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## Changing patterns of HIV incidence and prevalence among men who have sex with men in the United Kingdom

Thesis submitted for the degree of Doctor of Philosophy

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## Sarah Dougan

City University

July 2008



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# PAGES 28-39, 62-75, 108-117, 142-156 AND THE SIGNATURES ON PAGES 234-240

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- Paper 3.1: Macdonald N, Dougan S, McGarrigle CA, Evans BG, Fenton KA. Recent trends in diagnoses of HIV and other sexually transmitted infections in England and Wales amongst men who have sex with men. Sexually Transmitted Infections 2004; 80: 492-7
- Paper 3.2: Dougan S, Elford J, Chadborn T, Brown AE, Roy K, Murphy G, Gill ON. Does the recent increase in HIV diagnoses among men who have sex with men in the United Kingdom reflect a rise in HIV incidence or increased uptake of HIV testing? Sexually Transmitted Infections 2007, 83(2):120-5
- Paper 4.1: Dougan S, Elford J, Rice B, Brown AE, Sinka K, Evans BG, Gill ON, Fenton KA. The epidemiology of HIV among black and minority ethnic men who have sex with men in England and Wales. Sexually Transmitted Infections 2005; 81:345-50
- Paper 4.2: Dougan S, Elford J, Sinka K. Fenton KA, Evans BG. Men who have sex with men who are born abroad and diagnosed with HIV in England and Wales: an epidemiological perspective. *International Journal STD & AIDS* 2005; 16:618-21
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- Paper 5.2: Dougan S, Balogun MA, Elford J, Brant L, Sinka K, Evans B, Ramsay M.
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#### Declaration

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Sarah Dougan

#### Abstract

Men who have sex with men (MSM) remain the group at highest risk of acquiring HIV in the UK. The aim of this thesis is to examine the changing patterns of HIV incidence and prevalence among MSM in the UK, making use of national HIV surveillance data

This is a PhD-by-publication thesis, comprising seven peer-reviewed papers and four inter-related commentaries which explore the challenges of using HIV surveillance data to undertake epidemiological research in this area.

Chapter 2 explores the evolution of HIV surveillance among MSM in the UK over the past 25 years, and how this has responded to changes in HIV epidemiology and the availability of new data.

Chapter 3 examines time trends and geographic differences in diagnosed HIV among MSM in the UK. Specifically, the chapter investigates whether the recent increase in HIV diagnoses among MSM reflects an increase in HIV incidence or an increase in the uptake of HIV testing. A lack of detailed information on the 'at risk' population – the number of MSM living in the UK — constrains such analyses, however.

Chapter 4 explores an emerging area of research among MSM: ethnicity and migration. Using data from several large surveillance databases, the chapter describes the epidemiology of HIV among ethnic minority and migrant MSM and makes recommendations for improving the utility of ethnicity data on MSM.

Finally, Chapter 5 examines another emerging area of research – co-infection of HIV positive MSM with other sexually transmitted infections (STI) such as syphilis. gonorrhoea or hepatitis C. The chapter also explores sexual networks of MSM, and particularly HIV positive MSM.

In conclusion, this work highlights the increasing complexity of HIV epidemiology among MSM in the UK, and underscores the value of making full use of national HIV surveillance data. MSM continue to be disproportionately affected by HIV in the UK, emphasising the importance of continued surveillance, research, and prevention within this population.

#### Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
BME	Black and Minority Ethnic
CASI	Computer Assisted Self-Interviewing
CDC	Centers for Disease Control and Prevention
CDSSH	Common Data Set for Sexual Health
CEHR	Commission of Equality and Human Rights
CHAPS	Community HIV and Aids Prevention Strategy
СМО	Chief Medical Officer
E&W	England and Wales
E,W&NI	England, Wales and Northern Ireland
GUM	Genitourinary Medicine Clinic
HAART	Highly Active Antiretroviral Therapy
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HPA	Health Protection Agency
IPB	Indian / Pakistani / Bangladeshi
LGBT	Lesbian, Gay, Bisexual and Transgender
LGV	Lymphogranuloma Venereum
MSM	Men who have Sex with Men
MRSA	Methicillin-resistant Staphylococcus aureus
Natsal	National Surveys of Sexual Attitudes and Lifestyles
NHS	National Health Service

ONS	Office for National Statistics
SARS	Severe Acquired Respiratory Syndrome
SHA	Strategic Health Authority
SOPHID	Survey of Prevalent HIV Infections Diagnosed
STARHS	Serological Testing Algorithm for Recent HIV Seroconversion
STI	Sexually Transmitted Infection
тнт	Terrence Higgins Trust
UA	Unlinked Anonymous
UK	United Kingdom
UNAIDS	Joint United Nations Programme on AIDS

VCT Voluntary Confidential HIV Testing

## **CHAPTER 1**

## Introduction

#### Chapter summary

This introductory chapter provides a background to the research undertaken in this thesis and outlines the structure and content of the thesis which includes published papers and accompanying commentaries. It also provides details of the conferences where some of this research has been presented.

#### 1.1 The background to this thesis

Men who have sex with men (MSM) have been the group most affected by HIV in the UK, with an estimated 28,000 (range: 25,500-31,400) HIV positive MSM living in the UK in 2005 (UK Collaborative Group for HIV and STI Surveillance, 2006). MSM remain the group at highest risk of acquiring HIV in this country (Dougan et al., 2005a: UK Collaborative Group for HIV and STI Surveillance, 2006). In 2005, 84% of MSM newly diagnosed with HIV in the UK had probably acquired their infection in the UK (UK Collaborative Group for HIV and STI Surveillance, 2006). Surveillance data indicate that on average, it takes six years before HIV infection is diagnosed in the UK (CMO, 2003). with one-in-ten HIV positive MSM being diagnosed at an advanced stage of infection (Chadborn et al., 2005). These delays in diagnosis are highlighted by the UK's unlinked anonymous surveys which showed that 43% of MSM with undiagnosed HIV infection attending sentinel genito-urinary medicine (GUM) clinics in 2005 left the clinic unaware of their infection (UK Collaborative Group for HIV and STI Surveillance, 2006). This is despite recent increases in the promotion and uptake of HIV testing among MSM (Hickson et al., 2002; UK Collaborative Group for HIV and STI Surveillance, 2006). Delays in diagnosis have implications for the onward transmission of HIV infection among MSM and for effective treatment and care. Indeed, encouraging HIV testing to further reduce the time between HIV infection and diagnosis was a major theme in a recent Chief Medical Officer's annual report (CMO, 2003).

The introduction of highly active antiretroviral therapies (HAART) in the mid-1990s dramatically reduced the number of AIDS cases and deaths among HIV positive MSM in the UK (Aalen *et al.*, 1999; UK Collaborative Group for HIV and STI Surveillance,

2006). Similar trends were observed in other western European countries with large MSM populations, as well as in North America and Australasia (EuroHIV, 2006, CDC, 2003; National Centre in HIV Epidemiology and Clinical Research, 2006). There was some optimism that HIV incidence among MSM would decrease with the widespread use of HAART because the drugs lower viral load. But this did not materialize, and in the UK, available data show no evidence of a decrease (or increase) in HIV incidence among MSM (Murphy *et al.*, 2001; Murphy *et al.*, 2004; UK Collaborative Group for HIV and STI Surveillance, 2006). There have however, been significant increases in the transmission of other sexually transmitted infections (STIs) including outbreaks of infections that were considered to be practically eliminated (e.g. syphilis) (Simms *et al.*, 2004), and recognition of others not seen in Europe for decades (e.g. lymphogranuloma venereum) (Ward *et al.*, 2007). These outbreaks have accompanied increases in 'high risk' sexual behaviours, which have been well-documented since the introduction of HAART (Dodds *et al.*, 2000; Dodds *et al.*, 2004; Elford *et al.*, 2004).

When I began this thesis in 2004, there was evidence that patterns of HIV incidence and prevalence among MSM in the UK were changing. The observed increases in HIV diagnoses, rates of other STIs and high risk behaviours were poorly understood, as was their impact on the transmission of HIV in different areas of the UK. The diversity of MSM with HIV infection in the UK was also not appreciated or clearly documented. During the course of this work, I have tried to address some of these issues using the UK's HIV surveillance data. In section 1.3 below I give a broad outline of the chapters and peer-reviewed papers forming this thesis and describe how they are connected. While the proportion of the male population that are MSM is estimated to be around only 2% (Johnson *et al.*, 2001), understanding the changing patterns of HIV incidence and prevalence among MSM in the UK is important for a number of reasons. Firstly, a substantial number of MSM in the UK continue to become infected with HIV each year (Murphy *et al.*, 2004; UK Collaborative Group for HIV and STI Surveillance, 2006). While the prognosis for these men is much improved since the introduction of HAART. they still experience disproportionate levels of morbidity and a reduced life expectancy because of their HIV infection (Chadborn *et al.*, 2005; UK Collaborative Group for HIV and STI Surveillance, 2006). In economic terms, HIV infection is relatively expensive to manage: the average cost of treating HIV infection in the UK is £15,000 per patient per annum (Imrie *et al.*, 2006). Preventing the transmission of HIV infection is therefore a priority, in both public health and economic terms. To develop effective primary and secondary prevention programmes for MSM however, you need to have a clear understanding of the epidemiology of HIV.

While most of my research has concentrated on HIV among MSM in the UK, the findings may also have relevance for prevention and epidemiological research in other countries, specifically western European, North America and Australasia. This is because all these countries have observed similar trends in HIV, STIs and sexual behaviours among their populations of MSM (Elford, 2006; Fenton & Imrie, 2005; Truong *et al.*, 2006; Van der Bij *et al.*, 2005). The UK has some of the world's most comprehensive HIV surveillance systems, providing national-level epidemiologic data that are not available elsewhere. The research presented in this thesis has improved our understanding of HIV infection among MSM in the UK during a time of change not only in HIV epidemiology, but also in STI epidemiology and sexual behaviour.

#### 1.2 Structure of this thesis

This thesis for a PhD-by-publication consists of a series of peer-reviewed papers that have been published in international journals, accompanied by explanatory chapters. My research has also been presented at international and national conferences (table 1.1). I wrote six of the papers after registering for my PhD in February 2004. One of the papers was published shortly before I registered (Macdonald *et al.*, 2004). Consequently, this work is being submitted for a PhD-by-prospective-publication, rather than by prior publication. This thesis is divided into four main chapters (chapters 2-5) followed by a concluding chapter (chapter 6). Each of the main chapters is themed, consisting of one or two of the peer-reviewed papers and a commentary that addresses some of the major challenges in using HIV surveillance data for epidemiological research on HIV among MSM in the UK. Table 1.2 illustrates the structure and content of the thesis.

In the published papers I used a variety of different methods to answer specific research questions, including reviewing the literature, combining large surveillance datasets by matching individual patient records, and undertaking descriptive epidemiological analyses. In the remaining part of this Introduction I provide an overview of the chapters that make up this thesis.

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#### Table 1.1: Conference presentations of thesis research

Year	Conference	Title	Authors	Type of presentation
September 2004	HPA Second Scientific Conference. University of Warwick	Increasing numbers of new HIV diagnoses among men who have sex with men in England, Wales and Northern Ireland; have improvements in the uptake of HIV testing obscured a real rise in incidence?	Dougan S, Macdonald N, Brown AE, Murphy G, Evans BG, Lowndes CM, <i>et al.</i>	Oral
March 2005	CHAPS conference. Bristol	HIV among ethnic minority gay men in England and Wales.	Dougan S, Elford J, Rice B, Brown AE, Sinka K, Evans BG, <i>et al.</i>	Oral
June 2005	Ethnicity and cultural perspectives of HIV therapy in the UK: insights for 3 by 5', the Royal Society of Medicine, London	Epidemiology of HIV among black and minority ethnic men who have sex with men in England & Wales.	Dougan S, Elford J, Rice B, Brown AE, Sinka K, Evans BG, Gill ON, Fenton KA.	Oral
July 2005	International Society for Sexually Transmitted Diseases Research (ISSTDR) conference, Amsterdam	Does the recent increase in new HIV diagnoses among men who have sex with men in the United Kingdom reflect a rise in HIV incidence?	Dougan S, Elford J, Chadborn TR, Brown AE, Roy K, Sinka K, Murphy G, Macdonald N, Evans BG, Fenton KA.	Poster
July 2005	International Society for Sexually Transmitted Diseases Research (ISSTDR) conference, Amsterdam	Epidemiology of HIV among black and minority ethnic men who have sex with men in England & Wales.	Dougan S, Elford J, Rice B, Brown AE, Sinka K, Evans BG, Gill ON, Fenton KA.	Poster
March 2006	CHAPS conference, Leeds	Does the recent increase in new HIV diagnoses among men who have sex with men in the United Kingdom reflect a rise in HIV incidence?	Dougan S, Elford J, Chadborn TR, Brown AE, Roy K, Sinka K, Murphy G, Macdonald N, Evans BG, Fenton KA.	Oral

Table 1.2: Structure of the thesis and the papers published in peer-reviewed journals

CHAPTER	THEMES AND PEER-REVIEWED PAPERS
Chapter 1	Introduction
is cha	Public Health Surveillance
Chapter 2	Dougan S, Evans BG, Macdonald N, Goldberg DJ, Gill ON, Fenton KA, Elford J. HIV and other sexually transmitted infections among gay and bisexual men in the United Kingdom: two decades of public health surveillance. <i>Epidemiology and Infection</i> . 2007; Jul 30: 1-12 [Epub ahead of print]
idoogaaa.	Geography and time trends
Chapter 3	Macdonald N, Dougan S, McGarrigle CA, Evans BG, Fenton KA. Recent trends in diagnoses of HIV and other sexually transmitted infections in England and Wales amongst men who have sex with men. <i>Sexually Transmitted Infections</i> 2004; <b>80</b> : 492-7
	Dougan S, Elford J, Chadborn T, Brown AE, Roy K, Murphy G, Gill ON. Does the recent increase in HIV diagnoses among men who have sex with men in the United Kingdom reflect a rise in HIV incidence or increased uptake of HIV testing? <i>Sexually Transmitted Infections</i> . 2007; <b>83(2)</b> :120-5
- Group	Ethnicity and migration
Chapter 4	Dougan S, Elford J, Rice B, Brown AE, Sinka K, Evans BG, Gill ON, Fenton KA. The epidemiology of HIV among black and minority ethnic men who have sex with men in England and Wales. <i>Sexually Transmitted Infections</i> . 2005; <b>81</b> :345-50
	Dougan S, Elford J, Sinka K, Fenton KA, Evans BG. Men who have sex with men who are born abroad and diagnosed with HIV in England and Wales: an epidemiological perspective. <i>International Journal of STD and AIDS</i> 2005; <b>16</b> :618-21
ninne i	Co-infection with other sexually transmitted infections
Chapter 5	Dougan S, Evans BG, Elford J. Sexually transmitted infections in Western Europe among HIV positive men who have sex with men. Sexually Transmitted Diseases, 2007 34(10):783-90
	Dougan S, Balogun MA, Elford J, Brant L, Sinka K, Evans B, Ramsay M. MSM diagnosed with HIV and hepatitis C in England and Wales: findings from national surveillance. <i>BMC Public Health.</i> 2007; <b>7</b> :7
Chapter 6	Conclusions

#### 1.3 Overview of the thesis

#### 1.3.1 Chapter 2 — Public health surveillance

This chapter sets the scene for the thesis, providing the reader with a comprehensive background in HIV surveillance and outlining the challenges associated with using surveillance data for epidemiological research, which are then addressed in greater detail in chapters 3, 4 and 5.

The paper published in *Epidemiology and Infection* in 2007 shows how the UK's HIV surveillance systems have responded to the evolving epidemiology of HIV among MSM in the UK over the past 25 years and considers how they may need to continue to evolve in the future (Dougan *et al.*, 2007a). The commentary accompanying this paper begins by describing the definition, history and development of public health surveillance. The aims and special features of HIV surveillance are detailed, along with a description of the UK's main HIV surveillance systems from which most of the data in this thesis were derived. In the second half of the chapter, I address the differences between surveillance and research. The opportunities and challenges associated with using national HIV surveillance data for epidemiological research on HIV among MSM in the UK are then discussed.

#### 1.3.2 Chapter 3 — Geography and time trends

The number of HIV positive MSM living in the UK continues to increase both in London and elsewhere. This has placed an increased burden on local health promotion and treatment and care services over time. To obtain sufficient resource and to plan service provision therefore, epidemiological analyses are required for different geographic areas over time.

The first paper, published in *Sexually Transmitted Infections* in 2004, describes the rates of HIV and STI diagnoses among MSM across England, Wales and Northern Ireland between 1997 and 2002, stratified by London and outside London (Macdonald *et al.*, 2004). In spite of the availability of detailed surveillance data available on diagnosed HIV infections for smaller geographic areas, the time trends analysis was limited to London versus outside London because of a lack of suitable denominator data for the MSM population in smaller areas.

The second paper in this chapter, published in *Sexually Transmitted Infections* in 2006, examines factors underlying the increase in HIV diagnoses among MSM between 1997 and 2004. Analyses had to also be restricted to London versus outside London for two reasons: lack of suitable denominator data for MSM living in smaller geographic areas but also a lack of information on HIV incidence among MSM for smaller geographic areas (Dougan *et al.*, 2007b).

Following on from these two papers, in chapter 3, 1 discuss the challenges associated with creating a sampling frame for the MSM population that can be used to calculate rates of HIV diagnoses and diagnosed HIV prevalence. I consider the different ways of measuring the size of the MSM population and scrutinise the data sources that are currently available. By undertaking further analysis, 1 examine whether small area population denominators for MSM could be used with small area HIV surveillance data to provide much needed geographic analyses. Finally I make recommendations for improving the geographic data available on MSM and for further epidemiological analyses of HIV among MSM by geographic area.

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#### 1.3.3 Chapter 4 — Ethnicity and migration

There has been growing interest in the needs of black and minority ethnic (BME) and migrant MSM in the UK following the large increase in the overall number of HIV diagnoses in the UK, among *heterosexual men and women* of black African origin. The two published papers in this chapter describe for the first time, the epidemiology of HIV among black and minority ethnic (BME) and migrant MSM in England and Wales.

The first paper on BME MSM, published in *Sexually Transmitted Infections* in 2005, describes HIV epidemiology among MSM by ethnicity and country of birth (where ethnicity data were unavailable) from the main HIV surveillance systems in England and Wales (Dougan *et al.*, 2005b). It shows that approximately 10% of MSM newly diagnosed with HIV in England and Wales and 10% of those accessing HIV-related services were black or ethnic minority. The second paper on migrant MSM, published in the *International Journal of STD and AIDS* in 2005, describes the epidemiology of diagnosed HIV infections among migrant MSM (Dougan *et al.*, 2005c). This analysis indicated that about half the migrant MSM diagnosed with HIV in the UK.

Following on from these papers, chapter 4 discusses the derivation of the ethnic group categorisation used in the England and Wales census and its application, including an examination of the strengths and weaknesses of using these categories for HIV surveillance among MSM. In addition, I examine whether country of birth can be used as a proxy for ethnicity for HIV positive MSM and vice versa. Finally, I make recommendations for the use of data on ethnicity and country of birth for surveillance and epidemiological research among MSM with HIV.

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#### 1.3.4 Chapter 5 — Co-infection with other sexually transmitted infections

The number of MSM living with diagnosed HIV in the UK has increased substantially since the introduction of highly active antiretroviral therapies (HAART) in the mid-1990s (UK Collaborative Group for HIV and STI Surveillance, 2006). Some HIV positive MSM engage in 'high risk' sexual behaviours and, as a consequence, acquire other STIs (Fenton & Imrie, 2005). Co-infection with HIV and other STIs has important implications for: the transmission dynamics of both HIV and STIs (Fleming & Wasserheit, 1999; Wasserheit, 1992); the natural course and successful treatment of HIV infection; and the interpretation of epidemiological data. As a result, the epidemiology of HIV and STI co-infection has become increasingly important and topical.

In the first paper, published in *Sexually Transmitted Diseases* in 2007, I reviewed the literature on STIs among HIV positive MSM across Western Europe (Dougan *et al.*, 2007c). This was the first time that this information had been brought together in this way. This showed that similar trends have occurred across Western Europe, with HIV positive MSM disproportionately acquiring STIs since the introduction of HAART, compared with HIV negative MSM. In particular, there have been recent outbreaks of sexually transmitted hepatitis C infection among HIV positive MSM. Historically the sexual transmission of hepatitis C has been rare among MSM (and still is among HIV negative MSM). As a consequence, there are no surveillance data available to examine co-infection of HIV and hepatitis C among MSM. In the second paper I describe the results of an exercise combining records from HIV and hepatitis C surveillance databases that I undertook to try and provide further epidemiological information on HIV-hepatitis C co-infection (Dougan *et al.*, 2007d).

The emerging epidemiological trends in STI co-infection among HIV positive MSM appear to be the result of sexual networking. To better understand the epidemiological data on STIs among HIV positive MSM, in the commentary I review the literature around the formation and main determinants of sexual networks, and specifically HIV positive MSM. I consider what sexual behaviour studies of HIV positive MSM tell us about sexual networks, and also discuss the impact of the Internet on sexual networking. Sexual networking is an emerging area of research and so, in the last part of this chapter, I discuss areas for further research relating to the transmission of STIs among HIV positive MSM. Further knowledge of these sexual networks would aid interpretation of HIV and STI surveillance data and allow modelling of the transmission of STIs among MSM.

#### 1.3.5 Chapter 6 --- Conclusions

In the final chapter of this thesis, I summarise my findings on the changing patterns of HIV incidence and prevalence among MSM in the UK, and the factors driving these, from my examination of the UK's HIV surveillance data and published literature. I also summarise the recommendations for surveillance and future epidemiological research of HIV among MSM in the UK from my work.

## **CHAPTER 2**

## **Public Health Surveillance**

#### **Chapter Summary**

Following on from chapter 1, which outlines the background to this thesis and its structure, the second chapter provides a detailed description of public health surveillance and its role in monitoring HIV among MSM in the UK over the past 25 years.

This second chapter begins with a literature review on the evolution of HIV surveillance among MSM in the UK over the past 25 years, which was published in *Epidemiology and Infection* in 2007. Following this, I describe the development of public health surveillance over time and, specifically, the aims and special features of HIV surveillance. Most of the data presented in this thesis are from the UK's main HIV surveillance systems and so a description of these systems is provided. In the second half of the chapter, I address the differences between surveillance and research. Finally, the opportunities and challenges associated with using national HIV surveillance data for epidemiological research on HIV among MSM in the UK are discussed. These are explored in greater detail in chapters 3, 4 and 5.

#### Paper 2.1

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## **REVIEW ARTICLE HIV in gay and bisexual men in the United Kingdom: 25 years of public health surveillance**

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#### SUMMARY

It is more than 25 years since the first case of AIDS was reported in the United Kingdom. In December 1981 a gay man was referred to a London hospital with opportunistic infections indicative of immunosuppression. National surveillance began the following year, in September 1982, with the notification of deaths and clinical reports of AIDS and Kaposi's sarcoma plus laboratory reports of opportunistic infections. Since then epidemiological surveillance systems have evolved, adapting to, and taking advantage of advances in treatments and laboratory techniques. The introduction of the HIV antibody test in 1984 led to the reporting of HIV-positive tests by laboratories and the establishment of an unlinked anonymous survey in 1990 measuring undiagnosed HIV infection among gay men attending sexual health clinics. The widespread use of highly active antiretroviral therapies (HAART) since 1996 has averted many deaths among HIV-positive gay men and has also resulted in a large reduction in AIDS cases. This led to a need for an enumeration of gay men with HIV accessing NHS treatment and care services (1995 onwards), more clinical information on HIV diagnoses for epidemiological surveillance (2000 onwards) and the routine monitoring of drug resistance (2001 onwards). Twenty-five years after the first case of AIDS was reported, gay and bisexual men remain the group at greatest risk of acquiring HIV in the United Kingdom. Latest estimates suggest that in 2004, 26 500 gay and bisexual men were living with HIV in the United Kingdom, a quarter of whom were undiagnosed. In this review, we examine how national surveillance systems have evolved over the past 25 years in response to the changing epidemiology of HIV/AIDS among gay and bisexual men in the United Kingdom as well as advances in laboratory techniques and medical treatments. We also reflect on how they will need to continue evolving to effectively inform health policy in the future.

#### INTRODUCTION

Twenty-five years have elapsed since AIDS was first reported in the United Kingdom. During that time 30000 gav and bisexual men (referred to here as 'gay

 Author for correspondence: Ms S. Dougan, City University, Institute of Health Sciences, 24 Chiswell Street, London ECTY 4TY, UK, (Email: s.dougan@city.ac.uk) men') have been diagnosed with HIV, of whom 12000 have progressed to AIDS and 10000 have died [1]. Gay men remain the behavioural group at greatest risk of IIIV in the United Kingdom, accounting for three-quarters of HIV infections diagnosed in 2004 that were probably acquired in the United Kingdom [2]. Cumulative figures mask temporal changes, whereby health promotion initiatives and the introduction of highly active antiretroviral therapies (HAART)

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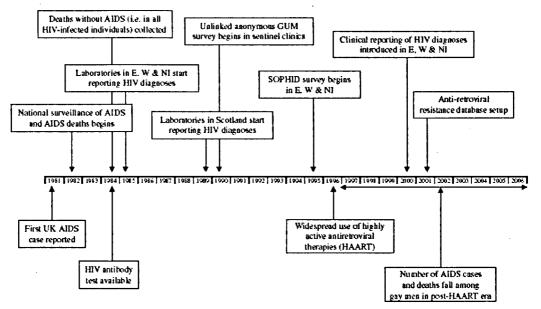


Fig. 1. Timeline of HIV/AIDS surveillance in the United Kingdom. SOPHID, Survey of Prevalent HIV Infections Diagnosed.

have profoundly changed the epidemiology of HIV at different times. Nonetheless, HIV transmission continues among gay men in the United Kingdom, coupled in recent years with increases in gonorrhoea and syphilis and an outbreak of lymphogranuloma venereum (LGV) [2]. Behavioural surveillance also indicates increases in 'high risk' sexual behaviours [3-6].

Surveillance is the systematic collection, collation and analysis of data and its timely dissemination so that important trends and events may be detected, and necessary action can be taken to promote and protect public health [7]. The United Kingdom's HIV surveillance systems are some of the most comprehensive in the world, providing a wealth of national epidemiological data (Figs 1 and 2). In this review, we examine how these surveillance systems have evolved over time in response to the changing epidemiological patterns of HIV among gay men in the United Kingdom, and consider how they may need to adapt in the future.

#### Search strategy and selection criteria

Sources for this review were identified by searches of Medline and references from relevant articles; numerous articles were identified through searches of the authors' files. Search terms were 'HIV infection', 'AIDS', 'homosexual', 'bisexual', 'gay', 'United Kingdom', 'surveillance', 'epidemiology'. Englishlanguage papers and reports were reviewed.

#### Early experiences: 1981-1983

The early picture of AIDS in the United Kingdom was a reflection of experience in the United States where, during 1981, Pneumocystis pneumonia (PCP) and Kaposi's sarcoma (KS) were reported among gay men in metropolitan areas [8, 9]. Described in December 1981, the first case of AIDS in the United Kingdom was in a 49-year-old gay man who regularly visited Florida and was referred with PCP and cytomegalovirus (CMV) infection to a London bospital [10].

In response to growing alarm and uncertainty surrounding the new syndrome, the Communicable Disease Surveillance Centre (CDSC) in collaboration with the Scottish Centre for Infection and Environmental Health (SCIEH) introduced national surveillance in September 1982 [11, 12]. Initially, surveillance consisted of death registrations mentioning PCP. KS and AIDS (provided weekly by the Office of Population Censuses and Surveys, now the Office for National Statistics, and the Registrar General's Office in Scotland), laboratory reports of opportunistic

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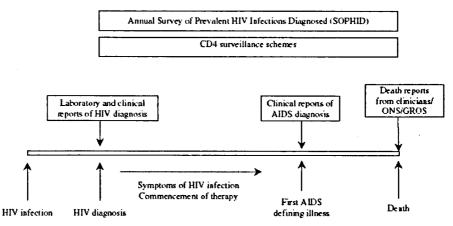


Fig. 2. How HIV/AIDS surveillance works at an individual level in the United Kingdom. ONS, Office for National Statistics; GROS, General Register Office for Scotland.

infections (with sexual orientation where possible) and clinical reports of PCP, KS and AIDS [11, 13, 14]. The American AIDS case definition was adopted at the outset, but by the early 1990s European and American case definitions had diverged, with Europe defining AIDS as having one of 28 illnesses and the United States, as having a CD4 cell count of < 200 cells/mm<sup>4</sup> or one of these 28 illnesses [15–17].

#### HIV antibody test: 1984 onwards

With the discovery of HIV as the causative agent for AIDS and the development of the HIV antibody test in 1984, surveillance was enhanced by asking microbiologists to report HIV-positive test results from 1985 [18, 19]. Prevalence studies using the HIV antibody test during 1984 revealed the extent of HIV infection among British gay men [20-24], and confirmed that AIDS cases were just the 'tip of the iceberg'. Retrospective testing of stored residual samples, taken for routine hepatitis B infection tests, established that HIV had been present among gay men in the United Kingdom since 1980 and that prevalence was increasing [21]. By 1984-1985, prevalence among gay men attending some genito-urinary medicine (GUM) clinics was 35% in London and 11% outside [22, 23]. While the rise in HIV prevalence among GUM clinic attendees in London during the early 1980s was comparable to that observed in San Francisco, subsequent behavioural change (principally a reduction in partner numbers) at an earlier epidemic stage in the United Kingdom probably prevented the continued rapid rise in prevalence that was seen in the United States [25-28].

#### Unlinked anonymous serosurveys: 1990 onwards

The above ad-hoc studies demonstrated the importance of measuring HIV prevalence, particularly the level of undiagnosed infections, and by the end of the 1980s there were calls for an 'unlinked anonymous' serosurveillance programme to accurately and routinely monitor prevalence within defined populations [29]. There would be no reliance on gay men seeking a named HIV test, therefore reducing participation bias. Such surveillance would improve the accuracy of future predictions about the size of the epidemic and the targeting of prevention campaigns. A range of unlinked serosurveys was proposed, including a GUM clinic survey incorporating 'high-risk' gay men where residual samples taken for routine syphilis serology would be irreversibly unlinked from any patient identifiable information and then tested for HIV (Fig. 3) [29]. Information on whether the person had been previously diagnosed would be retained, allowing a measure of undiagnosed HIV prevalence. There were lengthy debates about the individual's rights vr. the public health benefit, but by November 1988 the British government stated that it saw no legal or ethical objection to the surveys and implementation began early in 1990 [30].

The unlinked anonymous GUM survey revealed no significant changes in the scroprevalence of undiagnosed HIV infection among gay men attending GUM clinics with an acute STI between 1993 and 1998, indicating a high level of continuing transmission [1, 31]. This burden of undiagnosed HIV-1 infection in 1996 highlighted the need to extend the

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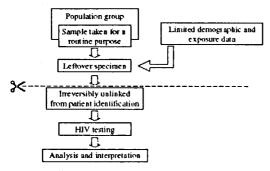


Fig. 3. Unlinked anonymous programme methodology. The unlinked anonymous programme measures HIV prevalence among defined populations in the United Kingdom. Gay men attending genito-urinary medicine (GUM) clinics having routine syphilis tests are one of these populations. After testing there is leftover specimen, which has limited demographic and exposure data attached to it, as well as sexual orientation and whether known to be HIV infected. Before testing the leftover specimen for HIV, all patient identifiable information (e.g. name, DOB) are irreversibly removed making it impossible to identify from whom the specimen came. The sample is then tested and results from all samples are analysed and interpreted at a population level.

practice of routine voluntary, named testing for HIV in GUM clinics [32].

Promotion of HIV testing among gay men in GUM clinics was emphasized in both the 2001 English Department of Health's National Strategy for Sexual Health and HIV and the Chief Medical Officer's report, as well as in Making it Count, the 1998 health promotion strategy aimed at reducing HIV incidence among gay men in England [33-36]. The Chief Medical Officer's report recommended that all GUM attendees should be offered a HIV test on their first attendance, and that gay men should be offered HIV testing annually in all health-care settings [34]. Data from the unlinked anonymous GUM survey show that the uptake of HIV testing among gay men attending sentinel GUM clinics increased from 47% (3490/7378) in 1998 to 79% (6865/8774) in 2004 (Fig. 4) [2, 37]. Increased testing has made a considerable contribution to the rise in the number of HIV diagnoses among gay men in the United Kingdom since 1997, but there has also been continued transmission of HIV [38, 39].

Despite the substantial increase in the uptake of HIV testing among gay men attending GUM clinics, one in ten of gay men continue to be diagnosed with HIV with a CD4 cell count <200 cells/mm<sup>3</sup> (Fig. 5)

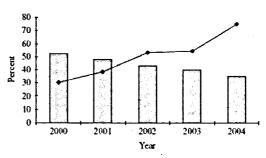


Fig. 4. Percentage of gay men attending 28 sentinel GUM clinics accepting a voluntary confidential HIV test (VCT) and percentage of HIV-infected gay men remaining undiagnosed after clinic visit, United Kingdom: 2000 2004.  $\Box$ , Percent of HIV-infected persons remaining undiagnosed after a clinic visit;  $- \Phi \rightarrow$ , percent of all attendees that accept a VCT. (Source: Unlinked anonymous serosurveys. From: The UK Collaborative Group for HIV and STI Surveillance. Mapping the Issues, HIV and other Sexually Transmitted Infections in the United Kingdom, 2005. London: Health Protection Agency Centre for Infections. November 2005.)

[40, 41]. In addition, in 2004, more than 40 % of gay men with undiagnosed HIV left sentinel GUM clinics remaining unaware of their HIV infection [2]. Late diagnosis of infection may lead to unnecessary morbidity and an increase in mortality within a short period of diagnosis [2]. One suggestion to reduce the number of men being diagnosed late during the course of infection has been the introduction of rapid HIV antibody testing in community settings. However, pilot schemes have reached different conclusions as to whether these services would be acceptable to users [42, 43]. Research also suggests that people are not diagnosed any earlier than in a standard GUM clinic [42]. Understanding why some men continue to present at a very late stage of infection and barriers to HIV testing, perhaps through qualitative research, will be important in reducing morbidity and mortality among HIV-infected gay men in the future. Surveillance will need to be able to monitor the uptake of testing among gay men in non-GUM settings if rapid testing becomes more widespread.

#### Estimates and projections: 1987 onwards

From the outset, it was clear that AIDS would have a major impact on health-care services. Surveillance data were used to predict the future burden [12, 25, 44]. Fortunately, early predictions were never realized. A Department of Health working group estimated

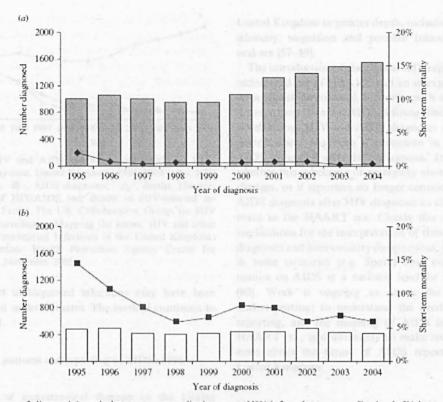


Fig. 5. Pattern of diagnosis\* and short-tern mortality† among HIV-infected gay men, England, Wales and Scotland: 1995–2004. (a) Estimated number of gay men diagnosed 'early' ( $\square$ ); short-tern mortality of gay men diagnosed 'early' ( $\neg \bullet -$ ). (b) Estimated number of gay men diagnosed late ( $-\square -$ ); short-tern mortality of gay men diagnosed late ( $-\square -$ ). (\* Late diagnosis: CD4 count <200 cells/mm<sup>3</sup> within 30 days of diagnosis; earlier diagnosis ≥ 200 cells/mm<sup>3</sup>. † Percentage of gay men known to have died within a year of diagnosis.) (*Source*: CD4 Surveillance Scheme, From: The UK Collaborative Group for HIV and STI Surveillance. Mapping the Issues. HIV and other Sexually Transmitted Infections in the United Kingdom, 2005. London: Health Protection Agency Centre for Infections. November 2005.)

that between 20000 and 50000 people were HIVinfected at the end of 1987, and that 16000-40000 people would develop AIDS over the next 10-15 years [25]. At the time it was still unclear as to whether all those infected with HIV would develop AIDS. A report published a year later revised the original estimates downwards predicting that 8750-17 500 gay men had been infected with HIV in England and Wales by the end of 1988 [44]. Some commentators argued that these were underestimates, with more than 60 000 people, possibly 100 000, having been infected [45].

Estimates of the number of people living with HIV in the United Kingdom have become more sophisticated over time. From 1995 onwards, the 'direct method' was used to calculate the number of people living with HIV in the United Kingdom by categorizing the population into a set of mutually exclusive risk groups of known size, and applying estimates of risk group-specific HIV prevalence to each group [46, 47]. In 2000, this method estimated that there were 17000 HIV-infected gay men living in the United Kingdom of whom 19% were undiagnosed [48]. In 2005, however, a new method, multi-parameter evidence synthesis (MPES) was introduced [49]. Using MPES, an estimated 26 500 HIV-infected gay men were living in the United Kingdom during 2004, of whom 34% were undiagnosed [2]. The distinctive feature of the MPES method is the simultaneous incorporation of multiple sources of information on model parameters and functions [49]. However, the proportion of undiagnosed gay men seems to be high compared to earlier estimates using the direct method especially since the uptake of HIV testing has increased substantially over time without a dramatic rise in HIV incidence [2]. On the other hand, earlier



Fig. 6. HIV and AIDS diagnoses and deaths in HIVinfected gaymen, United Kingdom: 1995–2004. –  $\blacklozenge$  –, HIV diagnoses; –  $\blacksquare$  –, AIDS diagnoses; –  $\bigtriangleup$  –, deaths. (Source: Reports of HIV/AIDS and deaths in HIV-infected individuals. From: The UK Collaborative Group for HIV and STI Surveillance. Mapping the Issues. HIV and other Sexually Transmitted Infections in the United Kingdom: 2005. London: Health Protection Agency Centre for Infections. November 2005.)

reports of undiagnosed infections may have been substantial underestimates. The method continues to be refined.

#### Changing patterns and reporting of AIDS: 1996 onwards

The use of antiretroviral therapy in the United Kingdom began in 1988 with clinical trials using zidovudine (AZT) as monotherapy and was superseded by dual therapy in the early 1990s [50]. However, it was only after the introduction and widespread use of HAART from 1996 onwards that the impact of treatment was seen at a population level. As in many other industrialized countries, HAART led to a large reduction in AIDS cases and deaths in HIV-infected gay men in the United Kingdom and a changing spectrum of AIDS-defining illnesses and causes of death, notably a decline in diseases caused by opportunistic infections (e.g. PCP and KS) and an increase in diseases such as non-Hodgkin's hymphoma (NHL) (Fig. 6) [2, 51–55].

In the context of HAART, AIDS was no longer an unbiased marker of irreversible end-stage disease progression, with fewer AIDS cases and even fewer AIDS reports with complete epidemiological information. To compensate for this information loss, clinicians in England, Wales and Northern Ireland were asked to report new HIV diagnoses as well as initial AIDS- defining illnesses from 2000, to supplement laboratory reporting [56]. The extra information collected on these reports has been used to examine the epidemiology of HIV among gay men in the United Kingdom in greater depth, including trends in ethnicity, migration and possible transmission via oral sex [57-59].

The introduction of the clinical HIV report and the widespread use of HAART had an unexpected effect on national surveillance, however, with a decline in the reporting of initial AIDS-defining illnesses. While simultaneous HIV and AIDS diagnoses are still reported, there has been a reduction in reports of AIDS occurring after HIV diagnosis. It is unclear whether this is because of ambiguity about reporting changes, or if reporters no longer consider an initial AIDS diagnosis after HIV diagnosis as clinically relevant in the HAART era. Clearly this change has implications for the interpretation of trends in AIDS diagnoses and inter-country comparisons, particularly as some countries (e.g. Spain) only collect information on AIDS at a national level for the present [60]. Work is ongoing to assess the extent of underreporting; to understand the need for AIDS reporting, and the meaning of AIDS in the post-HAART era; and ultimately to make recommendations about the future of AIDS reporting in the United Kingdom.

#### Mortality over 25 years - the impact of HAART

Information on deaths in patients with AIDS has been collected since the start of the epidemic. However, once the HIV antibody test became widely available in 1984, it became clear that deaths were occurring in HIV-infected individuals without AIDS [61, 62]. The AIDS report form was modified to include deaths in HIV-infected individuals who had not progressed to AIDS [61], and when electronic mortality records were made available from 1993 onwards, all deaths in those aged <60 years were routinely 'matched' to HIV/AIDS reports to capture 'non-AIDS' deaths and those where 'HIV/AIDS' was not stated on the death certificate perhaps because of the stigma attached to the infection and/or sexual risk behaviours [63]. With an ageing cohort of HIV-infected gay men-in 2004, 28% (5087) of gay men accessing HIV-related services were aged  $\geq$ 45 years [2]-the age cut-off of 60 years requires upward revision to ensure completeness of mortality data.

The impact of HIV on premature mortality among younger men and the impact of HAART has been clearly demonstrated using surveillance data, with the crude age-specific mortality rate for HIV rising from 0.9/100 000 men in 1985 to a peak of 10-3/100 000 in 1994 (accounting for 9.3% of deaths in men aged 15-44 years) [64]. In 1997, the 'all cause' mortality rate for MSM was 41/100 MSM, falling sharply to 1.0/100 MSM in 2003 [65]. While non-specific 'pneumonia' has been the most common cause of death in HIV-infected gay men in the pre- (35%) and post- (19%) HAART eras, of those who died during 2002-2004, the principal cause of death was cardiovascular disease in 12%, NHL in 10% and PCP in 9% [66]. There is little evidence as yet, of a significant increase in deaths from untreatable, multidrugresistant HIV infections in the cohort of gay men who have been on HAART since the mid-1990s [67]. However, existing data collection may not be sensitive enough to identify these deaths at a national level as information on antiretroviral therapies or drug resistance at death is not routinely collected. Improvements in the collection of this information may therefore be beneficial in monitoring future mortality trends and clinicians should remain vigilant.

# Gay men living with diagnosed HIV infection: 1996 onwards

By the mid-1990s surveillance of HIV/AIDS in the United Kingdom was evolving to encompass improvements in treatment and care and to meet the growing data needs of HIV service providers and financiers. An annual Survey of Prevalent HIV Infections Diagnosed (SOPHID) was introduced in England, Wales and Northern Ireland in 1995 to monitor the number of people accessing treatment and care through the (national) health service [68]. In Scotland, equivalent information is collected through a surveillance system involving the collection of CD4 count data [69]. Improvements in survival and continued diagnoses among gay men have led to increasing numbers living with diagnosed HIV; 17932 gay men were accessing services in 2004 compared with 11846 in 2000 (Fig. 7) [2]. Surveillance data are used to allocate funding for HIV care, and at an estimated average cost of £15000 per annum for each HIVdiagnosed person accessing HIV services, the implications for funding are evident as well as the advantage of accurate figures [52]. However, the use of surveillance data for allocating funds has its limitations since the data will not fully reflect the costs of treatment and levels of clinical activity as the system was not set up to capture this level of detail. Future estimates may be enhanced by

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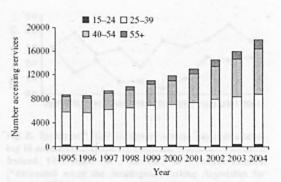


Fig. 7. HIV-infected gay men accessing treatment and care services by age group, United Kingdom: 1995–2004. (Source: SOPHID and CD4 Surveillance Scheme, From: The UK Collaborative Group for HIV and STI Surveillance. Mapping the Issues. HIV and other Sexually Transmitted Infections in the United Kingdom, 2005. London: Health Protection Agency Centre for Infections. November 2005.)

supplementing surveillance data with data from other sources.

# STIs in HIV-infected gay men in the post-HAART era

Historically it has been purported that population level increases in other STIs, particularly gonorrhoea. were indicative of increased HIV transmission. While analyses were always subject to ecological fallacy, they are now further complicated by a high proportion of STI diagnoses occurring in diagnosed HIV-infected gay men post-HAART. Enhanced surveillance of outbreaks of syphilis and LGV collect information on HIV status, as does the sentinel Gonococcal Resistance to Antimicrobials Surveillance Programme (GRASP) [2, 70-72]. Half (785/1583) of the gay men diagnosed with syphilis in London in 2004 were known to be HIV positive [2]. Similarly, 81 % (119/147) of gay men diagnosed with LGV in the United Kingdom in 2004 and 32% (123/381) of those with gonorrhoea were HIV positive [2]. There have also been recent reports of outbreaks of shigella, hepatitis A and hepatitis C among known HIV-positive gay men [73-75]. Behavioural surveillance since 1998 shows that 'serosorting'- where men select partners on the basis of their HIV status-is occurring, with HIV-positive men seeking HIV-positive (i.e. seroconcordant) partners [5, 76-79]. In view of these behaviours, our interpretation of STI trends in relation to HIV transmission needs to be re-evaluated.

