatment. In addition to deprivation, a poor health status (low CD4 count and high viral load) was more commonly found in those who had experienced an AIDS defining illness or who had died of an AIDS related illness, those who were new to the database in 2005, those who had had one or more stays in hospital and those who were taking antiretroviral therapy (ART) (chapter 5). Poor health indicators were more likely to be found in non-pregnant women compared to pregnant women (chapter 6) and in older populations compared to children (16 years and under: chapter 7). This is likely to be due to disease progression and an aging HIV positive population and the fact that pregnant women are more likely to be placed on ART to protect the unborn child.

Antiretroviral therapy use and cost

ART has been widely available since 1996 and chapter 2 illustrates the increasing new cases and total number of HIV positive people taking triple or more combination therapy (tables 2.4 and 2.8). Numbers taking these levels of therapies are predicted to increase over time with steeper increases in those taking quadruple or more drugs, a trend already been seen from 2004 to 2005 (figures 2.3 and 2.7). Chapter 5 shows that individuals taking ART are more likely to have a CD4 count less than 200 cells/mm³ and a viral load of 10,000 copies/ml or more. Although the goal of ART is to increase CD4 count and decrease viral load, this snapshot analysis included: a significant number of individuals who have been living for many years with HIV who may be less likely to see optimum results from ART; pre-ART indicators for those new to therapy; and people early in the course of HIV disease who have high CD4 counts but are not usually on ART. The cost effectiveness of ART is reviewed in chapter 12, and estimations are made of the cost of service use and the cost of ART in the North West. Guidelines promote ART as cost-effective when compared with the costs of additional inpatient care and expensive end of life care. However, many individuals were not experiencing optimum health benefits from their therapy: only 51% of those on ART had an undetectable viral load (table 5.3), and 9% had high viral load (over 10,000 copies/ml) coupled with a low CD4 count (less than 200 cells/mm³: table 5.4). Those taking ART also use more inpatient care than those not taking ART, with those taking higher levels of therapy (i.e. four or more drugs) having the greatest number of outpatient episodes (chapter 12). However, monitoring data cannot tell us whether ART continues to be cost effective, since it does not measure the wider costs and benefits of improved health and life expectancy. For example ART has enabled many people with HIV to be well enough to work and contribute to the economy. ART is prescribed more frequently to those who are symptomatic or have AIDS compared to asymptomatic people and more frequently to pregnant women compared to the general female population (chapter 6), and to a greater proportion of the child population (16 years and under) than the adult HIV positive population (chapter 7). People who died in the past five years were less likely to be taking ART than the general HIV positive population (chapter 9). Furthermore, individuals taking ART tend to travel further to their treatment centre and travel more additional miles than those not taking ART (chapter 11).

Non-UK nationals with HIV

Non-UK nationals have been included as a variable in much of the analysis included in this report. However, chapter 8 focuses specifically on this population to show that compared to the general population, non-UK nationals (i.e. asylum seekers and other migrant populations) consist of a higher proportion of females, heterosexuals and black Africans. Non-UK nationals also experience higher levels of deprivation and are younger than UK nationals. However, there is no significant association between residency status and stage of HIV disease, with two thirds of both UK nationals and non-UK nationals accessing services while still asymptomatic. It has already been reported that non-UK nationals were more likely to access voluntary services as their main source of HIV care and support in 2005⁷. This report shows that a higher proportion of non-UK nationals (specifically migrants other than asylum seekers) presenting to treatment centres also present to voluntary services than UK nationals (figure 8.1). There was no relationship between residency status and hospital admission; in fact a higher mean number of outpatient episodes was significantly related to being a UK national for all cases accessing treatment and care 2003-2005 (table 4.4) but not cases new to treatment and care 2005-mid 2006 (table 8.4). Analysis of mortality in chapter 9 showed that in general non-UK nationals were at no increased risk of dying. However, when only those who died were compared, asylum seekers and other migrants were more likely to die within a year of presenting for treatment and care in the North West than UK nationals (chapter 9; table 9.5). These data highlight the need for earlier diagnosis and quick and easy access to HIV services for vulnerable and marginalised groups.

