

**Are HIV services in England accessible and  
acceptable to adults diagnosed with HIV at  
age 50 years and over?**

**A mixed-methods study**

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## **Abstract**

In the UK, new HIV diagnoses are increasing in adults aged 50 years and over, a group that also has a higher likelihood of testing at an advanced stage of disease than younger people. Despite this, limited research has examined the pathway to HIV diagnosis and treatment experienced by this age group, or looked more broadly at the impact of living with HIV after diagnosis at this age. Using a mixed-methods approach, this thesis explores the acceptability and accessibility of HIV services in England to adults diagnosed at age 50+ years, from the perspective of these service users and healthcare professionals (HCPs) working in sexual health/HIV services and involved in caring for this age group.

This thesis draws on semi-structured interviews with service users; an online survey and semi-structured interviews with HCPs; as well as national data on sexual health/GUM clinic attendance, HIV test coverage, and new HIV diagnoses by age. Adults aged 50+ years are found to experience often complex and non-linear journeys to HIV testing, particularly if they do not belong to a 'risk group' targeted in HIV prevention and testing efforts. Barriers to prompt HIV diagnosis include (i) the non-specific nature of HIV symptoms and their misattribution as being age-related, (ii) an age-associated decline in risk perception, and (iii) the decreased likelihood of HIV test offer in advancing age.

Both service users and HCPs perceive HIV treatment services to provide exceptional care, which is associated with the benefits of closer health monitoring, clinician expertise in HIV, and consistency in care. General practitioners (GPs) by contrast appear to be underutilised in the management of older people with HIV, which may be particularly detrimental as these service users often develop additional, age-related, morbidities which extend beyond the remit of HIV clinician knowledge.

The thesis concludes by highlighting a need to reconsider the model of HIV care in England, especially with respect to the role of GPs in HIV service provision. It is likely that increased GP involvement would optimise care and encourage the normalisation of HIV, which would promote testing and reduce stigma.



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### **Authors' declaration**

I declare that the research presented in this thesis is my own and has not been submitted for an award elsewhere. Information included from other sources (e.g. journal articles and books) has been fully acknowledged and correctly referenced.



## Chapter 1: Introduction

In the UK, the human immunodeficiency virus (HIV) is mostly associated with younger adults; however, over time there has been an age-related shift in the epidemic and an increase in new diagnoses in older people: adults aged 50+ years (Public Health England (PHE), 2016a - Figure 1; Smith et al., 2010). A comparison of UK reports for 2000 and 2015 shows the number of new HIV diagnoses per annum in the over 50s has more than trebled, from 333 to 1018 cases (PHE, 2016a).

Adults aged 50+ years are more likely than younger people to be diagnosed at an advanced stage of disease; termed late diagnosis (CD4 count  $<350$  cells/mm<sup>3</sup> within 91 days of diagnosis) (Yin et al., 2014). Late HIV diagnosis is associated with increased morbidity and mortality risk (May et al., 2011; Mocroft et al., 2013; Nakagawa et al., 2012), greater likelihood of HIV transmission (Cohen et al., 2011; Fox et al., 2009; Marks et al., 2005) and higher healthcare expenditure (Beck et al., 2011; Farnham et al., 2013). As advancing age is associated with quicker disease progression (Phillips et al., 2004), the early diagnosis and prompt treatment of older people is particularly crucial (Churchill et al., 2015).

In response to an increase in new HIV diagnoses in older adults and the high proportion of late HIV diagnoses in this age group, this thesis presents findings from a mixed-methods study exploring the accessibility and acceptability of HIV services in England to adults receiving a positive HIV diagnosis at age 50 years and over. The study examines the journey to HIV detection and treatment for people in this age group; their experiences of accessing and using HIV and other healthcare services (e.g. general practice and dental practice), and in living with HIV. This research has included the perspectives of HIV service users aged 50+ years at diagnosis and healthcare professionals (HCPs) working in sexual health/HIV services.

The *Model of Pathways to Treatment* (MPT) (Walter et al., 2012), a framework used to promote understanding of health-seeking and journeys to treatment initiation, has been used to provide structure to the thesis and enable systematic data analysis.

This introductory chapter provides an overview of HIV, including the clinical stages of the disease, modes of HIV transmission and HIV epidemiology in the UK. It also discusses some of the factors associated with the increase in new HIV diagnoses in adults aged 50+ years. An outline of the methods used in this research will be provided, along with a description of the MPT and health-seeking theories, and an overview of the thesis structure.

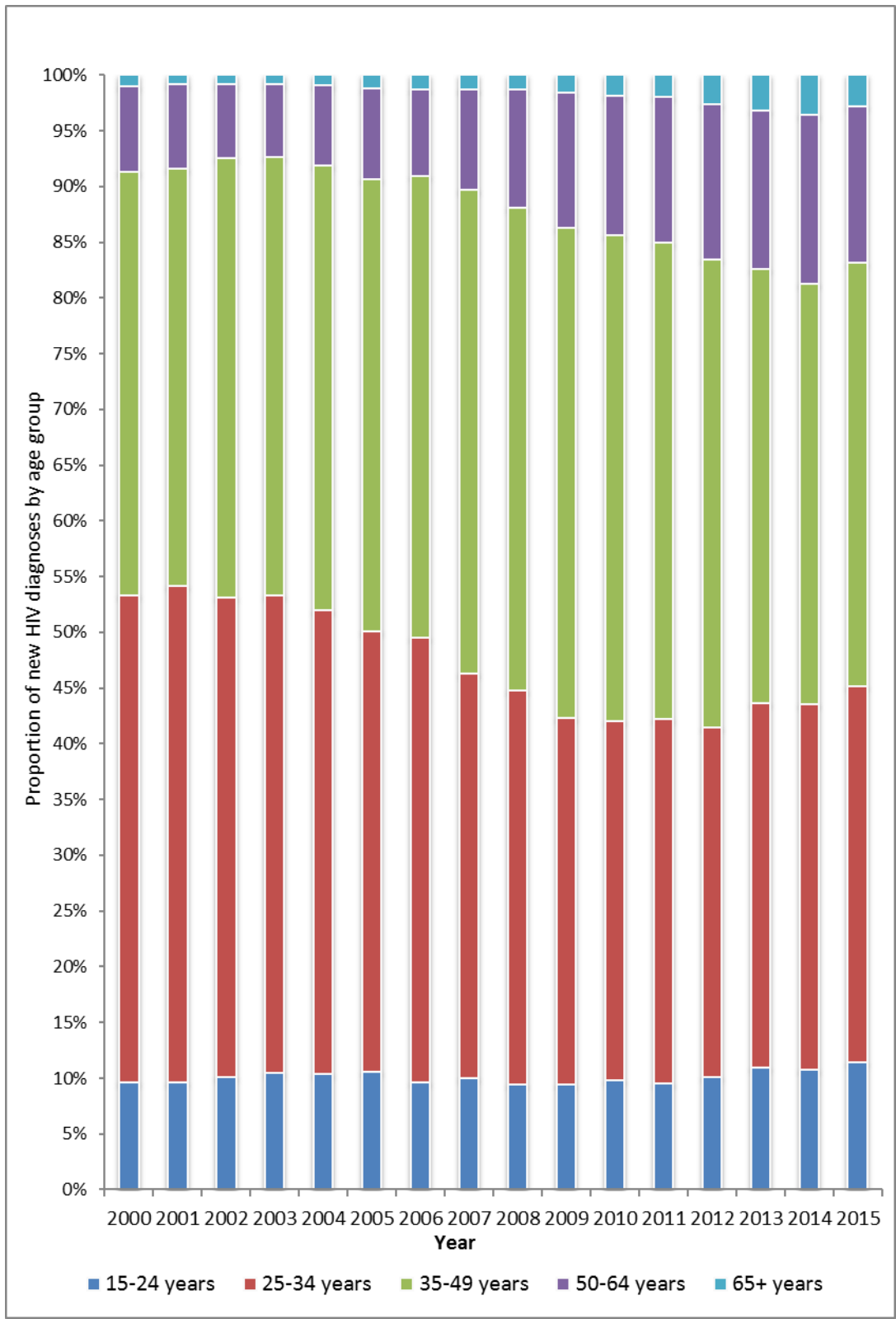


Figure 1: Proportion of total new HIV diagnoses by age group - 2000 to 2015, UK (PHE, 2016a)



## 1.1 What are HIV and AIDS?

HIV is a retrovirus that causes immune system suppression in infected individuals through the destruction of CD4+ T lymphocytes (Moir, Chun, & Fauci, 2008; Nairn & Helbert, 2007; Pratt, 2003; Wagner et al., 2008; Williams et al., 2011). CD4+ T lymphocytes perform a crucial role in the immune system by activating other immunological cells to defend the body against pathogens; these cells include B-lymphocytes, which produce antibodies (Mitchell & Aspinall, 2008). The depletion of CD4+ T lymphocytes by HIV renders someone at risk of developing potentially fatal opportunistic infections and malignancies (Williams et al., 2011). When the immune system has reached a level of severe compromise an individual is said to have developed acquired immune deficiency syndrome (AIDS) (Centers for Disease Control and Prevention (CDC), 2008a).

HIV was identified as the AIDS causing virus in 1983-84 (Barre-Sinoussi et al., 1983; Gallo et al., 1984; Levy et al., 1984; Popovic et al., 1984), following the first reports of AIDS in the USA in 1980-81 (CDC, 1981). The first cases of AIDS in the USA and UK were reported in men who have sex with men (MSM), leading to the initial labelling of the disease within the media as 'gay compromise syndrome' (Brennan and Durack, 1981) and 'gay related immunodeficiency syndrome' (GRID) (Altman, 1982). However, HIV was soon after found in other population groups and identified as a blood-borne disease, transmissible via: semen (Zagury et al., 1984), genital fluids (Ilaria et al., 1992; Pudney et al., 1992; Wofsy et al., 1986), blood (Gallo et al., 1984) and breast milk (Thiry et al., 1985).

## 1.2 What are the clinical stages of HIV infection?

At the primary stage of infection (*stage 1 HIV infection*), rapid HIV replication occurs (CDC, 2008a). Levels of HIV in the blood (referred to as HIV RNA or viral load) increase and as a consequence the number of CD4 cells starts to diminish (Pratt, 2003; Wagner et al., 2008). This stage can occur at any point within the first few months of infection (Pratt, 2003). Flu-like symptoms may be apparent at this time, such as fatigue, lymphadenopathy, fever, and myalgia (British HIV Association (BHIVA), British Association of Sexual Health & HIV (BASHH), & British Infection Society (BIS), 2008; Pratt, 2003). It is estimated that around 80% of people will display symptoms at the primary stage of infection (BHIVA, BASHH, & BIS, 2008).

The activation of an immune response to HIV results in a relative stabilisation of HIV RNA and a slowing down of CD4 cell destruction, establishing the next phase of infection; the clinical latency stage (*stage 2 HIV infection*) (CDC, 2008a). Without treatment, around 75% of HIV infected individuals can remain asymptomatic for up to 9-10 years from the establishment of

primary infection; however, throughout this time an individual with HIV remains infectious to others (Williams et al., 2011).

Ultimately, the body's immunological response to the virus becomes insufficient, viral HIV levels again begin to rise and CD4 cells are adversely affected (Wagner et al., 2008). Due to the high rate of HIV replication, coupled with viral transcription errors, HIV quickly mutates (Pratt, 2003). This makes the virus increasingly difficult for the immune system to recognise and fight. Extensive damage to the immune system, effectively depleting the immune response, leaves the individual severely immunocompromised and consequently at risk of acquiring opportunistic infections and malignancies (Wagner et al., 2008). At this stage, the infected individual has developed AIDS (*stage 3 HIV infection*) (CDC, 2008a). The CDC provides a list of AIDS-defining conditions (CDC, 2008b); these include tuberculosis, recurrent pneumonia, lymphoma and cervical cancer.

### 1.3 How can HIV transmission in adults be prevented?

In adults, HIV can be transmitted through receiving infected blood products (i.e. via transfusion), exposure to contaminated needles (i.e. via injection drug use (IDU) or needle stick injury), and engagement in unprotected sex.

The screening of donors and testing of blood components has successfully averted HIV transmission in the UK via contaminated blood products since 2002 (Aghaizu et al., 2013). The risk of acquisition through IDU in the UK has been effectively reduced using harm reduction approaches, such as needle and syringe programmes (National Institute for Health and Care Excellence (NICE), 2014).

The risk of sexually transmitted HIV can be greatly reduced through correct condom use (Smith et al., 2015; Weller & Davis-Beaty, 2002). In addition, limiting partner number has been found to decrease the likelihood of acquiring HIV and other sexually transmitted infections (STIs), although this approach has not been the focus of UK prevention efforts (National AIDS Trust (NAT), 2010a). Already having an STI, especially if ulcerative, is also associated with increased risk of HIV acquisition (Galvin & Cohen, 2004), highlighting the importance of regular sexual health screenings and prompt STI treatment to prevent HIV infection. In high HIV prevalence countries, such as those of sub-Saharan Africa, male circumcision is a further approach that has been encouraged to reduce the risk of HIV acquisition (World Health Organisation (WHO), 2016).

Another way of preventing HIV transmission is by using treatment as prevention (TasP), alongside condom use (Fidler et al., 2013; Rodger et al., 2014). In discordant couples (relationship in which only one partner is HIV positive) the treatment of the infected partner with antiretroviral therapy lowers the risk of vaginal HIV transmission by 96% (Cohen et al., 2011). A similar reduction is also estimated in MSM (Fidler et al., 2013).

Individuals potentially exposed to HIV, e.g. through sexual contact with someone known to be HIV positive, can take post-exposure prophylaxis (PEP) to reduce risk of HIV acquisition (Benn et al., 2011). PEP is more effective the earlier it is initiated; it must be started within 72 hours of exposure (Benn et al., 2011).

For individuals at high risk of contracting HIV, e.g. MSM, pre-exposure prophylaxis (PrEP) has been shown to reduce the risk of HIV acquisition (McCormack et al., 2016a; WHO, 2015). PrEP is currently unavailable through the NHS outside of study trials, although campaigners are striving for this to change (McCormack et al., 2016b) and have recently secured a high court ruling that funding PrEP falls under the NHS's remit (*National AIDS Trust v NHS England [2016]* EWHC (Admin)). NHS England unsuccessfully appealed against this ruling (2016a), with the judgment maintained that they have 'the ability but not the obligation to fund PrEP' (NHS England, 2016b). NHS England have since announced that a large trial of PrEP will commence in 2017, recruiting at least 10,000 participants, to investigate how the drug can most effectively be implemented on a wider scale (NHS England, 2016c).