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An additional impact of the acquisition of STIs by a significant number of diagnosed HIV-infected MSM is that diagnosed, and therefore total (diagnosed and undiagnosed), HIV prevalence can no longer be accurately measured by the unlinked anonymous GUM survey. This is because since the re-emergence of syphilis [80, 81], sexually active, diagnosed HIVpositive MSM have been encouraged to regularly test for syphilis. In the unlinked anonymous survey, residual blood from syphilis scrology is irreversibly unlinked from patient identifiable information and then tested for HIV [29]. As a consequence, the diagnosed HIV prevalence as measured by the survey has become substantially inflated. To overcome this source of bias, only undiagnosed prevalence has been reported in recent years [2].

# Continuing transmission of HIV in the post-HAART era: 1996–2004

Prior to HAART, back-calculation analyses from AIDS cases indicated that HIV incidence among gay men in the United Kingdom peaked in 1983 (when there were about 6000 infections), rapidly decreased and then remained stable [82]. Gonorrhoea incidence has declined dramatically [83]. There was no further reduction in HIV incidence during the late 1980s and mid-1990s [31, 84, 85]. Incidence was about 4/100 person-years among gay men attending four GUM clinics in London between 1988 and 1994, with a higher incidence (9/100 person-years) among younger (aged < 30 years) men [84].

In the post-HAART era, gay men still remain the group most at risk of acquiring HIV within the United Kingdom, with substantial evidence for continuing HIV transmission [2]. The use of HAART meant the end of back-calculation methods using AIDS cases to determine HIV incidence, as the natural course of infection had been altered. Since 1998, a laboratory technique the Serological Testing Algorithm for Recent HIV Seroconversion (STARHS) has been developed and applied using the unlinked anonymous technique (including retrospectively) to routine syphilis serology specimens from gay men attending the 16 GUM clinics in the unlinked anonymous survey in England, Wales and Northern Ireland [86-88]. Currently, it is only validated to be used for subtype B HIV infections. Annual HIV incidence in this sample of gay men has remained constant, varying between 2 and 3-5/100 person-years between 1995 and 2004, with no statistically significant trends over



Fig. 8. Estimated\* HIV incidence\* among gay men attending 16 sentinel GUM clinics, England, Wales and Northern Ireland: 1995-2004. - ◆ -, London; - ■ -, outside London (\* estimated using the Serological Testing Algorithm for Recent HIV Seroconversion (STARHS); † trend not significant]. (Source: Unlinked anonymous serosurvey. From: The UK Collaborative Group for HIV and STI Surveillance. Mapping the Issues. HIV and other Sexually Transmitted Infections in the United Kingdom, 2005. London: Health Protection Agency Centre for Infections. November 2005.)

time (Fig. 8) [87, 88]. In comparison to the early 1990s, however, incidence seems to be higher among older gay men (in 2004, highest at 4.5/100 personyears in men aged 35-44 years) [2]. This differential in HIV incidence between older and younger gay men has also been observed in The Netherlands [89]. There are future plans to test every newly diagnosed infection among gay men to see whether it is recent or not, and this will allow further analyses and monitoring of incidence in subtype B infections.

#### Monitoring transmitted drug resistance: 2001 onwards

The emergence of drug-resistant strains of HIV and transmission of these strains (transmitted resistance) has implications for the initiation of therapy, necessitating the use of resistance assays prior to treatment [90], and therapy options. The United Kingdom's HIV drug resistance database, established in 2001, collects information from resistance tests carried out during routine clinical care [90, 91]. Using these data it has been shown that up until 2002, the prevalence of transmitted *resistance* (all behavioural risk groups combined) increased over time, with the largest increase observed for non-nucleoside reverse transcriptase inhibitors, fitting in with UK prescribing practices [91]. Between 2002 and 2004, however, the prevalence of transmitted resistance declined [92].

#### CONCLUSION

Public health surveillance of HIV among gay men in the United Kingdom has come a long way over the last 25 years providing some of the most comprehensive surveillance data in the world. In this review, we have examined how national surveillance systems have evolved in response to the changing epidemiology of HIV/AIDS among gay men in the United Kingdom as well as advances in laboratory techniques and medical treatments.

There are several key challenges for HIV surveillance among gay men in the United Kingdom in the future. First, improvements in the monitoring of HIV incidence among gay men are needed to determine transmission patterns by age, geography and over time to better inform prevention services. This will involve expanding the coverage of incidence testing to all HIV diagnoses, linking demographic and clinical information to these samples and developing tests for non-B subtype incident infections. To further understand the behaviours that underlie the continuing transmission of HIV among gay men, behavioural research, such as the INSIGHT study, will need to investigate factors leading to seroconversion [93].

At the other end of the clinical spectrum, continued and further monitoring of the uptake of HIV testing and late-stage disease, including the role of AIDS surveillance in the post-HAART era will be important in reducing morbidity and mortality among HIVinfected gay men in the future. This should be supplemented by qualitative research to help us understand why some men continue to present at a very late stage of infection despite efforts to encourage routine HIV testing. Finally, the transmission of STIs among networks of HIV-positive gay men in the United Kingdom has created a need for enhanced surveillance systems collecting information on STI diagnoses and HIV status among gay men [94]. These have helped us understand the contribution of HIVpositive gay men to the recent increase in STIs but further work needs to be done to determine the implications for HIV transmission to HIV-negative gay men and the interpretation of STI surveillance data.

What is clear is that as the epidemiology of HIV and other STIs continues to evolve among gay men in the United Kingdom, our surveillance systems will need to further adapt, as they have done in the past, so that information can be effectively used to inform health policy in the years to come.

#### DECLARATION OF INTEREST

None.

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## 2.1 Introduction

This chapter sets the scene for the thesis, providing the reader with a broad background in public health surveillance, HIV surveillance in the UK, and the differences between surveillance and epidemiologic research. It also outlines the challenges associated with using surveillance data for epidemiologic research specifically in relation to the changing patterns of HIV incidence and prevalence among men who have sex with men (MSM) in the UK. These challenges are then addressed further in chapters 3, 4 and 5.

The literature review '*HIV* and other sexually transmitted infections among MSM in the UK: two decades of public health surveillance' which accompanies the commentary which follows, was a timely addition to the published literature as its publication coincided with the 25<sup>th</sup> anniversary of the first report of AIDS in the UK (Dougan *et al.*, 2007a; Du Bois *et al.*, 1981). It was also an important addition, as it was the first paper to comprehensively describe the surveillance of HIV among MSM in the UK and its evolution over the past two decades. The UK has some of the best HIV surveillance systems in the world, so this paper may not only be of interest to those working in this area in the UK, but also internationally.

## 2.2 What is surveillance?

In this section I detail the definition and scope of surveillance and how this has changed over time, the goals and aims of surveillance systems and how these differ depending on the infection or disease under surveillance, and finally, the different surveillance data collection methods, their attributes and the necessary trade-offs.

## 2.2.1 Definition and scope

In 1963, Alexander Langmuir defined public health surveillance as:

"the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data" (Langmuir, 1963).

Langmuir, who played a pivotal role in the development of public health surveillance while Chief Epidemiologist at the United States' (US) Centers for Disease Control (CDC), considered William Farr the father of disease surveillance (Koplan & Thacker, 2001; Langmuir, 1976). Farr had collected and analysed mortality statistics while working at the registrar general's office in London during the mid-19<sup>th</sup> Century, importantly taking public health action based on his findings (Eyler, 2002; Koplan & Thacker, 2001; Langmuir, 1976). It was Langmuir and colleagues during the 1940s. however, who shifted the focus of surveillance to the occurrence of specific diseases in populations, rather than just individuals (Thacker & Gregg, 1996). Prior to this, surveillance had been restricted to monitoring contacts of people with serious infectious diseases so that they could be promptly isolated and treated (Thacker, 2000). For example, in England and Wales, statutory notification of infectious diseases (smallpox, cholera, diphtheria, typhus, relapsing fever and scarlet fever) by the head of the household, and later the medical practitioner, became mandatory in 1891 in London and elsewhere in 1899 (McCormick, 1993). More infectious diseases were added to this list over time with the purpose of identifying and preventing further spread (HPA, 2007a; McCormick, 1993).

The first population level surveillance systems were archival, designed to document trends in disease occurrence. Over time however, they evolved to provide epidemiologically important information needed for the prevention and control of diseases. The Langmuir definition was adapted to incorporate this need for action and the use of data to inform prevention and control (CDC, 1988; Stoto, 2003). The current formal definition used by the United States' CDC and broadly adopted elsewhere is:

"Public health surveillance is the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know. The final link in the surveillance chain is the application of these data to prevention and control. A surveillance system includes a functional capacity for data collection, analysis, and dissemination linked to public health programs" (CDC, 1988; CDC, 2001).

The scope of surveillance has also evolved over time, paralleling developments in our understanding of health determinants and the epidemiologic transition from infectious to chronic diseases (Omran, 1971; Omran, 1977; McMichael, 2002; Stoto, 2003). As well as extending surveillance to encompass population-level data, Langmuir and colleagues began to widen the scope in the 1940s and since then it has most notably expanded to encompass chronic diseases such as cancer and diabetes (Thacker *et al.*, 1995). During the 1980s and 1990s the extent of surveillance continued to grow in industrialised countries, covering the areas of environmental hazards and illness (e.g. Thacker *et al.*, 1996), occupational health (e.g. Baker, 1989), injuries (e.g. Graitcer, 1988), health behaviours (e.g. Nardone *et* 

*al.*, 1997), and maternal and child health (e.g. Wright *et al.*, 2007). More recently, in the 21<sup>st</sup> Century, there have been intensified surveillance programmes for medical errors and iatrogenic injuries and since 9/11, on detecting outbreaks associated with bioterrorist attacks (see for example, Hewitt *et al.*, 2006; Panagiotakos *et al.*, 2007; Reis *et al.*, 2007; Stoto *et al.*, 2001).

## 2.2.2 Goals and aims

The following broad goals and aims for surveillance have been suggested (Meriwether, 1996):

- To recognise cases or clusters of cases to trigger interventions to prevent transmission or to reduce morbidity and mortality (includes the special case in which surveillance at the national level is to recognise regional clusters);
- To assess the public health impact of a health event or determinant and measure trends;
- To demonstrate the need for public health intervention programmes and resources, and allocate resources;
- To monitor effectiveness of prevention and control measures and intervention strategies;
- To identify high-risk population groups or geographic areas and to target interventions and guide analytic studies;
- To develop hypotheses leading to analytic studies about risk factors for disease causation, propagation or progression.

Clearly, specific goals and aims of surveillance systems vary at different levels of the health system; for different diseases and health outcomes; at different stages of epidemics; and with different levels of knowledge about the natural history of disease, risk factors, and epidemiology. At the local level, the use of surveillance data to trigger investigation and control activities predominates for infectious diseases and environmental hazards (CDC, 1990; Meriwether, 1996), as well as the detection of newly emerging conditions (for example *Clostridium difficile* as a hospital-acquired infection) (Baker, 1989). In contrast, monitoring for trends usually takes precedence at the national level where the total number of cases will be much larger (for example, gastrointestinal outbreaks such as *E. coli*). Similarly, at the beginning of an infectious disease epidemic or incident involving an environmental hazard, active case finding of infected individuals will be crucial in an attempt to limit spread and determine the size of the outbreak (for example, SARS (Schrag *et al.*, 2004) and Avian flu (HPA, 2007b; WHO, 2007), and the Polonium-210 incident in London in 2006 (HPA, 2007c)). However, once an infection becomes endemic and there are large numbers of cases, monitoring trends, elucidating environmental risk factors and their interactions, and measuring the effectiveness of specific interventions becomes more important.

The goals of surveillance for a particular infection, disease or behaviour should be clearly articulated but not remain static. They need to be reviewed periodically in light of evolving circumstances, including epidemiologic changes (e.g. incidence rates) because of variations in behaviours, economic or social circumstances, changes in the natural history of disease, changes in the health care system and societal costs, and changes in the availability of interventions and resources (CDC, 1990). For example, the surveillance of healthcare associated infections has intensified over the past few years with an increase in methicillin-resistant *Staphylococcus aureus* (MRSA) and the emergence of *Clostridium difficile*, increased funding and new interventions (HPA, 2006c). To adapt to these changing goals therefore, the surveillance system must have some degree of flexibility.

## 2.2.3 Methods and data sources

Resources are often scarce, particularly in publicly funded health care settings such as the National Health Service (NHS), and so data should be collected in the least labour-intensive and cost-effective way possible (CDC, 1990). Additionally, the completion of surveillance data and reports are often not a priority for health care workers. Nevertheless, the data collection methods should maximise the attributes (e.g. timeliness, sensitivity) of greatest importance for the surveillance system (CDC, 1988).

Just as the scope of surveillance has evolved over time, so the methods used to capture data have become multi-faceted and more sophisticated. The traditional surveillance method is case reporting by clinicians, whereby clinicians submit a hand-completed paper report on the case. In England and Wales for example, doctors have been obliged to notify the "Proper Officer" of the Local Authority of suspected cases of certain infectious diseases for over a hundred years (for example smallpox, cholera, diphtheria, typhus, relapsing fever and scarlet fever) (HPA, 2007a; McCormick, 1993). Other countries have similar systems (Wetterhall, 1996). Much of the evolution in surveillance methods can be accredited to advancements in technologies, particularly, in laboratory testing algorithms and record management systems.

New laboratory testing algorithms have enabled 'new' types of disease surveillance. For example, the introduction of the Serological Testing Algorithm for Recent HIV Infections (STARHS) in the early 1990s has allowed the measurement of HIV incidence among specific sub-populations (CDC, 2001; Janssen *et al.*, 1998; Murphy *et al.*, 2001; Murphy *et al.*, 2004). Coupled with appropriate information on

the population testing negative for HIV, incidence in a defined population can be directly estimated. Previously, HIV incidence had to be retrospectively modelled using AIDS cases, using the 'back-calculation method' (Day et al., 1990). Similarly, advances in computing technology and record management systems have enabled the development of syndromic surveillance. Rather than focusing on confirmed diagnoses (as in case reporting), syndromic surveillance is concerned with the frequency that a pre-identified sets of symptoms occurs within health care settings (CDC, 2004; Hurt-Mullen & Coberly, 2005; Doroshenko et al., 2005; Berger et al., 2006; Bravata et al., 2004). In the UK, syndromic surveillance has historically been used to detect outbreaks of food poisoning and influenza (HPA, 2008a; HPA, 2008b). To operate in real-time, for example to detect deliberate releases such as anthrax, this requires more advanced, computerised systems (CDC, 2004; Hurt-Mullen & Coberly, 2005; Doroshenko et al., 2005; Berger et al., 2006; Bravata et al., 2004; Blanton et al., 2006). Behavioural surveillance has also become increasingly common, with the recognition that gualitative research findings can significantly aid the interpretation of quantitative research and help to focus interventions (McGarrigle et al., 2002).

Today in the UK, the progression of surveillance methods and improvements in data quality are typically hindered by a lack of good computing structures and support within the NHS. In theory, much of the information required by national surveillance systems is being collected by health care workers as part of the diagnostic and treatment processes. But this information is not always entered into a single patient record, on a single database from which information can be easily captured. The government's *Connecting for Health* project, which aims to deliver new, integrated IT systems to the NHS to help modernise services, includes the provision of an electronic individual patient record (Department of Health, 2007). Once up and

running, this should help to improve the ease, timeliness and cost-effectiveness of surveillance data compilation, removing the need for people to complete paper forms (Backer *et al.*, 2001; Effler *et al.*, 1999; Panackal *et al.*, 2002; Wurtz & Cameron, 2005). There is however, a lot of scepticism in the media and elsewhere about electronic patient records, around their utility, the maintenance of patient confidentiality, the escalating project costs, and the extended timeline required to complete the project (BBC, 2006a).

## 2.2.4 A need for compromise

Surveillance systems are typically evaluated in terms of their simplicity, flexibility, acceptability, validity, reliability, sensitivity, specificity, representativeness and timeliness (table 2.1) (Birkhead *et al.*, 1991; Doyle *et al.*, 2002; CDC, 1988; Hall *et al.*, 2006; Jajosky & Groseclose, 2004; Jansson *et al.*, 2004; Kirk *et al.*, 1999; Kleinman

Abrams, 2006; Klevens et al., 2001; Samaan et al., 2005; Sprinson et al., 2006; Ward

*et al.*, 2005; Vogt *et al.*, 2006). Again, the importance of any of these in a surveillance system relates to its purposes and objectives. Trade-offs are usually necessary between attributes. Deciding which attributes are to be sacrificed depends on the goals and aims of the surveillance system.

In an infectious disease outbreak or deliberate release, for example, timeliness may be more important than completeness and exactitude in both data collection and analyses so that appropriate control measures can be quickly put in place (Birkhead *et al.*, 1991; Giesecke, 1994; Jajosky & Groseclose, 2004; Ward *et al.*, 2005). On the other hand, because chronic diseases operate on a much longer timescale than infectious diseases, a speedy response is not as essential, reflected by the

surveillance methodology employed (Stoto, 2003). Breast cancer for example, is caused by exposure to environmental factors over many years, and/or genetic factors inherited at birth (McPherson *et al.*, 2000). Cancer registries aim to gather as much information on every breast cancer case over time, and conduct active follow up to achieve this (IARC, 1991). The focus is on completeness and accuracy rather than timeliness, with the output being reported in statistical terms and used to project the future burden of disease and ultimately health care costs. In 2005, cancer statistics were being published for 2002 (Parkin *et al.*, 2002), whereas data from gastrointestinal outbreaks are available almost immediately (HPA, 2007).

Attribute	Description
Simplicity	Relates to the structure of the surveillance system and ease of operation. Simplicity may limit the function of the surveillance system, but may improve performance in other respects. It is difficult to achieve, and is very much dependent on the structure of the healthcare system. In comparison with other healthcare systems, the NHS is relatively simple in its organisational and reporting structures, and this has aided public health surveillance of HIV and other diseases (Imrie <i>et al.</i> 2006).
Flexibility	Elexibility is important within surveillance systems, so that systems can adapt to changing epidemiology and healthcare system structures. However, too much flexibility can interfere with time trend analyses as changes in the surveillance system can become confused with changes in the disease itself. For example clinical reporting of HIV was introduced in England, Wales and Northern Ireland. This additional route of obtaining information on HIV diagnoses has had some impact on the numbers of HIV diagnoses. In terms of MSM, this is discussed in my paper on what has caused the increase in HIV diagnoses among MSM in the UK (Dougan <i>et al.</i> 2007b).
Validity	This is the degree to which a system measures what it purports to measure
Reliability	This relates to replicability.
Sensitivity	Technically, sensitivity is the proportion of individuals with the target condition who are identified by the surveillance system. The completeness of a surveillance system is a common measure of sensitivity. Surveillance systems with low sensitivity can still be useful in monitoring trends, as long as sensitivity and specificity do not change. Sensitivity can also refer to a surveillance system's ability to detect epidemics. Matching studies with other HIV datasets (e.g. UK CHIC) show that the completeness of HIV diagnosis reporting in the UK is well completed (unpublished data, Dougan (2005)).
Specificity	Specific case definitions are more narrowly drawn to decrease the chance that individuals who do not have the condition are included. It is the proportion of individuals who are negative (do not have infection/disease) who are correctly identified as negative (not having disease). Requiring laboratory confirmation for instance increases specificity. Only laboratory confirmed cases of HIV are counted as HIV cases in the UK.
Representativeness	In the UK, the HIV surveillance systems - with the exception of the unlinked anonymous serosurveys - aim to collect data on everyone diagnosed with HIV. We presume therefore, that the data from these is fully representative of those who are diagnosed.

Table 2.1: Desired attrib	outes of surveillance	systems
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Source: Adapted from Meriwether, 1996.

## 2.3 How does surveillance differ from research?

Surveillance should lead to, but not be confused with, research (Meriwether, 1996). However, the boundary is sometimes blurred (CDC, 1999). Making the distinction between public health surveillance and research is important for a number of reasons. These include fully understanding the utility of surveillance data, the strengths and limitations of epidemiologic findings based on surveillance data, interpreting the data and drawing the correct conclusions, and importantly, the protection of individual patient rights.

The major difference between public health surveillance and research is intent (CDC, 1999). According to US regulations, "research means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalisable knowledge" (CDC, 1999). Its primary intent is to provide generalisable knowledge. In contrast, while undertaking public health surveillance may result in gaining generalisable knowledge, this is not its primary intent. The main purpose of surveillance is to contribute to disease control and prevention and to improve health, or to improve a public health programme or service (CDC, 1999). Any knowledge gained has to directly benefit the individuals or communities involved in surveillance.

Another difference between surveillance and research is that research is typically hypothesis driven, with information collected to prove or refute the null hypothesis. On the other hand, the starting point for epidemiological analyses of surveillance data, are the data themselves. These data are often more limited than those collected during research projects, as resources for surveillance are usually scarce, and so surveillance data should be collected in the least labour-intensive manner

and cost-effective way possible (Meriwether, 1996). One way to reduce person-time resource at a reporting level is to limit the number of variables collected. Surveillance systems therefore, tend to collect fewer variables than research projects. This may of course, limit analyses but does hopefully ensure that the most useful data items for the primary public health purpose are collected.

## 2.4 Public health surveillance of HIV

## 2.4.1 Special features of HIV surveillance

The general methods used for public health surveillance of HIV/AIDS are similar to those for other diseases, but there are particular features of HIV/AIDS that make surveillance (and epidemiologic research) in this area more difficult (Chin, 2007; HPA, 2007d).

- Undiagnosed cases. Initial infection may be asymptomatic: individuals with HIV may be asymptomatic for several years and may transmit infection before their clinical disease has become apparent. For example, in the UK, the average time between HIV infection and diagnosis is estimated to be six years and one-in-ten MSM still present at a late stage of diagnosis (<200 CD4 cells/mm<sup>3</sup>), reducing treatment efficacy (Chadborn *et al.*, 2005; CMO, 2003; UK Collaborative Group for HIV and STI Surveillance, 2006). To get a clear picture of HIV in the population therefore, you cannot just rely on counting the number of individuals who are diagnosed with HIV. A measure of undiagnosed HIV is required as well (Gill *et al.*, 1989; Nicoll *et al.*, 2000).
- Heterogeneity in transmission patterns and prevalence of infection: differences may be found between sub-populations (e.g. MSM, injecting drug users), as well as

at the general population level (by geography, age, sex, exposure category and behaviour).

- Importance of 'core groups': these are groups or sub-populations experiencing a disproportionate amount of transmission, usually because of 'high-risk' behaviours. This includes MSM, since there is a high risk associated with unprotected anal intercourse, with a lesser risk associated with unprotected oral sex (Mastro & Kitayaporn, 1998; Robinson & Evans, 1999; Rothenburg *et al.*, 1998). Core groups are often marginalised, and this can make surveillance and the interpretation and dissemination of surveillance data a highly sensitive area.
- Stigma and discrimination associated with both HIV and the modes of acquisition of the virus (e.g. anal sex, injecting drug use) (UNAIDS, 2002; UNAIDS, 2005). The stigma and discrimination surrounding HIV infection, means that the maintenance of patient confidentiality is paramount when undertaking surveillance of the infection, and this has been recognised since the beginning of the epidemic (Berridge, 1996; Dougan *et al.*, 2007a; Verity & Nicoll, 2002). To protect patient confidentiality there is strict adherence to Caldicott Guidelines (Department of Health, 1997). In addition, soundex codes are used instead of surnames (Mortimer & Salathiel, 1995). (A soundex code is an alphanumeric code (one letter followed by three digits) of an individual's surname. It is not unique to the surname, but in combination with other variables such as sex and date of birth, can be used to identify duplicate records of the same individual (Mortimer & Salathiel, 1995)).
- Importance of capturing **behavioural data**: to determine groups at potential risk, to help explain why some groups are disproportionately affected and to assist in

developing effective prevention initiatives (McGarrigle *et al.*, 2002). Behavioural data have been crucial in explaining the trends in HIV among MSM in the UK (Dodds *et al.*, 2000; Dodds *et al.*, 2004; Elford *et al.*, 2004; Elford *et al.*, 2005; Hart & Williamson, 2005; Nardone *et al.*, 1997; Weber *et al.*, 1986; Weller *et al.*, 1984; Williamson & Hart, 2004). Data from active behavioural surveillance systems and surveys are used to better understand sexual behaviours and target health promotion in the UK (Hickson *et al.*, 2002).

- The significant effect of treatment: where therapies have been available, AIDS and AIDS-related deaths have decreased substantially (Aalen *et al.*, 1999; Mocroft *et al.*, 2000). The 'treatment effect' has had implications for surveillance and epidemiologic methods, notably a decrease in the number of AIDS reports and associated information and the need to come up with new methods to estimate HIV incidence (e.g. Janssen *et al.*, 1998; Murphy *et al.*, 2004).
- Highly 'political' nature of HIV/AIDS: STIs in general, and HIV in particular, have attracted strong negative reactions often based on moral and religious views. There is a widespread view of "innocent" (e.g. those infected by mother-to-child transmission, contaminated factor VIII product or blood transfusion) or "guilty" (e.g. those infected through sexual or injecting routes). This can result in blaming others. Recent criminal cases in the UK have exacerbated the sensitivity in this area. In addition, communities and/or countries may deny that HIV is present, despite contrary evidence from surveillance. Whilst in no way doing justice to this complex area, I hope that this shows that the reporting of HIV surveillance data is a sensitive area.

## 2.4.2 Purpose of HIV surveillance in the UK

The broad goals and aims of HIV surveillance in the UK, as outlined by the Health Protection Agency, are as follows (HPA, 2007d):

- To determine and describe the geographic, demographic and risk factor distributions of the HIV positive population(s).
- To provide data and analyses for planning and targeting preventive activities (e.g. health promotion) aimed at reducing risk behaviours and interrupting transmission of HIV, and to evaluate their impact.
- To monitor the uptake of therapies and to detect the emergence of drug resistance to antiretroviral therapies, providing data to inform current and future healthcare planning.
- To estimate the present and future impact of HIV sequelae on various groups in the population and to project and monitor the effects of interventions and treatments on these estimates.

## 2.4.3 HIV surveillance methods in the UK

My paper on the evolution of HIV surveillance among MSM in the UK over the past two decades gives historical details on the UK's HIV surveillance systems and how they have evolved in response to medical and technological advances (Dougan *et al.*, 2007a). Here, I briefly describe the purposes and data collection methods of the main HIV surveillance systems in the UK. Elsewhere in this thesis, in both published papers and associated commentaries, I expand in more detail on specific aspects of these surveillance systems, including their strengths and weaknesses, and the use of the data for epidemiologic research, including in my own research.

## 2.4.3.1 Diagnosed HIV infections

There are three main HIV surveillance systems collecting information on diagnosed HIV infections among MSM in the UK.

## Reports of new HIV diagnoses

The Health Protection Agency and Health Protection Scotland receive voluntary confidential reports of new HIV diagnoses in England, Wales and Northern Ireland (E,W&NI) and Scotland, respectively. In both E,W&NI and Scotland, AIDS and death reports have been received since the beginning of the recognised epidemic (1982) and laboratory reports of HIV diagnoses since the introduction of HIV antibody testing (1985). Additionally, in E,W&NI, clinical reporting was introduced in 2000 because of the fall in the number of AIDS cases (Dougan *et al.*, 2007a). Data on probable route of infection (e.g. sex between men, injecting drug use) are collected on all reports. Information on probable country of infection is also collected but, where information is missing, this is only followed up for those infected through heterosexual intercourse (Gilbart *et al.*, 2005). Country of birth has been included in clinician reports of new HIV diagnoses since 2000.

## Number of HIV positive people accessing treatment and care services

In E,W&NI, the Survey of Prevalent HIV Infections Diagnosed (SOPHID) provides an estimate of the number of individuals living with diagnosed HIV infection (HPA, 2007e; Molesworth, 1997; Rice *et al.*, 2005). The cross-sectional survey is undertaken annually for the whole of E,W&NI and twice annually in London. It aims to include every individual with diagnosed HIV infection who has attended for HIV treatment or care at NHS services during a calendar year. Data collected include gender, age, ethnicity, probable route of infection, use of antiretroviral therapy (ART), CD4 count when last seen, and areas of residence and treatment.

## CD4 cell counts in HIV positive people

The CD4 surveillance schemes monitor trends in immunosuppression associated with HIV infection by collecting longitudinal data on CD4 T-lymphocyte (CD4 cell) counts performed by laboratories in England and Wales (Gupta *et al.*, 2000), and in Scotland (CD4 Surveillance Collaborative Group, 1992). In England and Wales, longitudinal data on CD4 cell counts are 'matched' to reports of HIV diagnoses to obtain further demographic and epidemiologic information. In Scotland, this survey provides equivalent data to the SOPHID survey in E,W&NI, on the number of people accessing HIV-related treatment and care services (CD4 Surveillance Collaborative Group, 1992).

## 2.3.3.2 Undiagnosed HIV infections

As previously mentioned, HIV positive individuals may be asymptomatic for a long period. To get a complete picture of a HIV epidemic therefore, it is necessary to have some measure of *undiagnosed* HIV infection.

## Unlinked anonymous genito-urinary medicine (GUM) survey

The UK's unlinked anonymous (UA) programmes measure the prevalence of undiagnosed HIV infection in different population sub-groups (Gill *et al.*, 1989; Nicoll *et al.*, 2000). The Genito-Urinary Medicine (GUM) clinic survey uses residual blood taken for syphilis serology and provides information on undiagnosed HIV prevalence among MSM attending 28 GUM clinics (seven in London, nine elsewhere in E,W&NI, and 12 in Scotland), as well as information on co-infection with acute STIs and the uptake of voluntary confidential testing (VCT). All samples have patient identifying details irreversibly removed before testing for HIV infection.

The UA methodology is the most complicated of all of the surveillance systems. It is

detailed pictorially in the published paper that accompanies this commentary (see figure 3 in Dougan *et al.*, 2007a).

# 2.5 Opportunities and challenges faced using surveillance data for this thesis

In this thesis, I focus specifically on the opportunities and challenges in the context of monitoring trends in HIV incidence and prevalence among MSM in the UK. These relate to examining trends over time, conducting meaningful geographic analyses, capturing the diversity associated with ethnicity and migration, and co-infection of HIV positive MSM with other sexually transmitted infections (STIs).

## 2.5.1 Opportunities

The UK's HIV surveillance systems collect a large amount of high quality data because of the sustained investment in the systems and the active follow-up of cases to ascertain missing, or check discrepant, information (Dougan *et al.*, 2007a; Gilbart *et al.*, 2005). For these reasons, and aided by the structure of the NHS (Imrie *et al.*, 2006), the UK's HIV surveillance systems are some of the most comprehensive and sophisticated in the world. Since these systems have been running for more than two decades now, there is also a wealth of historic data which can be used to put current trends in perspective.

Undertaking secondary analysis of existing surveillance data is a cost effective way of gaining an insight into epidemiological trends. Analyses can be used to identify areas for further primary research, and inform and support funding proposals (e.g. BME MSM (Elford, 2006)). Aside from the time taken to analyse, interpret and report the data, secondary analysis of existing surveillance data places no additional burden on public health surveillance sources (e.g. clinicians, health advisors, virologists who report cases) and programmes.

## 2.5.2 Challenges

There are however, also challenges encountered when using surveillance data for research purposes. These may hinder and limit data analyses, and the conclusions that can be drawn. To overcome these challenges and avoid erroneous interpretations of the data, an in-depth understanding is required of how the surveillance system works and has evolved; the epidemiology of HIV/AIDS and how this has changed over time; and the effects of public health initiatives (e.g. the introduction of screening or promotion of testing) and advances in treatment. Broadly speaking, the challenges of using surveillance data for research addressed in this thesis relate to the changing epidemiology of HIV and STIs among MSM, as a result of progress in the treatment of HIV infection and changes in the MSM population over time.

## 2.5.3 My research

## 2.5.3.1 Geography and time trends

The first challenge, addressed in detail in chapter 3, is related to examining geographic differences in HIV time trends among MSM in the UK. Robust epidemiological data on HIV rates among MSM are currently only available for London, Scotland, and the "rest of the UK" (Macdonald *et al.*, 2004). However, within these geographic areas, and particularly within the "rest of the UK", there is great diversity in the distribution of MSM. Cities such as Manchester and Brighton for example, have a large population of MSM and high levels of HIV infection reflecting this. Unfortunately however, we do not have robust estimates for the

denominator (i.e. the population of *all* MSM within these geographic areas). So, despite having detailed surveillance data on the number of MSM being diagnosed, and living with diagnosed HIV infection, detailed information on HIV rates for MSM cannot be produced. Having information on rates rather than absolute numbers alone is essential in accurately monitoring HIV levels, by putting counts in context and quantifying the "risk" of disease in a defined population (Chin, 2007).

## 2.5.3.2 Ethnicity and migration

Another challenge tackled in this thesis (chapter 4) is the adequate monitoring of the changing MSM population in terms of ethnicity and migration, using surveillance methods which collect information according to pre-defined ethnic categories that are not tailored specifically for the MSM population. This is an important challenge to address as black and minority ethnic MSM and those who have migrated from outside the UK may have different patterns of sexual behaviour and prevention needs. This is also a growing area of research, and so it is fundamental to understand the concept of ethnicity, ethnic categorisations, data collection, and the relation between ethnicity and country of birth, so that accurate and useful conclusions can be drawn from surveillance data.

## 2.5.3.3 Co-infection with other STIs

The final challenge addressed in this thesis (chapter 5), concerns the acquisition of other STIs among HIV positive MSM in the UK. The introduction and widespread use of highly active antiretroviral therapies (HAART) has led to increasing numbers of MSM living with diagnosed HIV infection since the mid-1990s (UK Collaborative Group for HIV and STI Surveillance, 2006). Over the same period, there have been increases in gonorrhoea diagnoses, and additionally, outbreaks of syphilis, emergence of lymphogranuloma venereum (LGV), and reported sexual transmission

of hepatitis C among MSM in the UK and elsewhere (Browne *et al.*, 2004; Simms *et al.*, 2005; UK Collaborative Group for HIV and STI Surveillance, 2006; Ward *et al.*, 2007).

Transmission of STIs among HIV positive MSM appears to be central to these emerging epidemiological trends, and a major underlying factor is sexual networking. To therefore better understand the epidemiological data on STIs among HIV positive MSM, I reviewed the literature around the formation and main determinants of sexual networks, and specifically HIV positive MSM. I consider what sexual behaviour studies of HIV positive MSM tell us about sexual networks, including the impact of novel environments for sexual network formation, notably the Internet. Finally, I consider areas of future research in this growing field of research.

In summary, I shall be utilising data from some of the most sophisticated and longrunning HIV surveillance systems in the world to elucidate current trends and patterns in HIV incidence and prevalence among MSM in the UK. During my research, I will push the surveillance data to its limits to investigate whether further insights into HIV among MSM can be gained beyond routine analysis. This will highlight some of the weaknesses of HIV/AIDS surveillance in the UK. These weaknesses, which are not unique to these surveillance systems, include difficulties in obtaining appropriate denominators, meaningfully categorising disparate populations, adapting to change, and interpreting data when several underlying factors (which are not easily measured) have changed.

# CHAPTER 3 Geography and time trends

## **Chapter Summary**

In the previous chapter I examined the role of public health surveillance, the evolution of HIV surveillance among MSM in the UK over the past 25 years, and the main opportunities and challenges associated with using surveillance data for epidemiological research. In this chapter I go on to examine recent trends in HIV among MSM in the UK and some of the underlying factors. I also consider in detail the challenge of conducting epidemiological analyses for different geographic areas over time.

The papers in this chapter, published in *Sexually Transmitted Infections*, describe current trends in HIV and STIs among MSM, and explore why there has been an increase in the number of HIV diagnoses among MSM over time. Analyses were undertaken nationally, and for London and the rest of the country separately. However, further geographic analyses at, for example, a regional level were limited by the lack of denominator data on the number of MSM in the population. In the commentary therefore, I discuss the challenges associated with estimating the size of the MSM population in Britain, and consider the data sources that are currently available. I make recommendations for improving the geographic data available on MSM and for further epidemiologic analyses.

## **EPIDEMIOLOGY**

## Recent trends in diagnoses of HIV and other sexually transmitted infections in England and Wales among men who have sex with men

N Macdonald, S Dougan, C A McGarrigle, K Baster, B D Rice, B G Evans, K A Fenton

Sex Transm Infect 2004;80:492-497. doi: 10.1136/sti.2004.011197

Objectives: To examine trends in rates of diagnoses of HIV and other sexually transmitted infections (STIs) in men who have sex with men (MSM) in England and Wales between 1997 and 2002. Methods: Estimates of the MSM population living in England and Wales, London and the rest of England

Methods: Estimates of the MSM population living in England and Wales, London and the rest of England and Wales were applied to surveillance data, providing rates of diagnoses of HIV and STIs and age group specific rates for HIV and uncomplicated gonorrhoea.

See end of article for authors' affiliations

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Accepted for publication 2 September 2004 Results: Between 1997 and 2002, rates of diagnoses of HIV and acute STIs in MSM increased substantially. Rates in London were higher than elsewhere. Rises in acute STIs were similar throughout England and Wales, except for uncomplicated gonorrhoea and infectious syphilis, with greater increases outside London. Rates of gonorrhoea diagnoses doubled between 1999 and 2001 (661/100 000, 1271/100 000, p < 0.001) in England and Wales followed by a slight decline to 1210/100 000 (p = 0.03) in 2002—primarily the result of a decline in diagnoses among men aged 25–34 (1340/100 000, 1128/100 000, p < 0.001) and 35–44 (924/100 000, 863/100 000, p = 0.03) in London. HIV was the third most common STI diagnosed in MSM in England and Wales and the second in London, with the highest rate (1286/100 000) found among men aged 35–44 in London in 2002.

Conclusions: Rates of diagnosis of HIV and other STIs have increased substantially among MSM in England and Wales. Increases show heterogeneity by infection, geography, and age over time. Rates in London were twice those seen elsewhere, with greatest changes over time. The observed changes reflect concomitant increases in high risk behaviour documented in behavioural surveillance survey programmes.

C ince the late 1990s, increases in sexually transmitted infections (STIs) and HIV diagnoses in men who have sex with men (MSM) have been reported from countries in Europe, North America, and Australia.<sup>14</sup> These increases are generally attributed to changes in the sexual behaviour of MSM and, indeed, steady increases in high risk sexual behaviour have been reported over this period in countries that conduct behavioural surveillance - Explanations to account for this increase in risk taking are numerous," 10 and in some instances controversial. An international comparison of treatment optimism conducted in 2000 in cities in Australia, Canada, France, and England using a standard scale found few MSM were optimistic in the light of new HIV drug therapies and suggested heterogeneity in men's responses to antiretroviral therapies in different countries," Researchers in London found similar rates of high risk sex reported among those optimistic about HIV treatments and those who were not," suggesting that treatment optimism alone would not account for the increase in risk taking. With no clear answers to explain these worsening trends it seems prudent to look in more detail at what HIV and STI surveillance can reveal.

This paper examines trends in diagnoses of HIV and other STIs in MSM since HAART became widely available in England and Wales. Data from a variety of surveillance and survey sources have been combined to present these trends within the context of the MSM population. This analysis is timely, not least because of the apparent rise in STI transmission in MSM, but also because of the availability of recent estimates of the population of MSM obtained from a national probability survey conducted in 2000<sup>11</sup> and applied to the 2001 census.<sup>44</sup>

#### METHODS

In the United Kingdom, surveillance of STIs, and for the most part HIV, is based on reports from genitourinary medicine (GUM) clinics that provide free, open access, and confidential diagnostic services to the public. The surveillance methods have been previously described,<sup>4</sup> and are summarised briefly.

#### **HIV infections**

Newly diagnosed HIV infections in England and Wales are reported to the Health Protection Agency. Communicable Disease Surveillance Centre (CDSC) by laboratories and clinicians. Voluntary confidential reporting methods are used to collect a range of epidemiological information including Soundex code," date of birth and gender, which permit the identification of duplicate reports of the same individual. This analysis includes all males reported with a first HIV diagnosis in England and Wales where the probable route of infection was sex between men. Data are from reports received by the end of 2003, censored at the end of 2002 to minimise the effects of delays in reporting and ascertainment of route of infection.

People living with diagnosed HIV infection and receiving care in England and Wales are reported annually to the Survey of Prevalent HIV Infections Diagnosed (SOPHID).<sup>44</sup> Men aged 16-44, where the probable route of infection was sex between men and who were reported as living in England and Wales for each year between 1997 and 2002 were included.

Abbreviations: GUM, genitourinary medicine; HAART, highly active antiretroviral therapy; MSM, men who have sex with men; STIs, sexually transmitted infections; UAI, unprotected and intercourse

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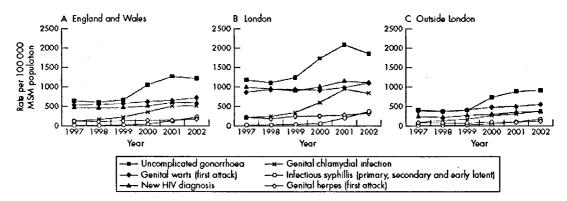


Figure 1 Trends in rates" of diagnoses of HIV1 and other sexually transmitted infections‡ in men who have sex with men. England and Wales 1997-2002 by year and region of diagnosis ("Rates are based on estimated MSM populations aged 16-44 years of 277 700 in England and Wales, 90 000 in London and 187 700 outside London. †Data source: Surveillance of new diagnoses of HIV infections. ‡Data source: KC60.)

#### Other STIs

Surveillance of other STIs in England and Wales is based on statutory quarterly aggregate statistical returns (KC60) from GUM clinics reported to CDSC and CDSC Wales. Male homosexual acquisition is reported for five acute conditions: uncomplicated gonorrhoea, infectious syphilis (primary, secondary, and early latent), genital chlamydia infection, genital warts (first attack), and genital herpes (first attack). Data on acute (male) homosexually acquired conditions were reviewed for the period 1997 to 2002. Information was available by region of diagnosis within England and for Wales for all five conditions. Age group at year of diagnosis is only reported for uncomplicated gonorrhoea in MSM.

Estimating the populations of men The second UK National Survey of Sexual Attitudes and Lifestyles (Natsal 2000)13 estimated the proportion of men, aged 16-44 years reporting sex with another man in the past 5 years to be 2.6% (95% confidence interval 2.2 to 3.1) in Britain, 5.5% (4.2 to 7.2) in Greater London, and 2.1% (1.7 to 2.7) in the rest of Britain. These point prevalances were applied to the 2000 mid-year census estimate of males aged 16-44 years to obtain estimates of the numbers of MSM living in England and Wales as a whole, and separately for London and the rest of England and Wales, as well as for specific age groups based on the KC60 categories. Rates of diagnoses in heterosexual mates, used as a comparison group for MSM, were estimated by subtracting diagnoses reported in MSM from those of men aged 16-44 and dividing these by adjusted population denominators (subtracting the MSM estimates from men aged 16-44).

#### **Statistical methods**

 $\chi^2$  Tests and  $\chi^2$  tests for trend were used to examine changes in the rates per 100 000 MSM populations of diagnoses of HIV and other STIs between 1997 and 2002 using Epi-Info 6 (v.6.04d); 95% confidence intervals around the rates were calculated using Stata 7 (StataCorp, 2001).

#### RESULTS

Between 1997 and 2002 the rate of diagnosis of all major acute STIs increased substantially among MSM in England and Wales (fig 1A). The biggest increases were in the rates of diagnoses of bacterial STIs, particularly between 1999 and 2001, with a doubling in gonorrhoea (661/100 000 (95% confidence interval 631/100/000-692/100/000) to 1271/ 100 000 (1229 to 1313), p<0.001) and in chlamydia (226/ 100 000 (208 to 244) to 504/100 000 (478 to 552), p<0.001).

These increases were not sustained in 2002 with gonorrhoca decreasing to 1210/100 000 (1170 to 1252) (p = 0.03) and chlamydia levelling off (524/100/000 (497 to 552), p = 0.302). Rates of diagnosis of syphilis rose from 7/100 000 (4 to 11) in 1997 to 225/100 000 (208 to 244) in 2002 (p<0.001).

In comparison with the bacterial STIs, the increases in diagnosis rates of viral STIs between 1997 and 2002 were steadier, with genital warts rising from 536/100 000 (509 to 563) to 727/100 000 (696 to 760) (p<0.001) and genital herpes from 121/100 000 (108 to 135) to 176/100 000 (161 to 192) (p<0.001). Rates of diagnoses of HIV infection increased from 478/100 000 (453 to 505) in 1997 to 601/ 100 000 (572 to 630) in 2002 (p<0.001). Gonorrhoea remained the commonest STI diagnosed in MSM in England and Wales followed by genital warts, HIV and then chlamydia. Rates of diagnosis of syphilis overtook those of genital herpes in 2002 (fig 1A).

#### London

Diagnosis rates were markedly higher in London with gonorrhoea rising from a low of 1107/100 000 (1039 to 1178) in 1998, peaking at 2088/100 000 (1995 to 2184) in 2001 followed by a slight decrease to 1853/100 000 (1766 to 1945) in 2002 (p<0.001) (fig 1B). A similar pattern was seen for chlamydia, which also peaked in 2001 (938/100 000 (876 to 1003)) and decreased slightly to 843/100 000 (784 to 906) (p = 0.024) the following year. Syphilis rose steeply from 50/ 100 000 (36 to 67) in 2000 to 364/100 000 (326 to 406) in 2002 (p<0.001). HIV infection was usually the second most commonly diagnosed STI in MSM in London with an annual rate of diagnosis of around 950/100 000 (888 to 1017) between 1997 and 2000 rising to over 1100/100 000 (1038 to 1176) in 2001 and 2002 (p = 0.001). Rates of diagnosis of genital warts were similar to HIV, increasing from 871/ 100 000 (811 to 934) in 1997 to 1101/100 000 (1034 to 1172) in 2002 (p<0.001). Herpes rose from 213/100 000 (184 to 246) to 313/100 000 (278 to 352) (p<0.001) over this period.