Smaller risk groups: injecting drug users and those infected via blood/tissue

Chapter 2 shows that the number of injecting drug users (IDUs) with HIV has declined over the years. However, 2005 saw an 18% increase in new cases compared to those seen in 1996 (figure 2.2). IDUs are more likely to be admitted to hospital, live in the least deprived areas (chapter 4), and travel an average amount a year for treatment (33 miles: chapter 11; table 11.1). They are also more likely to have a low CD4 count (but not a high viral load: chapter 5). Furthermore, individuals infected through IDU have a higher risk of mortality, possibly due to health risks associated with injecting drug use. There are consistently low numbers of individuals in the North West who are HIV positive via blood or tissue products. However, analysis on this group revealed that they lived in the least

deprived areas, were no more likely to be admitted to hospital (chapter 4), but travelled a lot further per year for specialist treatment (97 miles per year) (table 11.1). Individuals infected through blood/tissue were also more likely to have a low CD4 count (but not more likely to have a high viral load: chapter 5).

Conclusion

Even though the North West has substantial numbers of new cases of HIV each year (e.g. 22% of all cases in 2005)⁷, the majority of cases have been living with HIV for a year or more. Issues are arising as the HIV positive population begins to age. For example, young people infected through vertical transmission are now reaching adulthood and need further support as they transit into adult services and become sexually active; fewer people are dying and therefore there are more people who have progressed in their disease, experiencing AIDS defining illnesses and being treated with ART, which is becoming more costly for the health sector. More women are being diagnosed during antenatal screening, however there is no such contact with services for men. The majority of new cases are black Africans and a large proportion are non-UK nationals infected through heterosexual sex. Black Africans access expert help and advice from voluntary organisations. However, the numbers of contacts are much lower than that for other groups, despite the fact that black Africans are likely to represent more complex cases needing, for example, support with housing, and social care as they represent the most deprived group. The prevalence and incidence of HIV is many times higher in the most deprived areas, and those with HIV in the most deprived areas suffer greater levels of HIV-related ill-health. These individuals are likely to use their closest clinic for HIV treatment and are more likely to access voluntary sector support. The overarching effect of deprivation needs to be addressed at all levels in society and in the health services if we are to see an overall improvement in the health of those with HIV.

This report provides detailed analyses that aim to inform decision-making. It has also identified areas for further detailed research using existing surveillance data and has highlighted issues that would benefit from additional research studies. Further work is needed on cause of death and survival times to estimate how long people currently live with HIV for in the North West; travel to services including methods of travel and reasons for accessing specific services to inform planning and commissioning; on how deprivation causes ill-health in longer standing cases of HIV infection but apparently not in new cases; on why some of those from the most deprived areas in contact with the voluntary agencies apparently do not access the statutory sector for treatment. In addition a detailed cost-effectiveness analysis would help to provide a more complete economic picture of HIV in the North West, including the cost-effectiveness of ART and the potential benefits of the newly approved category of antiretroviral drugs.

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References

- ¹ UNAIDS. AIDS epidemic update: December 2006.
- ² Health Protection Agency A Complex Picture. HIV and other Sexually Transmitted Infections in the United Kingdom: 2006 Supplementary data tables. Centre for Infections. 2006. Available at http://www.hpa.org.uk/publications/2006/hiv_sti_2006/contents.htm [accessed 15th December 2006].
- ³ Evans B, McHenry A & Mortimer J. HIV and AIDS in the UK, an epidemiological review: 2000. Communicable Disease Surveillance Centre; 2001.
- ⁴ Health Protection Agency A Complex Picture. HIV and other Sexually Transmitted Infections in the United Kingdom: 2006 Supplementary data tables. Centre for Infections. 2006. Available at http://www.hpa.org.uk/publications/2006/hiv_sti_2006/contents.htm [accessed 15th December 2006].
- ⁵ Cook PA, Hargreaves S, Tocque K, Bellis MA. Relationships between the use of hospital services and place of residence deprivation score among HIV positive individuals in the North West of England. *Communicable Disease and Public Health* 2004; 7:319-321.
- ⁶ Wood J, Hennell T, Jones A, Hooper J, Tocque K, Bellis MA. Where Wealth Means Health. North West Public Health Observatory, 2006.
- ⁷ Cook PA, Downing J, Hargreaves SC, Madden H, Syed Q and Bellis MA. HIV and AIDS in the North West of England 2005, Liverpool John Moores University, Centre for Public Health; 2006.