#### 1.4 Commissioning of HIV services in the UK

Challenges to which organisation is responsible for funding PrEP appear to be a consequence of changes to HIV service commissioning in the UK, following the implementation of the *Health and Social Care Act 2012* (All-Party Parliamentary Group on HIV/AIDS (APPG HIV/AIDS), 2016). Since the Act, there has been a lack of clarity as to which organisation should be responsible and accountable for each aspect of HIV service provision (APPG HIV/AIDS, 2016).

STI/HIV prevention and testing is now largely commissioned by local authorities, while HIV treatment and care is commissioned by NHS England (NAO, 2016; NAT, 2014a). These changes have sparked concern about the potential for disjointed service user pathways (APPG HIV/AIDS, 2016).

Since the implementation of the *Health and Social Care Act 2012*, sexual health and HIV services, which were often delivered in an integrated care setting, have been separated. This

has the potential for poor linkage between testing and treatment services (APPG HIV/AIDS, 2016).

HIV support services are also under threat due to the lack of clear responsibility for local authorities to provide these services, in a climate of severe financial restrictions (APPG HIV/AIDS, 2016).

### 1.5 HIV epidemiology in the UK

In 2015, approximately 101,200 people were living with HIV in the UK (Kirwan et al., 2016). As a consequence of improved life-expectancy and an increase in new HIV diagnoses in older adults, one in three people currently accessing HIV treatment services in the UK are aged 50+ years (Chau et al., 2016).

Table 1 shows HIV prevalence (diagnosed and undiagnosed infection), new diagnosis and late diagnosis data for the UK by risk group. Globally, as within the UK, HIV is most commonly acquired through sexual contact. HIV transmission via IDU in the UK has been kept at comparatively low levels, along with mother to child infections. Transmissions via blood products, shown for 2015, were all acquired outside of the UK (PHE, 2016a). Only one mother to child infection in 2015 was acquired in the UK (Chau et al., 2016). In 2015, 38.7% of reported new HIV diagnoses were acquired through sexual contact in heterosexuals (16.6% males; 22.1% females) and 54.5% in MSM (PHE, 2016a). The two risk groups most affected by HIV in the UK are MSM and black Africans.

In the UK in 2014, 4.9% of MSM aged 15-44 years were estimated to be living with HIV in contrast to less than 0.1% of heterosexuals in this age group (Skingsley et al., 2015). MSM involved in "chemsex" (drug taking prior to, or during, sexual contact) are particularly at risk of HIV transmission through exposure to contaminated needles and engagement in risky sexual behaviour while under the influence of drugs (Bourne et al., 2014).

Approximately, 4.5% of female black African heterosexuals and 1.8% of male black African heterosexuals in the UK are living with HIV (Skingsley et al., 2015). This compares to around 0.1% of males and females of white ethnicity (Health Protection Agency (HPA) 2010 cited in NICE, 2011a). MSM are the group least likely group to receive a late HIV diagnosis; heterosexual males, particularly of black African ethnicity, are most likely (Table 1).

In terms of age, the proportion of total new HIV diagnoses in the UK in adults aged 50+ years increased from 8.7% in 2000 to 16.9% in 2015 (PHE, 2016a; Figure 1). Median age at diagnosis has remained relatively stable in MSM (35 years in 2005 compared to 33 years in 2015);

however, it is increasing in heterosexuals (Kirwan et al., 2016; Skingsley et al., 2015). For heterosexual women, median age at diagnosis increased from 32 years in 2005 to 39 years in 2015 (Kirwan et al., 2016; Skingsley et al., 2015). For heterosexual men, median age at diagnosis increased from 37 to 42 years during this time (Kirwan et al., 2016; Skingsley et al., 2015).

Table 1: HIV in the UK – latest prevalence (diagnosed and undiagnosed) and new diagnosis (Inc. late diagnoses) figures, by risk group

	Total (all risk groups)	Heterosexual males		Heterosexual females		Men who have sex with men (MSM)	Injection drug users (IDUs)	Mother to infant	Blood/ tissue products
		Black African ethnicity	Non-black African ethnicity	Black African ethnicity	Non-black African ethnicity				
<b>Number of people living with HIV in the UK (diagnosed and undiagnosed) - 2015 estimates*</b>	101,200 (95% CI 97,469-105,700)	9,264 (95% CI 8,873-9,838)	10,280 (95% CI 9,448 - 11,940)	19,310 (95% CI 18,710 - 20,040)	10,550 (95% CI 9,910 - 11,330)	47,040 (95% CI 44,219-50,860)	2,495 (95% CI 2,221-2,785)		
<b>Estimated % of people with undiagnosed HIV in the UK – 2015 estimates*</b>	13% (95% CI 10-17%)	11% (95% CI 8-16%)	21% (95% CI 14-32%)	10% (95% CI 8-12%)	20% (95% CI 16-25%)	12% (95% CI 7-19%)	13% (95% CI 7-21%)		
<b>No. of new HIV diagnoses in the UK – 2015</b>	6,095**	1,010**		1,350**		3,320**	210**	130***	50***
<b>Median age at diagnosis</b>		42 years (2015)*		39 years (2015)*		33 years (2015)*	47 years (2013) ****		
<b>% of late HIV diagnoses – 2015<sup>1</sup></b>	39%**	55%**		49%**		30%**	45%**		

\*Kirwan et al., 2016; \*\* PHE, 2016a; \*\*\* Chau et al., 2016, \*\*\*\* Yin et al., 2014

<sup>1</sup> Late HIV diagnosis is more common in heterosexuals of black African ethnicity than non-black African ethnicity. In 2015, 60% of heterosexual black African men were diagnosed late and 52% of black African women (Kirwan et al., 2016).

In 2013, 66% of black African men were diagnosed late compared to 61% of white men; 57% of black African women were diagnosed late compared to 42% of white women (Harris & Khatri, 2015).

## 1.6 Why are adults aged 50 years and over at risk of HIV?

It is argued that ageist attitudes in the HIV response have proven detrimental to adults aged 50+ years, fuelling the impression of the disease as exclusive to younger people (Gott, 2005). This statement highlights the damaging assumption that older adults are asexual (Gott, 2005), despite contradictory survey findings (Johnson et al., 1994; Mercer et al., 2013; Wellings et al., 1994):

*“Public concern has been too tightly caught up with ingrained fears about youthful sexual activity and the supposed threat of ‘alternative’ lifestyles to recognise the very real needs of older people in this area. Perhaps this recognition has fallen victim to the comfortable lie that our parents are no longer sexual beings (let alone our grandparents)...” (Kaufmann, 1993, p.1)*

Smith et al (2010) identified that approximately 48% of adults diagnosed with HIV at age 50+ years in England, Wales and Northern Ireland between 2000 and 2007 acquired the infection in older age. This highlights that transmission is occurring later in life.

At the highest level, despite research highlighting that older adults' are sexually active this group have been excluded from previous sexual health/HIV policies (Department of Health (DH), 2001a; Gott, 2005). In addition, no reference to sexuality or sexual health was included in the *National Framework for Older People* (DH, 2001b) (Gott, 2005). Older adults have also been neglected in policy-informing sexual health research (Gott, 2005), most notably adults over the age of 44 were excluded from the second National Survey of Sexual Attitudes and Lifestyles (NATSAL) (1999-2001) (Johnson et al., 2001), and the first NATSAL study (1990-91) only included adults to the age of 59 years (Johnson et al., 1994; Wellings et al., 1994).

It is suggested that as a result of these exclusions, personal perceptions of risk and HIV knowledge are lower in the over 50s than younger adults (Gott, 2005; Rosenfeld et al., 2015). Older adults, particularly those aged 75+ years, have consistently been found less knowledgeable surrounding modes of HIV transmission than younger age groups (NAT, 2014b). Coupled with lower levels of HIV knowledge, older adults are also considered at greater risk of HIV transmission due to age-related physical changes e.g. vaginal dryness and thinning of the vaginal wall (Drew & Sherrard, 2008).

Changes in societal norms, attitudes, and behaviours make the lower knowledge and heightened physical susceptibility in adults aged 50+ years of further concern. A rise in divorce rates in older adults, particularly aged 60+ years (Office for National Statistics (ONS), 2012a), an increase in online dating sites for the over 50s (e.g.

<http://www.sagaconnections.co.uk>), and the availability of Viagra, coincide with findings that this group engage with more sexual partners than previous older cohorts (Johnson et al., 1994; Wellings et al., 1994; Mercer et al., 2013). It has also been suggested that condom use declines in older age, particularly in people leaving long-term relationships:

*'You know for years you're married and all of a sudden they find themselves divorced and you haven't used protection when you are married and all of a sudden you just forget about it...and they find themselves out there and just, you know, having unprotected sex because they've been doing it for years, out of the habit of just having a husband and then now they're still doing it...'*

*(Female participant; Excerpt from McCord, 2013)*

The rise in travel to high HIV prevalence areas by the over 50s is also linked to an infection increase in this age group. Between 2002 and 2012, older UK born adults were found more likely to have acquired their infection outside the UK than younger adults (Rice et al., 2012). This association is considered a consequence of older adults' engagement with sex tourism and risky sexual interactions (Rice et al., 2012). Access to larger disposal incomes in older age is a factor that increases the ability of this age group to fund travel to high-risk countries, and potentially pay for commercial sex (Wright, 2003).

A further factor thought to contribute to the increase in new HIV diagnoses, and the high proportion of late diagnoses in older adults, is the oversight of this group in the small number of sexual health/HIV prevention campaigns conducted in the UK (Pratt et al., 2010). It has also been considered that sexual health and HIV in the over 50s may be overlooked by HCPs (Pratt et al., 2010).

## 1.7 Thesis aims

To date, little UK-based research has specifically concentrated on adults diagnosed with HIV at age 50+ years and their health-seeking journey. The aim of this thesis is to examine whether HIV services in England are meeting the needs of adults diagnosed at age 50+ years, exploring if they are accessible and acceptable to this age group.

Using a mixed-methods approach, the following processes and events are focused on: (i) pathways to HIV testing; (ii) HIV diagnosis and treatment; (iii) ongoing care and life after HIV diagnosis. The thesis objectives are outlined in table 2, alongside the research methods used to address them.



Table 2: Outline of research methods and objectives

Objectives of each method	<i>Method</i>
To explore service provision for adults aged 50+ years that are at risk of HIV and newly diagnosed with HIV, looking at the experience of caring for these service users.	Interviews with HCPs working in sexual health/HIV services.
To explore the pathway to testing experienced by adults diagnosed with HIV at age 50+ years. To look at the experiences of this age group in using HIV services and other health care services from the point of diagnosis, and their wider experiences of living with HIV.	Interviews with adults diagnosed with HIV at age 50+ years.
To explore HCPs knowledge surrounding HIV in adults aged 50+ years, attitudes towards discussing sexual health/HIV and offering HIV tests to adults aged 50+ years, and services provided for this age group.	Online survey of HCPs working in sexual health/HIV services.
To examine the age distribution of new HIV diagnoses in England per annum (2009-14) by sexual orientation and ethnicity.  Using a second dataset, to explore attendance and HIV test coverage (test offer and acceptance) in sexual health/GUM clinics in England per annum (2009-14) by service user age, gender and sexual orientation.	Analysis of national sexual health/GUM service data.

## 1.8 Chapter overview

In **chapter two** of this thesis, background information on the HIV response in the UK is provided. This chapter includes a discussion of the targeted approaches to prevention and testing in the UK and an exploration of HIV clinician and general practitioner roles in HIV care. Through comparison with the experiences of younger adults, it also provides an overview of the limited UK-based research on sexual health/GUM service access by the over 50s; the health-seeking journey of adults diagnosed with HIV in older age; and the experience of living with HIV after diagnosis at age 50+ years.

**Chapter three** discusses the mixed-methods approach used in the thesis, outlining the rationale for addressing the research objectives using qualitative interviews, surveys and PHE sexual health/GUM service data. **Chapter four** highlights the characteristics of interview participants (adults diagnosed with HIV at age 50+ years and HCPs), recruitment sites, and survey respondents.

Chapters **five** (Journey to testing), **six** (HIV diagnosis and treatment) and **seven** (Ongoing care and life after diagnosis) present the findings of this thesis. Qualitative interview, survey and national data, were integrated at the data analysis and interpretation stage with the use of a theoretical framework (section 1.9). The results are presented in the chapters outlined in table 3. **Chapter eight** incorporates findings from each of the results chapters in a final discussion, providing recommendations for HIV policy makers and suggesting future areas of research.

*Table 3: Overview of data integration in results chapters five, six and seven*

	Qualitative data	Survey	National data
CHAPTER FIVE: Pathway to HIV testing	✓	✓	✓
CHAPTER SIX: HIV diagnosis and treatment	✓	✓	
CHAPTER SEVEN: Ongoing care and life after HIV diagnosis	✓		

## 1.9 Application of a theoretical framework

In this thesis, social cognition models/theories and pathways models (see below) have been used to facilitate understanding of health-seeking behaviour (HSB) among adults diagnosed with HIV at age 50+ years.

### 1.9.1 Social cognition models

Social cognition models (SCMs) and theories, such as the Health Belief Model (HBM) (Rosenstock, 1966), Protection Motivation Theory (PMT) (Rogers, 1983), Theory of Reasoned Action (Ajzen & Fishbein, 1980) and Social Cognitive Theory (SCT) (Bandura, 1986), attempt to

outline the determinants of health behaviours (e.g. practicing safer sex by using condoms) and health-seeking behaviours (e.g. the decision to attend general practice or a sexual health clinic) (Conner & Norman, 2007; Ogden, 2012).

Each model outlines that an individual's health behaviour is decided through the process of balancing the perceived advantages and disadvantages of taking action (Becker, 1974; Conner & Norman, 2007; Rosenstock, 1966). SCMs highlight that perceptions of personal susceptibility to illness, and beliefs regarding illness severity are driving forces for action (Rogers, 1983; Rosenstock, 1966). These are measured against perceived disadvantages associated with health behaviours or health-seeking such as negative impact on lifestyle, expense, stigma, and embarrassment (Rogers, 1983; Rosenstock, 1966). Psychological barriers such as limited knowledge about a condition may also impact HSB (Rosenstock, Stretcher, & Becker, 1988). Cues to action, such as health promotion campaigns, are considered to encourage HSB (Abraham & Sheeran, 2007).