#### Outside London

Although rates of diagnoses of HIV and other STIs were generally lower than those in London, the increases seen between 1997 and 2002 were of similar magnitude (fig. 1C), The exceptions were gonorrhoea and syphilis, which exhibited larger increases outside London. Gonorrhoea rose steeply between 1999 and 2000 (385/100 000 (358 to 414) to 730/ 100 000 (692 to 770), p<0.001) followed by a further increase to 879/100 000 (837 to 922) in 2001 (p<0.01) and levelling off to 902/100 000 (859 to 946) in 2002. Syphilis

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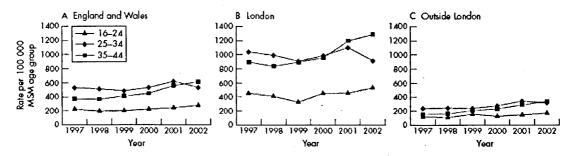


Figure 2 Trends in age group specific rates of diagnoses of HIV" in men who have sex with men. England and Wales 1997–2002 by year and region of diagnosis. ("Data source: Surveillance of new diagnoses of HIV infections.)

increased from 3/100 000 (1 to 7) in 1997 to 159/100 000 (141 to 178) in 2002 (p<0.001).

#### Age group specific trends HIV

Between 1997 and 2002 in England and Wales, the rate of HIV diagnosis was highest in men aged 25-34, rising from 527/100 000 (486 to 570) in 1997 to 621/100 000 (577 to 668) in 2001 (p = 0.001) (fig 2A). Men aged 35-44 had the second highest incidence of diagnosis, rising steadily from 363/ 100 000 (327 to 402) in 1998 to 613/100 000 (566 to 663) in 2002 (p<0.001) overtaking those aged 25-35 that decreased to 534/100 000 (493 to 557) in that year. Men aged 16-24 generally had the lowest rate of HIV diagnosis. Nevertheless, diagnoses increased significantly from 200/100 000 (166 to 240) in 1998 to 283/100 000 (241 to 329) in 2002 (p = 0.004). New HIV diagnosis rates were substantially higher for all age groups in London (fig 2B) compared with elsewhere (fig 2C). Between 2000 and 2001, rates in men aged 35-44 overtook those aged 25~34 in London. This crossover occurred a year later in the rest of England and Wales.

#### Gonorrhoea

Men aged 25-34 generally had the highest rate of diagnosis of gonorrhoea in England and Wales, closely followed by those aged 16-24. In contrast, men aged 35-44 had the lowest rate (fig 3A). Between 1997 and 1999 rates were fairly stable, but between 1999 and 2001 rates increased markedly in all age groups. This increase was maintained for men aged 16-24 in 2002 while rates decreased slightly in both the older age groups. Rates of diagnoses of gonorrhoea were higher for all age groups in London (fig 3B) compared to elsewhere (fig 3C). However, men aged 25-34 consistently had the highest rates in London. Outside London the highest incidence was seen in men aged 16-24, particularly from 1999 onwards. Between 2001 and 2002 rates in all age groups in London decreased, although this was only statistically significant for men aged 25–34 (2170/100 000 (2033 to 2314) to 1729/100 000 (1607 to 1858), p<0.001) and men aged 35– 44 (1754/100 000 (1606 to 1911) to 1525/100 000 (1388 to 1672), p = 0.028) and not for men aged 16–24 (1744/100 000 (1552 to 1953) to 1540/100 000 (1360 to 1737), p = 0.138). Outside London the slight decrease in diagnoses in men aged 25–34 between 2001 and 2002 was not statistically significant (865/100 000 (800 to 934) to 784/100 000 (722 to 850), p = 0.082) and diagnoses in men aged 16–24 continued in 2002 to 1243/100 000 (1138 to 1356).

#### Comparing rates in MSM with heterosexual men

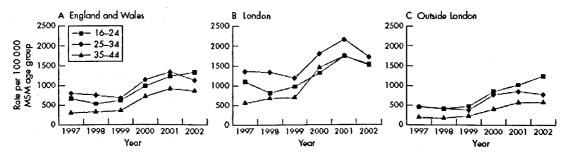
Equivalent estimates of the rates of diagnoses of HIV and other STIs in heterosexual males were estimated in order to place the findings for MSM in context (table 1). This snapshot for England and Wales in 2002 indicates that rates were higher in MSM for all the STIs considered, ranging from 1.5-fold for chlamydia (524/100 000 versus 341/100 000) to over 50-fold for syphilis (225/100 000 versus 341/100 000).

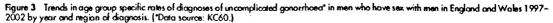
#### Prevalence of diagnosed HIV infection

The prevalence of diagnosed HIV infection in MSM accessing care increased steadily from 2654/100 000 (2593 to 2715) in 1997 to 3706/100 000 (3635 to 3778) in 2002 (fig 4). The prevalence in MSM living in London and accessing care reached 7031/100 000 (6859 to 7207) in 2002 compared to 2111/100 000 (2046 to 2178) in men living elsewhere.

#### DISCUSSION

These results demonstrate the increases in rates of diagnosis of HIV and other STIs during the post-HAART era in MSM in England and Wales. The increases in rates of HIV and other





	MSM	Heterosexual mens
Uncomplicated gonorrhoea	1210/105	140/105
Senital warts (first attack)	727/105	337/105
New HIV diagnosis	601/105	13/105
Genital chlamydia (first attack)	524/103	341/105
nfectious syphilis (primary, secondary and early latent)	225/10 <sup>3</sup>	4/105
Genital herpes (first attack)	176/105	63/105
Rates are based on estimated populations of 277 700 MSA England and Wales in 2002). †Data source: Surveillance of new diagnoses of HV infection ‡Data source: KC60 Data on hereosexual moles has been estimated by subtrac	ns.	• •

STIs in MSM in England and Wales have shown heterogeneity by type of infection, geographic location, and the age groups affected over time. Rates in London were twice those seen elsewhere and exhibited the greatest changes over time. There are some encouraging signs of a decrease in the rate of diagnosis of genorrhoca between 2001 and 2002, but rates are still higher than in 1999 and to date, this decrease appears to be restricted to men aged over 25 in London.

The rise in rates of diagnoses of HIV and other STIs demonstrate increasing levels of sexual ill health in MSM and the burden placed on GUM services. Comparisons with heterosexual males reveal the extent of inequalities the sexual health of MSM. MSM in England and Wales in 2002 showed higher rates of diagnoses for all of the STIs investigated than heterosexual men, ranging from a doubling in rates of genital warts, herpes, and chlamydia, to over eight times for gonorrhoea and as high as 50 times for HIV and syphilis.

The heterogeneity in rates of diagnosis observed between STIs in MSM may relate to both differential transmission probabilities, levels of asymptomatic infection, and delays between infection and diagnosis. For some acute STIs the rate of diagnosis is likely to closely reflect the incidence of infection. This is particularly true for gonorrhoea where the onset of clinical symptoms usually occurs within a week of infection.<sup>67</sup> Hence, rates of gonorrhoea are likely to be sensitive to changes in sexual behaviour, although treatment failure as a result of shifting patterns of antimicrobial resistance may also influence trends. Sentinel surveillance of antimicrobial resistance in England and Wales is provided by GRASP (Gonococcal Resistance to Antimicrobials Surveillance Programme).<sup>th</sup> GRASP found that ciprofloxacin resistance (≈1 mg/l) in isolates from MSM increased from

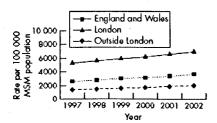


Figure 4 Trends in diagnosed HN\* prevalencert in men who have sex with men, aged 16-44 accessing NHS services by year and area of residence. England and Wales 1997-2002. ["Data source: SOPHID. #Rates are based on estimated MSM populations aged 16-44 years of 277 700 in England and Wales, 90 000 in London and 187 700 outside London.) 0.8% in 2000 to 2.2% in 2001 with a further increase to 8.5% in 2002.<sup>19</sup> Clinicians were notified of this decrease in susceptibility in May 2003; hence improved treatment is unlikely to account for the decrease in rates of diagnosis of gonorrhoea in MSM in London between 2001 and 2002.

Behavioural surveillance programmes, which monitor high risk sexual behaviour through sampling MSM attending commercial venues and GUM clinics in London, found the proportion of men reporting having engaged in unprotected anal intercourse (UAI) in the past year increased between 1997 and 2001.\* 12 However, no further increase in UAI was reported for 2002 and the proportion of men reporting UAI with partners of unknown or discordant HIV status decreased slightly from that reported for 2001.\* Such behaviour change may explain the decrease in rates of gonorrhoea observed in London. This apparent association between trends in high risk sexual behaviour and the rates of diagnosis of gonorrhoea in MSM requires further investigation, as surveillance of gonorrhoca may serve as a proxy for behavioural surveillance in areas where behavioural surveillance is lacking, such as in areas of England and Wales outside London. Further confirmation of this association would be provided through behavioural surveillance by asking men if they had been diagnosed with gonorrhoea.

The interpretation of trends in the incidence of diagnosis of HIV infection is more problematic. The delay between initial HIV infection and diagnosis may take years and consequently the rates described do not reflect the time or necessarily the place of infection. Nevertheless, between 1997 and 2002 there has been only a modest increase in the median age at diagnosis of HIV infection in MSM, and CD4 count at diagnosis has also remained fairly constant over this time.<sup>4</sup> This suggests that the rates of diagnoses may indeed broadly reflect previous patterns of incidence. Application of a detuned assay to residual blood samples from MSM attending seven GUM dinics in London for syphilis serology found an annual incidence of around 3% in these men with no statistically significant change between 1995 and 2001.24 That HIV was the third most commonly diagnosed STI in MSM in England and Wales (and the second in London) is surprising since the efficiency of transmission of HIV is believed to be far lower than other STIs." This may in part reflect a higher probability of ascertainment for HIV, as undiagnosed infection eventually progresses to illness and death, compared to other STIs that may remain asymptomatic. Also, the duration of infectivity for HIV (lifelong) and the rising prevalence of MSM living with diagnosed HIV infection that we have reported, suggests that MSM will have a much higher probability of having sex with a man with HIV than any other major acute STI. Coupled with increases in both HIV risk behaviours and STIs that can enhance HIV transmission,

the potential for future increases in HIV incidence is worrying

Increasing numbers of MSM living with diagnosed HIV infection may also be contributing to the rising incidence of the other STIs. Enhanced syphilis surveillance has shown that MSM with diagnosed HIV infection feature disproportionately in the emerging syphilis outbreaks associated with metropolitan areas of England and Wales.29 In London almost half of the MSM diagnosed with syphilis were co-infected with HIV. A large cross sectional survey of MSM conducted in the United Kingdom in 2002 found diagnosed HIV positive men reported higher numbers of sexual partners and a greater likelihood of having been involved in HIV serodiscordant UAI compared to HIV negative and untested men.\* While UAI between diagnosed positive men may not be a concern for the onward transmission of HIV (although transmission of antiretroviral resistant virus between HIV positive men is), such circumstances can present an ideal environment for the transmission of other STIs.

Our study has some limitations. The rates described are probably more reliable for HIV than the other STIs described, since KC60 reports represent diagnoses within a quarter rather than individuals, but this effect might be balanced somewhat by under-reporting of male homosexual acquisition in KC60. Such under reporting will tend to overestimate the rates calculated for heterosexual males. Using MSM denominators of men aged 16-44 will tend to overestimate the rates of diagnosis for those STIs prevalent in men aged over 44; however, the age group specific rates are unaffected by this bias. Data from GUM clinics will underestimate the true rate of diagnosis in the population; however, this effect is likely to be small for MSM. A recent national survey of MSM found that although 79% reported visiting a GP or local doctor in the past year, only 5% reported having a sexual health check up and 4% an HIV test, as a reason for their last visit to a GP surgery or local doctor." Open access for GUM means that patients may travel outside their area of residence to access services. This will tend to overestimate the rates for London (SOPHID recorded that 6% of HIV positive MSM seen for care in London in 2002 were resident outside London: B Rice, personal communication), but this effect is likely to be minimal for England and Wales as a whole. Although these limitations may result in a degree of error in the measurement of the rates described, this is likely to be consistent over time.

The trends presented may serve as a useful comparison with other countries where equivalent surveillance data and estimates of populations of MSM are available. A study of gonorrhoea in Denmark estimated the minimal yearly incidence between 1994 and 1999 to be 98/100 000 in MSM as a whole and 483/100 000 in MSM that were known to be HIV positive.20 Perhaps the small numbers of MSM reported in this study (n = 266) dissuaded the authors from reporting annual estimates and trends. However, such estimates, in combination with other indicators (behavioural, attitudinal, and health promotion) could reveal the relative performance of HIV and STI prevention programmes targeted at MSM in different countries.

Many of the limitations of KC60 data for the surveillance of STIs in MSM described in this paper are likely to be overcome with the introduction of disaggregate reporting of STIs, which is currently under development in England and Wales. In the mean time, the data included in this analysis have been sufficient to describe the recent trends in HIV and STI diagnoses in MSM in England and Wales. It is perhaps too early to hope that the downward trend in the incidence of gonorrhoea in London will continue and extend to areas outside London. However, whatever the trajectory, the determinants of such temporal trends merit further investigation to determine the relative contributions of behavioural modifications (sexual or health service use), GUM access and service provision, and prevention interventions.

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#### CONTRIBUTORS

NM, SD, and CAM conceived the paper; NM and SD wrote the initial drafts; CAM provided behavioural data and made comments on drafts; BDR provided data from the SOPHID survey and commented on drafts; KB provided expert statistical support; BE and KF assisted in the provisions of data and commented on drafts.

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Conflict of interest: None

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## 🖉 MSM 🕷

## Does the recent increase in HIV diagnoses among men who have sex with men in the UK reflect a rise in HIV incidence or increased uptake of HIV testing?

Sarah Dougan, Jonathan Elford, Timothy R Chadborn, Alison E Brown, Kirsty Roy, Gary Murphy, O Noel Gill on behalf of the group investigating rising HIV diagnoses among MSM in the UK\*

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Objectives: To determine whether the increase in HIV diagnoses since 1997 among men who have sex with

Additional table and references available online at http://sti.bmj.com/ supplemental

See end of article for authors' affiliations

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Accepted 18 October 2006 Published Online First 9 November 2006 Objectives: To determine whether the increase in HIV diagnoses since 1997 among men who have sex with men (MSM) in the UK reflects a rise in HIV incidence or an increase in HIV testing.

Methods: Estimates of HIV incidence were derived using data from UK HIV surveillance systems (HIV diagnoses; CD4 surveillance; unlinked anonymous surveys) for 1997-2004. Data on HIV testing were provided by KC60 statutory returns, voluntary testing and unlinked anonymous surveys in sentinel genitourinary medicine (GUM) clinics.

Results: HIV diagnoses among MSM in the UK rose by 54% between 1997 and 2004 (from 1382 to 2124), with variation by age and geographical location. The number of HIV diagnoses among MSM <35 years of age in London showed no increase, but in all other groups it increased. Throughout the UK, uptake of HIV testing increased significantly among MSM attending GUM clinics between 1997 and 2004, including "atrisk" MSM (p<0.001). Direct incidence estimates (serological testing algorithm for recent HIV seroconversion assay) provided no evidence of a statistically significant increase or decrease in HIV incidence. Indirect estimates suggested that there may have been a rise in HIV incidence, but these estimates were influenced by the increased uptake of HIV testing.

Condusions: The number of HIV diagnoses increased among MSM in the UK between 1997 and 2004, except among younger MSM in London, in whom there was no change. The increase in HIV diagnoses among MSM in the UK since 1997 seems to reflect an increase in HIV testing rather than a rise in HIV incidence.

The number of HIV diagnoses among men who have sex with men (MSM) in the UK has risen annually since 1999.<sup>4</sup> This rise may reflect increasing HIV incidence among MSM, or an increase in the uptake of HIV testing. Diagnoses may have also risen because of improved reporting and migration to the UK by HIV-infected MSM. Similar trends in increasing HIV diagnoses have been observed in The

Netherlands, Australia and the USA.<sup>3-4</sup> Rising HIV diagnoses among MSM in the UK have coincided with an increase in high-risk sexual behaviour and other sexually transmitted infections (STIs) that may facilitate HIV transmission.<sup>4-3-3</sup> However, over the same period, there have been initiatives to increase the uptake of HIV testing among genitourinary medicine (GUM) clinic attendees. The availability of effective treatment for HIV may have also encouraged more MSM to seek an HIV test.<sup>12-4</sup>

Although the increase in HIV diagnoses among MSM in the UK has been described before.<sup>4</sup> the reasons behind this increase have not been investigated. Does the increase in HIV diagnoses reflect an increase in HIV incidence or an increased uptake of HIV testing? An increase in HIV incidence would have important implications for HIV prevention and targets to reduce HIV transmission among MSM. On the other hand, increased uptake of HIV testing would highlight success in reducing the number of MSM with undiagnosed HIV.<sup>32-14</sup>

#### **METHODS**

National HIV surveillance data for MSM, 1997-2004, were examined to derive estimates of HIV incidence, patterns of HIV testing and changes in HIV reporting.

#### Data sources

We used surveillance data from the following sources:

- Laboratory and clinical reports of HIV diagnoses in the UK;
- CD4 surveillance providing information on CD4 cell count at diagnosis for MSM in England and Wales (70%) and Scotland (95%);
- Unlinked anonymous surveys in 28 sentinel GUM clinics throughout the UK (16 clinics in England, Wales and Northern Ireland (E,W&NI), and 12 in Scotland), providing data on prevalence of undiagnosed HIV and uptake of voluntary confidential testing (VCT) for HIV;
- KC60 and ISD(D)5 statutory returns on number of HIV tests from all GUM dinks in E,W&NI and Scotland, respectively;
- Data on voluntary named HIV testing collected in all settings throughout Scotland.

Further details on the sources of surveillance data are summarised in table A (available online at http://sti.bmjjournals.com).

#### **HIV incidence estimates**

HIV diagnoses do not provide a measure of incidence, as infection may not be recent. A direct estimate of HIV incidence

Abbreviations: E.W&NI, England, Wales and Northern Ireland; GUM, genitourinary medicine; MSM, men who have sex with other men; STARHS, serological testing algorithm for recent HIV seroomversion; STI, sexually transmitted infection; VCT, voluntary confidential testing can be obtained using a laboratory assay (scrological testing algorithm for recent HIV seroconversion (STARHS)).<sup>15</sup> Coupled with appropriate information on the population testing negative for HIV, incidence in a defined population can be directly estimated. The technique has been applied to leftover samples from routine syphilis tests among HIV-infected MSM unaware of their HIV status who tested positive on unlinked anonymous testing in 16 sentinel GUM clinics in E,W&NL<sup>16-17</sup>

#### Indirect methods to examine trends in HIV incidence

- We examined the proportion and number of HIV diagnoses where CD4 cell count at diagnosis was ≥700 cells/mm<sup>3</sup> ("early diagnoses"). An increase in the proportion and number of early diagnoses over time could reflect an increase in incidence, although this could also reflect an increase in HIV testing. Even if this cut-off point excluded some recent seroconverters with low CD4 cell counts, the index would still be valid if the excluded proportion remained constant over time. A cut-off of ≥500 cells/mm<sup>3</sup> was also investigated.
- 2. We examined the proportion and number of HIV diagnoses where CD4 cell count at diagnosis was <200 cells/mm<sup>3</sup> ("late diagnoses"). If the proportion and number of late diagnoses remain stable or decline over time, an increase in the number of HIV diagnoses could reflect an increase in HIV incidence. Again, this measure will also be influenced by changing patterns of HIV testing.

#### **HIV** testing

- The number of HIV tests in MSM can be obtained from KC60 statutory returns in E.W&NI and from the surveillance of voluntary named HIV testing in Scotland. Data for E.W&NI exclude 2003 and 2004, as the coding on KC60 statutory returns changed. Most HIV tests among MSM in the UK are conducted in GUM clinics.
- 2. The unlinked anonymous GUM survey in 28 UK clinks collects information on uptake of VCT. MSM with previously diagnosed HIV were excluded from all analyses. To determine whether there was differential testing among MSM at higher risk and lower risk of acquiring HIV, data are presented separately for all MSM, HIV-infected MSM, and MSM with an acute STL.

#### Reporting changes

Clinical reporting of HIV diagnoses in E,W&NI was introduced in 2000 to supplement information collected on laboratory, AIDS and death reports. Before 2000, HIV diagnoses were reported by laboratories only. The number of MSM with only a clinical report was examined in an attempt to quantify the effect of reporting changes on the increase in HIV diagnoses between 1997 and 2004. Patients with only a clinical report may reflect improved ascertainment (ie, before clinical reporting was introduced, these patients may not have been notified to the Health Protection Agency because of a lack of reporting by some laboratories). But they could also reflect "reporting compensation", whereby clinical reports are sent in place of laboratory reports. There were no such reporting changes in Scotland.

#### Data analysis

Changes between 1997 and 2004 were analysed using data from each year categorised into the following five groups: MSM <35 years diagnosed in London; MSM ≥35 years diagnosed in London; MSM <35 years diagnosed elsewhere in E,W&NI; MSM ≥35 years diagnosed elsewhere in E,W∋ all MSM diagnosed in Scotland. Categories were chosen to allow comparison with an earlier analysis (with 16–24 and 25– 34 years combined because of small numbers in the younger age group) and with a study from the Netherlands.<sup>34</sup> Thirty five years is also the median age of HIV diagnosis for MSM in the UK. Proportional increases over time are relative to the baseline value in 1997 when the current increase in high-risk sexual behaviour among MSM in the UK began to be documented.<sup>44</sup>

Statistical inference ( $\chi^2$  test for trend) was made only for data from sample populations (unlinked anonymous surveys). STARHS statistical analyses have been described elsewhere.<sup>4,17</sup> For sample populations, all years from 1997 to 2004 were included in the trend analyses, but only data for 1997 and 2004 are presented (annual data available on request). For population-based data, statistical tests were not undertaken, with comparisons made between 1997 and 2004 only.

## Confidentiality and ethics

Reports of HIV diagnoses are voluntary and confidential. To maintain patient confidentiality, no names are held, and soundex codes are used to avoid duplicate reports.<sup>30</sup> The ethical and legal bases for the unlinked anonymous surveys have been described elsewhere.<sup>41</sup> These surveys comply with guidelines published by the Medical Research Council.<sup>42</sup> and Department of Health interim guidelines on the use of human organs and tissue, and with the 2004 Human Tissue Act.<sup>30</sup> <sup>34</sup>. All data are stored on restricted and secure databases, with strict adherence to the Data Protection Act and Caldicott Guidelines.<sup>35</sup> Reporting systems in E.W&NI have approval under the section 60 regulations of the Health and Social Care Act 2001 (Statutory Instrument 1438–June 2002).

#### RESULTS

In 1997, 1382 HIV diagnoses were made among MSM in the UK, rising to 2124 in 2004 (an increase of 54%). In London, the number of HIV diagnoses did not increase appreciably between 1997 and 2004 among MSM <35 years of age (529 and 533), whereas the increase was noteworthy among MSM  $\geq$ 35 years of age (369 and 572; +55%). For MSM outside London (excluding Scotland), diagnoses increased for men <35 years (221, 463; +110%) as well as for those  $\geq$ 35 years (194 and 556; +187%). Diagnoses also increased for MSM in Scotland (79 and 131 +66%; fig 1).

### **Direct estimates of HIV incidence**

Annual HIV incidence among MSM attending GUM clinics in E.W&NI, estimated by STARHS, was 2.4% (95% CI 1.5 to 4.0) in 1997 and 3.0% (95% CI 1.9 to 4.6) in 2004, with no significant trend over time.<sup>16-17</sup> Estimates of incidence points seemed to rise for MSM  $\approx$  35 years, but there was no statistical evidence of an increase or decrease in any group (fig 2, table 1).

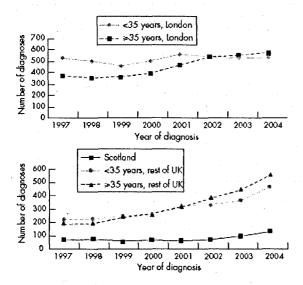
## Indirect estimates of HIV incidence

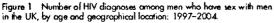
#### Early diagnoses

The overall proportion of MSM diagnosed in England, Wales and Scotland with a CD4 cell count of  $\geq$ 700 cells/mm<sup>3</sup> increased from 12% in 1997 to 26% in 2004 (+122%) (table 2). The greatest increase was among MSM  $\geq$ 35 years of age elsewhere in England and Wales (+235%). Similar patterns were found using  $\geq$ 500 cells/mm<sup>3</sup> as a cut-off.

#### Late diagnoses

The overall proportion of MSM in England, Wales and Scotland with a CD4 cell count of <200 cells/mm<sup>3</sup> at diagnosis decreased from 30% in 1997 to 21% in 2004 (-29%). The smallest decrease was seen among MSM <35 years of age in London





(-28%), whereas the largest was found among MSM in Scotland (-65%); table 2).

## HIV testing

## All GUM clinics

The number of HIV tests among MSM attending GUM clinics in London increased from 5114 in 1997 to 9387 in 2002 (+84%), elsewhere in E,W&NI from 5030 to 8864 (+76%), and in Scotland from 1040 in 1997 to 2513 in 2004 (+142%).

#### Unlinked anonymous GUM clinics

In 1997, 46% of  $\dot{M}$ SM attending sentinel unlinked anonymous GUM clinics in the UK had a voluntary HIV test, rising to 80% in 2004 (+73%; p<0.001). The largest increase was among MSM <35 years of age in London (+92%), whereas the smallest was among those <35 years elsewhere in E.W&N1 (+42%; p<0.001; table 3).

Among the HIV-infected MSM, uptake of VCT rose from 24% in 1997 to 57% in 2004 (+133%; p<0.001). The largest increase was among MSM <35 years elsewhere in E.W&NI (+171%; p<0.001), and the smallest among MSM >35 years in E.W&NI (+15%).

Uptake of VCT among MSM with an acute STI rose from 27% in 1997 to 75% in 2004 (+178%; p<0.001). The largest increase was among MSM  $\geq$ 35 years of age in London (+294%), and the smallest among MSM <35 years in E.W&N1 (+99%; p<0.001). Table 4 summarises the percentage changes in the number of HIV diagnoses, direct and indirect incidence estimates and uptake of HIV testing between 1997 and 2004.

#### Reporting changes

The proportion of MSM with only a clinical HIV report in E.W&NI increased from 0% (2/1382) to 22% (476/2214) between 1997 and 2004. The largest changes were observed outside London: for MSM <35 years, 0% (1/221) to 37% (169/463), and for those  $\geq$ 35 years, 0% (0/212) to 33% (183/556). Some of these increases can be explained by the change in methodology of the North West region from laboratory to only clinical reporting (data available on request).

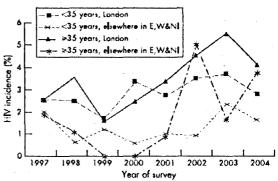


Figure 2 HIV incidence, as estimated by serological testing algorithm for recent HIV seroconversion, among previously undiagnosed men who have sax with men in the unlinked anonymous genitourinary medicine survey in London and elsewhere in England, Wales and Northern Ireland, (E, W&NI) 1997–2004.

#### DISCUSSION

There was a large increase in the number of HIV diagnoses among MSM across the UK between 1997 and 2004, except for younger (<35 years) MSM in London, in whom there was no change. Among all groups of MSM, a substantial increase in the uptake of HIV testing was observed, with the biggest increase being among those most at-risk of HIV infection. Increased uptake of HIV testing will have contributed substantially to the rise in HIV diagnoses. However, no evidence of a statistically significant increase or decrease in HIV incidence was observed among MSM in E,W&NI using the STARHS assay which provides a direct estimate of incidence. Indirect estimates of HIV incidence, using CD4 cell count at diagnosis, indicated an increase in incidence, as the proportion of MSM diagnosed earlier during the course of infection increased in all groups. However, this increase could also reflect a corresponding increase in the uptake of HIV testing. Outside London, in E,W&NI, improvements in the HIV diagnoses reporting system may have also contributed to the increase in the number of diagnoses among MSM.

The fact that HIV diagnoses among younger MSM in London did not increase at all is particularly interesting, given that there has been a substantial increase in HIV testing among this group. Increased uptake of HIV testing among HIV-infected MSM and those with an acute STI indicates that the increase in testing has not just been among low-risk younger MSM. Taken together, there is no evidence of an increase in HIV incidence among younger MSM in London, despite an increase in STIs and high-risk behaviour in this group.<sup>1</sup> <sup>37-9</sup>

#### Methodological issues

This is the first time that changing patterns of HIV incidence and testing among MSM in the UK have been systematically investigated to explain the recent increase in HIV diagnoses. The strength of this analysis is that data on HIV diagnoses, incidence and testing are all presented in the same paper, although disentangling a rise in incidence from an increased uptake of testing is methodologically challenging.

The only direct estimate of incidence was based on data collected from 16 sentinel GUM clinics in E.W&NI participating in the unlinked anonymous survey. Clinics were not randomly selected, and so these estimates may not be generalisable to all GUM clinic attendees, particularly outside London. Estimates will also be raised, as GUM clinic attendees tend to be at higher risk of acquiring HIV than other MSM. Table 1 HIV incidence, as estimated by serological testing algorithm for recent HIV seroconversion, among previously undiagnosedt men who have sex with men in the unlinked anonymous genitourinary medicine survey in Landon and elsewhere in England, Wales and Northern Ireland\*, 1997 and 2004

Area		1997 Est annual incidence per 100 py	95% CI	Negative specimens	Positive specimens	Recent infections by STARHS‡	2004 Est annual incidence per 100 py	95% CI	Negative specimens	Positive specimens	Recent infections by STARHS‡
London		2.58	(1.31 to	2750	142	22	2.80	(1.34 to 5.31)	2312	99	21
	<35 >35	2.58	4.85) {1.05 to 5.66}	1497	81	11	4.16	(2.06 to 7.68)	1751	110	24
Elsewhere in		2.04	(0.56 to	950	31	6	1.64	(0.58 to 3.81)	1855	26	10
E,W&N	<35 >35	1.90	5.67) (0.28 to 7.06)	532	14	3, .	3.78	(1.5 to 8.17)	1034	A7	13

E,W&NI, England, Wales and Northern Ireland; STARHS, serological testing algorithm for recent HIV seroconversion.

Data for other years analiable on request. Source: Unlinked anonymous genitourinary medicine surveys in England, Wales and Northern Ireland<sup>\*\*</sup> Those who were availed to their HIV status, including men an highly active antireroviral therapy and those with AIDS, were excluded from analyses. †Data were not available for Scotland.

#Missing specimens were allocated as reactive or non-reactive in STARHS by reallocation in the same proportion as known specimens by clinic and age group.

The indirect estimates of HIV incidence were based on an increase in early diagnoses, or a decrease in late diagnoses. However, these indices may also reflect an increase in HIV testing, as well as earlier presentation by MSM. The influence of reporting changes on the increase in HIV diagnoses is difficult to assess, as some centres changed their reporting patterns after the introduction of clinical HIV reporting in 2000.

Whereas increased migration to the UK by HIV-infected MSM may have also had an effect on the number of HIV diagnoses, there are as yet no discernible trends in selective migration of HIV-infected MSM to the UK.40 Unlinked anonymous data show an increasing HIV prevalence among MSM in the UK born in other world regions, although absolute numbers are small.27 Demographic changes within the UK MSM population itself may have also contributed to the stable number of diagnoses of HIV among younger MSM in London. However, interpreting census data on all men in relation to the changes in the MSM population is difficult and merits further examination.\*

#### International trends

In Amsterdam, increasing HIV incidence (measured using STARHS) was observed among MSM >35 years of age, but not <34 years attending STI dinics (1991-2001), accompanied by an increase in STI incidence and high-risk sexual behaviour.<sup>3 29</sup> Similar trends in HIV incidence has been observed in Australia.4 In E, W&NI, we did not observe an increase in HIV incidence among MSM using the STARHS assay on samples from GUM dinics participating in the unlinked anonymous GUM clinic survey. However, a similar increase was observed in STIs among MSM in the UK to The Netherlands.1 The reason for the differences in HIV incidence trends between MSM in Amsterdam and London is not clear. They might be due to differences in the sample populations or changes in the E.W&NI STARHS denominator over time.14 17

#### Conclusions

Our analysis shows that the number of HIV diagnoses increased among MSM in the UK between 1997 and 2004, except among younger MSM in London, in whom there was no change. A substantial increase in the uptake of HIV testing seems to explain the rise in HIV diagnoses. Direct estimates of HIV incidence among MSM in E,W&N1 provided no evidence of a statistically significant change in HIV incidence between 1997 and 2004, indicating that HIV transmission continued at a steady rate among MSM in the UK between 1997 and 2004.

Table 2 Early and late diagnoses of HIV (CD4 cell count at diagnosis) among men who have sex with men in London, elsewhere in England and Wales, and in Scotland in 1997 and 2004

				Year of	HN diagna	is .		Sec. 1	9. J. H. J.	a daga sa
		Geographical	Age group	1997			2004			Percentage chang
Indirect estimate	f incidence of HV	ereas			N	%	8	N	*	1997-2004
Early diagnosis	CD4 count	London	<35	47	352	13.4	77	317	24.3	82
	at diagnosis ≥700 cells/mm³		≫35	22	253	8.7	61	403	15.1	74
		Elsewhere in England	<35	16	100	16.0	118	329	35.9	124
		and Wales	≈35	8	87	9.2	129	419	30.8	235
		Scoland	All oges	6	59	10.2	18	95	18.9	86
			All ages	99	851	11.6	403	1563	25.8	122
Late diagnosis of	CD4 count of	London	<35	63	352	17.9	41	317	12.9	-28
HiV infection	diagnosis		⇒35	97	252	38.5	87	331	26.3	-32
5 /7 V 114/0CL (LST	<200 cells/mm <sup>3</sup>	Elsewhere in England	<35	25	100	25.0	48	329	14.6	-42
		and Wales	>35	43	87	49.4	124	419	29.6	-40
			All ages	25	59	42.4	14	95	14.7	-65
		England and Wales and Scotland	All ages	253	850	29.8	314	1491	21.1	-29

as available

Table 3 Uptake of voluntary confidential testing (VCT) among men who sex with men (MSM) in the unlinked anonymous genitourinary medicine (GUM) surveys in London, elsewhere in England, Wales and Northern treland, and in Scotland in 1997 and 2004

and the second secon			1997	14		2004			
	Geographical creas	Age group (years)	a	N	*	Ŋ	N	*	Percentage chang 1997-2004
Uptake of VCT among	London	<35	1191	2803	42.5	1458	1790	81.5	92
all MSM GUM attendees*		≥35	566	1533	36.9	968	1408	68.8	86
· .	Elsewhere in England	<35	626	982	63.7	1423	1572	90.5	42
	and Wales	≥35	285	545	52.3	689	875	78.7	51
	Scattand	All ages	451	955	47.2	1157	1533	75.5	60
	UK	All ages	3119	6818	45.7	5695	7178	79.3	73
Uptake of VCT among	London	<35	30	141	21.3	34	65	52.3	146
HIV+ MSM GUM attendees		≈35	20	82	24.4	46	82	56.1	130
	Elsewhere in England	<35	9	32	28.1	16	21	76.2	171
1	and Wales	>35	6	13	46.2	18	34	52.9	15
	Scatland	All ages	6	23	26.1	22	37	59.5	128
	UK	All ages	.71	291	24.4	136	239	56.9	133
Uptake of VCT omong	London	<35	265	1003	26.4	449	649	69.2	162
MSM with an paute STI*		>35	77	455	16.9	269	403	66.7	294
	Elsewhere in England	<35	132	299	44.1	600	683	87.8	99
	and Wales	≥35	32	119	26.9	223	297	75.1	179
	Scotland	All ages	75	283	26.5	318	452	70.4	165
	UK	All ages	581	2159	26.9	18.59	2484	74.8	178

n, number of MSM who accepted VCT; N, total number of MSM included in the unlinked anonymous GUM survey; Data for other years available on request. Source: Unlinked anonymous genito-uninary medicine surveys in England, Wales and Northern Ireland and in Scotland Those with previously diagnosed HIV infection are excluded.

Taken in concert with STI data, our analysis points towards a need for additional investment in targeted sexual health promotion if the goal of reducing HIV transmission among MSM is to be met.1244 This should be coupled with a further understanding of sexual risk behaviour among MSM.<sup>30</sup> In terms of surveillance, further examination of the relationship between HIV diagnoses, testing and HIV incidence data is required to explain trends among younger MSM in London and differences in trends between the UK and other countries. Finally, the substantial increase in the uptake of HIV testing among MSM in recent years highlights the recent success of sexual health promotion in reducing the number of MSM with undiagnosed HIV.

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SD and KF conceived the idea for the paper, with significant input from JE, TRC, AEB and KR; SD provided the UK diagnoses data, AEB the unlinked anonymous GUM survey data from E, W&NI, GM the unlinked anonymous STARHS data, TRC the CD4 surveillance data from England and Wales,

Table 4 Changes between 1997 and 2004 in the number of HIV diagnoses, direct incidence estimates, indirect incidence estimates and HIV testing among men who have sex with men (MSM) in the United Kingdom

			Direct incidence estimates	Indirect incidence	estim cles	·	HIV testing		
<ul> <li>Martin Carlos and Anna Anna Anna Anna Anna Anna Anna</li></ul>				Early diagnoses	Late diagnoses			s in the unlink	ISM* attendin ed anonymou
	Age group (years)	Number of diagnoses of HIV	STARHS incidence/ 100/py	CD4 count at diagnosis >700 cells/mm <sup>2</sup>	CD4 count at diagnosis < 200 cells/mm <sup>3</sup>	Number of VCT tests at all GUM clinics*	Ali	HIV+	Acute STI
	<35 >35	+0.8% +55%	2.58; 2.8 (NS) 2.58; 4.16 (NS)	+82% +74%	- 28% - 32%	+84%	+92% +86%	+146% +130%	+162% +294%
	≪35 ≫35	+110%	2.04; 1.64 NS 1.90; 3.78 NS	+124% +235%	- 42% - 40%	+76%	+42% +51%	+171% +15%	+99% +179%
Scotland	Ali ages	+66%	NA	+86%	- 35%	+142%	+60%	+128%	+129%

GUM, Genitourinary medicine; MSM, men who have sex with men; NA, non-applicable

and GM and KR the Scottish data. SD undertook the main analysis and writing of the paper, with all authors, particularly JE, involved in interpretation of the results and drafting of the paper. ONG is the guaranter, who oversow analyses at the Health Protection Agency and also commented on the drafts. SD is currently registered for a PhD at City University, London.

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The UK has one of the most extensive HIV registry systems internationally. The study by Dougan and colleagues is an impressive exercise to explore what we can learn from such registries.4 Still, in the end it remains challenging to conclude whether increased uptake of HIV testing, a rising HIV incidence or both have contributed to the increasing number of HIV diagnoses among (older) men who have sex with men (MSM) using ecological comparisons. A useful addition that may shed more light on this issue would be to construct a mathematical model that incorporates observed data. Such models have been successfully used in the past to predict HIV spread and to assess the influence of strongly interlinked parameters.\*\*

The data presented show a stable HIV incidence among MSM in the UK. A rise in HIV incidence is not unexpected considering ongoing high levels of risky sexual behaviour and sexually transmitted infection (STI) epidemics among MSM internationally. To measure the HIV incidence in a population, however, provides a methodological and logistical challenge. The current study uses the serologic testing algorithm for determining recent HIV seroconversion (STARHS) approach that, when incorporated in existing STI/HIV screening programmes at genitourinary medicine (GUM) dinics, is an easy tool to directly estimate HIV incidence. Its wider international (European) application, when standardised, would be of great benefit to HIV incidence surveillance, considering the puzzling discrepant incidence trends found in various countries.

The UK is like, for example, The Netherlands, a country with a historically conservative HIV testing policy. This likely resulted in the still lower testing rates than those found in MSM in, for example, the US or Australia, where testing has been promoted since the beginning of the epidemic.<sup>14</sup> After the introduction of highly active antiretroviral therapy (HAART), the UK and The Netherlands changed to an active approach followed by higher testing uptake. Recently several countries, including the UK, have adopted or are planning to implement the opting-out strategy for HIV testing. This strategy has been shown to drastically reduce the number of undiagnosed HIV infections.\*\*\* Considering that a substantial proportion of patients (one in five MSM in the UK and The Netherlands, and even higher among heterosexuals) are diagnosed late in their infection, the opting-out strategy may also help to diagnose people earlier, when they have a better chance for optimal treatment."-"

Finally, this study shows the importance of differentiating by age, and agrees with other reports showing an increase in the median age of MSM at HIV diagnosis and showing that HIV incidence is no longer highest in the younger age groups.14 13 Although conventionally attention is mainly focused towards the young, older MSM should be specifically targeted in HIV and STI prevention.

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Web table: Description of surveillance systems providing data to estimate changes in HIV incidence, HIV testing and reporting of diagnoses among MSM in the United Kingdom

Data source	Methodology	Coverage and exclusions	Used in this study for:
HIV diagnoses	Surveillance began in 1982 with AIDS case reporting and expanded to include laboratory reporting of HIV diagnoses in 1985 in England, Wales and Northern Ireland (E,W&NI) and Scotland. In E,W&NI clinical HIV reports collecting more detailed demographic and epidemiological were introduced in 2000 to supplement laboratory reporting. Probable route of infection is collected for all patients.	Laboratories and clinicians throughout E,W&NI and Scotland. These data are	a) HIV diagnoses b) changes in reporting resulting from the introduction of clinical HIV reporting in 2000 in E,W&NI
Unlinked anonymous genito-urinary medicine (GUM) clinic survey	The unlinked anonymous surveys measure the prevalence of undiagnosed HIV infection in different population sub-groups. The GUM survey estimates undiagnosed HIV prevalence among MSM using residual blood (taken for syphilis serology) for HIV testing after irreversibly unlinking and anonymising the sample from any patient identifiers. Limited information is collected on acute STI diagnoses and the uptake of voluntary confidential testing (VCT).	<li>27) GUM clinics in Scotland. Note Scotlish data (amalgamated with E,W&amp;NI for analyses) does not include data from</li>	a) direct incidence estimates through STARHS b) indirect indicators of incidence c) changes in uptake of voluntary confidential testing (VCT)
CD4 surveillance systems	In England, Wales (E&W) and Scotland surveillance systems monitor trends in immunosuppression among HIV-infected adults, collecting longitudinal data on CD4 cell counts. The CD4 cell count closest to the date of HIV diagnosis is selected if it falls 31 days either side of that date.	testing laboratories in Scotland. Data for	a) indirect indicators of incidence
KC60 statutory returns	Data on selected conditions seen and HIV testing at GUM clinics throughout E,W&NI are compiled from KC60 statistical returns. Aggregate data are submitted to the respective national units of the Health Protection Agency. Male homosexual acquisition is reported with HIV testing data.	testing changed. It is still unclear how this	a) changes in HIV testing
ISD(D)5 statutory returns	In Scotland, data concerning all episodes of patient care at GUM clinics are compiled from ISD(D)5 returns. Disaggregate, anonymous data are submitted to Information Services Division, National Services, Scotland		a) changes in HIV testing
HIV denominator study	Data on voluntary named HIV testing undertaken in all settings (including GUM clinics) throughout Scotland since 1988/89. Male homosexual acquisition is reported.	Laboratories throughout Scotland. For most parts of the country, data are derived from a standardised HIV request form.	

## 3.1 Introduction

As discussed in chapter 2, "descriptive epidemiology" describes the distribution of infection and disease in terms of time, person and place (Hennekens & Buring, 1987). Presenting these distributions as rates rather than as absolute numbers is an essential part of epidemiology. According to Chin, this distinguishes the epidemiologist from the non-epidemiologist, by placing the counts in perspective and by quantifying the risk of a disease in a defined population (Chin, 2007).

Morbidity and mortality rates are the most commonly used measures of risk in descriptive epidemiology. These rates can assist in monitoring the effectiveness of prevention initiatives and the impact of treatment and care. Unfortunately, HIV diagnoses rates among men who have sex with men (MSM) are only available for large geographic areas in the UK: London, Scotland and "the rest of the UK" (Macdonald et al., 2004; Dougan et al., 2007b). The same applies for rates of HIVpositive MSM accessing HIV-related treatment and care services. Yet, only by analysing HIV rates (rather than absolute numbers) for smaller geographic areas in the UK is it possible to determine whether there is any heterogeneity in HIV transmission and prevalence among MSM between these areas, and whether this is changing over time. Likewise, only by analysing HIV rates rather than numbers is it possible to ascertain how much of the increase in HIV diagnoses among MSM in the UK can be attributed to there being a larger population of MSM, in which HIV transmission rates have remained unchanged (Dougan et al., 2007b). Ultimately, a lack of reliable information on HIV rates (rather than just numbers) makes it is difficult to focus preventive initiatives in geographic areas where HIV transmission is likely to be highest and to assess whether prevention is failing or succeeding.