SCMs are arguably too simplistic to provide a full explanation for HSB and are based on the assumption that the decision to access health services is made through a rational process. As highlighted by Mackian, Bedri, & Lovel (2004) they are 'criticized for portraying individuals as a-social economic decision-makers' (p.139). SCMs often do not consider that responses may be maladaptive, for example, denial or fear may result in those most at risk of illness avoiding health-seeking (Rogers, 1983; Rosenstock, 1966).

### 1.9.2 Pathways models

Pathways models aim to predict or explain HSB through the exploration of health-seeking as a journey, with defined processes and events leading to health service access (Mackian, Bedri, & Lovel, 2004). This section describes two pathways models that specifically look at delays in health-care seeking: the *Model of Total Patient Delay* (Andersen Model) (Andersen, Cacioppo, & Roberts, 1995) and the *Model of Pathways to Treatment* (MPT) (Walter et al., 2012).

In the past, the MPT and Andersen Model have primarily been used to examine journeys to cancer diagnosis and treatment (Hall et al., 2015; Moodley et al., 2016; Mwaka et al., 2015; Walter et al., 2012). Around 1 in 4 people with cancer are diagnosed late and present as emergency hospital admissions (National Cancer Intelligence Network, 2010). Neither model has been identified as used to explore the journey to HIV diagnosis and treatment, although the similarities between cancer and HIV in terms of late diagnosis suggest their transferability to HIV. A high proportion of people with HIV are diagnosed at a late stage of disease; 39% of

diagnoses were classed as late in 2015 (CD4 count <350 cells/mm<sup>3</sup> within 91 days of diagnosis) (PHE, 2016a), with older adults disproportionately affected.

The Andersen Model examines the journey from the identification of bodily changes (symptoms) to the treatment of illness as a linear process (Andersen, Cacioppo, & Roberts, 1995; see figure 2). It highlights that delays may occur at any stage in this journey. There may be a lengthy duration to symptom recognition and motivation to take health action ('appraisal delay' and 'illness delay'), or in accessing health services ('behavioural delay') and first seeing a HCP ('scheduling delay'), or disease detection by HCPs and the starting of treatment ('treatment delay') (Andersen, Cacioppo, & Roberts, 1995).

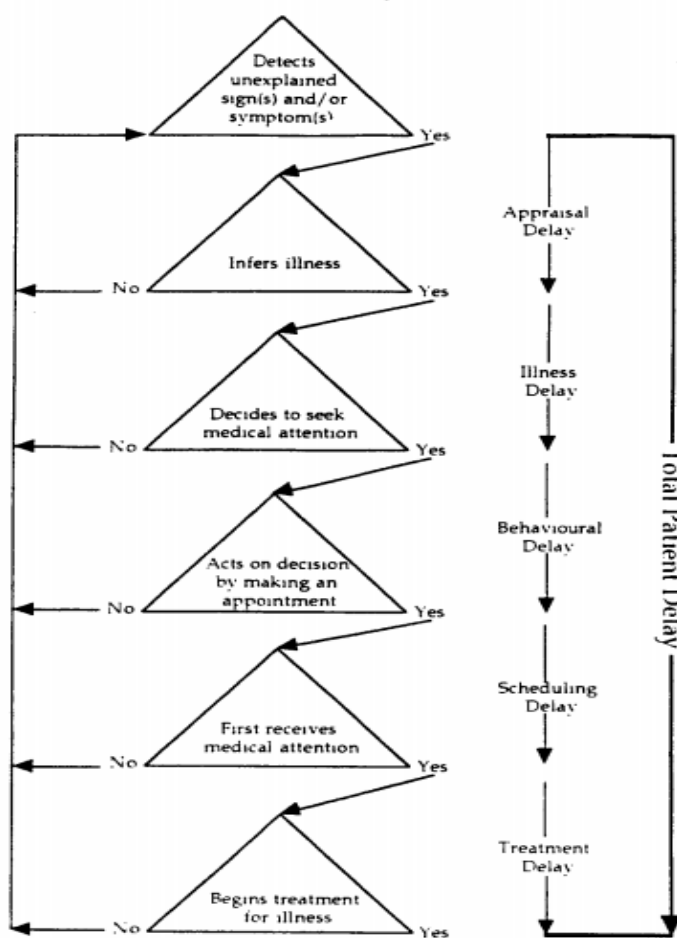


Figure 2: Andersen Model of Total Patient Delay. Extracted from Andersen, Cacioppo & Roberts (1995).

The MPT appears very similar to the Andersen Model. As shown in figure 3, the MPT highlights the following events in the journey to diagnosis and treatment: 1) detection of bodily changes; 2) perceiving a reason to access health services; 3) attendance at a health service; 4) diagnosis; and 5) treatment initiation (Scott et al., 2013; Walter et al., 2012).

Intervals exist between these events, during which multiple processes (cognitive, emotional behavioural, organisational or structural actions) may occur to hinder or promote the health-seeking pathway (Scott et al., 2013; Walter et al., 2012; Figure 3). Contributing factors, such as those related to the disease (e.g. symptom severity) and the patient (e.g. previous experience of illness) influence HSB.

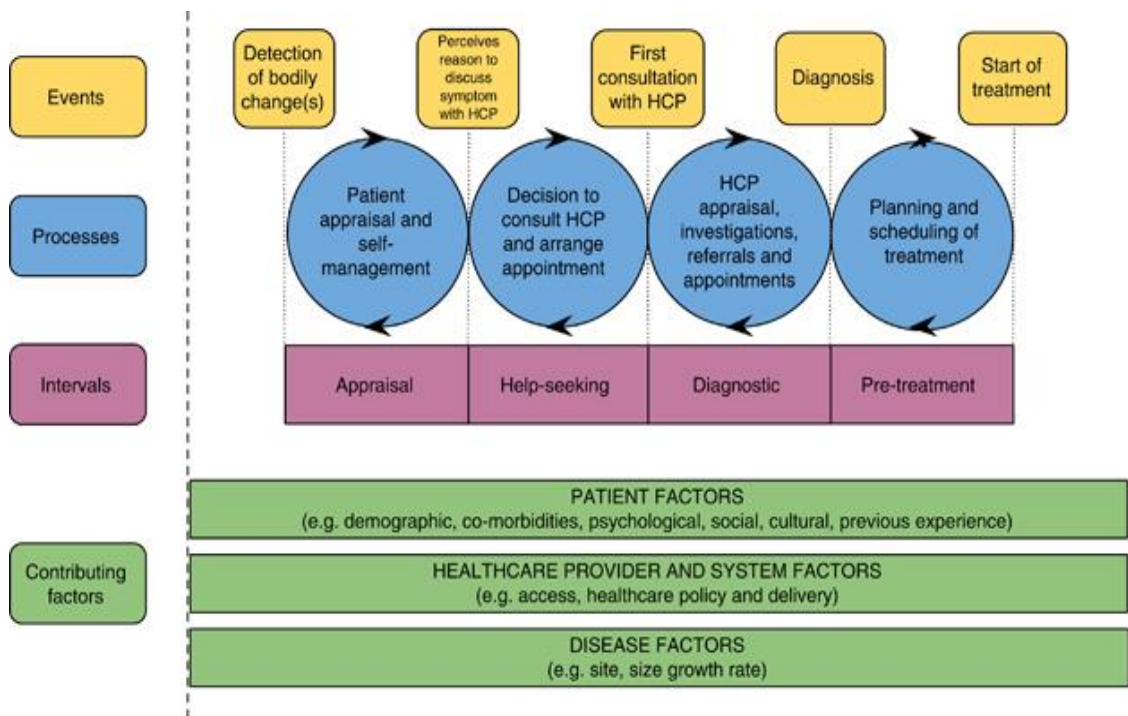


Figure 3: Model of Pathways to Treatment (MPT). Extracted from Walter et al (2012).

Although both models are similar, the MPT acknowledges that symptoms do not necessarily trigger health service access, and health problems may be asymptomatic (Scott & Walter, 2010; Scott et al., 2013). Illness does not need to be inferred for someone to access health services (Scott & Walter, 2010; Scott et al., 2013). Instead, disease may be detected through routine or opportunistic screening. As someone with HIV may be asymptomatic, for a lengthy period of time, this is an important consideration (see section 1.2). Other factors may be necessary to prompt health-seeking, such as awareness of engaging in 'risky' sexual behaviour, or the knowledge that a previous sexual partner is a HIV carrier. Unlike the Andersen Model, the MPT also takes into account misdiagnoses and delayed diagnoses which make the journey non-linear (Scott & Walter, 2010; Scott et al., 2013; Walter et al., 2012); these are frequent occurrences associated with the HIV testing pathway.

As the characteristics of the MPT are more applicable in the context of HIV than the Andersen Model, the MPT was selected as a framework for developing interview and survey questions, and in data analysis (see chapter three).

#### 1.10 Summary

The chapter has provided crucial information on HIV/AIDS and the rationale for focusing this thesis on adults diagnosed with HIV at age 50 years and over. It has provided an overview of the research methods, the use of the *Model of Pathways to Treatment* (MPT) as a theoretical framework, and the structure of the thesis. The following chapter will provide greater context to the UK HIV epidemic and explore existing research on the health-seeking pathway experienced by adults diagnosed with HIV at an older age.







## Chapter 2: Background and literature overview

### 2.1 Introduction

This chapter will provide an overview of current approaches to HIV prevention, testing, and management in the UK. It will examine existing literature exploring the pathway to HIV detection and treatment for adults aged 50+ years. It will look at the experiences of this group in accessing sexual health/HIV services, responding to a positive HIV diagnosis and living with HIV. This will be compared to the literature on younger adults experiencing this journey.

### 2.2 Approach to literature searching and reviewing

There are a range of different types of review which are used to provide a summary of existing research on a particular topic (see Booth, Sutton, & Papaioannou, 2016); these include the commonly used systematic review and literature review.

A systematic review uses a highly rigorous approach to literature searching and appraisal, in which reviewers adhere to a strict protocol to answer a pre-determined research question (Aveyard, 2014). The process involves multiple reviewers who follow a rigid checklist for the inclusion and exclusion of literature based on relevance and quality (Aveyard, 2014). By contrast, although a literature review also provides a comprehensive summary on a specific topic, this is done using a less rigorous and detailed approach and may address a broader research question(s) (Aveyard, 2014). As this review aimed to explore several broad research questions (highlighted below), a literature review was conducted instead of a systematic review. It was considered that conducting a systematic review would be unbeneficial in narrowing the scope of the review to a specific question.

#### *Literature review questions*

- 1) What are service users' experiences of accessing sexual health/GUM services at age 50+ years?
- 2) What are service users' experiences of accessing general practice for STI/HIV testing at age 50+ years?
- 3) What is known about the health seeking journey of adults diagnosed with HIV at age 50+ years?
- 4) What is known about the experience of living with HIV after diagnosis at age 50+ years?

Although not a systematic review, this review incorporated a systematic approach to literature identification, searching a range of sources and using clear search terms (Aveyard & Sharp, 2013). Included studies were found through searching the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid Medline and Google Scholar (see Appendices 1-3). Examples of the search terms used are highlighted in Appendix 4. To compare experiences by age, initial searches were conducted without age-restrictions prior to concentrating on adults aged 50+ years. Articles in English, primarily conducted after effective HIV treatment became available (1996 onwards), were included. It was anticipated that prior to this time period, when a HIV diagnosis was terminal, the experience of HIV diagnosis would be starkly different. The searches centred on studies with a qualitative component. Studies conducted with specific sub-groups of the population such as asylum seekers, prisoners, pregnant women or teenagers etc., were excluded as they are not the focus of this thesis and may face different barriers and challenges in relation to health service access, HIV testing and living with HIV.

Identified studies were evaluated for their quality, in terms of transparency, the clarity of the research question and the appropriateness of the study design (Aveyard & Sharp, 2013; Booth, Sutton & Papaioannou, 2016). Studies were also assessed for their relevance in addressing the research questions (Aveyard & Sharp, 2013; Booth, Sutton & Papaioannou, 2016).

These systematic approaches taken to identifying and appraising the literature are key features of a 'good literature review' (Aveyard & Sharp, 2013).

### 2.3 Targeted approaches to HIV and STI prevention and testing in the UK

Following the major public health campaign, '*AIDS - Don't Die of Ignorance*', in 1987 in which HIV education leaflets were distributed to every household nationally, the UK response to HIV has greatly diminished in scale (Berridge, 1996; Fowler et al., 2011) (Figure 4).

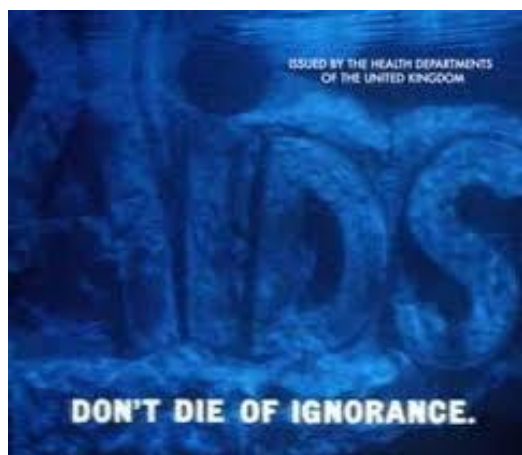


Figure 4: 'Iceberg' and 'Tombstone' adverts used in the 'AIDS - Don't Die of Ignorance' campaign. (Health Education Authority 1987 cited in Bourne, 2010)

From the 1990s, it is clear that HIV prevention and testing campaigns have become highly focused on the two groups proportionally most affected by HIV: MSM (Fowler et al., 2011; HIV Prevention England (HPE), n.d; NICE, 2011b; Terrence Higgins Trust (THT), n.d) and black Africans (African Health Policy Network (AHPN), n.d; Fowler et al., 2011; HPE, n.d; NICE, 2011a). There have been no further national campaigns aimed at the general population.

In relation to STIs more broadly, including HIV, approaches have historically been youth-focused (DH, 2001a; DH, DfE & NCSP., n.d; PHE, 2014). It can be argued that targeting sexual health campaigns at younger adults, mainly those aged less than 30 years, has fuelled the impression that STIs are only a concern for this group. In contrast to younger adults, there has only been one short campaign aimed at older adults in the UK. The Family Planning Association (FPA) ran '*Middle Aged Spread*', the first STI campaign aimed at adults aged 50+ years, as part of their sexual health week in 2010 (FPA, 2016; Figure 5).



Figure 5: Posters used in the '*Middle Aged Spread*' campaign in 2010 (FPA, 2016)

The near exclusion of older adults from STI/HIV campaigns appears to place this age group at a heightened risk of infection, and in a situation where they are more likely to be tested for HIV at a late stage of disease than younger people.

## 2.4 HIV testing

To promote early HIV detection in the UK, free voluntary and confidential HIV testing has been established as a public health initiative (BHIVA, BASHH, & BIS, 2008). Testing provides a

health promotion opportunity to discuss HIV risk and prevention measures (BHIVA, BASHH & BIS, 2008). It also promotes the identification and treatment of further HIV infections, through partner notification (Sullivan et al., 2015). In order to encourage HIV test uptake, there have been attempts to increase testing opportunities in healthcare and non-healthcare settings.

Currently, the NHS Choices website lists the following free HIV test providers: sexual health/GUM clinics; charity run centres e.g. Terrence Higgins Trust's Fastest clinic, Yorkshire MESMAC (2015); some general practices; some contraception and young people's clinics; local drug dependency services; and antenatal clinics (2014). Private clinics also provide testing; however, these services incur a fee (NHS Choices, 2014). In addition, it is now possible to request postal home sampling or home testing kits for HIV (NHS Choices, 2014); some of these are free.

#### 2.4.1 Testing in healthcare settings

According to current guidelines, HIV testing in the UK should be universally offered in:

*'GUM or sexual health clinics; antenatal services; termination of pregnancy services; drug dependency programmes; and healthcare services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma' (BHIVA, BASHH & BIS, 2008).*

Higher levels of uptake are achieved using an opt-out approach to testing (BHIVA, BASHH & BIS, 2008). This has been particularly evident in antenatal settings, which achieved a 98.2% test uptake in England in 2015 (PHE, 2017). Prior to the implementation of universal antenatal screening in 2001, test uptake was less than 10% in the majority of UK antenatal services (Tookey et al., 1998). GUM clinics in England have also achieved a good level of test uptake; the proportion of eligible GUM attendees offered a HIV test in 2015 was 86% and the proportion accepting this offer was 67% (PHE, 2016b).

Opt-out HIV testing is also recommended in general practices and hospitals in areas of high HIV prevalence ( $\geq 2$  in 1000 population aged 15-59 years), for new GP registrants and hospital admissions (BHIVA, BASHH & BIS, 2008). These guidelines are based on economic modelling performed in the USA (Paltiel et al., 2005), indicating that testing is cost-effective in areas where HIV prevalence is equal to or greater than 2 per 1000 people (HPA, 2011).

It is argued that due to high levels of service user access, general practices are in a pivotal position to provide sexual health/HIV services. (DH, 2001a):

*“...general practice is the only hope to improve [sexual health] services as it is the only provider with the capacity needed” (Spence 2002 cited in Gott et al., 2004).*

It is also recommended that testing should be considered, irrespective of local HIV prevalence, should an individual present with a clinical indicator condition for HIV, such as oral candidiasis (BHIVA, BASHH & BIS, 2008). Brown et al (2010) highlight the necessity of considering individual risk for HIV as late diagnosis may be more common in low prevalence areas (< 2 in 1000 population). Testing should also be offered when lifestyle factors indicate a greater risk of infection, e.g. MSM should be offered testing at least annually (BHIVA, BASHH & BIS, 2008).

#### 2.4.2 Testing at home

As of 2015, a self-testing kit for HIV has become available in the UK to order online, allowing people to test and receive their results within fifteen minutes at home. The only CE marked kit currently available in the UK is marketed as 99.7% accurate (BioSURE, 2016). Individuals who receive a positive result are advised to contact a HCP for a confirmatory test (BioSURE, 2016). It is also possible for people to collect a blood sample at home, via finger prick, to be sent for laboratory testing; this is referred to as home-sampling. In this instance, home-sampling users are contacted with their results within 3-5 days of testing. Both types of at home kits have been found to have reasonable levels of acceptability through pilot studies and surveys (Brady et al., 2014; Power & Slade, 2011) and the potential to reach individuals that are at high risk but have never tested (Elliot et al., 2012). In a survey of people that bought the BioSURE test between April 2015 and February 2016, 50.4% of respondents (1644/3259) had never tested before (Brady et al., 2016); although it is not clear whether these individuals were at risk of HIV, if they performed the test, or what their response was in the event of a positive result.

A concern with home testing is that 'self-diagnosis' as HIV positive may not result in those individuals accessing HIV services to report their positive result (NAT, 2008). There are also some worries regarding confidentiality (NAT, 2008). However, the advantages of at home testing such as greater privacy and convenience make the approach promising if properly regulated and linked to HIV services (NAT, 2008).

#### 2.4.3 HIV test coverage in healthcare settings (non-HIV specialists)

Overall, the offer of HIV testing beyond specialist settings (e.g. sexual health/GUM, antenatal services) has been reported as inadequate (Elmahdi et al., 2014; Page et al., 2011; Perry et al., 2010; Thomson-Glover, Mandal, & Smalley, 2011). In conducting a systematic review and

meta-analysis of testing in high prevalence areas outside of specialist settings, Elmahdi et al found that in hospitals settings test coverage was only 27%, a finding primarily linked to low levels of test offer (2014).

Despite emphasis on the importance of general practice in the sexual health/HIV response, HIV testing levels, although demonstrating some increase over time, remain low in this setting (Ellis et al., 2012; Evans et al., 2009). Only a small proportion of general practices in high prevalence areas have been found to offer testing to new GP registrants (BHIVA, BASHH & BIS., 2008; Ellis et al., 2012; Hartney et al., 2014). The recommendation to offer testing to individuals presenting with conditions potentially linked to HIV, or that belong to high risk HIV groups, has also been poorly adopted (Burns et al., 2008; Goodall & Leen, 2011; Hsu et al., 2013; Sudarshi et al., 2008; Sutton et al., 2010). There is also notable regional variation in the offering of HIV tests (Sadler et al., 2010); GPs are more likely to offer tests in urban settings, particularly London (Evans et al., 2009).

Numerous factors have been highlighted in the literature as barriers to delivering services in this setting. Regional surveys, although lacking generalisability, indicate problems surrounding the heavy workload of GPs, which limits their willingness and ability to implement sexual health/HIV guidelines (Markham et al., 2005; Rogstad & Henton, 2004). GP awareness of testing guidelines has also been reported as low (Milligan & Obasi, 2014; Mitchell, Bushby & Chauhan, 2011; Rogstad and Henton, 2004). Further barriers include lack of expertise, difficulties in discussing sexual activity and injection drug use, and issues surrounding confidentiality (Clarke, 1993; Davies, Gompels & May., 2015; Milligan & Obasi, 2014):

*'many general practice staff have not had specific sexual health training and are often reluctant to raise or discuss issues due to a fear of causing offence, the sensitivity of the subject matter and constraints around time and expertise' (DH, 2013, p.44).*

A substantial portion of individuals attend their GP prior to referral to sexual health/GUM services (Davies, Gompels, & May, 2015; Mercer et al., 2007), with reports of minimal STI/HIV testing conducted in this setting before GUM attendance (Matthews & Fletcher, 2001; Neale et al., 2008).

It is suggested that a surveillance system for the monitoring of STI/HIV testing in primary care should be implemented (Simms et al., 2003), in order to more effectively target and improve

services (Sadler et al., 2010). Currently, no mandatory monitoring of HIV testing is in place beyond sexual health/GUM clinics and antenatal settings (Elmahdi et al., 2014).

#### 2.4.4 Perceptions and experiences of using sexual health/GUM services

A critique of previous studies that have explored perceptions and experiences of using sexual health/GUM services is that they have largely focused on younger adults, and the majority have been conducted in high HIV prevalence areas such as London or Brighton (see Appendix 1). A further limitation is that several studies do not report the age range of their participants; where age is reported, few participants are older than 50 years (e.g. Dixon-Woods et al., 2001; Dowson et al., 2012; Llewellyn et al., 2012). In addition, many of the studies were conducted in the early 2000s and therefore may not reflect current perceptions and experiences.

Despite their limitations, a finding consistent across these studies is that sexual health/GUM services and STI testing are associated with high levels of stigma (Balfe & Brugha, 2009; Dixon-Woods et al., 2001; Mulholland & Van Wersch, 2007; Normansell, Drennan & Oakeshott, 2015; Scoular, Duncan & Hart., 2001). These settings are associated with 'seedy people' and 'filthy men' (Scoular, Duncan & Hart., 2001), and entering these services has been shown to cause anxiety:

*'I think (the entrance) is like a threat, it was horrible. Walking into here, everybody looking at you and thinking what diseases I had and, "I hope I don't get it"' (Male sexual health/GUM clinic attendee; Excerpt from Evans & Farquhar, 1996).*

Interestingly, once accessed negative perceptions of this setting appear to subside (Balfe & Brugha, 2009; Dixon-Woods et al., 2001; Evans & Cross, 2007; Scoular, Duncan, & Hart, 2001), and sexual health/GUM services are found to be much more acceptable than initially anticipated:

*"...coming here I was nervous at the beginning and sort of terrified...um...but they have made me very welcome, sort of well not welcome I suppose but they've had a very friendly atmosphere around them. Um...which did make me relaxed"' (Female GUM attendee, aged 18 years; Excerpt from Dixon-Woods et al., 2001)*

Reasons for attending sexual health services have been explored in several studies (Balfe & Brugha, 2009; Dixon-Woods et al., 2001; Leenaars, Rombouts & Kok, 1993). Dixon-Woods et al (2001) interviewed 37 females attending sexual health services (GUM clinic and/or family planning) in the East Midlands. The age range of participants was 15-53 years. Participants

reported five reasons for attendance: 1) detection of symptoms; 2) reporting of symptoms by a sexual partner; 3) concern that a sexual partner has engaged in 'risky' behaviour; 4) personally engaging in 'risky' behaviour; 5) for a routine sexual health screen (Dixon-Woods et al., 2001). When symptoms were present, a delay was reported in accessing services in the hope that symptoms would subside. It was only when symptoms increased in severity, did not resolve and became increasingly disruptive that help was sought:

*'I've left it and left it and left it 'cos I thought that basically, you know, I was just sore and then having sex again I hadn't had time to recover and I was still sore . . . um but it was getting to the point where you know it's causing me problems . . . going to just have to tell my boyfriend no all the time' (Female GUM attendee, aged 20 years; Excerpt from Dixon-Woods et al., 2001)*

Self-initiated testing for STIs was also linked to wanting a full screen before engaging in a monogamous sexual relationship without condoms (Balfe & Brugha, 2009).

HCPs working in sexual health/GUM services are widely regarded as the experts in testing and treating STIs (Balfe & Brugha, 2009); they are able to provide a wide range of tests that are not available in other settings (Llewellyn et al., 2012). These services are also considered less judgemental than general practice (Dixon-Woods et al., 2001; Normansell, Drennan & Oakeshott, 2015):

*'...you haven't got to be worried about it, 'cos you're not on your own and, well, nobody had two heads, nobody looked, like, strange at all. I mean obviously nobody judges you' (Female GUM attendee aged 18 years; excerpt from Dixon-Woods et al., 2001)*

Negatives associated with sexual health/GUM services include the busyness of these settings, long waiting times (Evans & Farquhar, 1996; Llewellyn et al., 2012; Normansell, Drennan & Oakeshott, 2015) and difficulties in booking appointments or accessing walk-in clinics:

*'The reason why I hadn't got checked out earlier is just trying to get an appointment in an STI clinic is very, very hard, especially when you're working full time. And even though they sometimes have a drop in time to go there, but sometimes it's not actually convenient times when you're working.'*  
*(Female GP practice attendee aged 27 years; Excerpt from Sutcliffe et al, 2011)*

There are also concerns surrounding anonymity:

*'at first it felt like—my God—does everyone know that I've got some kind of sexually transmitted disease—and I was looking about thinking don't let anyone catch my eye—I felt horrible' (Female participant; Excerpt from Mulholland & Van Wersch, 2007)*



Surrounding gender, it appears that females are more likely to experience and internalise feelings of shame in relation to STIs (Dixon-Woods et al, 2001; Mulholland & Van Wersch, 2007). Women may therefore experience different, perhaps additional, barriers to testing than men:

*'some people would probably think you were dirty . . . for a lass some people could think they were a slut or a slag—that's just the way people think and people would point a finger and think she has had so and so and she has been with him—that's the stereotype people get if they have an STD ...I think it would be harder for a woman...'* (Male participant; Excerpt from Mulholland & Van Wersch, 2007)

In one study, a participant also noted that her age affected the experience of attending a sexual health/GUM clinic, indicating that the environment may not feel comfortable to all age groups:

*'...the patients were all so young and here's me thinking oh my god I feel like you know. I felt like well I was old enough to be some of them's mother you know and I thought ...oh sugar!'* (Female GUM attendee aged 41 years; Excerpt from Dixon-Woods et al., 2001)

Older adults, particularly those aged 60+ years, have been found more likely to postpone attendance at GUM services for a longer time than younger people (Gott et al., 1999). In a questionnaire study, conducted at GUM sites in Sheffield, Nottingham and Leicester, Gott et al found that approximately 44% of adults aged 50+ years delayed GUM attendance for two weeks following symptom initiation (1999). More worryingly, almost 10% of participants aged 50+ years had delayed GUM attendance for two months (Gott et al., 1999). This is problematic as a delay in treatment seeking not only poses further potential health risks to the individual, but it may also increase the likelihood of onward STI transmission. The dominant reasons for lack of prompt GUM attendance were deciding to 'wait and see' if symptoms would subside, and embarrassment (Gott et al., 1999).

HIV testing figures also imply that HCPs working in sexual health/GUM may be less willing to offer a test as the age of the service user advances; this is particularly marked for older women (Skingsley et al., 2015). This would contradict HIV testing guidelines that recommend universal HIV testing in GUM clinics (BHIVA, BASHH & BIS, 2008).

An internet search produces large numbers of results for sexual health/HIV services specifically aimed at young people in England but none which obviously target the over 50s, aside from a London based clinic caring for older adults ageing with HIV (Waters et al., 2012).

Despite it being highlighted on the NHS choices website that 'you can go to a sexual health clinic whatever age you are' (2015a), it is not clear whether these clinics really feel accessible and acceptable to older adults and whether these clinics offer services and resources to reach this population.