In this chapter, I explore why HIV rates are not available for smaller geographic areas for MSM. In particular, I consider the challenges associated with determining an appropriate sampling frame for MSM and methodological issues in measuring MSM population denominators in England. I also investigate the impact of cross-boundary travel on HIV rates and the compatibility of numerators and denominators in rate calculations. To help illustrate these points, I present supplementary data from censuses, HIV surveillance systems and behavioural surveys, where appropriate. In the final part of this chapter, I discuss the implications of these findings for my own research. I also make recommendations for improving epidemiological information on HIV rates among MSM for smaller geographic areas in England.

Other UK countries (Scotland, Wales, Northern Ireland) are not formally considered here because of differences in health geographies (e.g. Strategic Health Authorities (SHAs) in England versus Health Boards in Scotland) (ONS, 2003), population censuses, behavioural surveys and the small number of HIV positive MSM even at a national level (The UK Collaborative Group for HIV and STI Surveillance, 2005). However, the major issues raised in this discussion are relevant to the other countries in the UK, as well as further afield.

# 3.2 Research findings from my published papers

In the first published paper, on recent trends in diagnoses of HIV and other sexually transmitted infections (STIs) in England and Wales, we presented data for: (i) MSM in London and (ii) MSM in the rest of England and Wales, since we were constrained by available population denominators i.e. the estimated number of MSM in London and the rest of England and Wales (Macdonald *et al.*, 2004). In 2002, the

crude HIV diagnosis rate among MSM in England and Wales was 601/100,000, with a much higher crude rate in London (>1100/100,000) and lower crude rate outside London (<500/100,000) (Macdonald *et al.*, 2004). As with diagnoses of gonorrhoea and syphilis, the crude HIV diagnosis rate among MSM increased substantially in England and Wales between 1997 and 2002 (Macdonald *et al.*, 2004).

Further research, presented in the second published paper, investigated whether an increase in HIV incidence or an increase in HIV testing had led to the observed increase in HIV diagnoses among MSM in England and Wales between 1997 and 2004 (Dougan *et al.*, 2007b). The published paper was accompanied by a commentary by Dukers (Dukers, 2007). MSM were broken down by both age and geography in this paper, as behavioural surveillance data and HIV surveillance data (from the Netherlands) indicated differences in behaviours (by age and geographic location) that would impact on HIV incidence rates (Dukers *et al.*, 2002; Dodds *et al.*, 2004). Comparisons were made between:

- (i) MSM aged less than 35 years in London
- (ii) MSM aged 35 years and above in London
- (iii) MSM of all ages in Scotland
- (iv) MSM aged less than 35 years in the rest of the UK
- (v) MSM aged 35 years and above in the rest of the UK.

In this paper however, the absolute number of HIV diagnoses had to be analysed rather than rates because of the lack of denominators for MSM by age and geographic location over time. I concluded that there was no evidence of an increase in HIV incidence among MSM in the UK and that the increase in the number of HIV diagnoses could be explained by an increased uptake of HIV testing and to a lesser extent, outside London only, in reporting changes (Dougan *et al.*, 2007b).

**.** .

In both papers (Macdonald *et al.*, 2004; Dougan *et al.*, 2007b), data analysis was constrained by the lack of MSM population denominators for calculating rates for small geographic areas broken down by age over time (Macdonald *et al.*, 2004; Dougan *et al.*, 2007b). Clearly, there will be considerable heterogeneity in the epidemiology of HIV among MSM within London but perhaps more importantly across the rest of the country. Manchester and Brighton are known to have large populations of MSM whereas more rural areas are likely to have fewer MSM. In addition, there may have been changes in the size of the MSM population in different geographic areas over time. The ability to assess regional and more 'local' trends over time is important for those working in the arena of gay men's sexual health at all levels, from national policy-makers to local health promoters.

# 3.3 Calculating crude rates of diagnosed HIV infections

To calculate crude rates, information is required on the number of HIV diagnoses or number of diagnosed HIV positive MSM (numerator) and the corresponding total population figures (denominator).

For example:

To calculate age-specific rates, the numerator and denominator need to be restricted to the specific age group.

Broadly, numerators and denominators should correspond in terms of:

- (i) definition of a 'MSM'
- (ii) geographic location and its measure
- (iii) age group
- (iv) time period

Numerator data are obtained from the two main HIV surveillance systems in England collecting epidemiological data on diagnosed HIV positive MSM for which rates can be calculated: (i) reports of HIV diagnoses (from laboratories and clinicians (The UK Collaborative Group for HIV and STI Surveillance, 2005)) and (ii) the Survey of Prevalent HIV Infections Diagnosed (SOPHID) (an annual cross-sectional survey obtaining information on people accessing National Health Service (NHS) HIV-related treatment and care services within a calendar year (Molesworth, 1998). Data are routinely available by age group and Strategic Health Authority (SHA) on an annual basis (The UK Collaborative Group for HIV and STI Surveillance, 2005).

Unfortunately, the available denominator data on the MSM population are not as sophisticated. Denominators on the number of *all* MSM in England are currently obtained by applying the prevalence of anal sex among men from the National Surveys of Sexual Attitudes and Lifestyles (Natsal) to the male population, enumerated in the census (Johnson *et al.*, 2001; Mercer *et al.*, 2004). Only those MSM who have had anal sex are included in the denominator because the risk of acquiring HIV and some STIs is much higher among MSM who engage in anal

sex. However this excludes men who only engage in oral sex who may also be at risk of STIs We used data from Natsal to provide denominators for the paper on rates of HIV and STI diagnoses among MSM in England and Wales (Macdonald *et al.*, 2004). However, as previously mentioned these are only available for large geographic areas and were not available by age group which severely constrains analysis.

# 3.4 Defining and enumerating MSM

## 3.4.1 Who is a 'MSM'?

Sexuality is multi-faceted and can be described in terms of sexual behaviour, sexual desire or sexual identity, or any combination of these factors (McManus, 2003; see also: Kinsey et al., 1948; Fay et al., 1989; Sell, 1997; Diamond, 2004). For example, a man who engages in anal sex may not identify as gay; a man who desires anal sex may not engage in it nor identify as gay; and a man who identifies as gay may not have had anal sex for several years. Weatherburn et al, state that "while there is no straightforward relationship between sexual identity and sexual behaviour, the vast majority of exclusively homosexually active men are probably gay (or bisexual), and the majority of behaviourally bisexual men are certainly not gay, and may not identify as bisexual" (Weatherburn et al., 1999). Concepts of sexuality also vary according to a range of social and demographic factors including ethnicity, migration and socio-economic status (Weatherburn et al., 1999; McManus, 2003). Sexuality is a fluid concept and may change within an individual over time and be felt differently by different individuals (McManus, 2003; Rosario et al., 2006; Savin-Williams & Ream, 2007). Fluidity, it is argued, is particularly relevant to young people (McManus, 2003; Rosario et al., 2006).

Several studies have shown discordance between sexual behaviours and selfreported sexual identity (Laumann et al., 1994; Sell et al., 1995; Huber & Kleinplatz, 2002; Smith et al., 2003; Pathela et al., 2006a). Data from the Australian Study of Health and Relationships undertaken in 2001-2002 clearly demonstrate quantitative differences in the prevalence of sexual behaviour, identity and desire (Smith et al., 2003). In the study, 1.6% of men identified as gay and 0.9% as bisexual. But overall, 8.6% of men reported either feelings of attraction to the same sex or some sexual experience with the same sex (Smith et al., 2003). Half of the men who had a same sex experience regarded themselves to be heterosexual rather than homosexual (Smith et al., 2003). The authors concluded that same sex attraction and experience are more common in Australia than is indicated by only those reporting a homosexual or bisexual identity. The nature of the question on sexual behaviour, sexual identity or sexual desire is therefore crucial in the collection of data on the number of 'gay men' or MSM in a population (Sell & Petrulio, 1996; Pathela et al., 2006b). The definition needs to be appropriate for the topic being researched (Sell & Becker, 2001; McManus, 2003). To examine discrimination, for example, sexual identity may be most appropriate. For sexual health research, including HIV epidemiology, however, sexual behaviour is likely to be the most appropriate measure. This is because the transmission of HIV and other STIs is associated with sexual behaviours and not with identity or desire alone.

To distinguish sexual behaviours placing individuals at risk of HIV (and other STIs) from sexual identity and desire, a new behavioural category began to be used in the epidemiological literature on HIV in the 1990s - 'men who have sex with men' (Young & Meyer, 2005). The acronym, MSM, began to be used shortly afterwards (Young & Meyer, 2005). In epidemiological terms, the use of MSM helps to avoid the complex social and cultural issues which are not directly related to HIV transmission.

The use of the term MSM may have helped reduce stigma in 'gay' populations. However, some commentators argue that it has undermined efforts to reduce HIV transmission (King, 1994) because it does not sufficiently describe the variations in sexual behaviours and no-one identifies as being a 'MSM' (Young & Meyer, 2005).

Nevertheless, many epidemiological studies and public health surveillance systems. collect data on MSM defined behaviourally. It is necessary to define what 'sex' is (e.g. oral, genital, anal), the frequency of these behaviours (e.g. daily) and timing (e.g. in the past five years). In the British National Survey of Sexual Attitudes and Lifestyles in 2000 (Natsal 2000), for example, 8.4% (95% confidence interval: 7.6%-9.3%) of men reported ever having a homosexual experience (defined as any experience with men such as touching and kissing that did not necessarily lead to genital contact) but only 5.4% (95% CI: 4.8%-6.1%) reported ever having homosexual intercourse (defined as oral or anal sex or any other genital contact with a man) (Mercer et al., 2004). This definition has been further refined by some, including the Health Protection Agency, to only include men who specifically reported insertive and/or receptive anal intercourse with at least one male partner in the five years prior to interview (Macdonald et al., 2004; The UK Collaborative Group for HIV and STI Surveillance, 2005). Of those who reported ever having homosexual intercourse in Natsal 2000, 44.7% (95%CI: 38.4-51.1%) reported only one male partner ever and 53.9% had not had a male partner in the past 5 years (Mercer et al., 2004). Those reporting no male partners in the past 5 years may be men who had a 'one-off male sexual partner, perhaps while young and experimenting with their sexuality. The time-frame used may therefore have implications for whether some men are considered as MSM. This is likely to affect estimates of younger MSM since the 'past 5 years' may include experimental periods, while the 'past year' may give a more realistic picture of behaviour.

These distinctions are important as the transmission of HIV and STIs requires specific sexual behaviours (i.e. not just touching or kissing) and the risk of acquiring an infection will increase with the number of sexual partners as well as the type of sexual act (Varghese *et al.*, 2002), and a man's current risk of having HIV or an STI may depend on how along ago they had sexual contact. These distinctions allow the exclusion of men who have experimented with their sexuality (e.g. young men), but who have not had homosexual intercourse that may lead to the transmission of HIV. If these men are not excluded, then any MSM denominator would be inflated by 'low risk' men.

The UK's HIV surveillance systems collect information on sexual behaviour (i.e. anal/oral sex between men) to derive the number of MSM diagnosed with HIV. In theory, sexual identity and desire should not be taken into consideration when health workers complete these surveillance forms. However, the accuracy of reporting depends on the individual disclosing details of their sexual behaviours to the health care worker. Disclosure may not always occur. For example, there is some evidence that black and other ethnic minority men may not disclose sex with another man for cultural reasons or because of stigma and discrimination, and have different sexual identities (e.g. "down-low" a term used in the US and to a lesser extent in the UK to describe men having sex with other men without their female sexual partner's knowledge) to white MSM (Kennamer et al., 2000; Millett et al., 2005; Miller et al., 2005; Wolitski et al., 2006). When calculating rates of HIV diagnoses or rates of MSM accessing HIV-related treatment and care services, it is important that the population denominator is MSM, based on sexual behaviour rather than sexual identity or sexual desire, as this will correspond with the numerators.

## 3.4.2 Can existing census data be used to derive a denominator for MSM?

Census data are the most comprehensive source of population data. However, information is not collected on sexual identity, behaviours or desire in any national censuses at present. Some censuses, including censuses in England and Wales, collect information on co-habiting same-sex couples as part of the household question (ONS, Census 2001), but as will be demonstrated here, these data are not suitable for obtaining a robust estimate of the MSM population in England. Many of the considerations below also apply to data that are becoming available on the number of civil partnerships between same-sex couples.

In the United States (US), census data on co-habiting same-sex couples have been collected since 1990 and have been used to give a measure of the number of gay men in the US (Gates, 2004). In the 2000 US Census there were 594,391 same-sex 'unmarried partner' co-habiting couples, of which 301,026 (51%) were male couples (Gates, 2004). While these data represent the largest and most comprehensive source of data on 'gay' couples living in the US, they will be a minimum estimate for the following reasons (Gates, 2004):

- men who have a same-sex partner but live alone or have other living arrangements will be excluded;
- those who lived together but did not consider themselves to be in an 'unmarried partnership' will not be included;
- fear of stigma and discrimination may have led some people to conceal this information.

In addition, there is also some ambiguity about what is being measured in terms of sexual behaviour, sexual identity and/or sexual desire. Do those co-habiting as a

same-sex couple identify as gay? Do they practise sexual behaviours that are consistent with being categorised as MSM?

Data from the England and Wales census are subject to the same limitations as in the US, but in addition, data are not published by gender and so it is not possible to distinguish between same-sex female or male couples. Table 3.1 contains data on co-habiting same-sex couples (men and women combined) collected in the 2001 Census by English region. As a proportion of total persons in each region, the prevalence of co-habiting same-sex couples is very low, ranging from 0.1% in the North East region to 0.4% in London. Data from Natsal 2000 indicates that using census data on co-habiting same-sex couples would grossly underestimate the number (and proportion) of MSM in England and Wales. Only 28.4% (95% confidence interval: 21.0%-37.1%) of MSM in Natsal 2000 reported currently cohabiting with a male partner (Mercer *et al.*, 2004). A further 54.8% (95% confidence interval: 46.3%-63.0%) described themselves as 'single, never married' (Mercer *et al.*, 2004).

Given the paucity of national data on lesbian, gay, bisexual and transgender (LGBT) populations and the recognition by the Commission of Equality and Human Rights (CEHR) of sexual orientation as a diversity strand of equal standing to race, gender, age, disability and religion, there have been consultations about the inclusion of a question on 'sexual orientation' in the 2011 Census (ONS, 2006). It is currently the only diversity strand which is not included in the census.

Debate has centred on the purpose of asking this question (political, health or discrimination). Following on from this, what should be measured (identity, behaviour or desire) and how this question could be asked (Breithenbach, 2004:

Table 3.1: Number and proportion of persons (men and women) living in same-sex couple households by English region, 2001

Region of residence	No. of persons* living in same sex couple household	Total no. of persons in households	% of persons* living in same- sex couple households
North East	2,308	1,976,268	0.12%
North West	8,346	5,226,576	0.16%
Yorkshire & Humber	6,310	3,868,291	0.16%
East Midlands	5,070	3,261,600	0.16%
West Midlands	5,552	4,093,944	0.14%
South West	7,018	3,882,983	0.18%
East of England	6,458	4,218,352	0.15%
London	21,366	5,632,491	0.38%
South East	13,318	6,232,799	0.21%
Total	5,552	4,093,944	0.14%

\*men and women

Source: Office for National Statistics, 2001 Census, table UV93

Statistics New Zealand, 2003; General Register Office for Scotland, 2006, ONS, 2006; Statistics Canada, 2006). There have also been concerns about the quality and accuracy of responses, and the acceptability and impact on census response rates (ONS, 2006). No census as yet, collects these data.

Conceptually there are difficulties in developing a single census question on sexual orientation that people can easily understand and interpret, given its multi-faceted nature (McManus, 2003). There are also concerns about the quality and accuracy of responses, and particularly that "inaccurate quantitative data could then be used to reduce the level of recognition, funding of or service provision to that community" if a significant proportion of the LGBT community did not disclose their sexual orientation (Barry, 2000; Statistics New Zealand, 2003). Given the relatively small size of the population, even modest measurement problems could result in serious errors (Black et al., 2000). In pre-testing potential questions for the forthcoming Scottish census, only 2.2% of respondents declared non-heterosexual sexual orientation (General Register Office for Scotland, 2006). Non-response to the sexual orientation question was around 6% with a further 8,5% of respondents selecting "Prefer not to answer", equating to a total of 14% of respondents providing no useful data on sexual orientation (General Register Office for Scotland, 2006). Reasons for non-disclosure may include fear of stigma and discrimination - there has been historical misuse of administrative data to persecute people on the grounds of sexual orientation, as in France during World War II (Nadeau & Barlow, 2004) - and people still experience stigma, discrimination and even extreme violence related to their sexuality (see for example: BBC, 2006b; BBC, 2007a; BBC, 2007b). Other reasons for non-response may include uncertainty about sexuality, particularly among young people (McManus, 2003; Statistics New Zealand, 2003); feeling that the question invades privacy (Statistics New Zealand, 2003); and because the census forms are completed by proxy by one person in the household who may not be aware of everyone's sexuality in their household (Statistics New Zealand, 2003). There are also concerns that the introduction of a question on sexual orientation may reduce the census response rate overall (McManus, 2003). Finally, a question on sexual orientation may not allow the census to accurately identify the population of "men who have sex with men".

As a result of these conceptual difficulties and operational concerns, ONS (and other international statistical agencies) will not be introducing a question on sexual orientation in the 2011 Census (Breithenbach, 2004; McManus, 2003; Statistics New Zealand, 2003; General Register Office for Scotland, 2006; ONS, 2006; Statistics Canada, 2006). ONS however, has recognised the need for more information on sexual orientation and will be setting up a programme of work to address the most suitable way of meeting this need in the future.

## 3.4.3 Using behavioural survey data to enumerate MSM

In the absence of census data, we have to rely on behavioural surveys to estimate the size of the MSM population. In conjunction with census population denominators for all men, behavioural survey data has been used to calculate the number of MSM.

For example:

MSM population		Prevalence of reported anal sex among		Male population
	=	men (aged 16-44 years) in the 5 years prior	х	(aged 16-44 years)
(aged 16-44 years)		to Natsal interview		(ageu 10-44 years)

In Britain, the Natsal surveys were conducted in 1990 and 2000 (Wellings *et al.*, 1990; Johnson *et al.*, 1992; Johnson *et al.*, 2001). These were large probability

sample surveys among adults aged 16-59 years (1990) and 16-44 years (2000) (1990: 13,765 respondents [6000 men]; 2000: 11,161 respondents [4762 men]) (Johnson *et al.*, 2001; Mercer *et al.*, 2004). Data were collected on the prevalence of ever having anal sex in men aged 16-44 years, and in the five years prior to interview (Johnson *et al.*, 2001; Mercer *et al.*, 2004). The actual number of men reporting homosexual intercourse was small (133 in 2000 (Mercer *et al.*, 2004)) but as the sample was large and considered to be representative, the resulting proportion is considered to be robust (Johnson *et al.*, 2004).

Natsal data highlight geographic differences in the prevalence of anal sex among men. In 2000, the proportion reporting anal sex in the five years prior to interview was higher for men in Greater London (4.3% [95% confidence interval: 3.2%-5.8%]) compared to the rest of England (1.6% [95%CI: 1.2%-2.1%]) (C Mercer, personal communication). In 2000, a greater proportion of MSM in the Natsal sample lived in London compared with other men (30.1% [95%CI: 23.5-37.5%] vs. 14.4% [95%CI: 13.3-14.7%]; p<0.0001) (Mercer *et al.*, 2004).

Data however, have not been published for smaller geographic areas than "Greater London" and "elsewhere in Britain" due to wide and overlapping confidence intervals around prevalence estimates for the different regions. Table 3.2 shows these prevalence estimates along with the size of the male population in each English region, and an estimate of the total number of MSM aged 16-44 by region. London has the highest prevalence of anal sex in the past 5 years among men aged 16-44 years at 4.3% (95%CI: 3.2%-5.8%). Combined with a large male population, this gives an estimate of 79,191 MSM residents in 2004, ranging from 58,980 to 105,650. Outside London, prevalence of anal sex was highest in Yorkshire and The Humber (2.6%) and the North West (2.0%) regions and lowest in the South West

(0.8%). Confidence intervals around these estimates for outside London however, are large and all overlap. The uncertainty around the prevalence estimates from Natsal 2000 translates into uncertainty about the number of MSM living in each region. For example, in the East Midlands there were an estimated 15,944 MSM resident in 2004, but this estimate ranged from 7255 to 34,587 MSM.

I used the MSM population estimates in table 3.2 to calculate rates of HIV diagnoses and diagnosed prevalence among MSM in different English regions in 2004 (table 3.3, figure 3.1). As would be expected, the diagnosed prevalence rate and rates of HIV diagnoses among MSM were highest in London, although there was a level of uncertainty around these rates. For example the diagnosed prevalence rate was 87.3 per 100,000 resident MSM in London, ranging from 65.4 to 117.2 per 100,000 (table 3.3). Outside London, ranges were wide limiting their utility. For example, the rate of HIV diagnoses in the North West was 8.3 per 100,000 resident MSM, ranging from 4.1 to 17.1 per 100,000. Despite the uncertainty around the rate estimates, the overall pattern did correspond to conventional wisdom about where MSM are resident in England, with highest HIV rates in London, South East (includes Brighton), South West (includes Bristol) and North West (includes Manchester).

Other behavioural surveys of MSM in the UK (such as London Gay Men's Sexual Health Surveys, London Gyms' Study and Sigma's National Gay Men's Sex Survey) do have larger samples of MSM than the Natsal surveys (Dodds *et al.*, 2004; Elford *et al.*, 2004; Weatherburn *et al.*, 2005). However, these are convenience samples and two of the surveys only recruit men in London (Dodds *et al.*, 2004; Elford *et al.*, 2004). Convenience samples typically capture 'higher risk' MSM so are not as useful as probability samples for examining the sexual behaviour of MSM in the population overall. For example, Dodds *et al.* compared MSM included in the Natsal 2000

survey with those participating in the London Gay Men's Sexual Health Surveys (Dodds *et al.*, 2006). They showed that those in the convenience sample engaged more frequently in high risk sexual behaviours and reported more STIs compared to MSM in Natsal (Dodds *et al.*, 2006). Similarly, Evans *et al.* compared the sexual behaviour of MSM in an online internet sample with Natsal 2000, and again found that the convenience sample was overestimating high sexual risk behaviour compared to Natsal (Evans *et al.*, 2007).

## 3.5 Age groups

The Natsal 2000 survey only interviewed people aged 16-44 years (Johnson *et al.*, 1992; Johnson *et al.*, 2001). Strictly therefore, rates of HIV diagnoses and diagnosed prevalence (numbers accessing HIV-related care) should be calculated only for those aged 16-44 years. Data from SOPHID however, show that the number of MSM aged over 44 years accessing HIV-related treatment and care services in England has increased over time, from 2565 in 2000 to 4877 in 2004 (HPA, 2005). This is related to improved survival since the introduction of highly active antiretroviral therapies (HAART) in the mid-1990s but also continued, and possibly increased, transmission of HIV among older MSM (Dougan *et al.*, 2007b). In 2004, 30% of diagnosed MSM accessing HIV-related services were aged over 44 years, with variation by region, from 25% in the North West to 38% in the South West (HPA, 2005). Given the substantial proportion of HIV-diagnosed MSM who are aged more than 44 years, it is appropriate to include them in rate calculations.

But is the prevalence of anal sex in the past 5 years, from which we derive our estimate of the MSM population, the same in older age groups as for men aged 16-44 years? Natsal data for London and the rest of England show no significant

Table 3.2: Estimates of the number of men who have sex with men (aged 16-44) living in English regions in 2004 using data from

Natsal 2000 and the Census

	Nats	al 2000		2004 mid-year Census estimates	2004 MSM estimates			
Government Office Region	Prevalence of anal sex with another man in past 5 years among men aged 16-44	Lower confidence interval	Upper confidence interval	Male population aged 16-44	Number of MSM aged 16- 44	Lower estimate	Upper estimate	
North East	1.8%	0.7%	4.9%	491,271	8990	3292	24121	
North West	2.0%	1.0%	4.2%	1,336,779	27270	13234	55744	
Yorkshire & The Humber	2.6%	1.2%	5.4%	996,430	25409	11858	53508	
East Midlands	1.9%	0.9%	4.1%	843,591	15944	7255	34587	
West Midlands	1.3%	0.5%	3.6%	1,050,588	14078	5148	37821	
South West	0.8%	0.3%	2.5%	936,398	7491	2435	22942	
East of England	1.3%	0.5%	3.1%	1,063,134	13502	5422	32745	
London	4.3%	3.2%	5.8%	1,837,389	79191	58980	105650	
South East	1.1%	0.5%	2.5%	1,590,081	17809	7791	39752	

**Sources:** National Survey of Sexual Attitudes and Lifestyles (Natsal) 2000, Dr Catherine Mercer, personal communication; Office for National Statistics, 2001 Census; Health Protection Agency, SOPHID 2004.

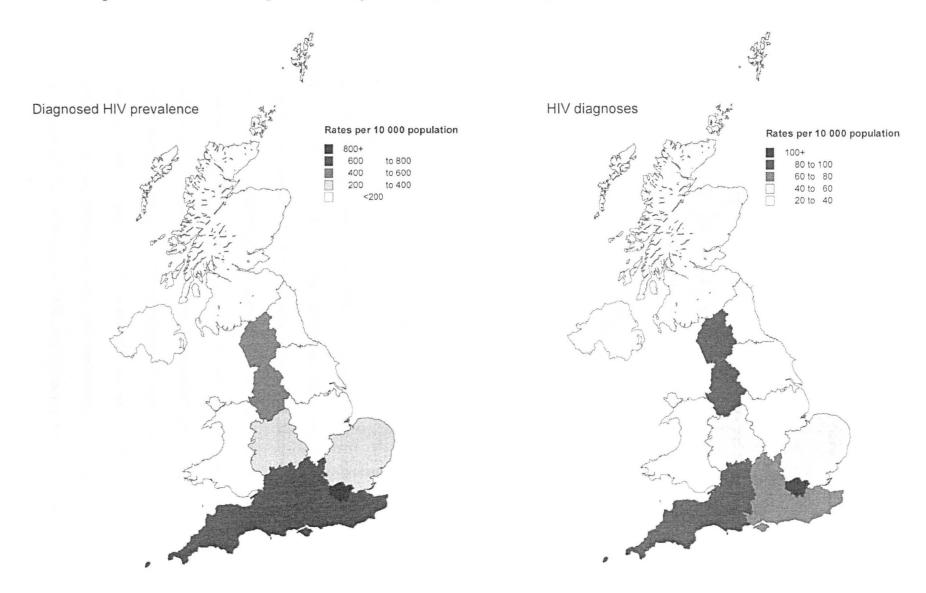
Table 3.3: Estimates of rates of diagnosed HIV prevalence and HIV diagnoses among men who have sex with men (aged 16-44)

by English region in 2004

Government Office Region	Diagnosed MSM a	ccessing HIV-related (SOPHID)		Newly HIV diagnosed MSM				
	Number of MSM aged 16-44 accessing care	Diagnosed prevalence rate per 100,000 MSM aged 16-44	Lower estimate	Upper estimate	Number of HIV diagnoses among MSM aged 16-44	Rate of HIV diagnoses per 100,000 MSM aged 16-44	Lower estimate	Upper estimate
North East	161	17.9	6.7	48.9	30	3.3	1.2	9.1
North West	1397	51.2	25.1	105.6	226	8.3	4.1	17.1
Yorkshire & The Humber	348	13.7	6.5	29.3	67	2.6	1.3	5.7
East Midlands	274	17.2	7.9	37.8	40	2.5	1.2	5.5
West Midlands	510	36.2	13.5	99.1	84	6.0	2.2	16.3
South West	466	62.2	20.3	191.4	65	8.7	2.8	26.7
East of England	404	29.9	12.3	74.5	70	5.2	2.1	12.9
London	6913	87.3	65.4	117.2	971	12.3	9.2	16.5
South East	1186	66.6	29.8	152.2	139	7.8	3.5	17.8

Sources: Survey of Prevalent HIV Infections Diagnosed (SOPHID), 2004; reports of HIV diagnoses, 2004; National Survey of Sexual Attitudes and Lifestyles (Natsal) 2000, Dr Catherine Mercer, personal communication; Office for National Statistics, 2001 Census.

Figure 3.1: Rates of HIV diagnoses and diagnosed HIV prevalence among men who have sex with men by English region, 2004



Source: Survey of Prevalent HIV Infections Diagnosed (SOPHID) and reports of HIV diagnoses, 2004

differences in the prevalence of anal sex in the past 5 years among MSM by age group. This could be due to the small sample size rather than there being no variation in behaviour by age (table 3.4).

Without further data, it is difficult to assess whether or not there are differences in the number of MSM by age but having information on the denominator of 'older' MSM will become increasingly important as HIV positive individuals continue to survive for longer.

## 3.6 Time period

There is some evidence that the size of the MSM population may have grown over time. Given that Natsal surveys are only undertaken on a decennial basis, and questions are asked about the five years prior to interview, this may impact on the accuracy of HIV rates at a given point in time depending on the magnitude of the increase relative to the baseline measurement. For example, in the first Natsal survey (Natsal 1990), 1.5% (95% confidence interval: 1.2%-1.9%) of men aged 16-44 years in Britain reported sex with another man in the 5 years prior to interview (Mercer et al., 2004). In Natsal 2000, the equivalent figure was 2.8% (95% confidence interval: 2.3%-3.3%) (Mercer et al., 2004). Mercer et al. emphasise that the increase in reporting of anal sex over time however, may not be entirely due to changes in sexual behaviour but may, in part, have resulted from changes in respondents' willingness to report this socially-censured behaviour (Mercer et al., 2004). Attitudinal changes in the acceptance of homosexuality may have increased the willingness to report these behaviours, as well as improvements in survey methodology – a computer assisted self-interviewing (CASI) was used for sensitive questions in 2000, whereas in 1990 pen-and-paper interviewing had been used Table 3.4: Prevalence of anal sex in past five years in London and the rest of England by age group, 2000

	Lond	on		Rest of England					
Age group	Prevalence of anal sex in past 5 years	A State of the Astronomy	nfidence erval	Prevalence of anal sex in past 5 years	95% confidence interval				
16-19	2.2%	0.7%	7.3%	0.2%	0.0%	1.3%			
20-24	5.6%	2.7%	11.3%	1.5%	0.6%	4.1%			
25-29	3.9%	2.0%	7.5%	2.2%	1.1%	4.1%			
30-34	5.7%	3.1%	10.2%	2.2%	1.2%	4.0%			
35-39	3.9%	2.1%	7.2%	2.0%	1.1%	3.6%			
40-44	3.3%	1.6%	6.8%	0.9%	0.4%	2.0%			
Total	4.3%	3.2%	5.8%	1.6%	1.2%	2.1%			

Source: Natsal, 2000

(Mercer *et al.*, 2004). Nevertheless, the authors conclude that some increase in the population numbers of MSM and/or the prevalence of risk behaviours among MSM between 1990 and 2000 is likely (Mercer *et al.*, 2004; Mercer *et al.* 2005). Migration of MSM to Britain may have also increased the size of the MSM population, but there are no available data on the sexuality of migrants. Boily *et al.* also suggest that some (<10%) of the increase in the MSM population between 1990 and 2000 was due to improved survival of HIV positive MSM from the introduction of HAART (Boily *et al.*, 2005a). Taken in concert, it seems likely that the increase in the prevalence of MSM between 1990 and 2000 was the result of several different factors, including a genuine increase in the proportion of men having homosexual sex (Mercer *et al.*, 2005).

# 3.7 Cross-boundary travel for HIV diagnosis and treatment

A further important consideration when examining the geographic distribution of HIV infection in England is the impact of cross-boundary travel for HIV diagnosis and treatment.

Calculations of rates of HIV diagnoses at a regional or SHA-level (pre-2006 SHAs) have to be made on the assumption that the majority of MSM are diagnosed within their region or SHA of residence, as information on area of residence is not collected by the HPA. GUM clinics however, are open access and MSM may travel to attend services outside their local area. Research has shown that patients may be influenced by choice of service on the basis of waiting times and reputation (Burge *et al.*, 2004). So is the assumption that MSM will be diagnosed within their region or SHA of residence valid, and if not, will it impact on the rates of HIV diagnoses? The answer to these questions can be elucidated by using data on MSM accessing HIV-

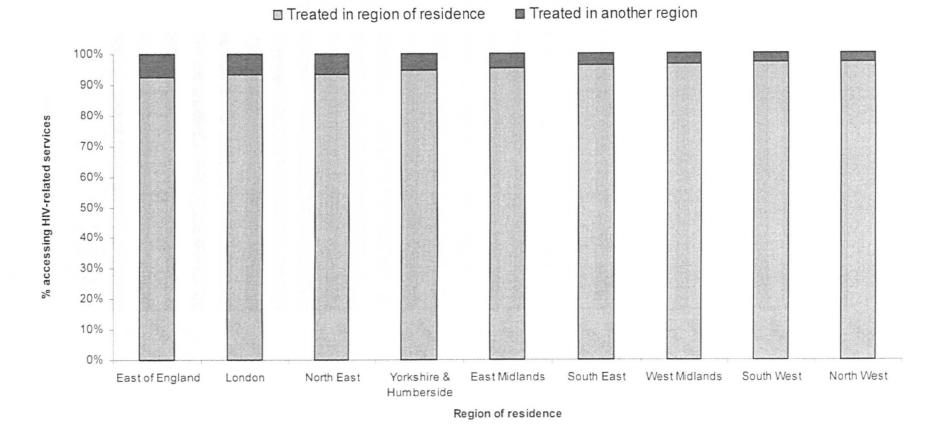
related treatment and care services (from the SOPHID survey) since data on both area of residence and area of treatment are collected.

Figure 3.2 shows the proportion of HIV-diagnosed MSM aged 16-44 that were accessing HIV-related services in, and outside their region of residence in 2004. For all regions, more than 90% of HIV-diagnosed MSM sought HIV care in their region of residence, ranging from 93% in the East of England (260/281), London (6877/7370) and the North East (156/167) to 97% in both the South West (391/403) and North West (1368/1409) regions. These percentages have been calculated using the number of HIV-diagnosed MSM aged 16-44 accessing HIV care in the region in which they were resident (numerator) and the total number of HIV-diagnosed MSM aged 16-44 accessing HIV care in the region is (denominator).

On the other hand, when looking at smaller geographic areas, MSM are not always seeking care in their area of residence. This is most pronounced in London. Figure 3.3 shows that less than half the MSM seeking care in North Central and North West London SHAs were resident there. Similarly, a third of MSM seeking care in South West and North East London SHAs and a quarter of MSM in South East London, are non-residents. Outside London, a fifth of MSM seeking care in County Durham and Tees Valley SHA and Northumberland Tyne and Wear SHA were non-residents.

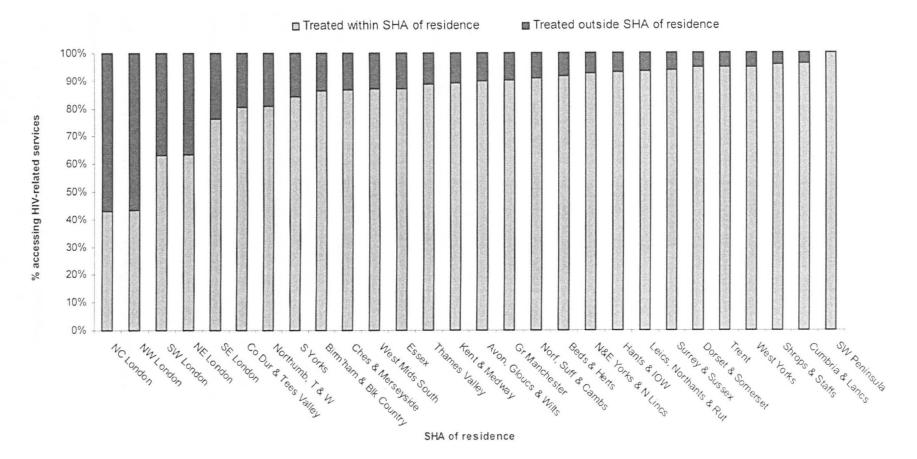
Assuming that patterns of cross-boundary travel for HIV-related treatment and care are similar for HIV diagnoses, my analyses suggest that region of treatment or diagnosis is a relatively good proxy for region of residence. SHA-level analyses

Figure 3.2: Proportion of HIV-diagnosed men who have sex with men (aged 16-44) accessing HIV-related treatment within or outside their English region of residence, 2004



Source: Survey of Prevalent HIV Infections Diagnosed (SOPHID), 2004

Figure 3.3: Proportion of HIV-diagnosed men who have sex with men (aged 16-44) accessing HIV-related treatment within or outside their English Strategic Health Authority (SHA)\* of residence, 2004



## \*pre-2006 SHAs

Source: Survey of Prevalent HIV Infections Diagnosed (SOPHID), 2004

however, are subject to error since a significant proportion of MSM in some areas are seeking care outside their SHA of residence.

# 3.8 Implications and recommendations

## 3.8.1 Implications for my research

A full appreciation of the difficulties in calculating HIV rates among MSM in smaller geographic areas will inform future routine surveillance and research work. Previous research (Macdonald *et al.*, 2004) could have been strengthened by calculating rates of HIV and STI diagnoses for MSM aged 45 years and above since a substantial proportion of those being diagnosed are in this older age group. Similarly, my research on why the number of HIV diagnoses has been increasing among MSM (Dougan *et al.*, 2007b), could have also been strengthened by providing rates of HIV diagnoses and testing, particularly outside of London.

Findings from this chapter suggest that rates of HIV and STI diagnoses, with clinicbased numerators and residence-based denominators, should *not* be calculated at SHA-level in the light of cross-boundary travel for HIV-related treatment and care. Since the SOPHID survey collects data on area of residence however, rates of diagnosed prevalence can be robustly calculated for smaller geographic areas.

# 3.8.2 Recommendations for calculating rates of HIV diagnoses and diagnosed prevalence

3.8.2.1 Appreciating the difference between sexual behaviour, sexual identity and sexual desire

It is important that those collecting and utilising HIV surveillance data understand the concept of 'MSM'. It is a measure of sexual behaviour rather than sexual identity or desire. It cannot just be assumed that those classified as MSM identify as gay or bisexual and will access services targeted at these men. Instead, they may identify as heterosexual. Because of the differences between sexual behaviour, identity and behaviour, denominator data should measure sexual behaviour rather than desire or identity when calculating rates of HIV diagnoses or diagnosed HIV prevalence.

## 3.8.2.2 Obtaining robust estimates of the number of MSM for different geographic

## areas

Data on sexual orientation is not collected in the census and there are no immediate plans for its introduction due to conceptual difficulties and concerns about quality, accuracy and response rates. The only suitable data on sexual behaviours for calculating the number of MSM living in England are obtained from the Natsal surveys (1990 and 2000), specifically the prevalence of anal/oral sex among men in the 5 years prior to interview. Unfortunately due to small sample size, robust estimates of the number of MSM are not available at a regional level. It would seem that estimates for London and the rest of England are the best available at the moment, because of the uncertainties around estimates for smaller geographic areas.

To be able to calculate rates of HIV diagnoses and diagnosed prevalence for smaller geographic areas robust denominator data on the number of MSM are therefore required. This would either involve increasing the sample size of the Natsal MSM population which may not be economically or logistically feasible, or collection of sexual behaviour on other national surveys. This latter method would be the best approach for obtaining denominators on MSM that could be stratified for

smaller geographic areas (e.g. by SHA). ONS is investigating the collection of data on sexual orientation on surveys other than the census (e.g. the Integrated Household Survey) (ONS, 2007), and it would be worth keeping abreast of these developments and consultations to see if small area geographic data become available in the future. However, if data are collected on the other dimensions of sexuality such as identity or desire rather than sexual behaviour, current research suggests that these will be of limited use in calculating HIV rates (Smith *et al.*, 2003; Mercer *et al.*, 2004).

## 3.8.2.3 Inclusion of older men in rate calculations

Given that nearly a third of all MSM accessing HIV-related treatment and care services in 2004 were aged over 44 years, rates of diagnosed prevalence and HIV diagnoses should be calculated for older age groups too. Historically rates have only been calculated for MSM aged 16-44 years (Macdonald *et al.*, 2004; The UK Collaborative Group for HIV and STI Surveillance, 2005), constrained by the Natsal prevalence estimates which are for this age group only. Until more data are available on sexual behaviours among men aged over 45 years however, this will be difficult to achieve with any precision.

## 3.8.2.4 Time considerations

The Natsal surveys are decennial, and factors other than actual changes in the size of the MSM population may affect estimates of the prevalence of MSM in Britain. Importantly, more willingness to report anal sex may contribute to increasing numbers rather than actual changes in behaviour. Furthermore, it is not possible to monitor whether more MSM are migrating to the UK from other countries and how many MSM in the UK are emigrating over time. Finally, improved survival of HIV positive MSM because of HAART may have had an impact (Boily *et al.*, 2004; Boily *et al.*, 2005a). However, Mercer *et al.* argue that this impact on the total MSM population will have been relatively small (Mercer *et al.*, 2005). Given these difficulties in quantifying changes in behaviour versus reporting changes and also migration patterns among MSM, I would recommend that those analysing and interpreting rates data are aware of these constraints.

## 3.8.2.5 Taking into account cross-boundary travel for diagnosis and treatment

While region of treatment or diagnosis is a relatively good proxy for region of residence, SHA (pre-July 2006) of diagnosis or treatment is not, because of crossboundary travel for care. Rates of HIV and STI *diagnoses* should not be calculated for some of these smaller geographic areas because of the magnitude of crossboundary travel in certain areas. This is not an issue for HIV epidemiology among MSM at present due to the lack of suitable denominators, but would become important if denominators became available.

If there were appropriate denominator data for MSM for smaller geographic areas, rates of *diagnosed prevalence* (i.e. regional and pre-July 2006 SHAs) could be calculated if the numerator were based on the area of residence and not area of treatment. This is possible because the SOPHID survey which counts the number of people accessing treatment and care services collects data on both these variables.

# CHAPTER 4

## **Ethnicity and migration**

## **Chapter Summary**

In chapter 3 I addressed the challenge of obtaining data on HIV rates among MSM in the UK which would help in local planning for HIV prevention and care services. Following on from this, in the fourth chapter, I investigate HIV among black and minority ethnic (BME) and migrant MSM in the UK — a complex area which is beginning to be addressed by HIV services.

The two published papers in this chapter describe, for the first time, the epidemiology of HIV among BME and migrant MSM in England and Wales. In the accompanying commentary, 1 discuss the derivation of the ethnic group categorisation, its application in the census and its use for HIV surveillance among MSM. In addition, I examine whether, in absence of other information, country of birth can be used as a proxy for ethnicity for HIV positive MSM and vice versa. Finally, I make recommendations for the use of data on ethnicity and country of birth for surveillance and epidemiological research among MSM with HIV.

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## Epidemiology of HIV among black and minority ethnic men who have sex with men in England and Wales

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Objectives: To examine the epidemiology of HIV among black and minority ethnic (BME) men who have sex with men (MSM) in England and Wales (E&W).

Methods: Ethnicity data from two national HIV/AIDS surveillance systems were reviewed (1997–2002 inclusive), providing information on new HIV diagnoses and those accessing NHS HIV treatment and care services. In addition, undiagnosed HIV prevalence among MSM attending 14 genitourinary medicine (GUM) clinics participating in the Unlinked Anonymous Prevalence Monitoring Programme and having routine syphilis serology was examined by world region of birth.

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Accepted for publication 28 November 2004 Results: Between 1997 and 2002, 1040 BME MSM were newly diagnosed with HIV in E&W, representing 12% of all new diagnoses reported among MSM. Of the 1040 BME MSM, 27% were black Caribbean, 12% black African, 10% black other, 8% Indian/Pakistani/Bangladeshi, and 44% other/mixed. Where reported (n = 395), 58% of BME MSM were probably infected in the United Kingdom. An estimated 7.4% (approximate 95% CI: 4.4% to 12.5%) of BME MSM aged 16-44 in E&W were living with diagnosed HIV in 2002 compared with 3.2% (approximate 95% CI: 2.6% to 3.9%) of white MSM (p<0.001). Of Caribbean born MSM attending GUM clinics between 1997 and 2002, the proportion with undiagnosed HIV infection was 15.8% (95% CI: 11.7% to 20.8%), while among MSM born in other regions it remained below 6.0%.

Conclusions: Between 1997-2002, BME MSM accounted for just over one in 10 new HIV diagnoses among MSM in E&W; more than half probably acquired their infection in the United Kingdom. In 2002, the proportion of BME MSM living with diagnosed HIV in E&W was significantly higher than white MSM. Undiagnosed HIV prevalence in Caribbean born MSM was high. These data confirm the need to remain alert to the sexual health needs and evolving epidemiology of HIV among BME MSM in E&W.

A greatest risk of acquiring HIV in England and Wales (E&W).<sup>1</sup> Recent years have seen a substantial rise in the number of new HIV diagnoses among these men.<sup>4</sup> While the ethnicity of people with heterosexually acquired HIV has been examined in detail.<sup>4</sup> there has been little consideration of HIV among black and minority ethnic (BME) MSM in E&W.