#### 2.4.5 Perceptions and experiences of using general practice for testing

A critique of previous studies that have explored perceptions and experiences of using general practice to discuss sexual health or test for STIs/HIV is that few have involved adults aged 50+ years (Dixon-Woods et al., 2001; Llewellyn et al., 2012). Several studies, conducted in and around Sheffield by the same researchers in the early 2000s, have focused on the over 50s; however, findings from these may not reflect current perceptions and experiences, or be transferrable beyond this region (Gott et al., 1999; Gott & Hinchliff, 2003; Gott, Hinchliff & Galena, 2004).

From the available literature, it has been found that GPs are often perceived to lack expertise in providing information, testing and treatment for STIs:

*"I think at the end of the day a General Practitioner is just that, a General Practitioner. It would be very nice of course if they could have these skills and competencies to be accessible... in this area [STIs] but you know a specialised GUM clinic I suppose is the ideal situation"* (Excerpt from Llewellyn et al., 2012)

Positives associated with attending general practice for STI testing may include the comfort of attending a familiar environment, in which a good relationship has been established with HCPs (Llewellyn et al., 2012). However, this familiarity can also make the situation more uncomfortable and create concerns regarding confidentiality and being judged.

Attending general practice may afford greater anonymity as the purpose of visiting is not apparent to others sitting in the waiting room:

*"... if you're in a general waiting room, nobody knows exactly what you're there for, so if you're seen it would be better than being in a specific building ... you feel a little bit awkward when you're with the GP talking, but at least that's only one awkward situation rather than a whole build-up as well."* (Heterosexual male participant aged 24+ years; Excerpt from Llewellyn et al., 2012)

*"You sit here [in a GUM clinic] and everyone knows why you're here. At least at the doctor it could be a case of you've got a bad back or something"* (Male GUM clinic attendee, aged 25 years; Excerpt from Sutcliffe et al., 2011)

A concern about STI/HIV testing in general practice is that the result will be recorded in medical records (Dixon-Woods et al., 2001). There is still the misconception that testing positive for HIV will have a negative impact on mortgage applications.

In relation to adults aged 50+ years, stigma and embarrassment are associated with discussing sexual health with a general practitioner; although older adults would prefer to discuss sexual health with their GP than attend sexual health/GUM services (Gott & Hinchliff, 2003). This is a theme strengthened by the suggestion that older adults are more likely than younger people to see their GP prior to referral to sexual health/HIV clinics (Tobin & Harindra, 2001). The age and sex of the GP may also affect whether the older adult feels comfortable discussing their sexual health (Gott & Hinchliff, 2003). Older people have reported being afraid of judgement in reporting a sexual problem to their GP:

*'I just don't know how much importance the doctor would attach to it you know what I mean? I mean getting to our age, he says it's about time you packed up anyway [laughs]. You know what I mean, I don't want him to think I'm a sex maniac or anything like that.'* (Male participant, aged 65 years; Excerpt from Gott & Hinchliff, 2003)

GPs have also reported that discussing sexual health is more difficult with older than younger adults (Gott, Hinchliff, & Galena, 2004):

*'I'm 50 so my upbringing was extremely Victorian and I don't think I have ever discussed anything to do with sex with my mother and certainly not my dad, you know you just didn't do it....So yes I have got lots of hang-ups, lots and lots'* (Female GP aged 50-59 years; Excerpt from Gott, Hinchliff & Galena, 2004).

Reasons for avoiding sexual health discussions with older adults include embarrassment, insufficient training, fear of causing upset or insulting the older person, and the perception that the service user should initiate the discussion (Gott, Hinchliff & Galena, 2004).

*'I think we presume from a biological point of view that all women are in the menopause by the age of 45...we don't approach it anymore and we don't ask them about their sexual health, we presume if they have a problem they will ask us.'* (Male GP, aged 30-39 years; Excerpt from Gott, Hinchliff, & Galena, 2004)

*'I wouldn't dream of saying we do a sexual health clinic for the over 40s on a Tuesday afternoon, which you can do for the under 20s. It's a much more personal private thing I think'* (Female GP, aged 50-59 years; Excerpt from Gott, Hinchliff, & Galena, 2004)

As a result, doctors may be less likely to take a sexual history from older adults (Bouman & Arcelus, 2001; Murphree and DeHaven cited in Gott, Hinchliff, & Galena, 2004). It appears that ageist stereotypes, if not consciously, permeate:

*'I also think older people have lost something of what it means to be older and to just appreciate and be content in that and are in their effort perhaps to feel valued and accepted in society are trying to look, feel and do younger things, instead of enjoying a very companionable relationship...'* (Male GP, aged 40-49 years; Excerpt from Gott, Hinchliff & Galena, 2004)

And GPs may consider that, with advancing age, the relevance of discussing sexual health with a patient decreases:

*GP: ...It is more significant if somebody of 20 becomes HIV or hepatitis B positive and it's more likely to happen because it's more prevalent in those age groups, so the risk gets less as you get older. It always feels like it might be a bit politically correct to talk to 60, 70 or 80 year olds about these things, but actually is it really right for the person?*

*Interviewer: But what about say 40s and 50s?*

*GP: Yes, it gets to be a gradation really.*

*Interviewer: Would you talk to a person in their 40s or 50s about safe sex?*

*GP: Probably not.*

*(Female GP, aged 40-49 years; Excerpt from Gott, Hinchliff & Galena, 2004)*

It has also been identified that older adults may not be aware of the existence of sexual health/HIV clinics (Gott & Hinchliff, 2003) and may therefore consider the GP as the only option in seeking sexual health advice.

## 2.5 Journey to HIV testing

The initial step on the health-seeking journey, including testing for STIs, is often considered to be the recognition and appraisal of symptoms (Mechanic, 1986; WHO, 1995). In relation to HIV, the journey to testing may be more problematic due to the absence of specific symptoms until the disease becomes advanced. The decision to self-initiate testing, or for HCPs to offer testing, is therefore often reliant on HIV risk awareness.

The self-initiation of HIV testing is commonly reported as based on concerns about possible exposure to the virus, e.g. the decision to access a sexual health/HIV clinic for testing is associated with the recommendation to test by friends, or by a sexual partner (Anderson et al., 2010; Balfe & Brugha, 2009). For some, testing is offered as part of a routine process (e.g. antenatal screening or frequent sexual health checks) (Anderson et al., 2010). Barriers to HIV testing include stigma, fear about prognosis, and concerns regarding confidentiality (Burns et al., 2007; Dowson et al., 2012). Clinic opening hours and waiting times have also been reported as barriers to testing (Flowers et al, 2013).

Given the main groups affected by HIV in the UK, research that has explored the decision to attend services for HIV testing has concentrated on black Africans (Ajuo, 2014; Burns et al., 2007) and MSM (Dowson et al., 2012; Flowers, Duncan & Knussen, 2003). Limited research has explored older adults' experience of HIV testing. It appears that older adults are more likely to present at a late stage of disease (Iwuji et al, 2013; Smith et al, 2010). It has been found that those aged 40+ years are more likely to experience 'missed presentations'; encountering health services, sometimes on multiple occasions, prior to being tested for HIV (Wohlgemut, Lawes, & Laing, 2012).

The only study found to specifically focus on the pathway to diagnosis for older people was conducted in 1996-1997, including participants that were tested for HIV before effective HIV treatment became available. Therefore, findings may not be applicable in the era of effective HIV treatment. In this study, barriers to testing included fear and considering the process as pointless, due to the terminal nature of HIV at this time (Lekas, Schrimshaw & Siegel, 2005).

## 2.6 Late HIV diagnosis

In 2013, 58% of adults diagnosed with HIV at age 50+ years in the UK were diagnosed late compared to 39% of younger people (PHE, 2016a; Yin et al., 2014). Several factors have been identified as associated with receiving a late HIV diagnosis (CD4 count <350 cells/mm<sup>3</sup> within 91 days of diagnosis) and are outlined below.

### 2.6.1 Low risk perception

The term candidacy is used by Dixon-Woods et al to describe 'the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services' (2006). There is a wide literature on candidacy and health service and treatment access (Hunter et al., 2013; Klassen et al., 2008; Koehn, 2009; Kovandzic et al., 2011; MacDonald et al., 2016).

In relation to HIV, unless considered to belong to one of the high risk groups targeted in HIV campaigns (section 2.2), it appears that individuals potentially exposed to HIV may not consider themselves at risk of infection, or be offered a HIV test by HCPs (Anderson et al., 2010; Gilbert et al., 2006; Schwartz, Block, & Schafer, 2014). The targeting of HIV prevention and testing campaigns towards MSM and black Africans appears to have created the perception that HIV is exclusive to these groups, leaving others less likely to be offered a test:

*“I had been begging them [her doctors] to find out what was going on with me. They were concerned with my lymph nodes to the point of having them biopsied and sonogrammed, because, you know, ‘white girl and somewhat successful, it’s gotta be cancer’ ” (Female participant; Excerpt from Schwartz, Block, & Schafer, 2014).*

In addition, HIV acquisition may be considered a result of promiscuity, instead of regarded as a disease that can be transmitted through unsafe sex with anyone of unknown HIV status:

*“With my kind of history, I would never have thought that would have been the thing because I’m not one of those that sleeps around” (Female participant, Caribbean; Excerpt from Anderson et al., 2010).*

In relation to older adults, Emlet (2006) reports the belief that age serves as a barrier to being considered at risk of HIV:

*‘there’s a lot of people that go—‘you’re awfully old to have this disease.’” (Male participant; Excerpt from Emlet, 2006)*

### 2.6.2 Symptoms not considered HIV related

Late diagnosis is associated with presenting to HCPs with symptoms, on multiple occasions, which do not trigger the offering of a HIV test (Schwartz, Block & Schafer, 2014). HIV testing is often not considered until a person has become acutely unwell (Schwartz, Block, & Schafer, 2014).

HIV/AIDS may produce symptoms in older adults that emulate conditions associated with advancing age or physical decline, as an expected or at least congruous part of ageing, such as dementia (Grabar, Weiss & Costagliola., 2006). Dementia is listed as a clinical indicator condition to prompt HIV testing (BHIVA, BASHH & BIS, 2008). However, given the relative commonality of dementia in older people, compounded with the dominant stereotypes regarding sex and 'risky' behaviour that surround this age group, a clinician may not consider HIV as a potential underpinning cause. Whilst HIV-related dementia is largely reversible

(Nightingale et al., 2013), untreated HIV-related dementia has a poor prognosis, with approximately a 3-6 month life expectancy following onset (Bouwman et al., 1998). There is a call for adults presenting with dementia to be routinely offered a HIV test (Nightingale et al., 2013).

Other conditions and symptoms that are clinical indicator conditions are more common in older age, such as lung cancer (Cancer Research UK, 2016) and pneumonia (National Heart, Lung & Blood Institute, 2011). It is crucial for clinicians to be aware of HIV-risk factors in older adults, and to understand which conditions are indicative of HIV. Studies suggest that non-HIV specialist knowledge of these conditions is inadequate (Gupta & Lechelt, 2011; Hunter et al., 2012; Sutton et al., 2010), with only 8.4% of non-HIV specialist consultants correctly identifying dementia as a clinical indicator condition (Hunter et al., 2012).

### 2.6.3 Afraid of testing positive

Another factor associated with late HIV diagnosis is test avoidance due to fear of testing positive (Flowers, Duncan, & Knussen, 2003; Schwartz, Block & Schafer, 2014).

*‘Well, I’d thought about for, you know, a long time, and kind of never . . . got round to going, because of, you know, I suppose the consequences if it had been positive, and how I would cope with that?’ (Interview participant, HIV negative, MSM; Excerpt from Flowers, Duncan & Knussen, 2003)*

This fear does not appear to have disappeared with the continuing advancements in HIV treatment (Flowers et al, 2013). It is linked to the high levels of stigma still associated with HIV (see section 2.8.1).

## 2.7 Receiving a positive diagnosis

This section will explore the experience of receiving a positive HIV diagnosis, collating research identified in the literature searches reported in Appendices 2 and 3. Literature focused on being diagnosed with HIV at age 50+ years, although limited, will be highlighted.

### 2.7.1 Impact of how a positive result is delivered

The choice of words and the manner in which someone is told their HIV test result has a major impact on how a positive diagnosis is received (Anderson et al, 2010; Stevens & Hildebrandt, 2006). Anderson et al (2010) found that HCPs were reported to either present HIV in a frightening way or as a chronic and manageable condition, without taking into account how psychologically devastating the diagnosis may be (Anderson et al., 2010). Some

people have reported receiving their diagnosis over the telephone, which left them dealing with their news without any social support:

*'My doctor told me this over the phone. I dropped down on my knees, dropped the phone and started crying hysterically. I was totally devastated. And all of a sudden I hear this voice coming out of the phone, "Are you all right? Are you all right?" I couldn't talk' (Female participant; Excerpt from Stevens & Hildebrandt, 2006)*

The support received immediately after diagnosis has also been reported as inadequate (Stevens & Hildebrandt, 2006; Foreman & Rathaille, 2015).

### 2.7.2 Am I going to die?

It appears that to some extent, the general public's knowledge of HIV has remained rooted in the HIV of the 80s, at a time when a positive diagnosis was considered to be a death sentence. In the most recent survey of *Public Knowledge and Attitudes towards HIV*, 9% still answered in agreement with the statement 'in the UK, if someone becomes infected with HIV they will probably die within three years', and 24% of participants chose the 'don't know' response (NAT, 2014b). Fear of dying is reported as a common response to diagnosis (Anderson et al., 2010; Flowers et al., 2011; Foreman & Rathaille, 2015)

*'And you know when you've got the old stereo [type]...with HIV, you know before you hear about people just dying, all of a sudden, so that was going through my head as well, because the first thing I [asked] was. "Am I going to die?"' (Female participant, Caribbean; Excerpt from Anderson, et al. 2010).*

Uncertainty about prognosis was created by the contradictory messages associated with HIV, the 80's reality of HIV in which a diagnosis was terminal, mixed with some information regarding the improvements of treatment and portrayal of HIV as a chronic condition:

*'you're getting all these mixed message about, all the eighties media stuff, thinking: well that's it that's my life over; but on the other hand there's all the optimistic stuff around have a long fulfilled life' (Male participant, MSM; Excerpt from Flowers et al., 2011).*

### 2.7.3 Shock and denial

Shock is a dominant reaction to HIV diagnosis (Anderson & Doyal, 2004; Anderson et al., 2010; Flowers et al., 2011; Hult, Maurier & Moskowitz., 2009; Stevens & Tighe Doerr, 1997); with the initial response being "I never thought it could happen to me!" (Anderson et al., 2010, p.1495). This reaction is associated particularly with individuals who perceive HIV to



affect only certain societal groups, to which they do not belong (Anderson et al., 2010; Stevens & Tighe Doerr, 1997).

It appears that for a large number of people, receiving a positive HIV diagnosis has never been considered a possibility; HIV is associated with 'other' people and personal risk perception is low (Anderson et al., 2010).

#### 2.7.4 Shame

Shame has also been reported, notably by women diagnosed with HIV (Grodensky et al., 2015; Stevens & Hilderbrant, 2006). In studies exploring living with HIV at age 50+ years, greater shame has been reported at being diagnosed at an older age:

*'I guess that the older you get, the more isolated you feel because you kind of feel stupid. Like, how could I do...I should know better. I should know not to have unprotected sex at my age. I should know better. So, I think that is on top of just feeling alone, you feel dumb.'* (Older female living with HIV; Excerpt from Grodensky et al, 2015)

#### 2.7.5 Suicidal ideation

For some, receiving a positive HIV diagnosis is associated with thoughts of suicide or suicide attempts (Anderson et al, 2010; Flowers et al, 2006; Stevens & Tighe Doerr, 1997):

*'I didn't cope; I cried and I cried...I took some pills that night'* (Female participant, Caribbean; Excerpt from Anderson et al., 2010).

Suicidal ideation has been identified as high in adults with HIV; almost a third of survey participants from a London clinic had experienced suicidal thoughts (Sherr et al., 2008a).

#### 2.7.6 'Biographical disruption'

Flowers et al (2011) found that participants experienced an identity crisis on being diagnosed with HIV, for example, one participant reported:

*'.....in lots of ways I didn't know who I was at that time, in the early days of being diagnosed and coming to terms with it, I couldn't stop thinking about it....I had to go through a process of finding out or finding myself again, and whilst I was around people that knew me well, I found it really, really exhausting because, well maybe they couldn't tell but I was paranoid that they would know that something was wrong, so I was constantly trying to be as near to how I imagined myself to being without HIV....'* (Male participant, MSM; Excerpt from Flowers et al., 2011)

For some, receiving a positive HIV diagnosis triggered a withdrawal from society, as it appeared pointless to continue the life they had before diagnosis (Anderson et al., 2009; Anderson et al., 2010):

*“I stopped living, I stopped going out, I stopped eating and I used to buy my clothes and furniture and everything, I didn’t buy anything, because I said what’s the sense, because I’m going to die within a year!” (Female participant, Caribbean; Excerpt from Anderson et al., 2010).*

The diagnosis of a chronic illness is considered to create a ‘biographical disruption’ (Bury, 1982) or a ‘critical situation’: ‘a set of circumstances which – for whatever reason- radically disrupts accustomed routines of daily life’ (Giddens, 1979, p.124). The term ‘biographical disruption’ was first used by Bury (1982) to describe the experience of people diagnosed with rheumatoid arthritis and the biographical impact of this diagnosis. It has subsequently been applied to other chronic illnesses (Greeve, Todd & Prevalin, 2007; Reeve et al., 2010; Sanders, Donovan & Dieppe, 2002; Trusson, Pilnick & Roy, 2016). The impact of HIV, and withdrawal from society, has been described as a disruptive event (Doyal & Anderson, 2005).

#### 2.7.7 Let’s get on with it

Uncertainty surrounding the cause of symptoms can have a major psychological impact e.g. in terms of stress and anxiety; therefore, great relief may be experienced at diagnosis (Mishel, 1988; Rogers & Walker, 2016). For some, being diagnosed as HIV positive brings a sense of relief and appears to be readily accepted (Anderson et al., 2010; Hult, Maurer & Moskowitz, 2009). Relief appears to stem from finally finding a cause of the symptoms, which is treatable.

People also appear to more readily accept their diagnosis when it is not unexpected; in this instance, their HIV knowledge is greater and the diagnosis is less of a shock:

*‘I was always very pragmatic and practical. I wasn’t distraught or upset...I just accepted it. I felt that if you have unprotected sex, then this is inevitably what might happen and it just happened to me! I think because I accepted it so well then, I didn’t really go through much of the denial phase; I just went straight to [the] get on with it phase’ (Male participant, Caribbean; Excerpt from Anderson et al., 2010).*

#### 2.7.8 Ways of coping with a positive diagnosis

Anderson et al (2009) identified four coping strategies demonstrated by their interview study participants, Caribbean adults living with HIV. These were labelled as: 1) Restricted disclosure;

2) Submersion; 3) Faith; and 4) Positive reappraisal (Anderson et al., 2009). The strategies were identified as interconnected.

*Restricted disclosure:* Adults living with HIV may choose to only disclose their status to one or two individuals, with whom they feel comfortable to discuss their diagnosis in complete confidence. Restricting disclosure provides reassurance that their status will not become more widely known (Anderson et al., 2009; Calin et al., 2007). This way of coping is particularly associated with being recently diagnosed with HIV (Anderson et al., 2009).

*Submersion:* Anderson et al (2009) found that many participants avoided the confrontation and acceptance of their diagnosis through submersion in other elements of their life. These participants did not discuss their diagnosis with others, and tried to block out HIV from their thoughts (Anderson et al., 2009). In its most extreme form, submersion has been found to lead to complete denial of having HIV (Anderson et al., 2009).

*Faith:* Many individuals turn to faith and religion in times of adversity. Turning to faith in response to a positive diagnosis may lead to an acceptance of living with HIV (Anderson et al., 2009). Faith may provide comfort, a sense of belonging and protection, and reassurance that poor health may be overcome through firm beliefs (Anderson et al., 2009). Numerous studies cite the importance of religion in helping people to cope with receiving a positive HIV diagnosis (Chinouya & O'Keefe, 2005; Ridge et al., 2008). This has been consistently reported in studies focusing on black African men and women.

*'I am strong. My belief is making me strong. God is helping me. I have medicine but God is helping me. Through prayer, I can talk to someone. Because I don't talk to anyone I talk to God...if I was not a Christian I would have killed myself...when I pray and read the Bible I get hope to live'*

*(African female participant; excerpt from Chinouya & O'Keefe, 2005)*

*Positive appraisal:* Over time, it was found that some participants achieved an optimistic outlook on their lives. Being diagnosed with HIV served as a catalyst for some people to make positive life changes, and gain a greater appreciation of life (Anderson et al., 2009). It has been reported that after diagnosis, many individuals adopt healthier behaviours e.g. exercising more often, eating healthily, drinking less alcohol etc. (Mazanderani & Paparini, 2015). Several studies have reported that being diagnosed with HIV has certain positive impacts.

*'...my life took a totally different perspective. It's like being, I don't know what it means to be born again, but it's like being born again, you know. My life took a totally different perspective. But the*

*funny thing is, you know, some very, very wonderful things have come out of it. And I'm very optimistic. I always look at my cup as being half full' (Female participant; Excerpt from Flowers et al, 2006)*

Acceptance appears to be achieved, in part, by individuals comparing their own health status to that of others with HIV, and considering themselves as healthier and to have a better prognosis (Dibb and Kamalesh, 2012). HIV has also been evaluated against cancer and diabetes, with the attitude that HIV is preferable over these health problems (Mazanderani & Paparini, 2015; Psaros et al., 2015):

*'I would rather be HIV-positive than have cancer or diabetes. Because as long as I stay clean and sober, live my life to the best of my ability, take my medications and do all the things my doctor tells me to do, I'm going to live a long and fulfilled life' (White female living with HIV, aged 52 years, living with HIV for 10 years; Excerpt from Psaros et al., 2015).*

*Facilitators to coping:* The following were identified as factors linked to effective coping: good social support, acceptance of HIV status by friends and family, feeling healthy and being informed by HCPs that HIV, when diagnosed promptly, is a chronic health condition (Anderson et al., 2009).

Contact with other adults living with HIV has been reported as a useful way of tackling internal stigma and coping with a HIV diagnosis (DeGrazia & Scrandis, 2015; Enriquez, Lackey & Witt, 2008; Foreman & Rathaille, 2015). This includes attendance at support groups and undertaking voluntary roles in HIV support and education (Psaros et al, 2015).

*'I think I get my biggest support from other people who are positive...and maybe over the years I don't realise how supportive we've actually been – you can actually by yourself, you're not careful about what you're saying, you can just be one hundred percent yourself (Adult living with HIV; Excerpt from Foreman & Rathaille, 2015)*

## 2.8 Management of a positive diagnosis

Guidelines state that individuals newly diagnosed with HIV should be assessed, considering psychosocial as well as physical issues, by an appropriate specialist HIV practitioner within 24 hours of diagnosis if symptomatic and fourteen days if asymptomatic (BHIVA, 2013).

Although presently without cure, HIV can be managed effectively using highly active antiretroviral therapy (HAART). HAART refers to a treatment regime which combines a minimum of three different antiretroviral active drugs. The aim of HAART is to achieve an

undetectable viral load which enables the restoration of immune function. To achieve this, and avoid the development of treatment resistance, adherence to HAART is paramount. Latest guidelines recommend the immediate initiation of HAART (Churchill et al., 2015). This recommendation is based on evidence from the Strategic Timing of AntiRetroviral Treatment (START) study, which found that participants with CD4 count  $<500\text{cells}/\text{mm}^3$  at treatment initiation were 53% less likely to develop a serious AIDS or non-AIDS related health problem or to die than those with CD4 count  $<350\text{ cells}/\text{mm}^3$  at the start of treatment (National Institute of Allergy and Infectious Diseases (NIH), 2015).

In general, it has been reported that older adults initially achieve a better virological response to HAART, the suppression of HIV viral load through medication adherence, than younger adults (Collaboration of Observational HIV Epidemiological Research Europe (COHERE) study group, 2008; Grabar et al., 2004). Although, this is not the case in all studies (Althoff et al., 2010). Improved virological response is associated with higher reported levels of HAART adherence in older adults (Barclay et al, 2007; Hinkin et al, 2004; Sherr et al., 2008b; Sherr et al., 2010; Silverberg et al., 2007).

Despite this, older adults experience a poorer immunological response, with a reduced regeneration of CD4+ cells when compared to younger adults (Althoff et al., 2010; COHERE study group, 2008; Grabar et al., 2004; Kaufmann et al., 2002).

Psychological issues, such as depression, are much higher in those with HIV (BHIVA, 2013), particularly older adults (Grov et al., 2010; Heckman, Kochman & Sikkema, 2002). Along with HIV, older adults living with HIV are more likely to be facing further co-morbidities; this requires well-integrated care and careful medication management to avoid interactions (BHIVA, 2013).

The number of HIV positive adults accessing HIV services have escalated dramatically as treatment for the disease has improved, increasing longevity. In 2003, 35,971 people diagnosed with HIV accessed care at HIV clinics; by 2013, this figure had more than doubled to 81,510 (Aghaizu et al., 2013; Yin et al., 2014). These statistics exemplify the high, and ever increasing, level of HIV service use. This degree of HIV service demand has created a challenge to meet service user needs, as sexual health/HIV HCPs are almost the sole prescribers of HIV treatment (Evans et al., 2009).

## 2.9 Living with HIV

The majority of qualitative studies that have explored the experience of living with HIV have focused on black African men and women (Anderson & Doyal, 2004; Calin et al., 2007; Dibb & Kamallesh, 2012; Doyal & Anderson, 2005; Doyal, Anderson, & Paparini, 2009; Flowers et al., 2006; Paparini, Doyal & Anderson, 2008) and MSM (Davis, Frankis, & Flowers, 2006; Flowers et al., 2011). There has also been a research focus on black Caribbean adults (Anderson et al., 2008; Anderson et al., 2009; Anderson et al., 2010). The age of study participants is inconsistently reported; however, several studies have included a small number of adults aged 50+ years (predominantly aged 60 years or younger). This section also reports literature from the USA, due to the greater volume of research conducted here on living with HIV at age 50+ years.

The majority of studies in the UK have been conducted in London or other high HIV prevalence areas (see Appendix 2), suggesting that they may not reflect the experience of living with HIV in lower prevalence places.

### 2.9.1 Stigma and HIV disclosure fears

*'The attitudes we normals have toward a person with a stigma and the actions I retake in regard to him, are well known, since these responses are what benevolent social action is designed to soften and ameliorate. By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances' (Goffman, 1963)*

In addition to the physical effects of HIV, the disease is associated with high levels of stigma. The stigma associated with HIV/AIDS is defined by the Joint United Nations Programme on HIV/AIDS as 'a 'process of devaluation' of people either living with or associated with HIV/AIDS' (UNAIDS, 2003). It is often underpinned by stigma closely related to the mode of HIV acquisition e.g. injection drug use and sexual behaviour, and prejudices associated with race and lifestyle (UNAIDS, 2003). HIV-related stigma, which is linked to depression, may affect a person's psychological wellbeing on receiving a positive diagnosis and living with HIV (UNAIDS, 2003). This in turn may affect adherence to antiretroviral medication (Katz et al., 2013).

Stigma, although hard to quantify (King, 2007), remains widely reported amongst adults with HIV (Anderson et al., 2008; Flowers et al., 2006; Mazanderani & Paparini, 2015). The stigma reported by adults living with HIV in the UK is more often expressed as felt (e.g. fear of violence or social exclusion), rather than enacted stigma (e.g. experienced violence, not

wanting to eat food cooked by someone with HIV, or any other form of discrimination) (Anderson et al., 2008). In a London based study, experiences of discrimination were reported by 30% of participants living with HIV when asked: “Have you ever been treated unfairly or differently because of your HIV status—in other words discriminated against?” (Elford et al., 2008). Stigma can lead to isolation and reluctance to access social support (Flowers et al., 2006). Older adults with HIV have reported feeling alone, linking this to stigma associated with their age and HIV status:

*‘I don’t have anybody to share with. It’s lonely sometimes; it really is’ (Female participant; Excerpt from Emlet, 2006)*

It has been reported that older adults living with HIV face a ‘double stigma’; associated with their HIV status and their age (ageism) (Emlet, 2006; Orel, Spence & Steele, 2005). Further stigma may also be based on sexual orientation, with older MSM living with HIV reporting additional stigma (Emlet, 2006).