An estimated 10 000-30 000 BME MSM aged 16-44 years currently live in E&W, according to population prevalence estimates from-the National Survey of Sexual Attitudes and Lifestyles (Natsal 2000) applied to the 2001 census,<sup>1-4</sup> (Dr Catherine Mercer, personal communication). Black communities in E&W, particularly black Caribbean and African communities, experience poor sexual health with relatively high rates of bacterial STIS.\* <sup>2</sup> There is also evidence that BME MSM in E&W are more likely to report high risk sexual behaviour than other MSM while lacking culturally appropriate information, safe spaces, and social networks to meet their sexual health needs.\* In the United States, BME MSM bear a disproportionate burden of incident HIV; among young BME MSM surveyed in six US cities between 1994 and 2000, HIV incidence was 14.7% compared to 2.5% among white MSM.\* To avert a similar public health crisis in E&W, HIV infection among BME MSM must be monitored and appropriate action taken.

This paper examines the epidemiology of HIV among BME MSM in E&W to provide an evidence base for clinicians, policy makers and those involved in health promotion. In this paper we focus on new HIV diagnoses, those accessing HIV treatment and care services within the National Health Service (NHS), and the prevalence of undiagnosed HIV.

#### METHODS

Data for 1997–2002 from three national HIV surveillance systems held at the Communicable Disease Surveillance Centre (CDSC) were examined. Analyses were limited to E&W to ensure comparability between sources.

#### New HIV diagnoses

CDSC receives' voluntary confidential reports of new HIV diagnoses from laboratories (since 1985) and clinicians (since 2000).<sup>30</sup> Data on probable route of infection (for example, sex between men) are collected on all reports, and followed up by a research nurse where incomplete. Information on ethnicity and probable country of infection is also collected. Country of birth has been included in clinician reports of HIV diagnoses since 2000. A "late" diagnosis is defined as an AIDS diagnosis within 3 months of an HIV diagnosis.

## Survey of Prevalent HIV Infections Diagnosed (SOPHID)

SOPHID has provided an estimate of the number of individuals living with diagnosed HIV infection in E&W since 1995.<sup>10</sup> The survey aims to include every individual living in E&W with diagnosed HIV infection who has attended for HIV treatment or care at NHS services during

Abbreviations: ART, antiretroviral therapy; BME, black and minority ethnic; CDSC, Communicable Disease Surveillance Centre; E&W, England and Wales; GUM, genitourinary medicine; IPB, Indian/ Pakistani/Bangladeshi; IQR, interquartile ranges; MSM, men who have sex with men; NHS, National Health Service; SOPHID, Survey of Prevalent HIV Infections Diagnosed; UAPMP, Unlinked Anonymous Prevalence Monitoring Programme; VCT, voluntary confidential testing a calendar year. Data collected include ethnicity, probable route of infection, level of antiretroviral therapy (ART), CD4 count when last seen, and area of residence.

#### Unlinked Anonymous Prevalence Monitoring Programme (UAPMP)

The UAPMP has measured the prevalence of undiagnosed HIV infection in different population subgroups since 1990.12 The genitourinary medicine (GUM) clinic survey uses residual blood taken for syphilis serology, providing information on HIV prevalence among MSM attending GUM clinics. A GUM clinic is synonymous with an STI clinic. Clinics provide treatment and care for patients with STIs and HIV. These free and strictly confidential services are open access; patients can refer themselves without going through their primary care physician. Fourteen (of 228) GUM clinics in E&W participate in the UAPMP GUM survey (seven (of 34) in London, seven (of 194) elsewhere in E&W). Information is collected on co-infection with acute STIs and the uptake of voluntary confidential testing (VCT). The term "previously undiagnosed HIV" only includes samples from HIV infected MSM who had not had a positive voluntary HIV test before clinic attendance; they were either newly diagnosed during the clinic visit or left without accepting VCT, therefore remaining undiagnosed. In the UAPMP all samples have patient identifying details irreversibly removed before testing for HIV infection.

#### Ethnicity

Ethnicity is established during clinic visits with the patient. Surveillance forms are subsequently completed by a healthcare worker, typically using patient notes. There is no reclassification at CDSC unless there is an obvious error in form completion. Broad ethnicity categories are used, collapsed from the 1991 census so that population denominators can be applied. These categories did not change over the period 1997–2002 and are white, black African, black Caribbean, black other, Indian/Pakistani/Bangladeshi (IPB), and other/mixed. "Black other" includes "black British" while "other/mixed" includes men from South America and Asia (excluding IPB). Those of black and white ancestry will be classified as "black other" or "other/mixed," depending on assignment at the clinic level. BME includes all these categories, except white.

Ethnicity data have been collected on laboratory reports of HIV diagnoses since 1996, on clinician reports of HIV/AIDS diagnoses since 2000 and were collected on AIDS reports until 2000. Completeness of ethnicity data on reports of MSM newly diagnosed with HIV ranged from 58% to 81% between 1997 and 2002. Ethnicity data have also been collected in the SOPHID surveys since they began in 1995; completeness ranged from 96% to 98% between 1997 and 2002. To improve the completeness of ethnicity data for new HIV diagnoses, reports among MSM where ethnicity was missing were matched to the SOPHID database using soundex code, sex, date of birth and other available information. If ethnicity was recorded in SOPHID it was used to classify the ethnicity of MSM newly diagnosed with HIV. The UAPMP GUM survey does not collect information on ethnicity. Region of birth is collected instead.

For these analyses, countries of birth or infection outside the United Kingdom were aggregated into broader regions. Men who were born or probably infected in England, Wales, Northern Ireland, or Scotland were classified as being born or infected in the United Kingdom. This classification could not be disaggregated.

#### Statistical methods

Where appropriate, data were analysed using Epi-Info 6 (v.6.04d) and Stata 8, with categorical variables analysed

using  $\chi^2$  tests. Interquartile ranges (IQR) for medians are presented. Data for E&W were analysed for 1997–2002. Those without reported ethnicity (new diagnoses, SOPHID) or country of birth (UAPMP) were excluded. New diagnoses are based on reports received by the end of December 2003. Statistical inferences were only made for data from sample populations (UAPMP GUM survey and estimates of the proportions of BME and white MSM living with diagnosed HIV), and not surveillance data relating to whole populations (new diagnoses and SOPHID).

The proportion of BME and white MSM living with diagnosed H1V in E&W was calculated by dividing the number of BME or white MSM aged 16-44 accessing H1V services (SOPHID) by the number of BME or white MSM in E&W. The denominators were calculated by multiplying the point estimate for the proportion of BME or white MSM aged 16-44 residing in E&W (from Natsal 2000) with the number of BME or white men aged 16-44 enumerated in the 2001 census,<sup>1-3</sup> (Dr Catherine Mercer, personal communication). Applying the 95% confidence intervals around the Natsal point estimates to the census data allowed us to determine approximate 95% CIs for the proportion of men living with diagnosed HIV.

#### Ethics

Reports of new diagnoses and of those diagnosed and living with HIV are voluntary and confidential. To maintain patient confidentiality no names are held on the database, soundex codes are used instead." The reporting system has approval under the section 60 regulations of the Health and Social Care Act (Statutory Instrument 1438-June 2002). The ethical and legal basis for UAPMP has been described elsewhere.14 In short, best practice guidance states that for purposes of public health surveillance, and where samples are anonymised, specific patient consent is not required, on condition that "active local arrangements" allow patients the opportunity to be aware of what may happen to their samples and mechanisins are in place for respecting spontaneous objections. The programme complies with guidelines published by the Medical Research Council," and Department of Health interim guidelines on the use of human organs and tissue.14 All data are stored on restricted and secure databases at CDSC, with strict adherence to the Data Protection Act and Caldicott Guidelines."

#### RESULTS

#### New diagnoses

Between 1997 and 2002, 1040 BME MSM were newly diagnosed with HIV, representing 12% (1040/8861) of all new diagnoses reported among MSM in E&W in that period (table 1). The number of new diagnoses among both BME and white MSM increased between 1997-2002. The contribution of BME MSM to the total number of new HIV diagnoses among all MSM did not vary significantly from one year to the next. Of the BME MSM newly diagnosed with HIV between 1997-2002 (1040), 27% (276) were black Caribbean, 12% (124) black African. 10% (101) black other, 8% (85) IPB, and 44% (454) other/mixed. The percentage of newly diagnosed BME MSM who were black Caribbean or black African increased during the study period. Median age at diagnosis was 32 years (IQR: 28-37) for BME MSM.

Overall, 11% (118/1040) of BME MSM were diagnosed "late" compared with 13% (927/7,062) of white MSM. There was some evidence that the proportion of late diagnoses differed between BME groups; 19% (16/85) of IPB MSM were diagnosed late, 14% (38/276) of black Caribbeans, 10% (10/101) of black other, 10% (44/454) of other/mixed, and 8% (10/124) of black Africans.

그 친구 아이가 옷 옷을	Year of	l diagnosi	<b>i</b>										120	
	1997		1998		1999		2000		2001		2002		Total	
Ethnic group	No	*	No	*	No	%	No	%	No	%	No	%	No	%
Black and minority ethnic	164	12.3	137	10.7	136	10.5	178	12.5	218	13.0	207	12.4	1040	12.0
White	1073	80.8	1084	84.6	1078	83.2	1154	80.8	1359	80.9	1314	78.8	7062	81.4
Not reported	91	6.9	61	4.8	81	6.3	97	6.8	102	6.1	147	8.8	579	6.7
All MSM	1328	100.0	1282	100.0	1295	100.0	1429	100.0	1679	100.0	1668	100.0	8681	100.0
Black African	8	4.9	15	10.9	13	9.6	28	15.7	27	12.4	33	15.9	124	11.9
Black Caribbean	33	20.1	32	23.4	42	30.9	42	23.6	61	28.0	66	31.9	276	26.5
Black other	21	12.8	15	10.9	-15	11.0	14	7.9	18	8.3	18	8.7	101	9.7
IPB	8	4.9	13	9.5	12	8.8	19	10.7	23	10.6	10	4.8	85	8.2
Other/Mixed	94	57.3	62	45.3	54	39.7	75	42.1	89	40.8	80	38.6	454	43.7
All BME MSM	164	100.0	137	100.0	136	100.0	178	100.0	218	100.0	207	100.0	1040	100.0

Probable country of infection was reported for 38% (395/ 1040) of BME MSM. Of these men, 58% (228/395) were probably infected in the United Kingdom. The percentage of BME MSM probably infected with HIV in the United Kingdom varied by ethnic group: black Africans 39% (22/56); other/ mixed 55% (90/165); black Caribbean 61% (62/102); black other 70% (26/37); and IPB, 80% (28/35). Of the 603 BME MSM diagnosed between 2000 and 2002, 53% (321/603) had country of birth reported. Of these, 29% (93/321) were born in the United Kingdom. This varied by ethnic group: black Africans 16% (7/45); other/mixed 19% (20/107); black Caribbean 35% (35/100); IPB 42% (15/36); and black other 48% (16/33). Nearly a third (34/107) of other/mixed ethnicity MSM were born in Central/South America, with a further third (34/107) born in Asia (excluding India/Pakistan/Bangladesh) and nearly 20% (20/107) in the United Kingdom.

Both probable country of infection and country of birth were reported for 197 BME MSM diagnosed between 2000 and 2002. Overall 60% (119/197) were probably infected in the United Kingdom while 30% (60/197) were born here. Of 32 black African MSM, 38% (12/32) were born in Africa but probably infected in the United Kingdom while 50% (16/32) were born and probably infected in Africa. For black Caribbean MSM (60), 33% (20/60) were born and probably infected in the United Kingdom, 27% (16/80) were born in the Caribbean but probably infected in the United Kingdom, while 37% (22/60) were born and probably infected in the Caribbean. **Prevalent diagnosed infections** 

In 1997, 10% (921/9,117) of all MSM receiving HIV treatment or care reported to the SOPHID survey were BME, rising to 12% (1625/13 990) in 2002 (table 2). Between 1997–2002, among BME MSM receiving HIV treatment or care, the proportion who were black African, black Caribbean, or IPB increased. Based on data from Natsal and the 2001 census we estimated that 7.4% (approximate 95% CI: 4.4% to 12.5%) of all BME MSM aged 16–44 in E&W were living with diagnosed HIV in 2002 compared with 3.2% (approximate 95% CI: 2.6% to 3.9%) of white MSM aged 16–44 (p<0.001).

While the majority of BME MSM receiving treatment and care lived in London, this decreased from 88% (810/921) in 1997 to 83% (1345/1625) in 2002. CD4 count and level of ART at last clinic attendance were reported for 88% (1433/1625) of BME MSM and 88% (10 480/11 954) of white MSM in 2002. Seventy one per cent (130/182) of BME MSM with a CD4 cell count <200 cells ×10<sup>6</sup>/l for whom level of ART was known, were receiving triple therapy or more, compared to 77% (1045/1353) of white MSM. The proportion recorded as taking ART at last clinic attendance was equivalent among BME groups.

#### Undiagnosed prevalence

Between 1997 and 2002, 4.3% (95% CI: 4.1% to 4.5%) of all MSM attending GUM clinics in the UAPMP survey were HIV infected and had not been previously diagnosed, ranging from 3.7% (95% CI: 2.4% to 5.3%) among Asian born men to

Table 2 MSM resident in England and Wales and seen for treatment and care at NHS services by ethnicity and year of SOPHID survey, 1997-2002

	Year see	in for HN	related	treatment	or care							
	1997		1998		1999		2000		2001		2002	
	No	%	No	%	No	%	No	*	No	*	No	%
Black and minority ethnic	921	10.1	1056	10.7	1169	10.9	1260	10.9	1414	11.1	1625	11.6
White	7869	86.3	8546	86.7	9331	86.6	9985	86.4	10 921	86.0	11 954	85.4
Not reported	327	3.6		2.6	273	2.5	317	27	359	2.8	. 411	2.9
All MSM	9117	100.0	9862	100.0	10 773	100.0	11 562	100.0	12 694	100.0	13 990	100.0
Black African	83	9.0	97	9.2	125	10.7	139	11.0	154	10.9	197	12.1
Black Caribbean	147	16.0	159	15.1	188	16.1	214	17.0	266	18.8	299	18.4
Black other	135	14.7	145	13.7	142	12.1	147	11.7	165	11.7	192	11.8
198	42	4.6	54	5.1	62	5.3	69	5.5	80	5.7	92	5.7
Other/mixed	514	55.8	601	56.9	652	55.8	691	54.8	749	53.0	845	52.0
All BME MSM	921	100.0	1056	100.0	1169	100.0	1260	100.0	1414	100.0	1625	100.0

Table 3 Prevalence of previously undiagnosed HIV\*, proportion remaining undiagnosed after clinic visit and uptake of voluntary confidential testing among MSA attending 14 GUM clinics in England & Wales by region or country of birth, 1997-2002

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		V positive sample ples tested") 95% Cl	s*/	individu diagnos clinic un	#V positive samples from als who could have been ed at dinic visit but left aware of intection/ V positive samples*) n/N		imples from individuals j VCT/no of samples n/N
Caribbean	15.8	(11.7 to 20.8)	42/265	45.2	19/42	52.1	138/265
Central/South America	5.7	4.4 10 7.4	57/993	57.9	33/57	59.7	593/993
Sub-Saharan Africa	4.6	{3.3 to 6.2}	40/870	62.5		54.4	473/870
Asia	3.7	(2.4 to 5.3)	27/739	51.9	14/27	56.4	417/739
Inited Kingdom	4.0	(3.7 to 4.2)	971/24 452	60.2	585/971	51.9	12 691/24 452
Totalt	4.3	(4.1 to 4.5)	1595/37 039	60.2	960/1595	52.3	19 387/37 039

\*MSM with "previously undiagnosed HIV" includes samples from HIV infected MSM whose HIV infection was not diagnosed before dinic attendance, but may eiher have had a new diagnosis at the diric visit or left remaining undiagnosed. It excludes men with a previously diagnosed HV infection. †Total includes men born in Australia and Oceania, Middle Eastern Crescent, North America, rest of Europe, and those where region of birth was not recorded.

15.8% (95% CI: 11.7% to 20.8%) among Caribbean born men (p<0.001) (table 3). The percentage of Caribbean born MSM attending GUM clinics with previously undiagnosed HIV significantly increased over the period (from 5.4% (95% CI: 0.6% to 18.2%) to 31.4% (95% CI: 20.9% to 43.6%), p<0.001). However, data for 2003 show a decrease in the prevalence of undiagnosed HIV among Caribbean born MSM (7.5% (3/ 40)). With 2003 data included, the test for trend was only of borderline significance (p = 0.06). For MSM born in Asia, there was some evidence that the proportion with previously undiagnosed HIV decreased over time (from 5.5% (95% CI: 2.0% to 11.6%) to 1.2% (95% Cl: 1.5% to 4.3%), p = 0.07), while for men born in Central/South America, sub-Saharan Africa, and the United Kingdom there were no significant changes over time (p = 0.3).

Overall, 60% (960/1595) of HIV infected MSM whose HIV infection could have been diagnosed remained unaware of their infection after leaving the clinic (table 3). This did not vary significantly by region of birth (including the United Kingdom) (p = 0.4).

Among MSM attending GUM clinics with previously undiagnosed HIV, 52% (19,387/37,039) accepted VCT. This varied significantly by region of birth (p<0.001), but all were in the range of 52% to 60% (table 3). Between 1997-2002, uptake of VCT significantly increased among MSM regardless of region of birth (p<0.001) (data available on request).

#### DISCUSSION

Black and minority ethnic (BME) MSM accounted for just over one in 10 MSM diagnosed with HIV in E&W between 1997 and 2002. Where probable country of infection was known, more than half had probably acquired their infection within the United Kingdom. In 2002, in E&W, a significantly higher proportion of BME MSM were living with diagnosed HIV infection than white MSM. Prevalence of undiagnosed HIV was high among Caribbean born MSM.

#### Methodological issues

Strengths of this analysis include triangulation of data from three national surveillance sources. In addition, results are based on laboratory confirmed HIV diagnoses. There are, however, some limitations. The number of BME men infected through sex between men may be underestimated because of misclassification of ethnicity and sexual orientation at the clinic level. Cultural taboos may inhibit disclosure of sex with another man and those having sex with both men and women may not perceive themselves to be bisexual, reporting heterosexual exposure only.<sup>14</sup> Without qualitative investigation it is impossible to quantify the extent of this misclassification.

In these analyses completeness of ethnicity data was high with over 90% of new diagnoses and SOPHID patients having ethnicity recorded. Nearly half the newly diagnosed BME MSM and those accessing services were classified as other/ mixed ethnicity, which in itself is not very informative unless combined with country of birth data; collection of such a broad ethnic category needs to be reviewed. Data on country of infection and birth for newly diagnosed BME MSM were incomplete and care should be taken when interpreting these results. It is difficult to ascertain how this incompleteness would bias results: for probable country of infection it is likely that where country of infection was uncertain it was not assigned.

Undiagnosed prevalence of HIV among BME MSM is based on a population from 14 GUM clinics, which may not fully represent BME MSM attending all 228 GUM clinics in E&W. A further consideration is that clinic attendees will not be fully representative of all BME MSM as those attending GUM clinics are generally at higher risk of acquiring HIV. The UAPMP survey collects information on region of birth rather than ethnicity, which in some instances may not be a good proxy for ethnicity, particularly for MSM born in Africa and South America.<sup>19</sup> The data presented in this paper indicate that nearly a third of newly diagnosed BME MSM were born in the United Kingdom. Using world region of birth as a proxy for ethnicity would not capture this information. Finally, it is important to note that although 52% of all MSM accepted an HIV test we could not ascertain how many men were offered a test. This data item has been introduced into the 2003 UAPMP GUM survey.

#### Diagnosed HIV among BME MSM

Between 1997 and 2002, BME MSM accounted for just over one in 10 new HIV diagnoses among MSM in E&W. More than half had probably acquired HIV in the United Kingdom. BME MSM were younger at diagnosis than white MSM, suggesting infection with HIV at an earlier age or earlier uptake of HIV testing. They were not diagnosed any later during the course of infection as evidenced by AIDS diagnosis within 3 months of HIV diagnosis. Rising diagnoses combined with improved survival have led to increasing numbers of BME MSM attending HIV treatment and care services,

with over one in 10 MSM attending services in 2002 being BME. Most lived in London. In E&W in 2002, a significantly higher proportion of BME MSM were living with diagnosed HIV than white MSM. According to our estimates there was a twofold difference. The proportion of BME MSM attending NHS HIV treatment and care services receiving triple therapy (with a CD4 count of less than 200 cells  $\times 10^6$ /l) did not differ significantly from white MSM. This is in stark contrast to the United States, where marked inequalities in HIV treatment and care exist between black people, Latinos and white people.<sup>20 21</sup> These differences may be explained by healthcare provision. Black people and Latinos in the United States are at economic disadvantage and are more likely to receive HIV care through publicly funded Medicaid rather than privately funded services. In the United Kingdom, HIV treatment and care services are typically provided free at the point of access to diagnosed patients, through the NHS.

#### Undiagnosed HIV among BME MSM

The prevalence of undiagnosed HIV among Caribbean born MSM exceeded that for other BME groups between 1997 and 2002. While there is no clear explanation for this differential, several factors could be contributing: high rates of bacterial STIs among black Caribbeans may be facilitating transmission of HIV22 23; compared with white MSM, black MSM may be more likely to engage in unprotected anal intercourse with an HIV infected partner or with a partner of unknown HIV status24; there may be differential immigration to the United Kingdom of HIV infected MSM from the Caribbean, driven by local stigma and discrimination.25 26 This wide disparity between black Caribbean MSM and other ethnicities merits further investigation. Other UAPMP results indicate that more than half the MSM who could have been diagnosed left the GUM clinic unaware of their infection, irrespective of where they were born. Conversely, between 1997-2002, VCT uptake increased significantly among MSM from all regions of birth, which may reflect promotion of HIV testing among clinic attendees, and is encouraging.

#### Comparisons with other studies

There are limited data with which to compare findings. Research into HIV testing and sexual risk behaviours among ethnically diverse MSM in a community based study in England in 2001 found that self reported HIV prevalence was 5.9% (50/853) among BME MSM overall ("black," "Asian," and "all others" combined) compared to 5.3% (655/12 462) among white MSM ("white British" and "white other" combined) (p = 0.4).<sup>24</sup> The lack of a statistically significant difference in self reported HIV prevalence between BME and white MSM in this study is at odds with our own prevalence estimates based on laboratory confirmed HIV diagnoses. In 2002, we found a significant twofold difference in the estimated proportion of BME and white MSM living with diagnosed HIV in E&W. However, the authors of the community based study did find that self reported HIV prevalence was higher among black MSM (11.3% (35/309)) than among Asian and "all other" men (1.5% (5/327) and 4.6% (10/217) respectively) (p<0.001). They recommended that HIV prevention programmes should prioritise black MSM.24 Our data would support this recommendation, with an elevated prevalence of undiagnosed HIV among black Caribbean MSM compared with other BME groups.

In the United States substantially higher levels of incident HIV infection have been reported among black MSM than white MSM, a disparity that is not explained by higher rates of unprotected anal and oral sex.\* 27 Similarly, HIV prevalence is much higher among black MSM, reaching 32% among those aged 23-29 years in metropolitan areas.\* Forninately, HIV has not reached these levels among BME MSM in E&W

but undiagnosed HIV prevalence was high among Caribbean born MSM between 1997 and 2002 and this situation needs to be monitored. HIV prevalence ranging from 5% to 15% has been found among MSM in the Caribbean.25

#### Implications of this study

Our findings have important implications for HIV surveillance and health promotion in E&W. Surveillance of HIV among BME MSM could be improved if data on ethnicity, country of birth and infection for new HIV diagnoses were complete. Reporting completeness, particularly for clinician HIV reports, needs to be addressed. The evidence of acquisition of HIV by BME MSM in E&W makes them an emerging target group for health promotion. The elevated undiagnosed HIV prevalence in Caribbean born MSM is of concern, highlighting a need for black Caribbean MSM to be prioritised when planning health promotion initiatives. HIV rates among BME MSM in E&W have not reached the level observed in the United States. None the less, high rates of bacterial STIs and sexual risk behaviours among black minority ethnic groups in E&W compounded by racism and cultural taboos surrounding sexual orientation demand that we remain alert to the sexual health needs and evolving epidemiology of HIV among BME MSM in E&W. Further research among BME MSM may provide an evidence base for those planning appropriate and culturally specific sexual health services.

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#### CONTRIBUTORS

SD conceived the idea for the paper with significant input from JE; SD, BR, and AB analysed the new diagnoses, SOPHID and UAPMP GUM surveys respectively, with support from KS and BE (new diagnoses and SOPHID), and OG (UAPMP); all authors were involved in interpretation of the results and drafting of the paper; SD undertook the main writing of the paper with JE and KF making a significant contribution. SD is currently registered for a PhD at City University London

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#### ORIGINAL RESEARCH ARTICLE

## Men who have sex with men who are born abroad and diagnosed with HIV in England and Wales: an epidemiological perspective

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Summary: Relatively little is known about the sexual health needs of men who have sex with men (MSM) born abroad who reside in the UK. We describe here the epidemiology of HIV among MSM born outside the UK and diagnosed with HIV in England and Wales.

Reports of HIV diagnoses in England and Wales received at the Health Protection Agency Centre for Infections were analysed. Between 2000 and 2003, 6386 MSM were diagnosed with HIV in England and

Between 2000 and 2003, 6386 MSM were diagnosed with HIV in England and Wales. Country of birth was recorded for 3571 (56%). Of those with country of birth reported, 2598 (73%) were born in the UK and 973 (27%) abroad. Of those born abroad (973), 424 (44%) were born in Europe, 141 (15%) in Africa, 104 (11%) in South/Central America and the remainder in other regions. Where reported (949), 69% of MSM born abroad were White, 12% other/mixed, 9% Black Caribbean and 7% Black African. Probable country of infection was reported for 612 MSM born abroad: 52% were infected in the UK, 43% in their region of birth and 5% in another region.

Men born abroad represent a significant proportion of HIV diagnoses among MSM in England and Wales. More than half probably acquired their HIV infection in the UK, strengthening the call for targeted HIV prevention and sexual health promotion among MSM who are not born in England and Wales.

Keywords: men who have sex with men, HIV infection, England and Wales, surveillance, epidemiology

#### Introduction

Population prevalence estimates from the National Survey of Sexual Attitudes and Lifestyles (Natsal 2000) (Johnson *et al.*,<sup>1</sup> personal communication) applied to the 2001 census<sup>2</sup> indicate that men who have sex with men (MSM) born outside the United Kingdom (UK) currently account for approximately 20% of all MSM resident in England and Wales. This means an estimated 24,000 to 68,000 MSM living in England and Wales were born outside Britain, of whom nearly half were born outside the European Union\*<sup>2</sup>(<sup>1</sup>Personal communication).

A recent qualitative report has highlighted the limited capacity of community organizations and

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\*European Union pre 1st May 2004

HIV service providers to support the HIV prevention, treatment and care needs of MSM born outside the UK.<sup>3</sup> One of the problems has been the lack of information on the epidemiology of HIV infection in this group of men. Such quantitative data could inform HIV prevention initiatives as well as the direction of future research. Here, we describe the epidemiology of HIV among MSM born outside the UK who were diagnosed with HIV in England and Wales between 2000 and 2003.

#### Methods

The Health Protection Agency Centre for Infections receives voluntary and confidential reports of HIV diagnoses from laboratories (since 1985) and clinicians (since 2000) in England and Wales.<sup>4</sup> No names are reported. Soundex code,<sup>5</sup> date of birth

and sex are used to link multiple reports of the same individual to limit duplication within the surveillance system. Probable route of infection is collected for all reports, and is 'followed up' where incomplete. Country of birth has only been collected on clinician HIV reports since their introduction in 2000. Details on previous HIV test results from abroad typically rely on patient selfreporting.

Data were analysed for 2000–2003 inclusive, based on reports of MSM received from laboratories and clinicians in England and Wales by the end of March 2004. Where possible, key demographic and clinical characteristics of MSM born abroad were compared with UK-born MSM.

#### Results

Between 2000 and 2003, 6386 MSM were diagnosed with HIV in England and Wales and reported to the Health Protection Agency Centre for Infections. Country of birth was recorded for 3571 (56%) MSM. MSM diagnosed outside London were more likely to have had country of birth reported than those diagnosed in London (69% versus 47%). Of those with country of birth reported, 2598 (73%) were born in the UK and 973 (27%) abroad (Table 1). Based on data from Natsal and the 2001 census, we estimate that 2.4% (1.4-4.1%) of MSM born abroad living in England and Wales were diagnosed with HIV between 2000 and 2003 compared with 1.5% (1.2–1.9%) of MSM born in Britain.

The median age at diagnosis for MSM born abroad was lower than for UK-born men (33 years versus 36 years). Three-quarters (734/973) of the MSM born abroad were diagnosed in London compared with 41% (1077/2598) of men born in the UK.

Of the 973 MSM born abroad, 424 (44%) were born in Europe (Table 1): 70 in Italy, 69 in France, 66 in Spain, 56 in Ireland, 41 in Portugal, 37 in Germany and the remaining 85 in other European countries. A further 15% (141/973) of the MSM born abroad were born in Africa (of whom 38% [53/141] were born in South Africa) and 11% (104/ 973) in South or Central America (of whom 56% [58/104] were from Brazil). Where the ethnicity of MSM born abroad was reported (949), 69% were White, 12% other/mixed, 9% Black Caribbean and 7% Black African (Table 1). Nearly all MSM born in the UK, Europe and Australasia were White, as were three-quarters of MSM born in North America and approximately half the MSM born in Africa and South or Central America.

Probable country of infection was reported for 612 of the 973 MSM born abroad (Table 2). Where reported, 52% of MSM born abroad were probably infected in the UK, ranging from 39% of men born in South/Central America to 61% of Asian-born men. Forty-three percent were infected in their region of birth, ranging from 31% of Asian-born men to 58% of North American-born men. Where reported, 94% of UK-born MSM were also probably infected in the UK.

Year of arrival was reported for 47% (454/973) MSM born abroad, of whom 64% (290/454) had been diagnosed within five years of arriving in the UK and 36% (164/454) between five and 60 years. For MSM born abroad, the median number of years of residence in the UK prior to diagnosis was two.

 Table 1 HIV diagnoses made in England and Wales among men who have sex with men by reg of birth and ethnicity: 2000 - 2003.

 Reports received by end of March 2004

	Ethnic	group	•		-											
	White			Other/ mixed		Black Caribbean				Black other I			Subtotal			
Region of birth	n	%	n	%	n	%	n	%	n	%	n	%	n	%	Not reported	Total
Outside UK	651	68.6	116	12.2	81	8.5	62	6.5	16	1.7	23	2.4	949	100.0	24	973
UK	2451	95.4	26	1.0	47	1.8	8	0.3	20	0.8	18	0.7	2570	100.0	28	2598
Not reported	1075	79.9	123	9.1	60	4.5	49	3.6	17	1.3	21	1.6	1345	100.0	1470	2815
All MSM	4177	85.9	265	5.4	188	3,9	119	2.4	53	1.1	62	1.3	4864	100.0	1522	6386
MSM born outside	the UK										1 -				· · · · · · · · · · · · · · · · · · ·	
Europe	395	96.3	12	2.9	2	0.5	· .		1	0.2			410	100.0	14	424
Africa	62	44.3	6	4.3			62	44.3	2	1.4	8	5.7	140	100.0	1	141
South/Central America	52	51.5	46	45.5	1	1.0	_	_	2	2.0			101	100.0	3	104
Caribbean	2	2.5	1	1.3	76	96.2							79	100.0		79
North America	56	73.7	7	9.2	2	2.6		· ·	11	14.5			76	100.0	2	78
Asia	13	18.3	43	60.6				_	—		15	21.1	71	100.0	3	74
Australasia	71	98.6	1	1.4				·				-	72	100.0	1	73
All MSM born outside the UK	651	68.6	116	12.2	81	8.5	62	6.5	16	1.7	23	2.4	949	100.0	24	973

MSM-men who have sex with men; IPB-Indian/Pakistani/Bangladeshi

	Proba	ble region	/country o	f infection	ו					
	Same birth*	as	UK		Anoth region	-	Subtota	l		
Region of birth	n	%	n	%	n	%	n	%	Not reported	Total
All MSM										
Outside UK	261	42.6	318	52.0	33	5.4	612	100.0	361	973
UK			1868	94.1	117	5.9	1985	100. <b>0</b>	613	2598
Not reported			379	79.1	100	20.9	479	100.0	2339	2815
All MSM	261	8.5	2565	83.4	250	8.1	3076	100.0	3313	6386
MSM born outside the UK										
Europe	96	36.8	157	60.2	8	3.1	261	100.0	163	424
Africa	51	46.4	50	45.5	9	8.2	110	100.0	31	141
Asia	15	30.6	30	61.2	4	8.2	49	100.0	25	74
Caribbean	27	50.0	23	42.6	4	7.4	54	100.0	25	79
North America	23	57.5	16	40.0	1	2.5	40	100.0	38	78
Australasia	19	48.7	19	48.7	1	2.6	39	100.0	34	73
South/Central America	30	50. <b>8</b>	23	39.0	6	10.2	59	100.0	45	104
All MSM born outside the UK	261	42.6	318	52.0	33	5.4	612	100.0	361	973

Table 2 HIV diagnoses made in England and Wales among MSM born abroad by region of birth and probable region/country of infection: 2000 - 2003. Reports received by end of March 2004

\* For man born outside the UK or where region/country of birth is not reported. It is referring to the same region of birth : i.e. a man born in spain and intected in France will appear in the same column as he was born and intected in Europe MSM = men who have sex with men

Of the 294 MSM born and infected outside the UK, 110 (37%) had been diagnosed abroad before being diagnosed in the UK, ranging from 21% (4/ 19) of Asian-born men to 71% (17/24) of North American-born men. The 110 men who were aware of their HIV diagnosis before coming to the UK accounted for 18% (110/612) of all MSM diagnosed with HIV in England and Wales who were born abroad and whose probable country of infection was recorded.

Excluding those infected outside the UK and diagnosed abroad, 13% (97/768) of MSM born abroad were diagnosed with AIDS within three months of their HIV diagnosis, compared with 16% (404/2594) of UK-born MSM.

#### Discussion

Nearly one in four MSM diagnosed with HIV in England and Wales between 2000 and 2003 was born abroad. Almost half were born in Europe (mainly Western Europe) and over two-thirds were White. Just over half the MSM born abroad were infected with HIV in the UK. This is in marked contrast to new diagnoses among heterosexuals born abroad most of whom are believed to have acquired their HIV infection outside the UK.<sup>6</sup> The majority of MSM born abroad were diagnosed HIV positive in London. Almost one in five were aware of their HIV diagnosis before coming to the UK. MSM born abroad were less likely than UK-born MSM to be diagnosed late in the course of infection; this difference may have occurred if

some MSM born abroad had already received treatment before being diagnosed in the UK and this was not reported.

For surveys and studies that do not collect data on ethnicity, region of birth has sometimes been used as a proxy for ethnicity.<sup>7,8</sup> Data presented here indicate that for MSM from some regions, this may be a poor proxy. Approximately half the men born in Africa and Central or South America were White. The inadequacy of region of birth as a proxy for ethnicity among MSM born in Africa and Central/South America must be considered when interpreting country-of-birth surveillance data for these men.

Country of birth was unknown for nearly half the HIV-infected MSM because clinician reports with country of birth are only received for about 60% of diagnoses in MSM, the remainder being reported by laboratories. It is difficult to determine whether this biases our findings, and this is clearly a limitation of these analyses. Our results may underestimate the number of diagnoses among MSM born abroad as there were significantly fewer reports from London with country of birth recorded compared with reports from elsewhere in England and Wales. The proportion of MSM born, infected and diagnosed abroad is probably underestimated, as this typically relies on patient self-reporting. Information on male rape is not explicitly sought, although anecdotally is reported. Finally, surveillance reports do not collect information on migration status, making it impossible to establish whether men were visitors, temporary residents or permanent residents. Consequently, the implications for HIV treatment and care services in the UK are not clear.

MSM born abroad represent a significant proportion of new HIV diagnoses among MSM in England and Wales. They are a heterogeneous group, which may increase in number with continuing in-migration and the recent expansion of the European Union. Over half the MSM born abroad probably acquired their HIV infection in the UK, lending support to the need for targeted HIV prevention and sexual health promotion among MSM born abroad.<sup>3</sup> Further research is needed to determine the mobility of this population and their HIV treatment and care needs. Our findings highlight a weakness in current HIV surveillance and its ability to clearly describe 'at-risk' groups. Measures to improve the completeness of country-of-birth data for MSM will enable better monitoring of epidemiological trends, and inform prevention interventions for MSM born abroad who reside in England and Wales.

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has

approval

voluntary reporting system under the section 60 regulations of the Health and Social Care Act (Statutory Instrument 1438 -June 2002).

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## 4.1 Introduction

Understanding the epidemiology of HIV among different sub-populations of men who have sex with men (MSM) is important for informing health promotion, treatment and care services. Qualitative research has indicated that ethnic minority MSM and migrant MSM may be disproportionately affected by HIV infection in the UK and are engaging in 'high risk' sexual behaviours (Keogh *et al.*, 2004a, Keogh *et al.*, 2004b). Given the paucity of quantitative data available (Hickson *et al.*, 2004), I examined the epidemiology of HIV among ethnic minority MSM and MSM born outside of the UK using national HIV surveillance data (Dougan *et al.*, 2005b).

In this chapter, I briefly describe my quantitative research findings on ethnic minority MSM and those born outside the UK. I then examine the concept of ethnicity and the collection of information on ethnic group in the England and Wales census, with discussion around the imprecision, fluidity and heterogeneity of ethnic group classifications. I go on to describe the collection and use of ethnic group and country of birth data in the surveillance of HIV infection among MSM in the UK, the use of country of birth as a proxy measure for ethnicity and vice versa. I also discuss and provide evidence for the imprecision, fluidity and heterogeneity of ethnicity in HIV surveillance. Finally, I reflect on the implications for my earlier research findings (Dougan *et al.*, 2005b; Dougan *et al.*, 2005c), and make recommendations for improving the collection of data on ethnic group and country of birth for HIV surveillance.

## 4.2 Research findings from my published papers

By analysing UK surveillance data, I found that between 1997 and 2002, just over one-in-ten MSM newly diagnosed with HIV and one-in-ten MSM accessing HIV treatment and care services in England and Wales were ethnic minority (Dougan *et al.*, 2005b). Nearly half (44%) of the ethnic minority MSM newly diagnosed with HIV were of 'other/mixed' ethnicity and 27% of black Caribbean ethnicity (Dougan *et al.*, 2005b). Fifty-eight percent of newly HIV-diagnosed ethnic minority MSM were infected within the UK, despite only 30% being UK-born (Dougan *et al.*, 2005b). Among MSM attending sentinel genito-urinary medicine (GUM) clinics between 1997 and 2002, undiagnosed HIV prevalence was high at 15.8% among Caribbean-born men compared to 4.0% among UK-born men (Dougan *et al.*, 2005b).

Further research showed that MSM born outside the UK represent a significant proportion of MSM being newly diagnosed with HIV in England and Wales (Dougan *et al.*, 2005c). Between 2000 and 2003, where information on country of birth was available, more than a quarter of MSM newly diagnosed with HIV in England and Wales were born outside of the UK (Dougan *et al.*, 2005c). Nearly half (44%) were born in other European countries, with a further 15% born in Africa and 11% in Central/South America (Dougan *et al.*, 2005c). The majority (69%) of these men were white and of the total, half were probably infected in the UK (Dougan *et al.*, 2005c).

## 4.3 Ethnicity

## 4.3.1 What is ethnicity and why is it useful in epidemiological research?

Ethnicity is a complex and inexact variable in epidemiologic research and infectious disease surveillance (Afshari & Bhopal, 2002; Witzig, 1996). Rather than being biologically determined, ethnicity is a construct drawn from social theory (McKenzie & Crowcroft, 1996). It is a complex and heterogeneous concept (Bhopal, 2004; Platt, 2007). Several interrelated factors may contribute to, or influence a person's ethnicity. These factors may include:

- Country of birth
- Nationality
- Language spoken at home
- Parent's country of birth in conjunction with country of birth
- Skin colour
- National/geographic origin
- Racial group
- Religion

However, while any of the above factors can be important in influencing a person's ethnic affiliation, they do not necessarily determine it (Statistics New Zealand, 2004). Instead, ethnicity is a subjective association that is only meaningful to the individual concerned, with the main element being the notion of shared history and belonging (Platt, 2007).

While the collection and use of ethnicity data is socially sensitive, if used properly it may help identify and tackle health inequalities, plan public health programmes and direct resource allocation (Afshari & Bhopal, 2002; De Cock & Low, 1997; Witzig,

1996). Differences in health inequalities among ethnic groups however, may mask differences in socioeconomic factors, such as social class, deprivation and educational achievement, making it important to monitor these factors too (Afshari & Bhopal, 2002; Senior & Bhopal, 1994). Use of ethnicity data may also increase stigma and discrimination experienced by some ethnic groups (Bhopal, 2004), reinforce stereotypes, and help transform minorities into mere statistical categories (Sheldon & Parker, 1992). By way of comparison, collecting information on country of birth is relatively unproblematic as it is a distinct, and usually undisputed, variable. However, it is not equivalent to ethnicity, providing information on only one aspect of a person's identity.

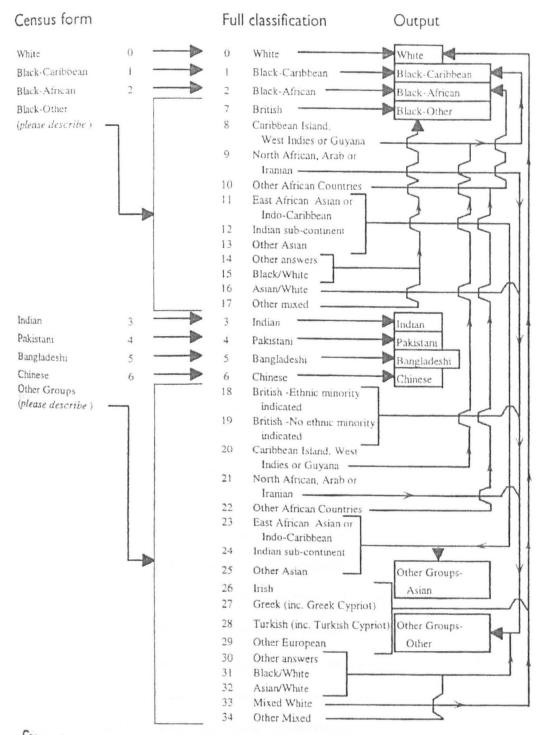
### 4.3.2 Ethnic group categories used in the census

The introduction of ethnic monitoring in the decennial census in England and Wales was initially resisted, with some people believing that collection and use of ethnic group data was discriminatory (Gill & Johnson, 1995). After much debate the 'ethnic group question' was excluded from the 1981 Census, but was introduced for the first time in the 1991 Census (Gill & Johnson, 1995). Most of the debate had surrounded the collection of information on a number of ethnic minority groups, with the majority of the population falling into the 'white' category. Since then however, collection of ethnic group data on the census and elsewhere has not been so hotly contested, and debates have moved on, discussing for example, collection of data on sexual orientation (see chapter 3).

The 1991 Census output for ethnicity comprised 10 ethnic groups ('white', 'black African', 'black Caribbean', 'black other', 'Indian', 'Pakistani', 'Bangladeshi', 'Chinese', 'other', 'mixed'); collapsed from an extended classification using 35

 Table 4.1: Office for National Statistics algorithm for redistributing write-in answers to output categories for 1991 Census

## OPCS's algorithm for redistributing write in answers to output categories



Categories encompassed by output classification

White	0 26-29 33	Indian	3	Other Group - Asian
Black Caribbean	1820	Pakistani	4	11-13 23-25
Black African	2 10 22	Bangladeshi	5	Other Groups - Other
Black Other	7 14 15 17	Chinese	6	916181921

Source: Apsinall, BMJ 1995; 311:1006-1009

categories (table 4.1) (ONS, 2003). The original 1991 Census classifications were mostly derived after extensive consultations with ethnic minority organisations and pretesting for public acceptability and understanding over a period of two decades by the Office for National Statistics (ONS) (ONS, 2003). The exception was the 'other Asian' category which was created at a later stage. ONS classifications are pragmatic, balancing the ease of data collection against a need to produce administrative data on the population (McKenzie & Crowcroft, 1994, ONS, 2003). The categories were designed to enable the majority of the population to identify themselves in a manageable way, and since 1991, there have been further recommendations by ONS for more specific ethnic group classifications depending on data collection needs (Gill & Johnson, 1995). For example, in the 2001 Census those identifying as 'Cypriot' were allocated to the 'other White' ethnic group (Gill & Johnson, 1995). However, if the population or area where ethnic group data were being collected included a large number of Cypriots then a Cypriot sub-category could be added under the 'White' heading (Gill & Johnson, 1995).