Although largely regarded as a chronic health condition for people with access to antiretroviral therapy, the stigma associated with HIV still outlines it as different to other medical conditions:

*‘Oh yes well from a medical point of view obviously it’s moved on a lot, but at the same time I think the stigma to do with it hasn’t moved on really...I’ve told people who don’t know that I’m positive that, yes, I had cancer in the past, because it’s kind of acceptable, but HIV is not socially acceptable’ (Adult living with HIV; Excerpt from Foreman & Rathaille, 2015)*

It appears that the label of being HIV positive overshadows the identity of a person:

*‘they just think, ‘Oh he’s HIV positive!’ rather than looking at the positive side of you’ (Male participants; excerpt from Flowers et al, 2006)*

Goffman (1963) argues that for individuals without a visible stigma, such as those living with well-managed HIV and no apparent symptoms or side effects, there is a challenge in determining who can be trusted with knowing their HIV status. Common themes across all of the identified qualitative studies were struggles and fears surrounding disclosure (Anderson & Doyal, 2004; Anderson et al., 2008; Emlet, 2008; Enriquez, Lackey & Witt, 2008).

Disclosure appears particularly difficult within African communities (Anderson & Doyal, 2004); particularly for MSM who may face additional stigma due to their sexual orientation (Paparini, Doyal & Anderson, 2008). The *Equality Act 2010* serves to protect people with HIV

from discrimination, making it against the law to treat someone differently due to their HIV status.

### 2.9.2 Use of healthcare services

The HIV Stigma Survey identified that adults with HIV may feel uncomfortable accessing healthcare services; particularly general practice (where 37% of participants had concerns about being treated differently) or dental practice (where 39% of participant also expressed this worry) (2015). It appears that concerns about being treated differently impact on service access; 13% of survey participants said they avoided attending general practice, and 14% avoided dental services (HIV Stigma Survey UK, 2015). Adults living with HIV still report discrimination in healthcare services (Foreman & Rathaille, 2015).

In a study conducted by Elford et al (2008), half of the participants reporting HIV discrimination had experienced this in healthcare settings; primarily at a dental practice, general practice or beyond their HIV clinic. HIV services were reported with praise due to the good relationships developed between service users and HIV clinicians (Paparini, Doyal & Anderson, 2008).

### 2.9.3 Uncertainties of ageing with HIV

As people with HIV historically have not expected to live into older age, there are now anxieties and uncertainties, for both service users and providers, as to what challenges will arise in ageing with HIV (Psaros et al., 2015; Rosenfeld, Ridge & Von Lob, 2014; Rosenfold et al., 2015):

*'The fact is, it's still a condition that is relatively new, and we don't know. Some of the learning about the condition is still emerging. We don't know how it's going to affect people, particularly older people as they age or if they happen to be diagnosed at an older age' (Policy maker; Excerpt from Rosenfeld, Ridge & Von Lob (2014), p. 25).*

Older adults with HIV, including those ageing with and recently diagnosed with the infection, have reported difficulties in categorising whether changes in bodily function are associated with their HIV diagnosis, other co-morbidities, or ageing (Enriquez, Lackey & Witt, 2008; Rosenfeld, Ridge, & Von Lob, 2014):

*'Of course when we are ageing, we get other ailments. What is the interaction? How do you even determine those interactions with HIV? How do you know? I didn't know when I was starting to have hot flushes. I was like, why am I hot all of a sudden? And it was not that kind of day to be*



*that hot and it just dawned on me and I'm thinking, oh my God, I'm that age!' (Female HIV activist, living with HIV; Excerpt from Rosenfeld, Ridge, & Von Lob (2014), p.27)*

Older adults have reported fears about both ageing and dying prematurely (Rosenfeld, Ridge, & Von Lob, 2014; Rosenfeld et al., 2015).

#### 2.9.4 Sexual/intimate relationships

The HIV Stigma Study, conducted in 2015, identified that 35% of participants were worried about sexual rejection, and 33% had avoided having sex in the year preceding the survey. 1 in 5 participants had experienced sexual rejection in the 12 months prior to study participation.

The avoidance of sexual/intimate relationships has also been reported in qualitative studies (Anderson et al., 2008; Doyal, Anderson, & Paparini, 2009), due to fears about partner response to HIV disclosure. Anderson & Doyal (2004) reported one participant as saying: 'my fear is to fall in love again' (p.102). Concerns about entering a new relationship are highlighted in several studies, which for some people may lead to a resignation to being alone:

*'Being intimate or close to someone that's the only problem. Other than that I live like a normal person.'* (Female aged 56 years, living with HIV for 7 years; Excerpt from Nevedal & Sankar, 2015)

Goffman highlights that as successful relationships are based on trust, there is a pressure on people with a stigmatising condition, such as HIV, to disclose this knowledge to a current partner or any future partners (1963). There may also be legal and moral obligations to disclosing to a partner.

#### 2.9.5 Financial difficulties

Ibrahim et al (2008) identified that living with HIV is associated with financial difficulties. This is particularly evident for black African people living with HIV in the UK (Anderson & Doyal, 2004; Doyal, 2009; Doyal, Anderson & Paparini, 2009; Erwin et al., 2002; Mazanderani & Paparini, 2015). It has been identified that older people living with HIV also face financial hardships (Rosenfeld et al., 2015).

#### 2.10 Summary

This chapter has provided an overview of the literature exploring the pathway to HIV detection and treatment, focusing on adults aged 50+ years. It has looked at the experiences of accessing sexual health/HIV services, responding to a positive HIV diagnosis and living with

HIV. Where possible, research involving adults aged 50+ years has been compared to that of younger people.

A lack of research surrounding older adults and their use of sexual health/HIV services, and of HIV testing in any healthcare setting, is evident. Studies looking at sexual health service access which have included older participants were conducted over ten years ago; the current applicability of these research findings is therefore uncertain. The research also concentrates on MSM and black Africans, the two groups targeted by HIV prevention and testing campaigns; therefore, it gives little insight into the experiences of people belonging to 'low risk' groups. It appears that adults aged 50+ years are placed at an elevated risk of HIV infection and late HIV diagnosis due to barriers in discussing sexual health, from both a personal and HCP perspective.

Limited research has explored the experience of older adults on being diagnosed with HIV, although being diagnosed at age 50+ years may be associated with greater shame. It appears that in living with HIV, older adults may face additional difficulties such as the uncertainties related to ageing, further health conditions, greater stigma, and financial hardship. The majority of this research, however, has been conducted with adults that have aged with HIV. It has also predominantly been conducted in high HIV prevalence areas, and much of the research is not up-to-date; this is a particular problem with a newly emergent condition such as HIV, for which therapies and services are rapidly developing.

This literature overview has highlighted the limited research available on adults diagnosed with HIV at age 50+ years in the UK. The next chapter outlines the methods used in this thesis to address this gap in understanding.





## Chapter 3: Methods

### 3.1 Introduction

A mixed-methods approach was used to address the aim of this research project: to explore the accessibility and acceptability of HIV services to adults diagnosed with HIV at 50 years and over. In this chapter, an explanation and justification for the use of mixed-methods, and a pragmatic approach, will be provided. The qualitative and quantitative methods used in this project will then be described, and a rationale provided for their use.

### 3.2 Mixed-methods and pragmatism

Research paradigms, or worldviews, are associated with different ontological and epistemological assumptions. Beliefs about knowledge and how this is generated inform methodological approaches. Quantitative methods are usually adopted by positivist researchers, who believe that there is one single reality that can be measured objectively. By contrast, qualitative methods are usually adopted by constructivist/interpretive researchers, who believe that there are multiple realities which are subjective.

Mixed-methods research combines qualitative and quantitative methods (Johnson & Onwuegbuzie, 2004), enabling the researcher to draw upon the strengths of both methodologies to address a research question. Using qualitative and quantitative methods allows a research question to be addressed in greater depth and breadth than can be achieved using one approach alone (Johnson & Onwuegbuzie, 2004).

*'Mixed methods research is an intellectual and practical synthesis based on qualitative and quantitative research; it is the third methodological or research paradigm (along with qualitative and quantitative research). It recognizes the importance of traditional quantitative and qualitative research but also offers a powerful third paradigm choice that often will provide the most informative, complete, balanced, and useful research results' (Johnson, Onwuegbuzie & Turner, 2007, p.129)*

Researchers have historically positioned themselves as quantitative (positivist/postpositivist) or qualitative (constructivist, interpretive); two paradigms considered incompatible by purists (Teddlie & Tashakkori, 2008). The mixed-methods approach is regarded as the third research paradigm (Johnson & Onwuegbuzie, 2004) and is considered compatible with pragmatism (Feilzer, 2010; Johnson & Onwuegbuzie, 2004; Morgan, 2007). Pragmatism and mixed-methods research are connected through their agreement that researchers should focus on using approaches that will most effectively address a research question; this is more important than the philosophical or research paradigm (Tashakkori & Teddlie cited in

Creswell & Plano Clark, 2011). The choice of methods should be practical and applied (Tashakkori & Teddlie cited in Creswell & Plano Clark, 2011).

### 3.3 Quality in mixed-methods research

Although no definitive framework exists to assess the quality of mixed-methods, several standards have been considered for this purpose (Bryman, Becker, & Sempik, 2008; Bryman, 2014; O’Cathain, Murphy & Nicholl, 2008; O’Cathain, 2010; Teddlie & Tashakkori, 2009). The following criteria to measure quality are consistently suggested and will be applied to this research project:

*Rationale provided for using a mixed-methods approach:* The decision to use a mixed-methods approach should be justified and considered appropriate to address the research question.

*Clear link between research questions and the mixed-methods used:* It should be evident which research questions have been addressed by which method.

*Research design explained:* The researcher should be explicit in explaining and justifying each aspect of the research. Sampling and recruitment, data collection, and data analysis should all be clearly documented. It should be evident that both the qualitative and quantitative research components have been conducted in a rigorous manner.

*Integration:* The researcher must provide clarity as to when and how methods were integrated.

*Transparency:* To enable the quality of mixed-methods research to be assessed, each stage of the research process must be transparently reported.

*Conclusions reached are reflective of the research findings:* It should be clear which research findings have originated from which method. The conclusions reached should be appropriately inferred from the research findings.

### 3.4 Why choose a mixed-methods design?

There are several rationales for using mixed-methods, as outlined by Bryman (2006). The primary rationale for using a mixed-methods approach for this project was to provide a more comprehensive account of the accessibility and acceptability of sexual health/HIV services to adults aged 50+ years than would be possible through using quantitative or qualitative methods alone. Using mixed-methods also allowed for the interpretation of findings from one method to those of another e.g. qualitative interview findings were compared with survey

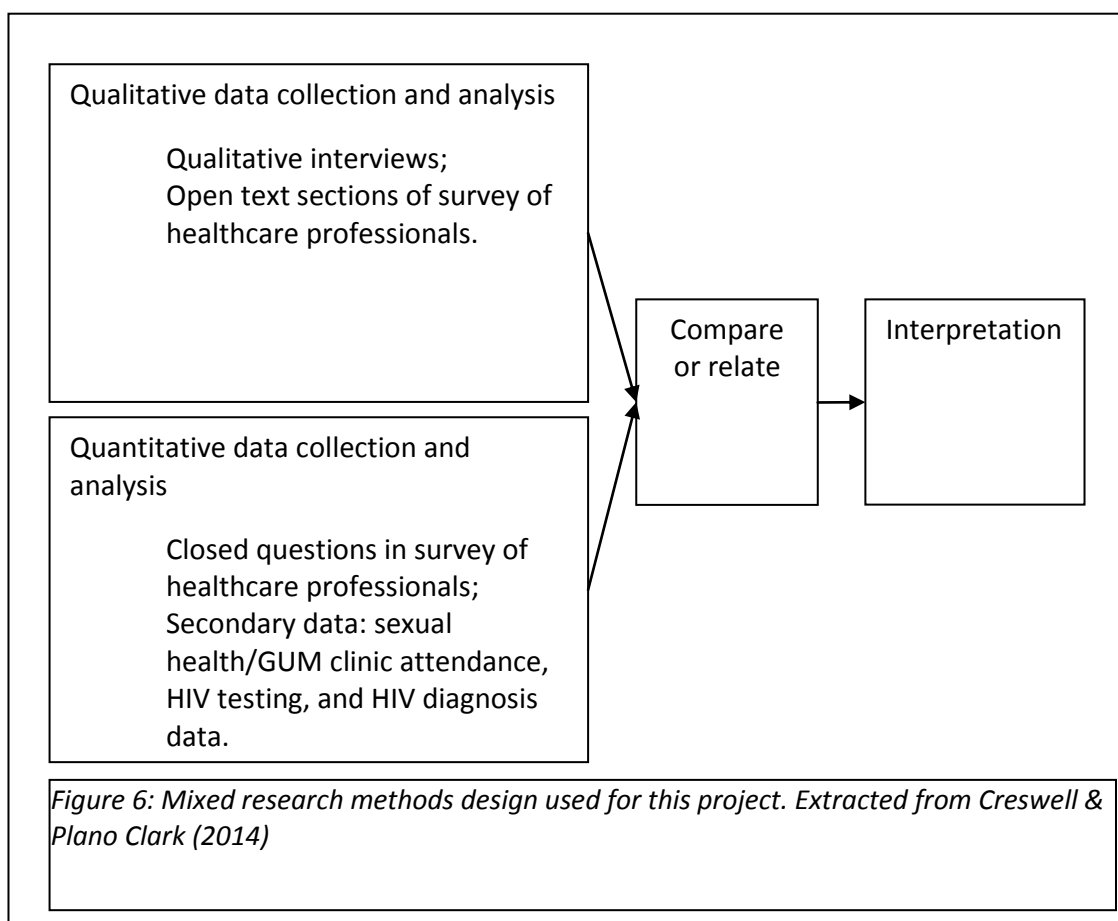
responses. This enhanced the credibility of the research, as findings from the qualitative and quantitative aspects were complemented.

The intention in using qualitative methods was to provide a detailed exploration of the experience of accessing and using HIV services at age 50+ years, and of providing these services. Quantitative methods were chosen to enable the development of a broader picture of service provision.

### 3.5 Mixed-methods study design

The qualitative aspect of this mixed-methods project comprised of an interview study with adults diagnosed with HIV at age 50+ years (service users) and HCPs involved in caring for this age group. A further qualitative component consisted of open response questions included in a survey of HCPs. The quantitative component consisted of closed questions within the survey of HCPs, and the descriptive analysis of secondary sexual health/GUM clinic attendance, HIV diagnosis and HIV testing data.