It is argued however, that these ethnic group categories may not be adequate to demarcate socio-cultural differences and to explain variations in infection and disease in the UK (Zenilman *et al.*, 2001). Indeed, Bhopal and others criticise researchers for using these existing ONS classifications, thereby endorsing their validity, when those who developed them have acknowledged that they have no scientific or anthropological basis (McKenzie & Crowcroft, 1996; Sheldon & Parker, 1992). Long argues that ethnic group categories are political; that neither the size of the population nor changing population structure influences their construction, but rather the political moves of ethnic communities who may benefit by being 'statistically visible' (Long, 2002). Clearly however, a balance must be struck between obtaining useful, descriptive information on the diversity of the population

which has a sound scientific and anthropological basis, with ease of data collection, and the ability to produce statistics that usefully summarize the general population.

## 4.3.3 Imprecision and fluidity of ethnic group categories

Bhopal and others also argue that ethnic group categories are determined by social pressures and psychological needs, making them imprecise (Bhopal, 2004; Witzig, 1996). This may result in inconsistent categorisation over time, affecting consistency of reporting and potentially the quality of the data. In the 1991 Census, one in four people from ethnic groups other than white provided non-standard responses to the ethnic group question, highlighting the importance of including free text fields for other' categories (Aspinall, 1997). Similar results were seen in a London study, where 17% of 93 subjects were unwilling or unable to define their ethnic group according to census categories (King et al., 1994). Multiethnic persons are often forced to self-identify, or will be identified by those completing the form, into a predetermined ethnic group particularly where there is no free text field available (Aspinall, 1997; Witzig, 1996). This will be an increasing problem as the number of people with multiethnic backgrounds continues to increase (Aspinall, 1997; Witzig, 1996). Indeed, the availability of free text fields (for black other and any other ethnic group) in the census was central (Aspinall, 1995; Aspinall, 1997), but its use has subsequently been dropped for National Health Service (NHS) data collection and also for most HIV and STI surveillance purposes, with the exception of Lymphogranuloma venereum (LGV) surveillance reports. Non-standard responses in free text fields can also inform the construction of new ethnic categories (Aspinall, 1997). This opportunity is lost where free text fields are omitted and so for example, it would be impossible to identify and introduce extra ethnic categories for another minority group that was disproportionately affected by a particular infection or disease.

Omitting free text answers may impact on the use of statistical output from the 1991 Census as ethnic group denominator data. Free text responses in the 1991 Census were mapped back to defined categories by using a complex algorithm, to give the 10 category output. Aspinall has shown that where census data are used as the denominator and data from other collection systems without free text fields as the numerator, the resulting proportions and rates will be of questionable validity for some groups (Aspinall, 1995). Indeed he purports that without the free text field, only data on 'white', 'black Caribbean', 'Indian/Pakistani/Bangladeshi' and 'Chinese' ethic groups collected without using free text fields will be reasonably comparable to census output data (Aspinall, 1995).

The concept of ethnicity is also fluid. Research on the longitudinal census dataset provides good evidence of this (ONS, 2007). Respondents in some ethnic groups have classified themselves differently between censuses (Platt *et al.*, 2005), which may result in non-comparability of routine data (De Cock, 1997). Lowest consistency in responses to the ethnic group question between 1991 and 2001 censuses was found among those categorised in the 'other' groups ('black other', 'other Asian' and 'other') and highest among those of white ethnicity (Platt *et al.*, 2005).

### 4.3.4 Heterogeneity within ethnic group categories

Ethnic group categories such as white, black African, Indian, Pakistani, hide massive heterogeneity within these groups (Bhopal, 2004; Sheldon & Parker, 1992; Witzig, 1996). Such heterogeneity will diminish

the value of ethnic group categorisation as a means of delivering culturally appropriate health care, and in understanding ethnic variations in disease (Bhopal, 2004). Again, this makes it important to also collect data on other factors such as country of birth, language, religion, and family origins (Bhopal, 2004).

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An implicit assumption in much of the work on inter-ethnic differences is that the majority represents a standard against which members of other ethnic groups may be compared. This ethnocentric approach remains apparent in ethnic categorisations where the vast majority of the population are classified as white (Senior & Bhopal, 1994). But this apparently homogeneous 'white' ethnic group conceals minorities subject to discrimination and disadvantage (Keogh *et al.*, 2004a, McAuley *et al.*, 1996; Zenilman *et al.*, 2001), and similarly other ethnic groups, such as black African and Indian/Pakistani/Bangladeshi, ignore the diversity of cultural and religious life in Africa and the Indian sub-continent (McKenzie & Crowcroft, 1994). It is however, common in epidemiological research to have a reference group – usually the majority, and to segment the remaining population into categories, so this is not so unusual. Nevertheless, it is important to recognise that within any given group there is likely to be significant diversity.

## 4.4 HIV surveillance and ethnicity

## 4.4.1 Collection of data on ethnicity and country of birth in UK HIV surveillance and use of proxy measures

There are three main HIV surveillance systems in England and Wales which collect information on MSM. These are: (i) the Survey of Prevalent HIV Infections Diagnosed (SOPHID); (ii) the unlinked anonymous genito-urinary medicine (GUM) survey; (iii) reporting of HIV diagnoses (table 4.2). Data on ethnicity, but not country of birth, are collected in the SOPHID survey; data on country of birth, but not ethnicity, are collected by the unlinked anonymous GUM survey; reports of HIV diagnoses contain data on both ethnic group and country of birth (The UK Collaborative Group for HIV and STI Surveillance, 2005).

Collection of only country of birth or ethnic group in HIV surveillance systems may limit the interpretation of the data and our understanding of HIV epidemiology, particularly for MSM. Collection of country of birth alone may lead to second generation migrants becoming 'statistically invisible' (e.g. British-born black MSM of Caribbean descent). In the unlinked anonymous GUM survey, these men are classified as UK-born. It may be the case, however, that there is higher HIV incidence and prevalence among UK-born black Caribbean MSM compared to UKborn MSM of other ethnicities because of strong links to Caribbean countries where there is a relatively high HIV prevalence (UNAIDS, 2005). Stigma and discrimination experienced by black Caribbean gay men (Cáceres, 2002; Keogh et al., 2004a), a higher incidence of bacterial STIs among Caribbean communities in the UK (Low et al., 2001; Radcliffe et al., 2001; The UK Collaborative Group for HIV and STI Surveillance, 2005), and differential 'high risk' sexual behaviours (Hickson et al., 2004) may further contribute to elevated HIV incidence and prevalence in this group of men. Furthermore, UK-born black Caribbean MSM diagnosed with HIV may have different experiences of, and access to NHS HIV-related treatment and care services compared with men born in the Caribbean who are also living in the UK. These treatment and care-related differences would not be captured by the SOPHID survey which only collects information on ethnic group but not on country of birth.

To overcome the lack of country-of-birth data in the SOPHID survey, where necessary, ethnicity is sometimes used as a proxy for country of birth (e.g. black Africans will be assumed to have been born in Africa). Likewise in the unlinked anonymous GUM survey, country of birth is used as a proxy for ethnic group (e.g. Caribbean-born individuals will be assumed to be black Caribbean) (Dougan *et al.*, 2004; HPA, 2006; Keogh *et al.*, 2004a; Sinka *et al.*, 2003; The UK Collaborative

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 Table 4.2: Description of three main HIV surveillance systems collecting information on HIV infection among men who have sex with

 men in England, Wales and Northern Ireland, and their collection of data on ethnic group and country of birth

HIV surveillance system	Purpose	Ethnic group/country of birth collection	Categories collected <sup>1</sup> and disseminated
	HIV/AIDS diagnoses are reported from laboratories and clinicians providing information on who, where and how	Ethnicity has been collected on reports of AIDS diagnoses since 1982, and on laboratory reports of HIV diagnoses since 1995. Reporting of HIV diagnoses by	<i>Ethnic group :</i> white; black African; black Caribbean; black other; Indian/Pakistani/Bangladeshi; other/mixed; not reported.
HIV/AIDS diagnoses and deaths in HIV-infected individuals	people being diagnosed with HIV in E,W&NI have been infected with HIV. Deaths in HIV-infected individuals are received from clinicians and the Office for National Statistics (ONS).	clinics (mainly GUM) was introduced in 2000 across E,W&NI to supplement information on laboratory reports. Clinical reports of HIV diagnoses collect both ethnic group and country of birth.	<i>Country of birth:</i> specific country collected, but disseminated as the UK and other world regions of birth (Africa; Latin America and the Caribbean; Asia; Europe (exc. UK); Australasia; North America)
Survey of Prevalent HIV Infections Diagnosed (SOPHID)	Provides information on diagnosed HIV- infected individuals (including MSM) accessing HIV-related National Health Service (NHS) treatment and care services in E,W&NI	Ethnic group has been collected since the survey began in 1995. Country of birth is not collected.	<i>Ethnic group:</i> White; black African; black Caribbean; black other/black unspecified; Indian/Pakistani/Bangladeshi; other Asian/Oriental; other/mixed; not reported.
Unlinked Anonymous Prevalence Monitoring Programme (UAPMP), Genito-urinary medicine (GUM) survey	Measures previously undiagnosed HIV seroprevalence among attendees (MSM and heterosexuals) at sentinel GUM clinics (16 clinics in E,W&NI).	Country of birth has been collected since the survey's inception in 1990. Ethnic group is not collected.	Country of birth: As for HIV diagnoses

<sup>1</sup>categories collected on surveillance forms as of end 2005

Group for HIV and STI Surveillance, 2005). The collection of both variables (i.e. ethnic group and country of birth) on clinical reports of HIV diagnoses has allowed us to investigate whether the use of such proxies is valid for MSM diagnosed with HIV in England and Wales in recent years (Dougan et al., 2005c). While country of birth is a reliable proxy for ethnicity for the largest group of HIV positive MSM in England and Wales – white MSM born in the UK – for other MSM populations, country or region of birth cannot be used as a proxy for ethnic group and ethnic group cannot be used as a proxy for country or region of birth among those newly diagnosed with HIV (table 4.3) (Dougan et al., 2005c). For example, half the MSM of reported Indian/Pakistani/Bangladeshi ethnicity were born in the UK, over a third in Asia and a sixth in Africa. Likewise, of the newly diagnosed HIV positive MSM born in Africa, 45% were black African, with a further 44% of white ethnicity, one-intwenty Indian/Pakistani/Bangladeshi, and the remainder of varying ethnicities. However, country or region of birth could reliably be used as a proxy for ethnic group for HIV-diagnosed MSM born in Europe (including the UK) and Australasia, of whom more than 95% were white.

### 4.4.2 Ethnic group categories used for HIV surveillance

The collection of information on ethnic group in HIV surveillance in England and Wales is based on the 10 broad output categories from the 1991 Census. There are however, some inconsistencies in ethnic group categories between the different HIV (and STI) surveillance systems (table 4.2). For example, in the SOPHID survey there is a category for 'other Asian/Oriental' whereas on reports of HIV diagnoses these individuals would be included in the 'other/mixed' category. Differences in classification between surveillance systems and the censuses will limit data comparability.

Table 4.3: Country of birth versus ethnic group of men who have sex with men newly diagnosed with HIV in England, Wales and Northern Ireland: 2000-2004

a) Ethnicity as a proxy for country/region of birth

	Ethnic group														
Country/region of birth	w	hite	Black	Black African		Black Caribbean		IPB*		k other	Other/mixed		Not reported		Total
	n	Col %	n	Col %	l n	Col %	n	Col %	n	Col %	n	Col %	n	Col %	
United Kingdom	3530	80%	13	13%	62	36%	33	50%	27	55%	44	22%	47	58%	3756
Africa	85	1.9%	86	86%	1	0.6%	9	14%	4	8.2%	7	3.4%	1	1.2%	193
Latin America/Caribbean	74	1.7%	-	-	103	60%	-	-	3	6.1%	65	32%	5	6.2%	250
Asia	19	0.4%	-	-	-	-	24	36%	1	2.0%	60	29%	4	4.9%	108
Europe (exc. UK)	537	12%	-	-	2	1.2%		-	2	4.1%	19	9.3%	21	26%	581
Australasia	85	1.9%	-	-	-	-	-		-	-	1	0.5%	1	1.2%	87
North America	68	1.5%	1	1.0%	4	2.3%		-	12	24%	8	3.9%	2	2.5%	95
Sub total (100%)	43	398		100	1	72		66		49	2	204		81	5070
Not reported	15	592		72		85		27	29		229		1900		3934
Total	59	990	1	172	2	57		93		78	433		1981		9004

b) Country/region of birth as a proxy for ethnicity

	Ethnic group														
Country/region of birth	White		Black African		Black Caribbean		IPB*		Black other		Other/mixed		Sub total	A STATE AND A STATE OF	Total
	n	Row %	n	Row %	l n	Row %	n	Row %	n	Row %	n	Row %	(100%)	reported	
United Kingdom	3530	95%	13	0.4%	62	1.7%	33	0.9%	27	0.7%	44	1.2%	3709	47	3756
Africa	85	44%	86	45%	1	0.5%	9	4.7%	4	2.1%	7	3.6%	192	1	193
Latin America/Caribbean	74	30%	-	-	103	42%	-		3	1.2%	65	27%	245	5	250
Asia	19	18%	-	-	-	-	24	23%	1	1.0%	60	58%	104	4	108
Europe (exc. UK)	537	96%	-	-	2	0.4%	-	-	2	0.4%	19	3.4%	560	21	581
Australasia	85	99%	-	-	-	-	-	-	-	-	1	1.2%	86	1	87
North America	68	73%	1	1.1%	4	4.3%	-	-	12	13%	8	8.6%	93	2	95
Not reported	1592	78%	72	3.5%	85	4.2%	27	1.3%	29	1.4%	229	11%	2034	1900	3934
Total	5990	85%	172	2.4%	257	3.7%	93	1.3%	78	1.1%	433	6.2%	7023	1981	9004

For HIV surveillance, ease of data collection is paramount as forms are voluntarily completed by a wide variety of clinicians and health advisors (mainly from GUM clinics) and virologists, whose own data collection systems are typically based on the 1991 Census classifications. Most categories within HIV surveillance, including ethnic group, are broad and pragmatic since HIV surveillance requires the systematic collection of information over substantial periods of time from numerous organisations. For example, any man reporting sex with another man is recorded as 'MSM', regardless of the man's sexual identity or desire. Use of existing census classifications also avoids the need for pretesting by the Health Protection Agency for public acceptability and understanding. The wide use of existing categories also allows comparison with other data sources.

## 4.4.3 Imprecision and fluidity of ethnicity in HIV surveillance

As previously discussed, some ethnicity commentators argue that ethnic groups are imprecise and fluid and this may have a bearing on the collection of ethnic group data in HIV surveillance and subsequent analyses and interpretations. My own research has shown that 44% of black and minority ethnic MSM diagnosed with HIV in England and Wales since 1997 were of 'other/mixed' ethnicity (Dougan *et al.*, 2005b), and therefore fall into an artefactual ethnic group category. Since there are no free text fields on HIV surveillance forms, country or region of birth has to be used to describe these MSM. This has indicated that a significant proportion of these 'other/mixed' MSM were born in either Asia or Latin America, leading to the recommendation that an 'other Asian' category, preferably with a free text field, should be introduced on the reporting forms (Dougan *et al.*, 2005b). Addition of free text fields would also help determine if there were specific, as yet undetected, population sub-groups of MSM that are disproportionately affected by HIV. It would allow reassignment of some of the 'other/mixed' MSM, and 'black other' and 'other

Asian' MSM, into more 'specific' categories using the 1991 Census algorithm that allows the 35 ethnic categories to be summarised as 10 output categories.

Ethnicity data from censuses are used as the denominator for calculating rates of HIV diagnoses and the prevalence of diagnosed HIV infection by ethnic group at national and local levels (Dougan et al., 2005b; The UK Collaborative Group for HIV and STI Surveillance, 2005). For example, in the paper on black and ethnic minority MSM, 1 estimated that 7.4% (approximate 95% confidence interval: 4.4% to 12.5%) of ethnic minority MSM aged 16-44 in England and Wales were living with diagnosed HIV in 2002 compared with 3.2% (approximate 95%CI: 2.6% to 3.9%) of white MSM (p<0.001) (Dougan et al., 2005b). For this analysis I used denominator data from Natsal 2000 and the 2001 national census. The omission of a free text field in HIV surveillance systems could therefore lead to non-comparability between the numerator and denominator in the calculation of these rates because those identifying as "other/mixed" cannot be re-assigned in the HIV surveillance data in line with the algorithms that are used for the census data. For MSM however, the main limitation in calculating rates of diagnoses or diagnosed HIV prevalence relates to the lack of denominator data on the number of all MSM living in this country. Sexual orientation is not collected in the census (consultation is currently ongoing regarding its inclusion in the England and Wales 2011 Census (see chapter 3)). Applying the prevalence of anal sex among men as measured by the National Surveys of Sexual Attitudes and Lifestyles (Natsal 1990 and 2000) to the male population in the census yields an estimate of the number of MSM. Because of small numbers these data are only published for large geographical levels (London and the rest of Britain) and for white versus non-white (i.e. ethnic minority) MSM (Johnson et al., 2001; Mercer et al., 2004). If in future robust MSM denominator data are available by ethnicity, then the potential non-comparability between census and HIV surveillance data for some ethnic groups would need to be examined.

For HIV surveillance systems (reports of HIV diagnoses and SOPHID) inconsistencies in ethnic group may occur in a patient record as multiple reports for an individual may be received over several years. It is unclear whether these inconsistencies arise from patients re-classifying their ethnicity over time, from clinic staff assigning different ethnicities; or if inconsistencies reflect transcription errors. In principle, ethnic group should be self-assigned by the patient during clinic visit(s), but this may not always be happening in practice. This will also lead to error (Bhopal, 2004), given that self-identification is central to the concept of ethnicity.

## 4.4.4 Heterogeneity within ethnic group categories in HIV surveillance

As with the general population, the majority of MSM diagnosed with HIV and accessing HIV-related services in England and Wales are of white ethnicity (Mercer *et al.*, 2004; ONS, 2001). Table 4.3 and other work (Dougan *et al.*, 2005c; Weatherburn *et al.*, 2005), illustrate that 'white' MSM diagnosed with HIV are a heterogeneous population, with one-in-five born outside of the UK (Dougan *et al.*, 2005c). Comparisons are often made between 'white' MSM and ethnic minority MSM in HIV surveillance and research (Dougan *et al.*, 2005b; Hickson *et al.*, 2004; The UK Collaborative Group for HIV and STI Surveillance, 2005). Care should be taken however, when interpreting these data, particularly when assuming that access to prevention and treatment services by 'white' MSM is the standard, as there is likely to be significant heterogeneity within this group. Classification of those of white ethnicity into smaller groups would therefore be useful for surveillance of HIV infection among MSM in England and Wales, particularly in surveys (e.g. SOPHID) where country of birth is not reported. The Office for National Statistics

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recommends that where appropriate for England and Wales, 'white' can be subdivided into 'white British', 'white Irish', 'any other white background' (ONS, 2003).

## 4.5 Implications and recommendations

#### 4.5.1 Implications for my research

A fuller understanding of the classification of ethnic group and its relation with country of birth will undoubtedly guide further research into ethnic minority and migrant MSM.

My paper on ethnic minority MSM concludes that there are differences in the percentage of MSM diagnosed with, and living with HIV by ethnic group. However, further analysis in this commentary highlights the difficulties of using these ethnic group classifications. Consequently the conclusions in the paper need to be interpreted with care (Dougan *et al.*, 2005b). In particular, this commentary reinforces one of the conclusions from my research on ethnic minority MSM (Dougan *et al.*, 2005b). That is to say that the 'other/mixed' ethnic group variable is not useful in terms of describing the epidemiology of HIV among ethnic minority MSM for a number of reasons: (i) there is inconsistency in identifying with this group over time; (ii) there is heterogeneity among 'other/mixed' MSM; (iii) that men may be categorised into this artefactual group because of a lack of a free text field. Furthermore, I have clearly illustrated the need to be cautious when using country of birth and ethnic group as proxies for each other in the surveillance of HIV among MSM. This needs to be considered when interpreting earlier research findings (Dougan *et al.*, 2005b; Dougan *et al.*, 2005c).

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#### 4.5.2 Recommendations for improvements in HIV surveillance

The concept of ethnicity is complex, since it is determined by a multitude of underlying factors. Some have argued that it is imprecise and fluid, relies on self-identification, and categories have no scientific or anthropological basis (Bhopal, 2004; Sheldon & Parker, 1992). On the other hand, data on country of birth is much easier to collect and interpret. Ethnicity and country of birth however, are not in themselves risk factors for HIV and STI acquisition but markers which help us to better understand risk (CDC, 1993; Fenton *et al.*, 1997).

There are a number of ways in which the collection of data on ethnic group and country of birth in the surveillance of HIV infection among MSM could be improved, and several limitations that need to be considered when interpreting the available data. A series of recommendations are made below. Such recommendations however, need to balance improvements in the collection of ethnicity and country of birth data for HIV surveillance with maintaining ease of data collection and allowing the interpretation of trends over time.

#### 4.5.2.1 Ethnic group categories in HIV surveillance

#### Standardisation

Ethnic group categories should be standardised across HIV (and STI) surveillance systems to ensure comparability of data. It would seem sensible to use the ethnic category coding used by the NHS (table 4.4), which is currently being incorporated into the GUM clinic data systems being developed by external companies.

Table 4.4: Revised ethnic categories for use in the National Health Service

## National Codes:

## White

- A British
- B Irish
- C Any other White background

## Mixed

- D White and Black Caribbean
- E White and Black African
- F White and Asian
- G Any other mixed background

## Asian or Asian British

- H Indian
- J Pakistani
- K Bangladeshi
- L Any other Asian background

## Black or Black British

- M Caribbean
- N African
- P Any other Black background

## Other Ethnic Groups

- R Chinese
- S Any other ethnic group
- Z Not stated

Note: <u>ETHNIC CATEGORY</u> is the classification used for the 2001 census, replacing ETHNIC <u>GROUP</u> in the flows through the NHS-wide Clearing Service. The Office of National Statistics has developed a further breakdown of the group from that given, which may be used locally.

### Expansion of categories collected

For the surveillance of HIV infection among MSM in England and Wales, the ethnic group categories 'white' and 'other/mixed' are very broad; the majority of MSM are white and two-fifths of ethnic minority MSM are 'other/mixed'. It would be more informative, particularly where country of birth is not reported, if the white ethnic group was split into 'white British', 'white Irish', 'white European' and 'white other'. Ideally, country of birth would also be available, and the 'white European' and 'white other' categories would become more useful in identifying MSM from high and low HIV prevalence countries. Qualitative research by Sigma Research suggests that even MSM born in Ireland are at greater risk of acquiring HIV than UK-born MSM (Keogh *et al.*, 2004b). Addition of an 'other Asian' category would help to reduce the number of newly diagnosed MSM being identified as 'other/mixed'. These categories are already part of the standard NHS coding, as referred to above (table 4.4).

### Free text fields

The addition of free text fields for 'black other', 'other Asian' (when incorporated), 'other/mixed' and 'white other' (if incorporated) on HIV (and STI) surveillance forms should be considered. This would allow re-assignment of non-standard responses to specific categories using the census algorithm and therefore improve comparability with the census outputs and inform future ethnic group classifications.

## 4.5.2.2 Interpretation of ethnic group and country of birth data on HIV positive MSM

### Proxy measures of ethnicity/country of birth

Those using and interpreting surveillance data on HIV positive MSM should be aware that ethnic group *cannot* be used as a proxy for country of birth and that country or region of birth can *only* be used as a proxy for white MSM, when country or region of birth is the UK, Europe or Australasia.

#### Heterogeneity within ethnic groups

The heterogeneity of HIV positive MSM within ethnic groups should be recognised by those using and interpreting HIV surveillance data, particularly for white MSM Care should be taken if this group is used a 'standard' to make comparisons against.

#### Calculation and interpretation of rates

If sexual orientation is collected by a census in the future (after 2011 Census), and free text fields are still not utilised in HIV surveillance, the degree of non-comparability between census and HIV surveillance ethnicity data would need to be examined because of a lack of reassignment from free text answers.

#### 4.5.2.3 Collection of ethnic group and country of birth in HIV surveillance

#### Improving reporting completeness of HIV diagnoses

Unfortunately, country of birth and ethnic group are not reported for all newly diagnosed MSM. Of the MSM diagnosed with HIV between 2000 and 2003, only 56% (3571/6386) had country of birth reported. Reporting incompleteness may lead to biases in the data. Improving the reporting of ethnic group and country of birth of newly diagnosed HIV positive MSM (and others) is an ongoing goal within the HIV surveillance system.

#### Collection of country of birth by the SOPHID survey

The SOPHID survey collects ethnic group but not country of birth. In theory however, all patients reported to SOPHID should also have been reported as newly

diagnosed with HIV. Since the same patient identifiers are collected within both systems, patient records can be linked to investigate the relationship between ethnic group and country of birth among HIV-diagnosed MSM attending HIV-related services. Work is ongoing to improve linkage between these systems.

### Collection of ethnic group data by the unlinked anonymous GUM survey

The unlinked anonymous GUM survey currently collects data on country of birth but not ethnic group. Given that country of birth can only be used as a proxy for ethnic group for MSM in a few instances, interpretation of these data and comparability with other HIV surveillance data is limited. Since records are completely anonymised in this survey, they cannot be linked to reports of HIV diagnoses or SOPHID. Recommendations have been made previously to incorporate the collection of ethnic group into the unlinked anonymous survey (De Cock & Low, 1997; Nicoll *et al.*, 1997), and this will become increasingly important as the number of multi-ethnic MSM (and heterosexuals) born in the UK increases.

# **CHAPTER 5**

## **Co-infection with other**

## sexually transmitted infections

## Chapter Summary

In chapter 4, I explored a new area of HIV epidemiology among MSM in the UK – ethnicity and migration — which has created new challenges for the collection and interpretation of surveillance data. In this chapter (chapter 5) I examine how the widespread use of highly active antiretroviral therapies (HAART) and their positive effect in prolonging survival and improving quality of life has affected HIV epidemiology among MSM. The introduction of HAART has led to a growing population of sexually-active HIV positive MSM, which not only presents challenges for HIV prevention and care services, but also in interpreting HIV and STI surveillance data. This important, emerging area in HIV epidemiology is the last main issue addressed in this thesis.

The first published paper in chapter 5 reviews the literature on STIs among HIV positive MSM across Western Europe to try to understand the pattern of spread of STIs among HIV positive MSM. In the second paper, I addressed the lack of information on sexually-transmitted hepatitis C infection among HIV positive MSM in the UK by combining national HIV and hepatitis C datasets. Finally, to further explore and understand the transmission of STIs among HIV positive MSM, the commentary focuses on sexual networks which are central to explaining the epidemiological patterns of HIV and STIs among MSM in the post-HAART era.

# Sexually Transmitted Infections in Western Europe Among HIV-Positive Men Who Have Sex With Men

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Background: Since 1996, there has been a resurgence in sexually transmitted infections (STIs) among men who have sex with men (MSM) in Western Europe. This has coincided with a significant decrease in HIV-associated mortality following the introduction of highly active antiretroviral therapies (HAART) and a corresponding increase in the number of MSM living with HIV. Levels of improtected anal intercourse have also increased. In this article, we use STI surveillance data from a number of Western European countries to better understand the contribution of HIV-positive MSM to the recent increase in STIs.

Methods: Published literature, surveillance reports, and ad hoc publications relating to HIV prevalence trends and STIs among HIVpositive MSM in Western Europe were reviewed.

**Results:** Post-HAART, HIV prevalence among community samples of MSM ranged from 5% to 18%. HIV prevalence among MSM diagnosed with an STI was substantially higher. On average, HIV prevalence among MSM diagnosed with syphilis in 11 countries was 42% (range 14%-59%), Most HIV-positive MSM with syphilis were aware of their HIV status. In England and Wales, 32% of MSM with gonorrhea were HIV-positive in 2004. Outbreaks of hymphogranuloma vencreum have been documented in 9 countries: HIV-positive MSM accounted for 75% of cases on average (range 0%-92%). Cases of sexually transmitted hepatitis C have been predominantly identified among HIV-positive MSM in Rotterdam. Paris, Amsterdam, and the United Kingdom.

Conclusions: In Western Europe, STIs have been disproportionately diagnosed among HIV-positive MSM post-HAART. Improved survival coupled with serosorting among HIV-positive MSM appears to explain the high prevalence of HIV among MSM with STIs. STI transmission among HIV-positive men will have contributed substantially to increasing STI trends seen among MSM in Western Europe, since 1996. These findings highlight the need for routine STI testing among HIV-positive MSM as well as safer sex messages highlighting the implications of STI coinfection.

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THE INCIDENCE OF SEXUALLY transmitted infections (STIs) among men who have sex with men (MSM) in Western Europe began to decline in the late 1970s and continued falling during the early 1980s, mainly because of the behavioral change in response to H1V/AIDS.<sup>4</sup> STI incidence among MSM remained relatively low until the introduction of highly active antiretroviral therapies (HAART) for the treatment of H1V in 1996.<sup>2</sup> Over the last 8 years, however, a resurgence in STIs among MSM has been reported in many Western European countries.<sup>2,3</sup>

Increased levels of unprotected anal intercourse among MSM were documented from 1996 onwards in the United Kingdom, France, Germany, and Switzerland, although there is some evidence that levels may have now stabilized in some cities,4-19 However, although some MSM are reporting unprotected sex, they are also adopting HIV risk reduction strategies, such as "serosorting," where sexual partners are chosen on the basis of HIV serostatus to be accurately known and communicated) will prevent HIV transmission, the risk of STI transmission remains.

The widespread use of HAART has dramatically changed the epidemiology of HIV among MSM, with significant decreases in HIV-associated morbidity and mortality from 1996 onwards.<sup>12–14</sup> As a consequence, there is now an increasing number of MSM living with diagnosed, asymptomatic HIV infection who are sexually active.<sup>12,15</sup>

For the first time, we examine HIV prevalence among MSM with STIs across Western Europe, and compare and contrast outbreaks in different countries. Understanding STI epidemiology among known HIV-positive MSM is important for 3 reasons. First, to inform "positive prevention" which focuses on the sexual health of HIV-positive men and the prevention of STI as well as HIV transmission. Second, to inform the need for STI testing of HIV-positive MSM during routine HIV care. Finally, for the interpretation of epidemiologic data on STIs, specifically the use of STI trends as a proxy marker for HIV incidence.

#### Methods

We reviewed the published literature, surveillance reports and ad hoc publications relating to trends in HIV prevalence and STIs among HIV-positive MSM in Western Europe in the post-HAART era (1996–June 2006). We focused on diagnoses of gonorrhea,

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				HIV Prevalence		
Country	City/Area	Source of HIV Status	Year	%	n/N	
Denmark <sup>12</sup>		Self reported	2001	10	116/1160	
France <sup>19</sup>		Self reported	2004	13	658/5062	
Germany <sup>e</sup>		Self reported	2003	12	387/3221	
Ireland <sup>20</sup>		Self reported	2000	5	38/751	
Spain <sup>21</sup>	Barcelona	Unlinked anonymous testing	2002	18	60/328	
Switzerland <sup>22</sup>		Self reported	2004	× 9	87/961	
United Kingdom	London+	Unlinked anonymous testing	2000	11	132/1206	
-	Outside London <sup>23</sup>	Self reported	2002	6	106/1771	

#### TABLE 1. HIV Prevalence Among MSM in Gay Community Settings

Adapted from Table 2.2, Ref.<sup>12</sup>

syphilis, lymphogranuloma venereum (LGV), and sexually transmitted hepatitis C because of epidemiologic synergies with  $HIV_1^{16,17}$  their historical use as markers of unsafe sex and their recent (re-)emergence among MSM. We limited publications to those where data on both HIV status and STI diagnoses were collected for the same individuals. Where surveillance data have been published more than once, we present the most recent data.

## HIV Prevalence

HIV prevalence estimates were obtained from behavioral studies of MSM in community settings where oral fluids had been taken for unlinked anonymous testing or self-reported HIV prevalence data had been collected.

#### STIs

Enhanced surveillance systems have been set up to monitor syphilis and LGV in many Western European countries.<sup>18</sup> These collect information on sexual orientation and HIV status. Similarly, this information has been gathered during clinical studies investigating sexually transmitted hepatitis C infection. Unfortunately, there are not many enhanced surveillance systems collecting data on gonorrhea and for the most part in routine systems, sexual orientation and HIV status are either not collected or not well reported.

#### Results

#### **HIV** Prevalence

In Western Europe, HIV prevalence among community surveys of MSM conducted between 2000 and 2004 ranged from 5% to 18% (Table 1),48.12.19-23

### Syphilis Outbreaks

Post-HAART, the first syphilis outbreak among MSM was reported in Hamburg in 1997.<sup>24</sup> Increasing trends have been observed since then across Western Europe, with a recent decline in some countries.<sup>15,25,26</sup> The largest reported outbreaks have been in London, Paris, and Dublin.<sup>26–28</sup>

HIV prevalence varied widely among MSM diagnosed with syphilis (14%-59%) by country and within countries, with an average of 42% across the region (Table 2).<sup>24,27–39</sup> Despite this variation, HIV-positive MSM were disproportionately diagnosed with syphilis.

In London, HIV-positive MSM with syphilis were older than HIV negative MSM [49% (272/556) aged 35-44 years vs. 33% (158/483)] (P < 0.001) and they had an altered presentation, being

more likely to present with secondary syphilis rather than primary or early latent syphilis.<sup>27,37</sup> Similar observations were made in other cities.<sup>40</sup> Where calculated, syphilis incidence rates were higher among HIV-positive MSM. At a Dublin sexual health clinic, the crude incidence rate of syphilis in HIV-positive MSM was 10 times greater than in HIV negative MSM, peaking at 7280 per 100,000 in 2001, and then falling to 1553 per 100,000 in 2002.<sup>45</sup> Incidence rates among HIV-positive MSM in Germany also exceeded 1000 per 100,000.<sup>24</sup>

There was evidence of a temporal decline in HIV prevalence among MSM with syphilis in some settings. In Hamburg, the proportion of syphilis cases among HIV-positive MSM decreased from 80% in 1997–1998 to 40%–50% in later years<sup>44</sup> and similarly, in the IIe de France region from 72% in 2000 to 47% in 2003.<sup>28</sup> Conversely, there were no observed decreases in other French regions<sup>28</sup> or in Denmark.<sup>20</sup>

The majority of HIV-positive MSM diagnosed with syphilis were already aware of their HIV status (Table 2).<sup>27–29,32,33,35,38</sup> At a Paris hospital (2000–2002), HIV-positive MSM had been HIV diagnosed for a median of 8.8 years (range 0–19) before syphilis diagnosis.<sup>40</sup> Two-thirds (48/71) were receiving HAART.<sup>40</sup> In Germany, the proportion of reported syphilis reinfections was significantly higher among HIV-positive MSM.<sup>24</sup>

Across Western Europe, a significant proportion of MSM with syphilis reported unprotected oral intercourse (Table 2), with no difference by HIV status,<sup>25–27,37,42</sup> In Rotterdam, as elsewhere, MSM frequently reported using condoms for anal intercourse but not with oral contacts,<sup>33,34</sup>

#### Trends in Gonorrhea

Since the late 1990s, increases in diagnoses and rates of gonorrhea have been observed across the region, although recently there has been evidence of a levelling off and even a decline in some countries.<sup>2,3,43</sup>

In Denmark (1994–1999), gonorrhea incidence was 6 times higher among known HIV-positive MSM (P < 0.001).<sup>44</sup> A study in a Parisian clinic showed that at least one-third (30/92) of MSM diagnosed with gonorrhea between January 1999 and May 2001 were HIV-positive; more than half the MSM reported oral sex as the sole risk factor.<sup>45</sup> In Sweden, 5.4% (4/74) of gonorrhea cases were in HIV-positive MSM in 2000.<sup>46</sup> By comparison, at sentinel sites in England and Wales, 32% (123/381) of MSM with gonorrhea were HIV-positive in 2004.<sup>15</sup>

#### Reemergence of LGV

The first outbreak of LGV (serovar  $L_2$ ) among MSM was reported in Rotterdam in 2003.<sup>47</sup> Since then, LGV outbreaks

				HIV Posi	ive MSM		
Country	City/Region	Dates	MSM Cases	Percent	(No/Total)	Knowledge of HIV Positive Status at Syphilis Diagnosis	Oral Sex
Belgium <sup>29</sup>		October 2000– March 2004	147	59	81/138	70% (57/61) HIV positive for >3 months before syphilis diagnosis; 6.5% (7) recently diagnosed; 22% (18) co-diagnosed	
Denmark®		2003-2004	243	35	58/166		
France		2000-2003	903	55	482/871	66% were aware of their HIV status (stable proportion over time) 71% on HAART at time of syphilis diagnosis	39% of MSM probably infected by steady partner reported exclusiv oral sex and 3% exclusive anal sex versus 60% and 8%, respectively in those infected by casual partner
Germany <sup>24</sup>		2001-2004	1724	Sentinel data ind 50% of MSM of syphilis are HN	liagnosed with		
Ireland <sup>31</sup>		2000-June 2005	503	21	99/467		Of HIV positive MSM diagnosed with syphilis since 2000 in a sexual health clinic in Dublin, 89 (32/36) reported unprotected ora intercourse and 36% (13/36) unprotected anal intercourse, similar proportions to all MSM <sup>20</sup>
italy <sup>32</sup>	Milan	2000-2002	261	26 (inc.non- MSM)	79/308 (inc. non- MSM)	Of the 74 HIV positive men with early syphilis, 53% (39) knew they were HIV positive	
Netherlands <sup>29</sup>	Rotterdam	2002	41	30	6/20	Four knew about their HIV positive status; two were newly diagnosed with HIV	No information was available on or sex or condom use, but 63% (3 41) of all MSM reported anal set in the 6 months before syphilis diagnosis
Norway <sup>34</sup>		1998-2002	129	18	20/129		For years 1999–2000, it was reported that 54% (21/39) of MSM in Oslo never used condoms for oral sex, whereas consistent condom use was reported by 30% (15/42) but 17' (7/42) never used condoms for anal intercourse**
Spain	Barcelona	2002-2003	88	39	29/75	At least three-quarters of HIV positive MSM were aware of their status	
Sweden® United Kingdom	Londor#7	2004 April 2001– September 2004	101 127 <del>0</del>	29 53	25/87 556/1048		Oral sex was the likely mode of transmission for 40% (167/417) $\cdot$ HIV positive MSM and 43% (167 390) of HIV negative MSM ( $P = 0.42$
	Manchester <sup>27</sup>	January 1999– October 2003	443	36	126/354		Oral sex key transmission route, 88% (220/250) of all MSM did n use a condom for oral sex, whereas 28% (89/250) did not u a condom for anal sex (Continuu

## TABLE 2. Syphills Outbreaks Among HIV Positive MSM in Western Europe

TABLE 2.	IABLE 2. (Continued)						
				HIV Positive MSM	tive MSM		
Country	City/Region	Dates	MSM Cases	Percent	(No/Tota)	Knowledge of HIV Positive Status at Syphilis Diagnosis	Oral Sex
	Brightoner	July 1999- 1 October 2003	172	41	71/172	62% knew they were HIV positive; 38% were newly diagnosed with	Reported as the likely route of transmission in 37% of all cases
	Newcastle-	January 2002- October 2003	92	44	10/74		16% of all MSM considered oral sex
	Walsaltz South Walesz	to October 2003 June 2002-	548	17 20	2/12 0/30		
	Scotland <sup>30</sup>	October 2003 2004	1 <b>0</b> 2	28	33/119		45% (15/34) HIV positive MSM probably acquired infection itrouch oral sex versus 35% (30/
	Northern Irelanda	January 2001– September 2004	86	9 (inc. ron-MSM)	11/128 (inc. non-MSM)	Eight of the HIV positive patients were previously aware of their status (includes non-MSM)	66) of HIV regative MSM 41% (18/44) MSM diagnosed between July 2000 and March 2003 considered that the most
							likely route of infection was oral sex, with a further 15 staring that it could have been through oral or

among MSM have been documented in 9 Westem European countries: the largest in the United Kingdom and France (Table 3)<sup>48–59</sup> (Eline op de Coul and Fenke Koedijk, personal communication). Again, HIV-positive MSM were disproportionately affected, accounting for 75% of all reported cases on average (range 0%– 92%). The LGV outbreaks have shared similar characteristics to the syphilis outbreaks: most cases were among older, while MSM who had probably acquired infection in Europe.<sup>48,59</sup> In Rotterdam and in the United Kingdom, LGV infection has been associated with concurrent STIs, particularly sexually transmitted hepatitis C (as shown in Eline op de Coul and Fenke Koedijk, personal communication and Ref. 57).

## Sexually Transmitted Hepatitis C

intercourse<sup>42</sup>

anal

Active case finding has identified sexually transmitted hepatitis C among HIV-positive MSM in Rotterdam, Paris, Amsterdam, and the United Kingdom.<sup>60–66</sup> More than 225 HIV-positive MSM had been diagnosed with

More than 225 HIV-positive MSM had been diagnosed with sexually transmitted hepatitis C in London and Brighton by February 2006.<sup>95</sup> Significant risk factors were a high number of sexual partners, unprotected anal intercourse, mucosally traumatic practices (e.g., fisting), group sex, and use of 'club' drugs.<sup>95</sup> In Rotterdam, investigation of LGV cases and contacts of an index patient identified 17 HIV-positive MSM with sexually transmitted hepatitis C; 4 had confirmed LGV.<sup>90</sup> Twenty-nine cases of acute hepatitis C among HIV-positive MSM were identified in Paris between March 2001 and October 2004.<sup>61,62</sup> Twelve (41%) of the MSM had an STI coinfection.<sup>61</sup> Median time between HIV and hepatitis C diagnosis was 6.5 years; 76% (22) of MSM were on HAART.<sup>61</sup>

#### Discussion

STIs have been disproportionately acquired by HIV-positive MSM across Western Europe in the post-HAART era. Although HIV prevalence among MSM in community settings ranged from 5% to 18%, in contrast it averaged 75% among MSM diagnosed with LGV, 42% among those with syphilis, and in England and Wales, 32% among those with gonorrhea. The majority of HIVpositive MSM diagnosed with STIs were already aware of their HIV-positive status and in some instances, had been on HAART for several years. Nearly all MSM diagnosed with sexually transmitted hepatitis C have been HIV-positive, but there has been active case finding among HIV-positive MSM. However, the incidence of sexually transmitted hepatitis C among HIV negative MSM is low.67 In Western Europe since the introduction of . HAART, transmission among HIV-positive MSM has accounted almost entirely for the outbreaks of LGV and established cases of sexually transmitted hepatitis C; it has also contributed significantly to the syphilis outbreaks and, probably, the increase in gonorrhea too.

### Strengths and Limitations

The main limitation of the analyses is the heterogeneity of the studies and surveillance systems from which these data are derived. In their review of European STI surveillance, Lowndes and Fenton found differences at all levels, including case definitions, coverage, STI screening, partner notification, and treatment practices.<sup>18</sup> All of these will impact on the reported number of STI diagnoses.<sup>2,18</sup> Similarly, the HIV prevalence figures from community studies of MSM vary in their sampling techniques and measurement of HIV status may be inaccurate because some men will not be aware of their positive status. In addition, although

TABLE 3. L	GV Outbreaks	Among HIV	Positive MSM	in Western	Europe
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				HIV Positive MSM	
Country	City/Region	Dates	MSM Cases	Percent	(No/Total)
Belgium <sup>48</sup>	Antwerp	January 2004–July 2005	13	92	12/13
France <sup>49</sup>	Paris and Bordeaux	August 2005	208	85	69/81
Germany <sup>50,51</sup>		March 2005	20		
	Hamburg	2003	4	75	3/4
Ireland <sup>52</sup>		2004	Ó		-
Netherlands50,59*	Mainly Amsterdam	January 2003–June 2005	160	65	53/82
	Rotterdam	May 2003-October 2003	13	85	11/13
Switzerland54	Zurich and Lucerne	2003-2005	10	70	7/10
Sweden <sup>55</sup>	Stockholm	2004	. 2	50	1/2
Spain <sup>56</sup>	Barcelona	March 2005	2	0	0/2
United Kingdom <sup>57</sup>	Mainly London and Brighton	October 2004-March 2006	313	74	233/313

\*Eline op de Coul and Femke Koedijk (personal communication).

community based studies give more realistic measures of HIV prevalence among MSM when compared with sexual health clinic attendees. HIV prevalence may still be overestimated.<sup>48</sup> Despite these limitations, however, this is the first time that data on a range of STIs among known HIV-positive MSM have been systematically collated in Western Europe, with enhanced STI surveillance systems providing valuable information.

## Serosorting and Survival

Improved survival and reduced morbidity coupled with unprotected MSM who, like themselves are also HIV-positive (i.e., serosorting) would explain the very high prevalence of HIV among MSM diagnosed with STIs. In the early 1990s, it was estimated that every 20 AIDS deaths per 100.000 adult men were associated with a decline of about 7%–12% in syphilis incidence rates.<sup>69</sup> Since the introduction of HAART however, sexual networks of HIV-positive MSM have grown substantially.<sup>10,11</sup> The Internet in particular, has facilitated serosorting among HIV-positive MSM.<sup>70,71</sup> Evidence also points toward acquisition of multiple STIs and in Germany at least, high levels of syphilis reinfection among some HIV-positive MSM. This has led some researchers to refer to 'the core of the core'—a network of HIV-positive MSM where there is intense circulation of STIs making a disproportionate contribution to overall STI diagnoses.<sup>72</sup>

Presently, LGV and sexually transmitted hepatitis C transmission are circulating almost exclusively among HIV-positive MSM. In contrast, both HIV-positive and negative men are being diagnosed with syphilis and gonorrhea. There are likely to be several explanations for these differences including differences in transmission probabilities and epidemiologic synergies with HIV<sup>16,17</sup>: sexual partnerships and sexual networks including serosorting and time since introduction of the STIs to the network; differential sexual behaviors: differences in testing and case finding; and the differential impact of public health interventions.73.74 Equally, these factors may explain variations in HIV prevalence among MSM with syphilis in different settings. The number of HIVpositive MSM may also play a role in this. Where population size is limited, dissortative sexual mixing is more likely to occur-in this case, serodiscordant partnerships.<sup>75</sup> Taken together, the epidemiologic and behavioral data highlight a role for "positive prevention", i.e., prevention that focuses on the sexual health of HIV-positive MSM in 'high-risk' sexual networks as well as on the transmission of STIs and HIV to uninfected MSM.

## Impact on HIV Transmission

The resurgence in STIs among MSM led to concerns about a corresponding increase in HIV incidence because historically HIV incidence had broadly mirrored STI incidence among MSM in Western Europe.<sup>1,7</sup> 6 Disproportionate circulation of STIs among known HIV-positive MSM would however, change the relationship between HIV and STI incidence. In addition, use of syphilis as a proxy marker is complicated by the significant proportion of cases among MSM acquired through unprotected oral sex, which has a much lower risk of HIV transmission than unprotected anal intercourse.<sup>27</sup>

The relationship between STI incidence and HIV incidence is difficult to assess because of ecological fallacy: most studies do not measure trends in HIV and STI incidence in the same individuals. In the Amsterdam cohort study however, STI incidence has been increasing among all MSM but strikingly there has only been an increase in HIV incidence among older (34+ years), but not younger men.<sup>78</sup> A similar observation has been made in San Francisco.<sup>79</sup> Taken in concert, this evidence indicates that STI incidence may no longer be a suitable proxy for HIV incidence among MSM and that care should be taken when interpreting these epidemiologic trends.

## Comparisons With the United States

The United States has also been experiencing a resurgence in STIs among MSM.<sup>80–85</sup> Syphilis has increased since the introduction of HAART,<sup>79</sup> with HIV-positive MSM being disproportion-ately affected.<sup>86,87</sup> In 2004, gonorrhea positivity in 9 US cities was higher among HIV-positive MSM than among those who were HIV negative or of unknown status [e.g., urethral gonorrhea: 17% (range 12%–25%) vs. 10% (range 6%–12%)].<sup>80</sup> A case of LGV has also been confirmed.<sup>88</sup> Furthermore, matching of STD and AIDS databases in San Francisco has shown that people on HAART are more likely to develop an STL<sup>89</sup>

### **Conclusion and Recommendations**

STIs have been disproportionately diagnosed among HIV-positive MSM in the post-HAART era in Western Europe. Although HIV prevalence among MSM with STIs varied by infection and by setting, the majority of HIV-positive MSM diagnosed with STIs were already aware of their positive HIV status.

These findings highlight the need for routine testing for STIs among known HIV-positive MSM in Western Europe. For example, in the United States, routine laboratory screening for common STIs for all MSM (HIV-positive, negative and of unknown status) is recommended on an annual basis for those who are sexually active.80 Routine screening for HIV would help to diagnose more HIV-infected MSM: our findings indicate that in some settings, a targe proportion of HIV-positive MSM with STIs were unaware of their HIV status.

Safe sex messages have typically focused on HIV prevention but with a growing population of sexually active HIV-positive MSM, messages need to also highlight the consequences of STI infection. The consequences include their impact on HIV treatment response, coinfection affecting the natural history of HIV infection, and increased transmissibility of HIV infection.91-93 Safe sex messages also need to underline the risks associated with sexual practices other than unprotected anal intercourse with a partner of unknown or discordant HIV status. In epidemiologic terms, the disproportionate circulation of STIs among HIV-positive MSM means that changes in STI incidence may no longer reflect corresponding changes in HIV incidence among MSM.

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## Paper 5.2

Research article

# **Open Acces**

# Can current national surveillance systems in England and Wales monitor sexual transmission of hepatitis C among HIV-infected men who have sex with men?

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## Abstract

**Background:** Recent reports suggest an increase in sexually-transmitted hepatitis C infection among HIVinfected men who have sex with men (MSM) in European cities. We investigated whether current national surveillance systems in England and Wales (E&W) are able to monitor sexual transmission of hepatitis C infection among HIV-infected MSM.

Methods: Routine laboratory reports of hepatitis C diagnoses and data from sentinel hepatitis C testing surveillance were matched to HIV diagnosis reports to determine: (i) the number of MSM diagnosed with HIV and hepatitis C (1996-2003); (ii) the number of HIV-diagnosed MSM tested for hepatitis C and found to be positive at sentinel sites (2003).

**Results:** (i) Between 1996–2003, 38,027 hepatitis C diagnoses were reported; 25,938 (68%) were eligible for matching with HIV diagnoses. Thirty-one men (four in London) had both a HIV and hepatitis C diagnosis where the *only* risk was sex with another man. Numbers of "co-diagnosed" MSM increased from 0 in 1996 to 14 in 2003. The majority of MSM (22/31) tested hepatitis C positive after HIV diagnosis. (ii) Of 78,058 test results from sentinel hepatitis C testing sites in 2003, 67,712 (87%) were eligible for matching with HIV diagnoses. We identified 242 HIV-diagnosed MSM who did not inject drugs who tested for hepatitis C in 2003; 11 (4.5%) tested hepatitis C positive (95%CI: 2.3%-8.0%). Applying this percentage to all MSM seen for HIV-related care in E&W in 2003, an estimated 680 MSM living with diagnosed HIV would have tested positive for sexually-transmitted hepatitis C (95%CI: 346–1208).

**Conclusion:** Matching routine laboratory reports of hepatitis C diagnoses with HIV diagnoses only identified 31 HIV infected MSM with sexually-transmitted hepatitis C infection. Clinical studies suggest that this is an underestimate. On the other hand, matching sentinel surveillance reports with HIV diagnoses revealed that in E&W in 2003 nearly 5% of HIV-diagnosed MSM tested hepatitis C positive where the only risk was sex with another man. Reports of sexually-transmitted hepatitis C infection were not confined to London. Enhanced surveillance is needed to monitor sexually-transmitted hepatitis C among HIV-infected MSM in E&W.

## Background

There have been recent reports of an increase in sexuallytransmitted hepatitis C infection among HIV positive men who have sex with men (MSM) in London and other European cities [1-5]. Historically, sex between men has accounted for relatively few cases of hepatitis C, with most hepatitis C infections being acquired through injecting drug use [6]. National surveillance of HIV and hepatitis C infections reflects this historical picture, with diagnoses of HIV and hepatitis C and sentinel surveillance of hepatitis C testing being monitored by separate systems. For reasons of confidentiality, HIV status is not recorded for hepatitis C diagnoses, and hepatitis C status has not been systematically collected for HIV diagnoses. Co-infection is only routinely monitored for injecting drug users through an unlinked anonymous survey [7].

Evidence of an increase in sexually transmitted hepatitis C infections among HIV-infected MSM in England and Wales (E&W) comes from clinical studies only, mainly confined to London and the south east of England [1,8]. At a central London sexual health clinic, Browne et al identified 26 HIV positive MSM with sexually transmitted hepatitis C infection between 1997 and 2002. More recently, between October 2002 and August 2005, Danta et al reported on 225 HIV positive MSM with sexually transmitted hepatitis C seen in six large London genito-urinary medicine (GUM) clinics and one in Brighton [1,8]. Hepatitis C infections among HIV positive MSM appear to be associated with the following: unprotected anal intercourse; non-injecting drug use; concurrent sexually transmitted infections; and mucosally traumatic practices such as fisting, which may result in parenteral transmission [2,4,5,8]. HIV infection itself, may facilitate hepatitis C infection by promoting viral receptivity and increasing levels of hepatitis C RNA in semen [9,10]. Transmission of hepatitis C among HIV-negative MSM however, still appears to be rare [11,12].

While clinical studies suggest a rising number of sexually transmitted hepatitis C infections among previously diagnosed HIV-infected MSM it is unclear as to whether this is a national phenomenon and, if so, the extent to which this is happening across E&W. Unfortunately there is currently no single national surveillance system that can monitor HIV-hepatitis C co-infection among MSM. Since the same patient information (soundex code of surname [13], date of birth (DOB) and sex) is collected on reports however, there may be an opportunity to identify individuals who appear in both HIV and hepatitis C surveillance datasets by 'matching' individual reports.

In this exploratory study using national surveillance data, we investigate whether existing national HIV and hepatitis C surveillance systems can be used to estimate the number of HIV-infected MSM in E&W diagnosed with sexually transmitted hepatitis C in two ways. First, we try to match individual case reports of HIV and hepatitis C diagnoses between 1996–2003. Secondly, we try to match case reports of HIV diagnoses with all hepatitis C test results from laboratories participating in a sentinel surveillance study during 2002–2003. This is the first time these matching exercises have been conducted in E&W to examine sexually transmitted hepatitis C among HIV-infected MSM.

## Methods

## Data sources

## HIV diagnoses

Reports of HIV diagnoses are received by the Health Protection Agency (11PA) Centre for Infections from laboratorics (since 1985) and clinics (since 2000); the latter also report new AIDS diagnoses (since 1982). Patient information (soundex code of surname [13], DOB, sex) is collected on all reports, enabling the identification of multiple reports of the same individual without revealing their identity or compromising confidentiality. A report cannot be entered onto the system until all patient information is complete. Missing information is followed up with the laboratory or clinic. Probable route of infection is also collected on all reports (i.e. sex between men, sex between men and women, injecting drug use, blood transfusion etc), and followed up where incomplete.

### Hepatitis C diagnoses

Laboratory confirmed cases of hepatitis C have been routinely reported to the HPA Centre for Infections since the early 1990s. Patient information (soundex code [13], DOB, sex) is collected along with the likely route of infection, reporting laboratory and region of diagnosis. Unlike HIV diagnoses, laboratory-confirmed hepatitis C cases are not routinely followed up where information is missing, so some reports do not have complete information on soundex code, DOB, sex and how the infection was acquired. A laboratory case is confirmed by the detection of antibody to HCV (anti-HCV) or HCV RNA in serum. Current available laboratory assays for HCV infection cannot distinguish between acute and chronic infections. While requests have been made for information on symptomatic acute infections to be provided on laboratory reports since 1996, this is rarely available.

## Sentinel surveillance of hepatitis C testing

In the sentinel surveillance study of hepatitis C testing, data were collected on all hepatitis C tests (negative, positive, equivocal) undertaken in eight laboratories (two in London, six elsewhere in England) between January 2002 and December 2003 only [14]. Patient information (soundex code, DOB, sex) was collected for each individual but was not followed up where missing. As for the routine surveillance of hepatitis C diagnoses, a case was confirmed by the detection of antibody to HCV (anti-HCV) or HCV RNA in serum.

## Matching exercise

## (i) Matching individual HIV and hepatitis C diagnoses

Laboratory reports of hepatitis C diagnoses made between January 1996 and December 2003 (reports received by the end of May 2004) were matched to reports of HIV diagnoses since reporting began in 1982 through to December 2003 (reports received by end of September 2004). Reports without enough patient information were excluded. Exact matching was undertaken, for example, where reports with exactly the same soundex code, DOB, sex and reporting laboratory were identified. Further matching was also undertaken to allow for errors in data transcription. For example, soundex code, sex, reporting laboratory, month and year of birth would be matched exactly, allowing for errors in the transcription of the day of birth. All matches were verified by eye.

# (ii) Matching individual HIV diagnoses to reports from sentinel hepatitis C testing

Reports from the sentinel surveillance of hepatitis C testing from January 2002 to December 2003 were also matched to reports of HIV diagnoses using the procedure described above.

MSM identified with both hepatitis C and HIV diagnoses are described as "co-diagnosed". Probable route of infection is recorded in both the HIV and hepatitis C laboratory diagnoses datasets and in the sentinel surveillance of hepatitis C testing. Co-diagnosed MSM were assumed to have acquired their hepatitis C infection as a result of sex with another man if no other risks (e.g. injecting drug use) were reported in either dataset. Men with other risks were excluded from the analysis.

## Patient confidentiality and ethics

In England and Wales, reports of HIV diagnoses and diagnoses of hepatitis C infection are voluntary and confidential. To maintain patient confidentiality no names are held on the HIV database: soundex codes (a pseudonomyised code of a surname) are used instead [13]. The reporting systems have approval under the section 60 regulations of the Health and Social Care Act 2001 (Statutory Instrument 1438 – June 2002). All data are stored on restricted and secure databases at the HPA, with strict adherence to the Data Protection Act and Caldicott Guidelines [15]. Ethical approval was obtained for the sentinel surveillance of hepatitis C testing from the Northern and Yorkshire Multi-Centre Research Ethics Committee (MREC1/3/76) and the Public Health Laboratory Service Ethics Committee.

## Results

## Matching individual HIV and hepatitis C diagnoses

Of the 38,027 hepatitis C infections diagnosed between 1996 and 2003 and reported to the HPA, 68% (25,938/38,027) were eligible for inclusion in the matching exercise. The number and proportion of hepatitis C laboratory reports eligible for inclusion rose over time, from 50% (1.256/2,499) in 1996 to 74% (4,749/6,448) in 2003. The number of reports and degree of matching varied by region (table 1).

The matching exercise identified 199 individuals diagnosed with both hepatitis C and HIV ("co-diagnosed") of whom 47 were men who reported sex with another man (MSM) (table 2). Of the 47 co-diagnosed MSM, 16 were recorded as having injected drugs, having received a blood transfusion or blood factor products. These 16 MSM were therefore excluded from further analysis as they may not have acquired hepatitis C sexually.

For the 31 remaining MSM with no other reported risk, median time between HIV and hepatitis C diagnoses was 26 months (IQR: 4–90 months); 22 were diagnosed with hepatitis C after their HIV diagnosis, three before and six in the same year. Median age at HIV diagnosis was 32 years and at hepatitis C diagnosis, 36 years. A rise in the number of co-diagnosed MSM was observed over time, from zero in 1996 to 14 in 2003 (figure 1).

Twelve of the 31 MSM were diagnosed with hepatitis C in the North West, five in the South West, four in London, four in the West Midlands, three in East Midlands and three elsewhere (figure 2a). Where ethnicity was reported (n = 25), the majority (n = 23) were white, while two were black Caribbean. Where probable country of HIV infection was reported (n = 16), 75% (12) were infected with HIV in the UK

# Matching individual HIV diagnoses to reports from sentinel hepatitis C testing

Of the 78,058 individuals tested for hepatitis C in 2002 or 2003 by laboratories participating in the sentinel surveillance of hepatitis C testing, 87% (67,712/78,058) were eligible for inclusion in the matching exercise. Overall, 6% of the 78,058 individuals were tested at CUM clinics but records from CUM clinics represented 40% of the 10,346 excluded records (i.e. 82% of records from GUM clinics were excluded). This is because GUM clinics do not usually report soundex code/surname on laboratory test request forms. The number and proportion of hepatitis test results eligible for inclusion varied by region (table 1), reflecting both the sentinel nature of the surveillance system and the quality of patient information recorded. Table 1: Number of HIV diagnoses, hepatitis C laboratory diagnoses and reports from the sentinel surveillance of hepatitis C testing received and eligible for inclusion in the matching exercise by region of diagnosis/test

Region of diagnosis/test	HIV diagnoses (1982–2003)		Claboratory di (1996–2003)	agnoses	Sentine	surveillance of hepatit (2002–2003)	tis C testing
	No of diagnoses	No of reports	No included matching ex		No of reports	No included in the mat	ching exercise*
			n	%		n	%
East Midlands	1675	1721	1017	59	8337	7927	95
Eastern	2561	3859	2488	64	na	na	na
London	35401	2630	1822	69	3187	2959	92
North East	848	926	693	75	11814	9848	83
North West	3840	8107	6280	77	31576	27381	87
South East	5514	5655	3615	64	03	na	na
South West	1937	5748	4441	77	na	na	na
West Midlands	2454	4345	2895	67	9489	7282	76
Yorkshire & Humberside	2246	2162	1639	76	13513	12315	91
Wales	864	2874	1028	36	na	na	na
Total	57340	38027	25918	68	78058	67712	87

\*reports were excluded from the matching exercise if patient information was missing or there were other anomalies. na=not available

Table 2: Probable route of HIV infection and hepatitis C risk for individuals identified as 'co-diagnosed' through matching

Probable route of HIV infection	Probable route of hepatitis C infection	Number of "co-diagnosed"
Sex between men	Injecting drug use	4
	Blood transfusion/product	~ I
	No risk reported	31
Sex between men & injecting drug use	Injecting drug use	2
	No risk reported	9
injecting drug use	Injecting drug use	33
	Heterosexual intercourse	I
	No risk reported	61
Heterosexual intercourse	Injecting drug use	2
	Heterosexual intercourse	l
	No risk reported	26
Blood transfusion/product	Blood transfusion/product	5
	No risk reported	18
Not reported	Injecting drug use	1
	No risk reported	4
	Total	199

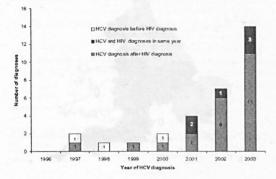


Figure I

Number of MSM co-diagnosed with hepatitis C and HIV in England and Wales identified through the matching exercise, by year of hepatitis C diagnosis.

The matching exercise identified 782 individuals who tested for hepatitis C in 2002–2003, who had also been diagnosed with HIV. Of these 782 individuals, 319 were MSM. Five of these men also had a history of injecting drug use and so were excluded from further analysis. Of the remaining 314 MSM with an HIV diagnosis who had had a hepatitis C test, 13 (4.1%) tested hepatitis C positive (95% confidence interval: 2.2%, 7.0%). Data for 2002 only: 2.8% (2/72) hepatitis C positive (95%CI: 0.3% to 9.7%). Data for 2003 only: 4.5% (11/242) hepatitis C positive (95%CI: 2.3% to 8.0%).

Median age at hepatitis C testing was 40 years and for HIV diagnosis, 33 years, which did not vary by hepatitis C test result. The percentage of MSM with diagnosed HIV who tested positive for hepatitis C varied between regions (figure 2b). Where ethnicity was reported on HIV reports, 94% (204/216) were white, again not varying by test result. Where probable country of HIV infection was reported, most MSM (134/155) were infected with HIV in the UK.

In 2003, 15;121 MSM with an HIV diagnosis were seen for treatment and care in E&W [16]. If 4.5% of these men tested positive for hepatitis C (assuming the same percentage tested positive in the overall MSM population seen for HIV-related care as seen here), we estimate that 680 MSM living with diagnosed HIV in E&W tested positive for sexually transmitted hepatitis C in 2003 (95%CI: 346 to 1208).

## Discussion

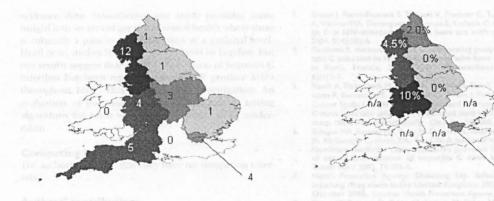
By matching individual hepatitis C and HIV diagnoses in England and Wales between 1996–2003, we identified 31 HIV-infected MSM with sexually transmitted hepatitis C infection, of whom only four were in London. Clinical studies suggest that this is a substantial underestimate [1,8]. For example, at one central London GUM clinic alone, 26 HIV positive MSM were diagnosed with sexually transmitted hepatitis C between 1997 and 2002. Across six large GUM clinics in London and Brighton, 225 HIV positive MSM with sexually transmitted hepatitis C were identified between October 2002 and August 2005 [1,8]. On the other hand, matching HIV diagnoses and hepatitis C tests from sentincl sites suggested that, in 2003, nearly five percent of MSM diagnosed with IIIV who were tested for hepatitis C were found to be positive. Sexual transmission of hepatitis C was the likely route of infection. While this matching exercise was more successful, the true percentage may be underestimated since those attending GUM clinics, and likely to be at higher risk because of their sexual behaviours, were less likely to be included in the analysis because of a lack of patient identifiable information.

The percentage of HIV-infected individuals (mainly MSM) testing hepatitis C positive rose over time in a London GUM clinic, from 0.6% in 1996 to 9.3% in 2002 [1]. The estimates from our sentinel sites for 2002 and 2003 were more conservative (2.8% and 4.5%, respectively). Assuming that these percentages can be applied to all HIV positive MSM receiving treatment and care, we estimate that, in 2003, at least 680 MSM (95%CI: 346 to 1208) with diagnosed 1HV tested positive for sexually transmitted hepatitis C in E&W.

Our analysis also shows that sexually transmitted hepatitis C among HIV-infected MSM is not confined to London and Brighton. Outside London, the number of HIV infected MSM with sexually transmitted hepatitis C infection was highest in the North West, which includes Manchester with a large MSM population and good reporting of both HIV and hepatitis C diagnoses (table 1) [unpublished, HPA]. Again however, these figures are likely to be underestimates due to a lack of reported patient identifiable information.

## Limitations of current surveillance systems

Our analyses are dependent on MSM being diagnosed with HIV and hepatitis C infection: both infections may be asymptomatic for a significant length of time and some may have died without being diagnosed with HIV and/or hepatitis C. The analyses also rely on MSM diagnosed with hepatitis C and/or HIV being reported to national surveillance systems. The hepatitis C laboratory data appeared to be poorly reported in London (table 1), relative to the number of diagnoses in other regions. Incomplete reporting within a region will affect the number of hepatitis C reports that can be matched to HIV diagnosis reports, and subsequently the number of co-diagnoses detected in that



#### Figure 2

(a) Number of co-diagnosed MSM (1996–2003) and (b) proportion of diagnosed HIV-infected MSM with a positive hepatitis C test (2002–2003) by region of hepatitis C diagnosis/test in England and Wales, as identified through the matching exercise.

area. In addition, for the sentinel surveillance of hepatitis C testing, only two small London laboratories were included. These laboratories do not serve GUM clinics with large MSM populations and are not necessarily representative of all MSM testing for hepatitis C in London. On the other hand, many of the sentinel sites outside London were large laboratorics in major provincial cities (Manchester, Leeds, Birmingham, Nottingham and Newcastle) so it is likely that a substantial number of MSM receiving HIV care outside London were included.

There are limitations to the matching process: individuals may be incorrectly matched or individuals may not be matched if information has been incorrectly recorded. Reports must also contain sufficient information for the matching process; overall nearly a third of the hepatitis C laboratory reports and more than ten percent of the hepatitis C test requests from sentinel surveillance could not be matched to HIW diagnoses because of missing patient information. This varied by region, and for hepatitis C diagnoses, over time. In the sentinel surveillance study, the majority of records for GUM clinic attendees, who may be at higher risk of acquiring HW and sexually transmitted hepatitis C infection, had to be excluded because of a lack of reported soundex code/surname. Incomplete reporting will lead to underestimation and introduce bias, particularly in London. On the other hand, increases in hepatitis C testing and improvements in the reporting of patient information on laboratory diagnoses of hepatitis C may have led to improved ascertainment of co-diagnosed individuals over time. There may also be a bias in that hepatitis C testing might have been prompted by abnormal liver function tests or by injecting drug use that had not been disclosed at the time of HIV diagnosis.

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#### Conclusion

It was not possible to use current national surveillance systems to accurately monitor sexually transmitted hepatitis C infection among HIV-infected MSM across E&W. The number of HIV infected MSM with sexually transmitted hepatitis C infection was underestimated due to the limitations of the surveillance systems, particularly reporting of hepatitis C diagnoses, the matching process, and the sentinel nature of the hepatitis C testing data. Improved or enhanced surveillance methods (such as for lymphogranuloma venereum (LGV)) are needed to monitor sexually transmitted hepatitis C infection among HIV-infected MSM nationally, as well as in London. The recording of soundex codes and dates of birth on test request forms from GUM clinics would also improve the quality of surveillance data. Nonetheless, our study provides some insight into an area of gay men's sexual health where there is currently a paucity of information at a national level. Until now, studies have focused on MSM in London, but our results suggest that sexual transmission of hepatitis C infection has been reported among HIV positive MSM throughout E&W. This merits further investigation. An evaluation of the most appropriate hepatitis C testing algorithms for MSM with HIV also needs to be undertaken.

#### **Competing interests**

The author(s) declare that they have no competing interests.

## **Authors' contributions**

SD collated the HIV diagnoses data, performed the matching exercises and drafted the manuscript. MB and LB provided the hepatitis C diagnoses and hepatitis C testing data respectively, and guided on their use in the matching exercises and interpretation of results. JE, KS, BE and MR all provided guidance on the study design, the interpretation of the resulting HIV and hepatitis C data, study limitations and conclusions, and drafting of the manuscript. All authors read and commented on manuscripts.

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## 5.1 Introduction

My two papers on sexually transmitted infections (STIs) among HIV positive MSM investigated an emerging theme in HIV and STI epidemiology among MSM: the transmission of STIs other than HIV within sexual networks of HIV positive MSM (Dougan *et al.*, 2007c; Dougan *et al.*, 2007d). Early studies revealed that HIV positive MSM were more likely to acquire other STIs (such as syphilis or gonorrhoea) than HIV negative MSM (Evans *et al.*, 1993; Lavreys *et al.*, 1995). However, significant improvements in survival and quality of life with the widespread use of highly active antiretroviral therapies (HAART) have led to a growing population of sexually-active HIV positive MSM who are disproportionately contributing to the recent rise in STIs (Aalen *et al.*, 1999; Dougan *et al.*, 2007c, Fenton & Imrie, 2004).

In this chapter, I focus on sexual networks of MSM, and particularly sexual networks of HIV positive MSM in western Europe, north America and Australasia in which gonorrhoea, syphilis, LGV and sexually-transmitted hopatitis C are being transmitted (Fenton & Imrie, 2004; Dougan *et al.*, 2007c). In particular, I:

(i) examine network theories and the role of networks in infectious disease epidemiology;

(ii) describe what is known about sexual networks among HIV positive MSM,

(iii) examine the important features of these networks;

(iv) make recommendations for interpreting HIV, STI and behavioural surveillance data in the context of these sexual networks and consider areas for future research to better inform prevention initiatives.

# 5.2 Research findings from my published papers

The first paper in this chapter published in *Sexually Transmitted Diseases* in 2007, describes the disproportionate burden of STIs among HIV positive MSM in western Europe in the post-HAART era (Dougan *et al.*, 2007c). While this was not a systematic review, the literature was comprehensively searched and appraised through MEDLINE and also by searching each country's national surveillance centre websites and reports. Bibliographies within references were also searched for other sources that may have been missed in searches of the published and grey literature. A meta-analysis was not attempted because of the differences between the source populations, methods of case ascertainment, and timeframes.

The paper showed that while HIV prevalence among community samples of MSM was 5%-18%, the prevalence of HIV among MSM diagnosed with an STI was much higher. In western Europe, on average, 42% of MSM diagnosed with syphilis were HIV positive (range: 14%-59%), as were 32% of MSM diagnosed with gonorrhoea, 75% (range: 0%-92%) of MSM with LGV and most MSM with sexually-transmitted hepatitis C infection (Dougan *et al.*, 2007c). These averages were crudely calculated, with the denominator being the number of HIV positive MSM (± STI) in all the different studies (for all countries combined) and the numerator the number of HIV positive MSM with the STI in all the studies. Patterns were remarkably similar across western Europe. Improved survival coupled with "serosorting" among HIV positive MSM in the post-HAART era seems to explain the disproportionate burden of STIs among HIV positive MSM in western Europe. Serosorting is a risk reduction strategy employed by some MSM to decrease the likelihood of acquiring or transmitting HIV, by seeking a sexual partner of the same HIV serostatus (Elford, 2006).

The second paper in this chapter (Dougan *et al.*, 2007d), examined whether existing national surveillance systems could be used to capture information on HIV and hepatitis C co-infection among MSM in England and Wales. It highlighted the difficulties of using existing surveillance systems to monitor changing patterns of HIV and hepatitis C co-infection (Dougan *et al.*, 2007d). In this paper, using surveillance data I tried matching diagnoses of HIV with diagnosis of hepatitis C to investigate sexually-transmitted hepatitis C infection among HIV positive MSM. Lalso examined data from the hepatitis C denominator study. However, there were considerable difficulties associated with using existing surveillance systems to describe the changing patterns of HIV and hepatitis C co-infection, even where disaggregate data with patient identifiable information were available (i.e. individual patient records rather than counts of patients). I concluded that to monitor HIV and sexually-transmitted hepatitis C co-infection in MSM either a new surveillance system collecting enhanced data would need to be set up or an existing one would need to be substantially modified. The former is now underway (HPA, 2006).

# 5.3 Serosorting among MSM

The high levels of HIV-STI co-infection among HIV positive MSM that I described in my two peer-reviewed papers are likely to be the result of serosorting. Serosorting is a risk reduction strategy that has been increasingly adopted by MSM in the post-HAART era, whereby MSM with HIV seek partners of the same HIV status (i.e. positive-positive) for unprotected anal intercourse (UAI) (Elford *et al.*, 2006). While there is no risk of onward transmission of HIV to an un-infected partner (assuming HIV status is accurately determined), there is the risk of transmission of other STIs (e.g. gonorrhoea, syphilis) and potentially 'super-infection' with HIV, whereby an HIV

positive individual becomes infected with a second strain of HIV (Poudel et al., 2007).

Behavioural studies indicate that serosorting has emerged as a risk reduction strategy among MSM in London and other western European and north American cities (Cox et al., 2004; Elford et al., 2005; Halkitis et al., 2005a; Halkitis et al., 2005b; Troung et al., 2006; Wolf et al., 2003; Xia et al., 2006). In the London gym study, the proportion of HIV positive MSM reporting UAI only with a casual partner. who was also HIV positive increased from 6.7% in 1998 to 17.7% in 2005 (p<0.001) (Elford et al., 2005). In a more recent paper, Elford et al. observed that among MSM attending a London outpatient clinic for HIV care, more than half of the HIV positive MSM intentionally seeking UAI had looked for sex only with another HIV positive MSM (Elford et al., 2007). In San Francisco, while community-based surveys indicated that UAI among MSM increased overall between 1998 and 2004 (p<0.001), UAI with partners of unknown HIV serostatus decreased among HIV positive MSM from 30.7% in 2001 to 21.0% in 2004 (p<0.001) (Truong et al., 2006). This suggests that serosorting has been adopted as a risk reduction strategy in San Francisco and is likely to explain the observed stabilization in HIV incidence among MSM (Truong et al., 2006).

The adoption of serosorting as a social norm therefore seems to have resulted in the formation of distinct sexual networks of HIV positive MSM who engage in UAI with other HIV positive men. Within these networks of HIV positive MSM, a lack of condom use, 'high risk' sexual behaviours (e.g. fisting) and HIV infection appear to have contributed to the transmission of syphilis, LGV, hepatitis C (Browne *et al.*, 2004; Dougan *et al.*, 2007c; Simms *et al.*, 2005; Ward *et al.*, 2007b), and even *Shigella* (Aragón *et al.*, 2007). To further understand these emerging behavioural

and epidemiological patterns, I examine what is known about the sexual networks of MSM, and specifically HIV positive MSM. An appreciation of how sexual networks form and grow and the factors influencing them is important in understanding the transmission dynamics of HIV and other STIs among HIV positive MSM and following on from this, the effective targeting of preventive measures. First, I begin by looking at networks in infectious disease epidemiology in general. Then I go on to look at sexual networks and their special features, what we know about sexual networks of MSM and specifically of HIV positive MSM. Finally, I make recommendations for further research.

# 5.4 Networks in infectious disease epidemiology

Network theory has been widely applied to fields such as anthropology, ecology and computer science, but only relatively recently to infectious disease epidemiology (Barabasi & Albert, 1999; Doherty *et al.*, 2005). Interest in network theory in infectious disease epidemiology began with the aim of improving our knowledge of HIV transmission dynamics in the mid-1980s (Klovdahl, 1985; Klovdahl, 2001). Since then, the application of network theory to infectious disease epidemiology has assumed increasing importance, and the breadth of research has widened, encompassing STIs, as well as emerging infections such as SARS (Meyers *et al.*, 2005; Meyers *et al.*, 2006; Leo *et al.*, 2003; Booth *et al.*, 2003; Donnelly *et al.*, 2003).

Network theory enables epidemiologists to analyse patterns of human interaction that impact on the spread of infectious disease and, combined with infectious disease modelling, the potential impact of interventions to prevent or limit the spread of infection (Meyers *et al.*, 2003). Network theory is now favoured by some, over the

more traditional approach of "compartmental analysis" (i.e. splitting people into 'high' or 'low' risk groups) for describing the transmission dynamics of HIV and other STIs because it can incorporate heterogeneity in patterns of sexual contact (Pourbohloul & Brunham, 2004).

The course of an infectious disease epidemic is governed by  $R_0$  - the basic reproduction number (also known as the "basic reproductive rate") (Anderson & May, 1991).  $R_0$  gives the average number of other individuals an infected individual will infect in a population with no immunity to the disease. For an epidemic to occur  $R_0$  must be greater than 1; for endemic transmission,  $R_0$  must equal 1; and for elimination or eradication,  $R_0$  must be less than 1.  $R_0$  is a product of three factors: (i) the transmissibility of the infectious disease agent; (ii) the duration of infection; and (iii) the rate of contact between susceptible and infected people.

Traditionally, infectious disease networks were assumed to have a random distribution in which individuals connected with others independently, uniformly and at random, with 'full-mixing' of the population (Meyers *et al.*, 2005). Over the past few years however, it has become apparent that many real-world networks do not conform to a random distribution (Doherty *et al.*, 2005; Christley *et al.*, 2005, Paster-Satorras & Vespignani, 2001). Instead of every individual having an equal chance of spreading infection to every other individual, the majority of people have very few contacts while a small group of people are extremely well connected (Holland-Jones & Handcock, 2003; Doherty *et al.*, 2005; Gladwell, 2002). This could give rise to the distributions as shown in figure 5.1. In a network with this type of distribution, the more connected people tend to acquire links at a more rapid rate than people with fewer connections (i.e. *"the rich get richer"*) (Doherty *et al.*, 2005; Gladwell, 2002). They are termed "scale-free" networks relating to the lack of a typical number of

connections between people in the network (i.e. most people have a small number of connections while a small number of people have a large number of connections). Whether or not networks are actually "scale-free" is currently under debate. A truncated power-law distribution seems more likely, where the power-law distribution continues to a particular point, after which for example, the number of further contacts is limited (e.g. boundaries in the number of sexual partners).

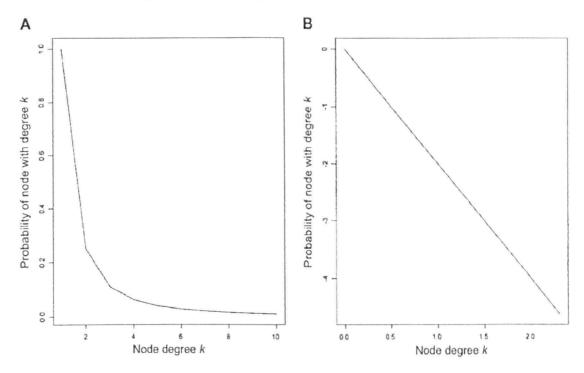
## Figure 5.1: Power-law distribution for scale-free networks

A, Example of a power-law distribution. B, Power law plotted on a log-log scale.

Node degree is equivalent to the number of sexual partners.

The equation for a power-law curve is, where P(k) is  $P(k) - k_a$  the probability that a node has degree k and a is the slope of the line when the distribution is plotted on a log-log scale.

A shows that in a scale-free network, most people have a small number of sexual partners, while a few have a large number of sexual partners.





The large difference in contact patterns between scale-free and traditional network structures leads to differences in transmission dynamics within these networks. While  $R_0$  may be the same at a population-level in both networks, it will vary at an individual level. In traditional, homogeneous networks, each individual who acquired an infection would transmit it to  $R_0$  others. In essence, every individual has an equal chance of acquiring and transmitting the infection. On the other hand, in highly heterogeneous scale-free networks, some individuals may have no chance or a very small chance of acquiring or transmitting the infection ( $R_0 < 1$ ), whereas a minority have a large chance ( $R_0 >>1$ ) (Meyers *et al.* 2005).

It is the individuals in the right hand tail of the distribution – those with many contacts (i.e.  $R_0 >>1$ ) – who are a particular focus in terms of infectious disease transmission and prevention, as these so-called "superspreaders" can dramatically alter transmission dynamics despite being small in number (Meyers *et al.*, 2005; Anderson & May, 1991; Pastor-Satorras & Vespignani, 2001). Modelling shows that infection will preferentially occur among "superspreaders" and that once infection is established, transmission will be rapid (Kiss *et al.*, 2006). In theory, preventing these "superspreaders" from acquiring infection or promptly diagnosing and treating them once infected, should reduce the transmission of infection.

# 5.5 Sexual networks

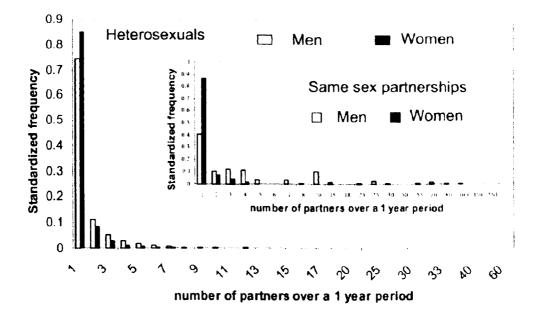
Sexual networks are critical for the spread of STIs. The term "sexual network" refers to a set of people who are linked directly or indirectly through sexual contact. HIV and STI epidemiology has traditionally focused on individual risk factors and behaviours. In recent years however, increasing attention has been paid to the role of sexual networks in HIV and STI epidemiology. This has followed the recognition that the fundamental determinants of population-level health go beyond the individual, and that studies of sexual networks can provide unique insights into HIV and STI transmission dynamics that are not captured using traditional surveillance and epidemiologic methods (Adimora & Schoenbach, 2005; Doherty *et al.*, 2005; Koopman & Lynch, 1999; Liljeros *et al.* 2003; Link & Phelan, 1995).

It has been apparent for some time that the number of sexual partners within a population is not normally distributed and that partners are selected non-randomly (Liljeros *et al.*, 2001). There only has to be a small number of individuals who change partners frequently to have a dramatic effect on the transmission and persistence of a curable STI in a population (May & Anderson, 1987). Frequent re-infection of the same group of people with curable bacterial STDs has led to the "core group" concept that has been central to HIV and STI transmission dynamics (Yorke *et al.*, 1978). This core group is composed of sexually active individuals who became infected (e.g. with gonorrhoea) and without whom infection would die out (Yorke *et al.*, 1978). In HIV epidemiology (as opposed to other STIs), the core group concept does not strictly apply as there is no re-infection. Nonetheless, populations at 'high risk' of acquiring HIV are referred to as core groups. This includes MSM, along with commercial sex workers, injecting drug users, and truck drivers in developing countries (see for example: Aral, 2000; Lowndes *et al.*, 2002; Morris *et al.*, 1996).

Data from the National Surveys of Sexual Attitudes and Lifestyles (Natsal 1990 and Natsal 2000) indicate that the distribution of the number of sexual partners among MSM in Britain, as expected, is heterogeneous, with many men having a relatively small number of partners and a small number of men having many partners (figure

5.2) (Mercer *et al.*, 2004). In the 2000 survey, the median number of partners reported by MSM in the five years prior to the survey was four, but the mean was 24 (Mercer *et al.*, 2004). This distribution of partners reported by MSM follows a power-law distribution as described in the previous section, with the majority of MSM having a smaller number of partners and a minority with a large number of partners. While a high number of sexual partners (20+ in a year) has been associated with HIV infection among MSM (Valleroy *et al.*, 2000), I could not find any studies specifically examining the distribution of partners for HIV positive MSM. Presumably, numbers of sexual partners for HIV positive MSM will also follow a power-law distribution, but with a higher mean number of partners than for HIV negative MSM (Elford *et al.*, 2005; Elford *et al.*, 2007).

Figure 5.2: Comparison of sexual partner distribution for men who have sex with men (MSM), heterosexuals and women who have sex with women (WSW), Natsal 2000



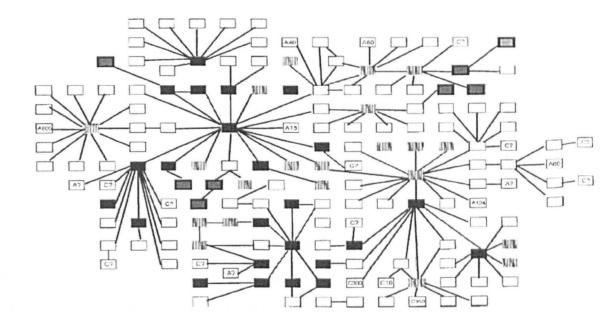
Source: Schneeberger et al., 2004

There have been very few empirical studies of sexual networks (Ward, 2007), and only a handful on sexual networks of MSM. One reason that there have only been a limited number of studies on sexual networks is because both practically and ethically they are difficult to investigate (Ward, 2007). Practically, individuals may not be able to recall their own sexual partners so that an accurate picture of the network. cannot be built up. This is a particular issue among some MSM who have a high rate of partner change and a high proportion of anonymous sexual partnerships (e.g. Ekstrand et al., 1999). In one sexual network of gonorrhoea cases and contacts in London for example, there were 138 individuals and over 1200 contacts (Parker et al., 1998). Most of these cases were MSM. The network structure had several very dense areas and several "cycles" (see figure 5.3) but obviously given the substantial number of "unknown" contacts, density may have been significantly underestimated (Parker et al., 1998; Ward, 2007). There is also evidence of a bias whereby "superspreaders" - those with a large number of sexual partners - forget about some of their partners (De et al., 2004; Brewer et al., 2005). Again, this will lead to underestimation of the densities of sexual networks and therefore the potential for transmission of an STI.

As with the distribution of sexual partnerships among HIV positive MSM, there have been few sexual network studies of HIV positive MSM. The two exceptions are a study which investigated 43 HIV positive MSM in San Francisco and their 176 unique partnerships (McConnell & Grant, 2003) and one in a small community in Iceland (Haraldsdottir *et al.*, 1992), in relation to network size and sexual mixing patterns (which I give details of in the next section). However, this work only seems to have been published as a conference abstract, with limited information available. Figure 5.3: Sexual network of MSM and other contacts in London: overall network

structure of 138 individuals linked over an 18 month period

Individuals are shown as boxes; those in black are know to be HIV positive, those in grey are negative and those in white are of unknown HIV status. Purple boxes are women, the rest are men. Boxes with A or C indicate an unknown (?) or estimated (number) of anonymous and commercial contacts respectively. Lines indicate sexual partnerships.



Source: adapted from Parker et al., 1998 and taken from Ward, 2007

Characterisation of the sexual networks provided some evidence of serosorting among HIV positive MSM, with 15% of partnerships with HIV negative men; 36% with other HIV positive men, and the remainder with men of unknown serostatus (McConnell & Grant, 2003). However, the serostatus of the partner seemed to influence the level of risk-taking. Notably, the partners of seropositive men reported receptive UAI in only 7.4% of serodiscordant partnerships, but in 91% of seroconcordant partnerships (McConnell & Grant, 2003).

# 5.6 Main characteristics of sexual networks

The three important characteristics of sexual networks are *size*, *connectivity* or density, and *time* (Adimora & Schoenbach, 2005, Ward, 2007). In this section, I consider why these characteristics are important, and what we know about them in sexual networks of HIV positive MSM.

# 5.6.1 Size

The exact relationship between network size and STI transmission is not clear (Scheeneeberger et al., 2004; Anderson & May, 1991; Ward, 2007). One of the unusual characteristics of STIs is the lack of a density threshold which means that STIs can persist in very small populations compared to diseases such as measles which require a high population density of susceptible individuals (Anderson & May, 1991). This has puzzled epidemiologists (Holland-Jones & Handcock, 2003), but it seems to be explained by heterogeneity in sexual behaviour (Hethcote & Yorke, 1984), and also a lack of acquired immunity to infection, allowing re-infection to occur. The size of the sexual networks of HIV positive MSM who are engaging in serosorting, is unknown. However, in the UK, in 2005, there were 19,863 diagnosed HIV positive MSM (HPA, 2006). A recent study of nearly 500 HIV positive MSM in a London outpatient clinic observed that 6.4% of the men reported having UAI in the previous 3 months only with casual partners who, like themselves, were HIV positive partner (i.e. serosorting) (Elford et al., 2007). Applying this proportion to the population of diagnosed HIV positive MSM, gives an estimated population of 1271 HIV positive MSM who consistently serosort in the UK in a three month period. A further 6.2% of the men reported having UAI with some casual partners who were HIV positive and others whose HIV status was unknown or discordant. Applying this proportion to the population of diagnosed HIV positive men suggests that a further 1232 HIV positive MSM in the UK serosort, but do so inconsistently. There are also likely to be MSM visiting from other countries participating in these networks, since travel is relatively frequent among MSM (Fenton & Imrie, 2006).

It seems that the size of a sexual network has an impact on sexual mixing patterns. Sexual mixing patterns may be "assortative" or "disassortative". In assortative sexual mixing, individuals select partners with similar characteristics, for example, age, ethnicity, country of origin, numbers of sexual partners, or in the case of serosorting, HIV status (Barlow *et al.*, 1997; Doherty *et al.*, 2005). Empirical studies suggest that most sexual networks seem to conform to assortative sexual mixing (Potterat, 1985, Granath *et al.*, 1991; Ramstedt *et al.*, 1991). For example, in a study of genorrhoea in south London, it was observed that people tended to choose sexual partners from their ethnic group (Barlow *et al.*, 1997). This resulted in genorrhoea remaining concentrated within the black Caribbean population. Assortative sexual mixing does seem to predominate in sexual networks (Kolader *et al.*, 2006; Choudhury *et al.*, 2006), and so it is perhaps not surprising that in the post-HAART era. HIV status is one of the characteristics determining sexual mixing patterns, through serosorting.

On the other hand, in dissortative sexual mixing, the characteristics of sexual partners will differ in terms of for example, age, ethnicity, country of origin, numbers of sexual partners or HIV status. Dissortative sexual mixing increases the odds of infection in a sexual partnership, and will ultimately generate a larger HIV/STI epidemic than if assortative sexual mixing predominates (Aral *et al.*, 1999; Doherty *et al.*, 2005; Liljeros *et al.*, 2003). A well-known example is the sexual mixing of younger women with older men in Africa (Gregson *et al.*, 2002). These young women are at increased risk of STI and HIV infections (Gregson *et al.*, 2002). Similarly, among MSM, a New York study observed that younger MSM having sex

with older MSM were at higher risk of acquiring HIV, and the author hypothesised that it is these younger MSM, engaging in dissortative sexual mixing, who are driving HIV transmission within their generation (Morris *et al.*, 1995). Sero-discordant sexual partnerships among MSM, where HIV-positive and HIV-negative MSM have UAI, is another example of dissortative sexual mixing, and its extent is key in determining HIV transmission dynamics among MSM.

There is limited evidence that smaller sexual networks result in more dissortative mixing, which in theory, will result in greater spread of infection. Haraldsdottir *et al.* constructed a sexual network from 22 of the 35 known HIV positive cases and their sexual contacts in 1980-1987 in an isolated community in Iceland (Haraldsdottir *et al.*, 1992). They showed that sexual mixing was quite dissortative, with people with fewer partners linking in with those with multiple partners (Haraldsdottir *et al.*, 1992). While this was only a small study undertaken two decades ago, the question of how sexual network size affects sexual mixing patterns is worthy of further research. Presumably, the tendency towards dissortative sexual mixing in this small community in Iceland arose from the limited availability and choice of sexual partners. Relatively small populations of HIV positive MSM may limit the scope for serosorting and result in more sero-discordant sexual partnerships and therefore increased HIV transmission, as well as transmission of other STIs.

# 5.6.2 Connectivity

The degree of connectivity or density will also affect the likelihood of transmission in sexual networks (Adimora & Schoenbach, 2005). A prominent feature of sexual networks is the heterogeneity of sexual behaviours, as previously mentioned. The sexual behaviour of people at a population level may not be sufficient to support an epidemic or maintain endemic STI: it is the heterogeneity in behaviours, particularly

those of "superspreaders" which allows an epidemic to grow or an infection to persist (Handcock & Holland Jones, 2003).

Different STIs require different levels of connectivity in a network to persist. For example, Chlamydia can persist at a relatively high prevalence among more loosely connected network structures (Potterat *et al.*, 1985), similar to those found in nondiseased populations (figure 5.4) (Ward, 2007). However, syphilis and gonorrhoea require more densely connected structures (figure 5.4) (Rothenberg *et al.*, 1998). Rothenberg *et al.*, 2001). These differences in sexual network structures necessitate different prevention interventions (Ward, 2007). The more loosely connected structure will require a population-level intervention since having only a relatively small number of sexual partners (i.e. around average for the population) confers an appreciable risk of infection (Ward, 2007). On the other hand, the more densely connected structure will require more targeted intervention (Ward, 2007), fitting in with the more traditional 'core group' model, because the nature of the infection will mean that it will remain concentrated among those with higher numbers of sexual partners (i.e. requires densely connected structure).

The available behavioural data on HIV positive MSM and the transmission dynamics within these networks suggest that they are likely to be highly connected, with high levels of partner change (Schneeberger *et al.*, 2004). These men are thought to make a disproportionate contribution to the transmission of gonorrhoea, syphilis, LGV and sexually-transmitted hepatitis C (Dougan *et al.*, 2007c), which require dense network structures. Data from the enhanced surveillance of STIs, suggest that HIV positive MSM are often diagnosed with more than one STI and one study in Germany suggests a high level of re-infection with syphilis (Marcus *et al.*, 2005;

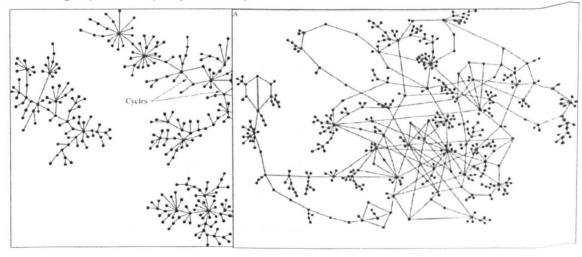
Ward *et al.*, 2007b). However, there is limited information on this because STI surveillance systems are usually separate reporting systems, with little data, if any, on whether a person has been diagnosed with another STI. As a consequence, information on co-infection is not well recorded or published.

Figure 5.4: Sexual network structures associated with (a) Chlamydia and (b)

gonorrhoea in Colorado Springs

(a) Shows the four largest components of the sexual network identified from patients with Chlamydia infection between 1996 and 1999. The dominant characteristic is of long branching structures with few loops or cycles.

(b) In contrast, (b) shows the single largest component from a gang-associated outbreak of gonorrhoea infection in Colorado in 1988-1991. The dominant characteristic is of a densely connected group with multiple cycles or loops.



(a)

(b)

Source: Potterat et al., 2002

# 5.6.3 Time

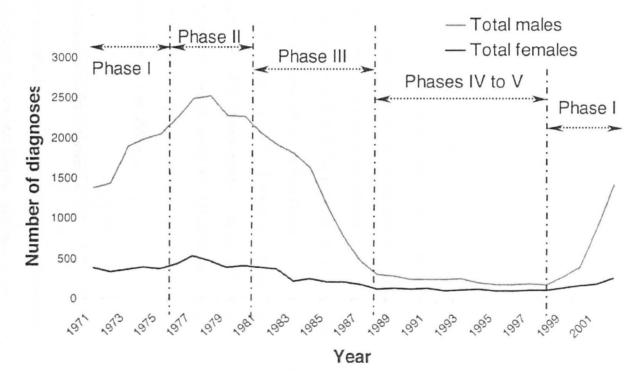
Sexual networks change over time, in terms of size, shape and partnership types (Rothernberg, 1998). These changes occur as the phase of the epidemic progresses, as the cohort ages, and as there is demographic change (Ward, 2007). For example, in their studies of 595 people at high risk of acquiring HIV (i.e.

prostitutes, injecting drug users) and their 6,000 contacts in Colorado Springs in the United States, Rothenberg *et al.* showed that membership of the sexual networks varied from year to year, and that people with large networks had a greater changeover of partners than those with small networks (Rothenberg *et al.*, 1998). However, most studies have not tracked the evolution of sexual networks over time, and present a static picture of the network (Rothenberg, 1998; Ward, 2007). This is mainly because of the methodological difficulties and labour intensive process involved in obtaining these data. The relationship between epidemic phase and sexual network structure has recently been reviewed by Ward (Ward, 2007). Figure 5.5 shows the different epidemic phases or growth stages of a STI epidemic as described by Wasserheit and Aral (Wasserheit & Aral, 1996).

In the early epidemic phase networks are densely connected with multiple short loops. In later hyperepidemic phases, networks appear more loosely connected with a dominance of long branching structures (figure 5.5) (Ward, 2007). There is speculation that during the late 1970s, (i) the networks of MSM in New York and San Francisco consisted of large connected components, (ii) that the proportion of potential risk interactions by each individual was high, (iii) that short-term network stability was low, and that (iv) complex microstructures abounded (Rothenberg *et al.*, 1998). Rothenberg *et al.* also postulate that the decrease in HIV transmission among MSM from the mid-1980s was due to changes in micro- and macro- sexual network structures as well as a reduction in partner numbers at an individual level (Rothenberg *et al.*, 1998).

Figure 5.5: Growth stages of a STI epidemic: diagnoses of syphilis seen in genitourinary medicine clinics in England, Wales, and Scotland: 1971–2002

Phase I – the growth period, as the invasion of a host population occurs; phase II – the peak of the epidemic and hyperendemic phase when no controls have yet been imposed; phase III – a decline phase as controls are introduced and take effect; phase IV, a new endemic phase; phase V – elimination, and potentially eradication.



Source: Simms et al., 2005

Demographic change over time has also been central to the formation of sexual networks of HIV positive MSM in western Europe, north America and Australasia since the introduction of HAART (mid-1990s) because survival has dramatically improved (CASCADE collaboration, 2000). This means that many more sexually active MSM are living with HIV. In particular, the introduction of HAART is likely to have had a large impact on the survival of the "superspreaders" within MSM populations, because pre-HAART, these men may have acquired HIV infection in the 1980s and died prematurely (Aral et al., 2005). Indeed, Chesson et al. believe that the selective deaths of individuals who engaged in high-risk sexual activity prior to HAART resulted in decreased rates of HIV and syphilis during the early-mid 1990s, because these men were removed from the sexual network (Chesson et al., 2003). Using mathematical modelling, Boily et al. hypothesise that the impact of HAART on survival of more sexually active MSM has contributed to the increase in STIs in the post HAART era because of the increased availability of sexual partners who are willing to engage in 'high risk' sexual activities (i.e. "superspreaders") (Boily et al., 2004; Boily et al., 2005b). Although not statistically significant, the proportion of MSM reporting high numbers of sexual partners (10+ in the past year) in Britain, did increase from 4.9% (95% confidence interval: 2.0%-11.3%) in 1990 to 15.1% in 2000 (age-adjusted odds ratio: 2.70; 95%CI: 0.93-7.88) according to the Natsal surveys (Mercer et al., 2004).

## 5.7 Determinants of sexual networks

The formation of sexual networks and the spread of an STI through these networks is also strongly influenced by societal factors, including underlying social, economic, cultural and political forces, and technological advances (Doherty *et al.*, 2005; Adimora & Schoenbach, 2005; Aral *et al.*, 2005). These factors are difficult to quantify but they affect the availability of sexual partners and influence partnership choices (Aral, 2002). In this section, I consider the social norms and environment of HIV positive MSM in the post-HAART era, as these have also been key determinants in the formation of sexual networks.

Social norms are shaped by cultural factors at a societal level. They influence individual and partnership behaviours that affect network structure, density and growth over time, and continuously develop within the network itself (Doherty *et al.*, 2005). For example, among MSM, visiting bathhouses to find anonymous sex partners in the US became a social norm during the 1980s, and created the early sexual networks in which the first AIDS cases were identified (Shilts, 1987; Doherty *et al.*, 2005). In other instances, however, social norms may constrain sexual networks. For example, in their study of adolescents' sexual networks, Bearman *et al.* found that their model over-estimated the density of the network compared to empirical observations (Bearman *et al.*, 2004). A social norm – not having sexual relations with an ex-boyfriend's (or ex-girlfriend's) previous partner – explained the difference.

Another critical determinant of sexual networks is the environment (i.e. physical place) where they are formed (Doherty *et al.*, 2005). At the beginning of the HIV epidemic in the US, these environments were the bathhouses in Los Angeles, San Francisco and New York which some of the first MSM with AIDS frequented (CDC, 1981). The importance of venues where sex partners met was also demonstrated in 1985 by Potterat *et al.* in their study of gonorrhoea in Colorado Springs in the US (Potterat *et al.*,

1985). They found that out of 300 'nighttime leisure sites', six major sites were associated with gonorrhoea infection.

In the post-HAART era, the Internet has become an important environment for MSM to meet partners, particularly for HIV positive MSM (Elford et al., 2001; Kim et al., 2001; Bolding et al., 2005; Hospers et al., 2005; Liau et al., 2006). This new "venue" for meeting sexual partners has also given rise to a new set of social norms, and so in the post-HAART a new way in which sexual networks form and influence the incidence of HIV and STIs has been created (Doherty et al., 2005). For example, in London, HIV positive MSM appear to meet through the Internet other HIV positive casual partners for unprotected anal intercourse (i.e. serosorting) (Bolding et al., 2005; Elford et al., 2005). This does not pose a risk for onward HIV transmission, only for other STIs such as gonorrhoea, syphilis and LGV (Elford et al., 2006). HIV positive men find the Internet to be a less stigmatizing environment for disclosing their HIV status than bars, clubs and other offline venues. Consequently, HIV positive MSM find it easier to meet online, rather than offline, sexual partners who, like themselves, are also HIV positive (Davis et al., 2006). With a growing number of young MSM (<30 years) using the internet to meet their first sexual partner, the Internet is likely to remain an important environment for sexual networking (Bolding et al., 2007). Of importance in terms of HIV transmission however, is the finding that HIV positive MSM were no more likely to meet casual UAI partners of unknown or discordant HIV status - where there is the potential for HIV transmission - online rather than offline (Bolding et al., 2005).

The importance of the environment where sexual networks of MSM are formed has been increasingly recognised by those undertaking surveillance of STIs among MSM. In

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both the US and the UK information on where MSM have formed partnerships are collected in the enhanced syphilis and LGV surveillance (Ward *et al.*, 2007b; Simms *et al.*, 2005). The venues identified by these surveillance activities can then be specifically targeted by health promotion initiatives. In the UK, the most successful story so far of this approach has been enhanced LGV surveillance, where the Terrence Higgins Trust (THT) have been involved in targeting venues identified as meeting places for 'high risk' partnerships (Ward *et al.*, 2007b). Targeting specific venues while the infection is still relatively contained also avoids alarming, and needlessly testing, those who are at low risk.

#### 5.8 Recommendations

In this chapter, I have focused on sexual networks of HIV positive MSM in the context of serosorting in the post HAART era. Serosorting and the formation of distinct networks of HIV positive MSM, aided by the Internet, has resulted in an increase in the transmission of other STIs among HIV positive MSM. Understanding the dynamics of STI transmission, through knowledge of risk behaviours and sexual networks, is important when interpreting trends in HIV and STI incidence, in informing prevention initiatives and also in assessing the impact of these initiatives.

Given my research findings (Dougan *et al.*, 2007c; Dougan *et al.*, 2007d) and discussions within this chapter, I make the following recommendations for the following broad areas:

## 5.8.1 Improving our knowledge of sexual behaviours and networks of HIV positive MSM

Currently, there are limited data on the sexual behaviours of HIV positive MSM. While modellers are developing more complex models to simulate the course of HIV and STI epidemics, at the moment, they are seriously constrained by a lack of behavioural data (Handcock & Holland Jones, 2003; Pourbohloul *et al.*, 2003; Pourbohloul & Brunham, 2004). Further knowledge of sexual partner distribution, and of sexual mixing patterns, including the extent of assortative *vs.* dissortative sexual mixing and important characteristics influencing these mixing patterns such as HIV status, age and geographic location would be useful in informing public health interventions. This would also assist in interpreting trends in STIs and sexual behaviours among HIV positive MSM, as well as the potential for onward HIV transmission to HIV negative MSM.

Better information would also help to explain which HIV positive MSM would be at risk of acquiring different types of STIs. Take for example, hepatitis C. Early research seems to associate this with high numbers of sexual partners and 'high-risk' behaviours such as fisting (Browne *et al.*, 2004; Gambotti *et al.*, 2005; Ghosn *et al.*, 2004; Götz *et al.*, 2005; Rauch *et al.*, 2005). Research into sexual networking could help to determine why some infections have only become outbreaks of a limited size (e.g. *Shigella* infection and LGV) while others are more widespread (e.g. syphilis) (Aragón *et al.*, 2007; Simms *et al.*, 2005; Ward *et al.*, 2007b). Since sexual networks of MSM are likely to differ by time, place and person, it will be important to gather information on a range of HIV positive MSM networks (Pourbohloul & Burnham, 2004).

#### 5.8.2 Interpretation of sexual behaviour and STI surveillance data

The population-level effects of serosorting have impacted on how data on sexual behaviours and STIs should be reported and interpreted.

#### 5.8.2.1 Reporting of UAI

It is common practice for behavioural surveys to collect and disseminate information on the proportion of MSM engaging in UAI (Dodds *et al.*, 2004; Elford *et al.*, 2005; Elford *et al.*, 2007; Hart & Williamson 2006). These studies indicate that some of those engaging in UAI are HIV positive MSM and that some of these men are reporting UAI only with a HIV positive partner (i.e. serosorting). In some instances however, it is only the proportion of *all* MSM engaging in UAI from these behavioural studies that is used to assess levels of risk-taking and the potential for HIV transmission (i.e. proportion of MSM engaging in UAI has increased, therefore HIV transmission predicted to increase). Reported in a such a way, UAI is a blunt instrument to assess the potential for onward HIV transmission, and the realities of the transmission dynamics of HIV in the post-HAART era among MSM in the UK are oversimplified. It is important that UAI figures are stratified by HIV status and further by the partners' HIV status to determine the proportion of sexual acts that have the potential for HIV to be transmitted (i.e. positivenegative UAI) and how these risks change over time.

#### 5.8.2.2 STI surveillance

In terms of STI trends, it has historically been assumed that if STI diagnoses increase, then HIV transmission would also be increasing. However, enhanced STI surveillance systems, as reported in my research paper on STIs among HIV positive MSM in

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western Europe (Dougan *et al.*, 2007c) show that a high proportion of STIs among MSM are in HIV positive MSM. Given that "accurate" serosorting by HIV positive MSM will not result in onward transmission of HIV to a negative man, the interpretation of STI trends in relation to HIV incidence needs to be re-assessed in the post HAART era. Overall trends in STIs (for all MSM) will not be a good indication of HIV incidence, but trends in STIs among HIV negative MSM may still be. However, only the enhanced STI surveillance systems currently collect data on HIV status. The main reporting system – the KC60 statistical returns – can only be analysed for all MSM. Collecting and disseminating STI data by HIV status would be more useful for monitoring the changing epidemiology of HIV and STIs among MSM, and also for informing HIV and STI prevention. This may be achieved by the new Common Data Set for Sexual Health (CDSS) which aims to collect a standardised, disaggregate dataset on STIs from GUM clinics supplemented by a reduced dataset from other providers such as primary care (Department of Health, 2006). However, this is still being piloted and has yet to be rolled out at a national level.

Another area where it would be useful to have more information is re-infection rates. Currently there are limited data on this from STI surveillance systems in the UK. In Germany, one study showed that 25% of syphilis infections among HIV positive MSM may be re-infections (Marcus *et al.*, 2005). To better quantify the number of HIV positive MSM who are acquiring these other STIs, in addition to the number of infections, data on re-infection would need to be collected. It may be the case that a low proportion of MSM (e.g. 10%) are responsible for a high proportion of STIs (e.g. 80%). This would fit in well with the model of a scale-free distribution, and would have implications for prevention, particularly if one could identify these "superspreaders". In reality,

identifying and targeting superspreaders in sufficient time to prevent the transmission of HIV and STIs would be very difficult.

## **5.8.3** Prevention of HIV and STI transmission to HIV negative MSM (HIV & STIs) and to other HIV positive MSM (STIs)

Assuming that sexual networks of HIV positive MSM do have a scale-free distribution, the "superspreaders" (i.e. those with a very high number of partners) who disproportionately impact on the spread of other STIs, should be targeted by control measures (Anderson & May 1991; Kiss *et al.*, 2006). This is because one of the properties of a scale-free network is that they are very sensitive to the strategic removal or behavioural change of "superspreaders" (Albert *et al.*, 2001; Liljeros *et al.* 2003). Removal of such highly connected individuals tends to make the network break into smaller, separate components, limiting the transmission of infection.

Modelling suggests that traditional methods of contact tracing will only identify "superspreaders" at a later stage of an epidemic, when it is too late to prevent most transmission (Kiss *et al.*, 2006). Instead, it seems that "intelligent tracing" – identifying highly connected individuals prior to an outbreak – would be more effective (Kiss *et al.*, 2006). However, whether this would be feasible in practice remains to be seen.

In conclusion, it is clear is that the evolution of sexual networks has had an increasingly important role in shaping the epidemiology of HIV and other STIs among MSM in the UK since the introduction of HAART. To better target HIV and STI prevention in the future, more information on this emerging area of research will be required.

# **CHAPTER 6**

### Conclusions

#### **Chapter Summary**

In this concluding chapter, I pull together my findings and recommendations from the previous five chapters. I consider the changing patterns in HIV incidence and prevalence among MSM in the UK in terms of changes over time, increasing diversity of the HIV positive MSM population, and the introduction of effective therapies. My recommendations relate to improving HIV surveillance and epidemiological research among MSM in the UK.

#### 6.1 Introduction

In this final chapter, I synthesise my findings on the changing patterns of HIV incidence and prevalence among MSM in the UK based on my examination of UK HIV surveillance data as well HIV and STI surveillance data from other European countries. I also make several recommendations for improving HIV surveillance, interpreting future epidemiological trends, and for health care delivery and prevention interventions among MSM.

## 6.2 Changing patterns of HIV incidence and prevalence among MSM in the UK

The epidemiology of an infectious disease is usually dynamic and HIV is no exception. Among MSM in the UK, there have been large changes in HIV incidence and prevalence since the introduction of HIV into this population in the late 1970s (Dougan *et al.*, 2007a). Several factors have been behind these changes. These include behavioural changes in the 1980s when AIDS was first identified among MSM in the USA and then in the UK, which resulted in a decline in HIV incidence (Department of Health, 1988; Carne *et al.*,1987). The introduction of highly active antiretroviral therapies (HAART) in 1996, led to a dramatic reduction in AIDS mortality and subsequently an increase in HIV prevalence (The UK Collaborative Group for HIV and STI Surveillance, 2006). While these are the two most significant changes in HIV epidemiology among MSM in the UK, in the post-HAART era there have been other, more subtle changes. These other changes are a consequence of the introduction of HAART as well as factors operating at a national level (such as immigration) and are worthy of investigation. My research over the past four years has focussed on some of these changes, namely: (i) describing and examining time trends in HIV incidence and the number of HIV diagnoses among MSM (Macdonald *et al.*, 2004; Dougan *et al.*, 2007b); (ii) the diversity of MSM with HIV in terms of ethnicity and country of birth (Dougan *et al.*, 2005b; Dougan *et al.*, 2005c); and (iii) STI transmission among the growing population of HIV positive MSM in the UK and elsewhere (Dougan *et al.*, 2007c; Dougan *et al.*, 2007d).

Probably the most important question addressed in this PhD is whether or not HIV incidence has increased among MSM in the UK over the past few years. My synthesis of surveillance data for the period 1997-2004 indicates that HIV incidence remained high but constant during this time (Dougan *et al.* 2007b). More recent UK surveillance data indicate that this pattern persisted to 2007 (The UK Collaborative Group for HIV and STI Surveillance, 2007). International studies report similar findings (Stall, 2008). These recent trends of stable HIV incidence are somewhat surprising because during the same time period there have been measurable increases in STI diagnoses and 'high-risk' sexual behaviours among MSM. In the past, increases in STI diagnoses and high risk sexual behaviour were accompanied by an increase in HIV incidence. So what has changed?

The major change is related to the widespread use of HAART, which has resulted in a growing population of HIV-positive MSM on treatment with undetectable viral loads (Aalen *et al.*, 1999; The UK Collaborative Group for HIV and STI Surveillance, 2007). The likelihood of these men transmitting HIV is low, although co-infection with other STIs may increase the probability of transmission (epidemiological synergy) (Fleming &

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Wasserheit, 1999; Wasserheit, 1992). With the growing population of HIV-positive MSM there has also been the growth of assortative sexual mixing by HIV status — "serosorting", whereby HIV positive MSM seek HIV positive male partners to have unprotected anal intercourse (Elford, 2006). Presumably there has always been some degree of serosorting as sexual mixing has a tendency to be assortative, but now, since HIV positive MSM are surviving for much longer. larger and more stable HIV positive networks have emerged (Fenton & Imrie, 2005).

The emergence of sexual networks of HIV positive MSM seems to be the main explanation for the significant increase in STI diagnoses and 'high risk' behaviours with no evidence of an increase in HIV transmission, although HIV incidence does remain stable and high. There is a growing body of evidence showing that HIV positive MSM are disproportionately engaging in 'high risk' sexual behaviour (unprotected anal intercourse) and disproportionately acquiring STIs, both of which are included in routine STI and behavioural surveillance data (Dougan *et al.*, 2007c; Fenton & Imrie, 2005; Williamson *et al.*, 2008).

There is also evidence that some HIV positive MSM are simultaneously co-infected with multiple STIs, and that re-infection rates are high which would result in a further increase in the number of STI diagnoses (Marcus & Hamouda, 2005). Taken in concert, this all indicates that the transmission of STIs among sexual networks of HIV positive MSM may account for a significant proportion of STI diagnoses among MSM overall. However, STI surveillance data are not always stratified by HIV status making it difficult to analyse trends for HIV positive MSM alone and how they have changed over time. There is also a paucity of data on co-infection with multiple STIs and re-infection rates.

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Enhanced STI surveillance (e.g. for syphilis, gonorrhoea and LGV) has provided some insight, but real improvements in the understanding of this increasingly complex area of STI epidemiology will hopefully be provided in the future by the new GUM dataset which will collect information on STI diagnoses by HIV status (NHS ISB, 2006). In the meantime, it is important for epidemiologists working in this area to realise that for trends in STIs to be a useful proxy for changes in HIV incidence among MSM, data need to be stratified by HIV status, with trends for HIV-negative MSM (rather than HIV-positive MSM) being indicative of the HIV transmission rate.

Migration is unlikely to have played a major role in the increase in HIV diagnoses and continuing high level of HIV incidence among MSM in the UK. Available evidence indicates that the number of black and minority ethnic MSM being diagnosed with HIV remained stable at about one-in-ten between 1993 and 2003, and with the exception of men born in the Caribbean and Central/South America, HIV prevalence is similar among UK-born and foreign-born MSM (Dougan *et al.*, 2005b). This is in stark contrast to heterosexual men and women with HIV in the UK, among whom the majority acquired their infection in sub-Saharan Africa prior to coming to the UK (The UK Collaborative Group for HIV and STI Surveillance, 2007). The trend in HIV diagnoses among heterosexuals in the UK is directly influenced by changing patterns in migration (Sinka *et al.*, 2003).

Of course, not all HIV positive MSM are diagnosed and on treatment, and not all diagnosed HIV positive MSM on treatment exclusively serosort. Some of these men must be engaging in unprotected anal intercourse with a partner of unknown or discordant HIV status for there to be continuing HIV transmission among MSM in the

UK. Until recently the contribution of diagnosed and undiagnosed HIV positive men to onward transmission at a population level was not clear in the UK. Is transmission being driven by undiagnosed HIV positive MSM, particularly those who have just become infected and who have very high viral loads, or by diagnosed MSM who on are treatment? Knowing the answer to this question is important for informing HIV prevention. For example, if diagnosed HIV positive MSM are responsible for most transmission, then prevention efforts should focus on diagnosing and treating STIs among HIV positive MSM as well as interventions to reduce sexual risk among these men. On the other hand, if most transmission is being driven by undiagnosed HIV positive MSM, then the focus should be on encouraging regular HIV testing. However, if transmission is occurring among recently-infected men with very high viral loads it seems unlikely that the interval between infection and testing could be reduced substantially. In 2003, this interval was estimated to be six years on average (CMO, 2003).

A recent paper by Williamson *et al.* throws some light on this topic (Williamson *et al.*, 2008). By combining the data from behavioural studies in London, Brighton, Manchester, Glasgow and Edinburgh, the authors were able to analyse risk behaviours among diagnosed and undiagnosed HIV positive MSM, and HIV negative MSM. Their results show that diagnosed HIV positive MSM are more likely to engage in unprotected anal intercourse, followed by undiagnosed HIV positive MSM, and then HIV negative MSM. As would be expected on the basis of their behavioural data, diagnosed HIV positive MSM were the most likely to have an STI.

In reality, the continuing high transmission rates of HIV are likely to be driven by a small number of recently-infected MSM with very high viral loads and a high probability of transmitting HIV, plus a larger population of diagnosed HIV positive MSM who are not having sex exclusively with other positive MSM, with a lower probability of transmitting HIV. In relation to HIV prevention, both groups need to be targeted.

To further understand the growing complexities of HIV and STI transmission among MSM a comprehensive mathematical model is needed. The parameters within the model would have to be correctly identified and measured. Currently, there are insufficient data on MSM sexual networks, their size, the sexual behaviours of HIV positive MSM, co-infection with multiple STIs, and STI re-infection rates to build a model which would truly reflect what is happening among MSM in the UK. However, beginning to think about the information that would be required for such a model would be a start. It is important to remember that infectious disease epidemiology is dynamic. For example, enhanced surveillance data suggest that over the past few years proportionately more HIV negative MSM have become infected with STIs possibly indicating that the boundaries of HIV positive sexual networks are becoming blurred (Dougan *et al.*, 2007c). This in turn, may result in the long-anticipated increase in HIV incidence.

#### 6.3 Recommendations for HIV surveillance and epidemiological

#### research

I have several key practical recommendations for HIV surveillance and epidemiological research among MSM in the UK.

#### 6.3.1 Existing surveillance data

The key message from this research is that existing national surveillance data can provide a valuable source of epidemiological information on HIV among MSM in the UK with little additional resource required for detailed data analysis and interpretation. Not only are national data available from several large surveillance systems, but data have been collected continuously over time allowing temporal trends to be examined. The analysis of these data can provide a focus for more in-depth research projects in this area.

**Recommendation:** Epidemiologists and other researchers should make full use of national HIV surveillance data. The HPA should facilitate this, promoting its use for epidemiological research both among HPA epidemiologists and also external researchers.

#### 6.3.2 Expanding the Unlinked Anonymous GUM Survey outside of London

While there is good representation of London MSM in the UA GUM survey, coverage is not so good in the rest of England and Wales. For example, GUM clinics in Brighton and Manchester, which are both known to have large populations of MSM, do not participate in the survey. This makes it difficult to interpret patterns and trends in undiagnosed HIV infection and HIV testing patterns outside London. It also makes it difficult to interpret trends in HIV incidence outside London since the STARHS assay which measures HIV incidence relies on samples from the UA GUM survey. In comparison, coverage of the UA GUM survey is good across Scotland with 28 GUM clinics participating in the survey. However, there is no STARHS testing undertaken on the samples. To analyse patterns and trends in HIV incidence among MSM in Scotland, and to make comparisons with the rest of the UK, STARHS testing should be undertaken routinely as part of the Scottish UA GUM survey.

**Recommendation:** The UA GUM survey in England, Wales and Northern Ireland should expand to include GUM clinics in Manchester and Brighton to ensure better representation of MSM outside London, allowing more robust interpretation of patterns and trends in undiagnosed HIV infection, HIV testing, and HIV incidence. The UA GUM survey in Scotland should expand to incorporate STARHS testing to allow analysis of patterns and trends in HIV incidence.

#### 6.3.3 Presenting STI and behavioural surveillance data for MSM

For STI and behavioural surveillance data to provide insights into trends in HIV incidence among MSM, they need to be stratified by HIV status. STI trends among HIV negative MSM — but not among HIV positive men — could be used as a proxy for trends in HIV incidence. This is particularly useful outside London where there is much less behavioural surveillance data. Analysis of STI data by HIV status would also provide useful information on the burden of STIs among diagnosed HIV positive MSM and inform policies on regular STI screening at routine check-ups.

Stratification of behavioural surveillance data by HIV status, with information on serosorting, would provide additional data on the risk of HIV transmission from 'high risk' sexual behaviour i.e. unprotected anal intercourse with a partner of unknown or discordant HIV status rather than UAI with a partner of the same HIV status.

**Recommendation:** Wherever possible, STI and behavioural surveillance data for MSM should be stratified by HIV status. When planning or modifying studies and surveillance systems, the ability to stratify by HIV status should be taken into consideration to enable maximum utility of the data in informing HIV prevention among MSM.

#### 6.3.4 Better information on the size of MSM population

To substantially improve the utility of national HIV surveillance data on MSM in the UK, better information on the size of the MSM population as a whole is needed. As I discussed in chapter 3, these data would provide a denominator so that rates of HIV diagnoses and diagnosed HIV prevalence could be calculated. At a minimum, it would be useful to have good quality data on the number of MSM at a regional level, and if feasible at a Strategic Health Authority and Primary Care Trust level as well. With more focus on commissioning at a local level within the NHS, such information will be vital for priority setting.

If the Natsal survey in 2010 were to increase its MSM sample size, regional level estimates could be derived but expansion of this survey would have financial implications and is unlikely to be practical. It would be much better if the Census or other ONS surveys could collect data on sexual behaviour as suitable denominators could then be acquired. However, given the sensitivity of asking questions about sexual behaviour in such surveys, it is more likely that questions on sexual identity rather than behaviour will be included.

**Recommendation:** Data on sexual behaviour should be collected in a national survey to enumerate the population of MSM. Ideally this would be the Census, but failing this,

another national ONS survey such as the General Household or Omnibus Survey. In reality, data on sexual identity rather than behaviour will probably be collected.

## 6.3.5 Better information on sexual behaviour and sexual networks of HIV positive MSM

To further understand trends in HIV incidence, more information on the sexual behaviour and sexual networks of HIV positive MSM is needed. This would be particularly useful outside London where only limited data are currently available. Some of this information could probably be gained by incremental changes to current behavioural surveys. This information on sexual behaviour and sexual networks, specifically stratified by HIV status, could be used in mathematical models to estimate current and future trends in HIV incidence. The usefulness and accuracy of these models relies on the input of robust data on essential parameters.

**Recommendation:** More research on sexual behaviours and networks of HIV positive MSM should be undertaken. The most cost-effective way of undertaking this work would be to expand existing behavioural surveys among MSM to collect specific data on HIV positive MSM (e.g. number of sexual partners, serosorting, etc.). This work could feed into mathematical models of the epidemiology of HIV and STIs among MSM which may further understanding.

#### 6.4 Recommendations for health care delivery and prevention

Based on my findings, I have several recommendations for health care delivery and HIV/STI prevention among MSM in the UK.

#### 6.4.1 Regular testing for STIs among HIV positive MSM

Given the high prevalence of STIs among HIV positive MSM, the evidence that reinfection rates among this population are also high (Dougan et al., 2007c, Marcus & Hamouda, 2005), and behavioural surveillance findings (Williamson et al., 2008), HIV positive MSM should be tested for other STIs on a regular basis. This could be incorporated into their regular treatment consultations for HIV infection and may help to prevent onward transmission of STIs at a population-level as well as improving the individual's sexual health.

**Recommendation:** HIV positive MSM are tested for other STIs during routine appointments. The offering and uptake of these tests should be monitored as part of the Government's sexual health indicators.

## 6.4.2 Raise awareness of sexually-transmitted hepatitis C infection among HIV positive MSM

While some HIV positive MSM may believe that prompt diagnosis and treatment of STIs will not have a long-term detrimental impact on their health, co-infection with hepatitis C has serious implications for the effective treatment of both infections and long-term prognosis. It is now clear that the first cases of sexually-transmitted hepatitis C detected among MSM were not isolated cases and that there has been transmission in HIV positive sexual networks across Western Europe and elsewhere (Dougan *et al.*, 2007c). Given that this is a relatively new phenomenon, awareness needs to be raised among HIV positive MSM. Providing information on the infection, how to prevent it, and its consequences may help to reduce further spread.

**Recommendation:** There should be campaigns to increase the awareness of sexuallytransmitted hepatitis C, including likely routes of transmission, implications for HIV treatment and future prognosis, among HIV positive MSM.

#### 6.4.3 Sexual risk reduction among HIV positive and HIV negative MSM

Given the evidence that some MSM report unprotected anal intercourse with partners of unknown or discordant HIV status, HIV prevention messages, including condom use, partner numbers, and risk reduction strategies (serosorting and strategic positioning) need to be continually promoted among MSM in the UK. As highlighted by Williamson *et al.*, recent reviews have demonstrated the efficacy of behavioural interventions in reducing high risk sexual behaviour among both HIV positive and negative MSM (Crepaz *et al.*, 2006; Herbst *et al.*, 2005; Herbst *et al.*, 2007), but translating this into effective HIV promotion across the UK to impact on HIV and STI transmission will be challenging.

**Recommendation:** Safer sex messages and sexual risk reduction strategies need to be continually promoted among MSM in the UK to encourage behavioural change to reduce HIV and STI transmission.

#### 6.5 Concluding remarks

My work highlights the growing complexity of HIV epidemiology among MSM in the UK. What remains clear is that although more than 25 years have passed since the first case of AIDS was reported, MSM continue to be disproportionately affected by HIV in the UK and are at 'highest risk' of *acquiring* HIV in this country (Dougan *et al.*, 2005a; The UK Collaborative Group for HIV and STI Surveillance, 2006). MSM may only represent a small proportion of the UK's population, but within this population there is a considerable burden of HIV, resulting in substantial morbidity and premature mortality. The high incidence and prevalence of HIV among MSM underlies the importance of continued surveillance, research and prevention, and particularly the use of existing surveillance data for epidemiological research.

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## **APPENDIX A** Further details

#### STARHS methodology relating to paper 3.2

The Serological Testing Algorithm for HIV Seroconversion (STARHS) identifies recent HIV infections using two assays: one that is sensitive to low levels of HIV-antibody and one that is less sensitive (Janssen *et al.* 1998). Using the algorithm and combined with the appropriate data<sup>1</sup>, a distinction can be made between recent seroconvertors and those with long-standing infection, allowing an estimate of HIV incidence at a population-level. Annual incidence is given by the formula:  $I = \frac{1}{4}$  (n/N) (365/T) (100). where I is the annual incidence, n is the number of recent infections, N is the susceptible population (the recent infections plus those testing negative for anti-HIV) and T is the mean number of days between seroconversion in the sensitive and less sensitive assays (Janssen *et al.*, 1998; Murphy *et al.*, 2004).

The validity of the HIV incidence estimates using STARHS may be affected by a number of different things. Firstly, at the end of the 1990s there was a lack of availability and subsequent withdrawal of the Abbott 3A11 assay which had been used in England and Wales for STARHS testing (Murphy *et al.*, 2004). Another assay (Organon Teknika Vironostika Assay) had to therefore be used for testing from 2000 onwards. While these two assays did have slightly different window periods (the number of days after seroconversion on the standard assay until the less sensitive assay reached the cut off of 1.0) – 129 and 133 respectively - investigations by CDC had shown that the different assays had similar performance characteristics (Murphy *et al.*, 2004). Other factors that may affect the validity of the STARHS estimates include inadequate samples for

<sup>&</sup>lt;sup>1</sup> this includes information on whether the individual has AIDS and/or is receiving HAART and demographic data

STARHS testing; loss of samples; and mis-categorisation of samples. With good laboratory practice, however, these events should be uncommon.

Other considerations in terms of the validity of the STARHS estimate relate to the calculation of HIV incidence particularly the composition of the susceptible population (denominator). In England and Wales the susceptible population used in the algorithm is the number of people (who have not been previously diagnosed with HIV) attending GUM clinics participating in the Unlinked Anonymous Survey and having a syphilis test. Depending on HIV testing campaigns and policies, and the offering of syphilis tests, the characteristics of this susceptible population may change to include for example, people at lower risk of acquiring HIV (i.e. the "worried well"). If the susceptible population changes in this way over time then, all else being equal, HIV incidence estimates based on STARHS would decrease over time.

#### Calculation of confidence intervals in paper 4.1

From paper 4.1: "an estimated 10,000 – 30,000 BME MSM aged 16-44 currently live in England and Wales, according to population prevalence estimates from the National Survey of Sexual Attitudes and Lifestyles (Natsal) applied to the 2001 Census".

Given the small number of BME MSM reported in the Natsal 2000 sample, a range of the number of BME MSM was presented in the paper to highlight the uncertainty around the estimate. The lower and upper bounds of this range were calculated by taking the lower and upper 95% confidence limits from the Natsal 2000 point prevalence and applying these to the appropriate Census denominator.

The number of English and Welsh men who reported their ethnicity as 'non-white' in Natsal 2000's core and ethnic boost surveys combined was 508 (weighted), 867 (unweighted). Of these men, 8 (weighted), 23 (unweighted) reported having had homosexual anal sex (receptive and/or insertive) in the 5 years prior to interview. This gives a (weighted) prevalence of homosexual anal sex among "non-white" men of 1.62% (95% CI: 0.96%-2.72%) (Dr Catherine Mercer, Personal Communication). The lower and upper 95% confidence limits of 0.96% and 2.72% were used in calculating the number of BME MSM aged 16-44 living in England and Wales. These percentages (0.96%, 2.72%) were multiplied by the number of BME men aged 16-44 years living in England and Wales according to the 2001 census.

While the number of 'non-white' MSM captured within the Natsal 2000 sample is small, these data give us the best estimate of the number of BME MSM in England and Wales, as the Natsal methods are robust (large probability sample) and there was a relatively large number of BME men interviewed overall (508 weighted).

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# **APPENDIX B** Contributions of authors

## HIV in gay and bisexual men in the United Kingdom: 25 years of public health surveillance

Dougan S, Evans BG, Macdonald N, Goldberg DJ, Gill ON, Fenton KA, Elford J

SD conceived the idea for the literature review with input from JE and BE. SD undertook the literature review and wrote the first draft. All authors commented on subsequent drafts and gave expert guidance on specific areas of HIV surveillance in the UK at different times. All authors read and approved the final draft.

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Recent trends in diagnoses of HIV and other sexually transmitted infections in England and Wales among men who have sex with men

Macdonald N, Dougan S, McGarrigle CA, Baster K, Rice BD, Evans BG, Fenton KA

NM, SD, and CM conceived the paper. NM and SD wrote the initial drafts. CM provided behavioural data and made comments on drafts. BR provided data from the SOPHID survey and commented on drafts. KB provided expert statistical support. BE and KF assisted in the provisions of data and commented on drafts.

Neil Mardonald.

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Does the recent increase in HIV diagnoses among men who have sex with men in the UK reflect a rise in HIV incidence or increased uptake of HIV testing?

Dougan S, Elford J, Chadborn TR, Brown AE, Roy K, Murhpy G, Gill ON on behalf of the group investigating rising diagnoses among MSM in the UK

SD and KF conceived the idea for the paper, with significant input from JE, TC, AB and KR. SD provided the UK diagnoses data, AB the unlinked anonymous GUM survey data from E,W&NI, GM the unlinked anonymous STARHS data, TC the CD4 surveillance data from England and Wales, and KR the Scottish data. SD undertook the main analysis and writing of the paper, with all authors, particularly JE, involved in interpretation of the results and drafting of the paper. NG is the guarantor, who oversaw analyses at the Health Protection Agency and also commented on the drafts.

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### Epidemiology of HIV among black and minority ethnic men who have sex with men in England and Wales

Dougan S, Elford J, Rice BD, Brown AE, Sinka K, Evans BG, Gill ON, Fenton KA

SD conceived the idea for the paper with significant input from JE. SD, BR, and AB provided the new HIV diagnoses, SOPHID and UAPMP GUM surveys data respectively, with support from KS and BE (new diagnoses and SOPHID), and NG (UAPMP). SD undertook statistical tests where appropriate and calculated the proportions of black and minority ethnic and white men who have sex with men living with diagnosed HIV infection in England and Wales using census 2001 and Natsal 2000 data. SD undertook the main writing of the paper and subsequent revisions in line with referees' comments, with JE and KF making a significant contribution. All authors were involved in interpretation of the results and developing drafts and revisions of the paper.

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Men who have sex with men who are born abroad and diagnosed with HIV in England and Wales: an epidemiological perspective

Dougan S, Elford J, Sinka K, Fenton KA, Evans BG

SD conceived the idea for the paper with significant input from JE. SD provided and analysed the new HIV diagnoses data, with support and advice from KS. SD undertook the main writing of the paper, with JE and BE making a significant contribution. All authors were involved in interpretation of the results and developing drafts of the paper.

Barry Grans

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### Sexually Transmitted Infections in Western Europe among HIVpositive men who have sex with men

Dougan S, Evans BG, Elford J

SD conceived the idea for the article with input from JE. SD undertook the literature review and wrote the first draft. JE and BE commented on subsequent drafts. All authors read and approved the final draft.

Bany Evans

## Can current national surveillance systems in England and Wales monitor sexual transmission of hepatitis C among HIVinfected men who have sex with men?

#### Dougan S, Balogun MA, Elford J, Brant LJ, Sinka K, Evans BG, Ramsay ME

SD collated the HIV diagnoses data, performed the matching exercises and drafted the manuscript. MB and LB provided the hepatitis C diagnoses and hepatitis C testing data respectively, and guided on their use in the matching exercises and interpretation of results. JE, KS, BE and MR all provided guidance on the study design, the interpretation of the resulting HIV and hepatitis C data, study limitations and conclusions, and drafting of the manuscript. All authors read and commented on manuscripts.

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