For this research, a concurrent, predominantly qualitative approach was adopted, incorporating a smaller quantitative element (QUAL+quan) (Johnson & Onwuegbuzie, 2004; Figure 6). The mixing of methods took place at the stage of comparing and contrasting data, and interpreting findings (Creswell and Plano Clark, 2011).



The methods used in this project will now be described in full, starting with the qualitative interviews.

### 3.6 Qualitative interviews with service users and healthcare professionals

A qualitative approach, using interviews, was chosen as this seeks to explore individual experiences and perspectives in relation to a phenomenon (Greenhalgh & Taylor, 1997; Pope and Mays, 2006):

*'Qualitative research... involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them' (Denzin and Lincoln, 2011, p.3)*

It was considered essential to ask people directly about their experiences through interviews; obtaining a depth of information that is not achievable through other methods of data collection e.g. questionnaires. Individual interviews were conducted, rather than focus groups, due to the sensitive nature of the subject matter and concerns around confidentiality in this population group.

The intention of the service user interviews was to explore the journey to HIV detection and treatment for people in this age group; their experiences in accessing and using HIV and other healthcare services (e.g. general practice), and in living with HIV. Service user interviews focused on:

- Knowledge and awareness of HIV/AIDS prior to diagnosis.
- The pathway of the individual to receiving a HIV diagnosis, with a focus on health service encounters preceding and at the point of testing positive for HIV.
- Perception of the HIV prevention and testing services available from the perspective of an older adult. Are sexual health/HIV clinics and general practices accessible and acceptable settings for adults aged 50+ years to discuss risk factors for HIV and obtain a HIV test?
- The perceived impact of age on the experience of HIV diagnosis.
- The experience of using HIV services and other health care services following diagnosis.
- Life after diagnosis.



To gain a clear understanding of current service provision, service expectations and requirements, the decision was made to interview HCPs involved in caring for adults diagnosed with HIV at age 50+ years, as well as these service users. The aim of HCP interviews was to explore service provision for older adults at risk of HIV and newly diagnosed with HIV, looking at:

- Viewpoints surrounding HIV services and their accessibility and acceptability to older adults;
- Attitudes towards discussing HIV risk with older adults and offering a HIV test;
- Experiences of testing older adults for HIV and diagnosing older adults with HIV;
- Provision of sexual health/HIV services for older adults within their own clinical setting.

The interviews were semi-structured, which meant that although topic guides were used by the interviewer to assist the interviews (see Appendices 5 and 6), the interviewer added additional questions and explored topics further depending on interviewee responses (Britten, 2006). The topic guides served to ensure that areas identified as important from the literature review and stages in the *Model of Pathways to Treatment* (MPT) (Walter et al., 2012; Figure 3) were explored. However, the wording of questions was not standardised nor the format rigid. It was important to keep the 'agenda flexible', so that any topics important to the individual were not overlooked even if they were not outlined in the interview topic guide (Britten, 2006). Both topic guides were developed with PhD supervisor guidance.

### 3.6.1 Inclusion/exclusion criteria

#### ***Inclusion criteria - Interviews with service users***

- Diagnosed as HIV positive within the last 3 years.
- Aged 50+ years at diagnosis.

#### ***Inclusion criteria - Interviews with HCPs***

- Working in sexual health/HIV services at one of the selected study sites.

#### ***Exclusion criteria***

- Unable to speak English: Although, it may have been potentially advantageous to interview non-English speaking participants, this was not a feasible option for the PhD project due to the practicalities and expense of involving a translator.

- Unable to provide informed consent.

### 3.6.2 Research sites

Sexual health/HIV services in five NHS Trusts were approached and agreed to act as sites for the qualitative interview study with service users. These sites were based in different geographical locations: one in a London borough (Site A), one in a city within North East England (Site B), one in a city in the Yorkshire and Humber region (Site C), one in a town in the Yorkshire and Humber region (Site D), and one in a city in the East Midlands (Site E).

Part of the rationale for selecting sexual health/HIV services from a wide range of NHS Trusts was to gain insight into people's experiences of receiving a HIV diagnosis and the provision of sexual health/HIV services in areas of contrasting HIV prevalence. It was considered that the pathway to reaching a HIV diagnosis and the care provided by HIV services may be influenced by this. For example, it is known that the proportion of late HIV diagnoses varies by geographical location (PHE, n.d.A). It is also known that spending per capita on HIV prevention in high prevalence areas of London is greater than in high prevalence areas beyond the city, and spending varies heavily even amongst local authorities within London (NAT, 2015). It was anticipated that local level HIV prevalence may influence sexual health/HIV service provision and impact upon service user awareness and knowledge of HIV. By accessing several varying HIV prevalence sites, it was hoped that a broader insight would be gained into the experience of receiving an HIV diagnosis at an older age in England and HIV service provision for this group of HIV service users.

For the qualitative interview study with HCPs, only the sexual health/HIV services in London (Site A) and the city in the Yorkshire and Humber region (D) were approached to act as study sites; both agreed to take part. These sites were selected due to their highly contrasting HIV prevalence levels, and the strong partnerships already established with these sites.

### 3.6.3 Process of recruitment and data collection

#### ***Interviews with service users***

Potential participants were approached at each site by their GU/HIV clinicians. All clinicians performing this role were trained in Good Clinical Practice (GCP) and added to the Site Specific Information (SSI) form required by each Research and Development department.

Each approached individual was given a participant information sheet (PIS) (Appendix 7), fully detailing the study procedures and explaining all aspects of participation including their right to withdraw from the research and issues surrounding confidentiality and data protection.

The PIS also included information on how to take part in the study; to do this individuals were asked to contact myself via email, telephone or post.

Each potential participant was given a minimum of 24 hours in which to read the PIS prior to meeting with myself, completing and signing a written consent form (Appendix 8). In reality, participants had much longer (approximately a week or more) in-between receiving a PIS and meeting to sign the consent form. The interview date and time were arranged through discussion with the participant and clinic staff (to ensure the availability of an interview room).

At the start of each interview, I discussed the PIS again with the participant and invited any questions about the study. I was sure to stress the aims of the study, the right to withdraw and issues surrounding anonymity and confidentiality. I then went through the consent form with the individual, prior to them signing the form. Copies of the consent form and PIS were given to the participant at that stage and one copy of the consent form was kept for study records.

Due to later difficulties in service user recruitment at sexual health/HIV services, beyond high HIV prevalence sites, the study was also advertised via HIV charities, such as the Bristowe Project (<http://www.brigstowe.org/>) and Tagadere (<http://www.tagadere.org.uk/>). These charities were emailed to ask if they would advertise the study, using a poster (Appendix 9); study details were provided on the poster, which invited potential participants to contact myself via email, telephone or post if interested in taking part. One telephone interview was conducted with a participant recruited using this approach. Prior to the interview, again the PIS was discussed and the consent form signed. The decision to conduct the interview over the phone was due to practical reasons as at the time the service user was not in the UK.

### ***Interviews with HCPs***

Potential participants were only approached at Site A and Site D. Eligible potential participants were identified at these sites through communication with clinicians already involved in recruitment for the service user study. Identified HCPs were contacted via email.

Each approached individual was given a PIS fully detailing the study procedures and explaining all aspects of participation (Appendix 10). The PIS also included information on how to take part in the study; individuals were asked to contact myself using details provided in the PIS.

As with the service user interviews, each potential participant was given a minimum of 24 hours in which to read the PIS prior to meeting with myself and signing a written consent form (Appendix 11). The PIS and consent form were discussed with the participant before they consented to take part.

#### 3.6.4 Interview locations

Participants for both qualitative interview studies were offered the choice of being either interviewed within their own homes or in clinic, where this was possible. If a participant was interviewed in clinic this was timed around a pre-existing appointment for service users and around workload commitments for HCPs. Every effort was made to ensure that the researcher adjusted their time schedule to suit the participant.

All interviews taking place on site were performed in private rooms, in comfortably furnished and quiet environments away from the clinical area.

#### 3.6.5 Data analysis

The interview data was analysed using thematic analysis (Braun & Clarke, 2006), the stages of which have been summarised and outlined below:

*1. Familiarisation with the data:* Interviews were transcribed verbatim. The accuracy of transcription was checked through the replaying of the audio-recorded interviews. The interview transcriptions were then uploaded to NVivo, a software package used to manage qualitative data.

To enable familiarisation, I purposefully chose to perform data transcription. I listened to and read through each interview several times. I also re-read hand written interview notes. During the familiarisation process, I documented any thoughts about the data as they surfaced.

*2. Coding:* Interviews were coded using initial codes generated from the interview topic guide and the stages outlined in the *Model of Pathways to Treatment* (Walter et al., 2012; see Figure 3).

To enhance the rigour of the analysis, the first two interviews were also analysed separately by one of the academic supervisors. We then discussed coding approaches.

*3. Searching for themes:* Following the coding of each interview transcript, codes were collated to generate broader sub-themes and themes. For example, the codes and sub-themes generated under the over-arching theme of trust are presented in table 4. The relationships between codes, sub-themes and themes were re-visited and refined, as part of an iterative

process. At this stage, several sub-themes and themes were removed, or combined with another sub-theme or theme, and some of the data was re-coded. This process continued until sub-themes and themes were clearly distinct from one another.

To assist in the identification of sub-themes and mind maps were created for service user and HCP interviews. A matrix was also created, using events and processes within the Model of Pathways to Treatment (to populate the columns of the matrix) and participants (to populate the rows) (see 1.9.2).

Table 4: Examples of codes and sub-themes collated to form the over-arching theme of trust

<u>Overarching theme</u>	<u>Sub-themes</u>	<u>Codes</u>
Trust	<ul style="list-style-type: none"> <li>• Continuity of care</li> <li>• HIV clinicians as ‘substitute GPs’</li> <li>• Stigma and concerns about confidentiality</li> <li>• ‘Enhanced’ care in HIV services</li> </ul>	<ul style="list-style-type: none"> <li>• Consistency</li> <li>• Appointment length</li> <li>• Ease at scheduling appointments</li> <li>• Familiarity</li> <li>• Friendship</li> <li>• Concerns about HIV disclosure</li> <li>• Expertise</li> <li>• Health monitoring</li> <li>• Advocacy/support</li> <li>• Frequent clinician visits</li> <li>• Perceived better health outcomes/life expectancy</li> </ul>

### 3.6.6 Ethical approval

#### ***Interviews with service users***

This study was granted ethical approval by three governing bodies: the Health Sciences Research Governance Committee (HSRGC) at the University of York, North East - York NHS Research Ethics Committee (REC reference: 15/NE/0040), and local hospital Research & Development departments at each study hospital (sites A to E).

#### ***Interviews with HCPs***

This study was granted ethical approval by two governing bodies: the HSRGC at the University of York and the local hospital Research & Development departments at each study hospital (sites A and D).

### 3.7 Analysis of national sexual health/GUM clinic attendance, HIV testing and HIV diagnosis data

The aim of this quantitative analysis was to examine the association between age and sexual health/GUM clinic attendance; HIV test coverage (offer and acceptance of testing) in sexual health/GUM clinics; and new HIV diagnoses. Using national data provided by Public Health England (PHE), the following research questions were addressed:

- What is the association between age and sexual health/GUM clinic attendance?
- In sexual health/GUM clinics, what is the association between age and HIV test offer?
- In sexual health/GUM clinics, what is the association between age and accepting a HIV test offer?
- In sexual health/GUM clinics, what is the association between age and a HIV test being performed?
- What is the association between age and reported new HIV diagnoses?

#### 3.7.1 About Public Health England (PHE)

The purpose of PHE, an executive agency of the Department of Health, is to: 'protect and improve the nation's health and wellbeing, and reduce health inequalities' (PHE, 2015). One of the 'core functions' of PHE is to protect the public from infectious diseases, such as HIV, through effective disease surveillance and control (PHE, 2015). PHE collates data in relation to sexual health/GUM clinic attendance, the number and proportion of eligible GUM attendees offered a HIV test, and the number and proportion of attendees that accept the offer of HIV testing. PHE also collects data on reported new HIV diagnoses, including those classed as late (CD4 count <350 cells/mm<sup>3</sup> within 91 days of diagnosis). These data are available publicly and presented at regional and national levels.

#### 3.7.2 How does PHE obtain its data?

##### ***Sexual health/GUM clinic attendance data***

Sexual health/GUM clinic attendance and HIV testing data are provided by level 2 and level 3 sexual health services; services which are most involved in STI/HIV testing and providing contraception etc (PHE, 2015). It is compulsory to report attendance numbers and the services provided in these settings, including HIV test offer and acceptance, using this system.

Test offer and acceptance data is not routinely collected and monitored beyond these settings, aside from by antenatal services (UK National Screening Committee, 2010).

### ***Diagnosis data***

HIV diagnosis data are currently collected and collated by PHE through the HIV & AIDS new diagnoses database (HANDD). The reporting of new HIV diagnoses to this system is voluntary. Data are reported from laboratories as well as a variety of HIV test settings e.g. GUM/sexual health clinics and general practices (PHE, 2013a).

Data regarding CD4 cell counts are collected under the CD4 surveillance scheme (PHE, 2013b); at least sixty laboratories in the UK provide CD4 count data to PHE through this system (PHE, 2013b). Data are then linked to HANDD and the survey of prevalent HIV infections diagnosed (SOPHID) (2013c), to identify CD4 cell counts for new HIV diagnoses (PHE, 2013b).

#### **3.7.3 Data requested from PHE**

Historically, sexual health/GUM clinic attendance, HIV testing and HIV diagnosis data have been presented by gender, ethnicity and sexual risk group; however, they have only been available publicly in broad age ranges, i.e. with older age adults pooled into a 50+ age group, or most recently either 45-64 years or 65+ years (Aghaizu et al., 2013; Yin et al., 2014). This makes it difficult to understand the epidemic amongst adults aged 50 years and over and therefore initiate an effective response to address their needs.

For this study, I requested data stratified by gender, ethnicity, sexual risk group (heterosexual male; heterosexual female; MSM; women who have sex with women (WSW)) and also by much smaller age categories (data in 5 year age bands).

#### **3.7.4 Data provided by PHE**

PHE provided all data broken down by sexual risk group. Classification by sexual risk group is based on the self-reporting of sexual behaviours; individuals are categorised to the most 'risky' group they report sexual contact with. For example, males that identify as bisexual are categorised as MSM; females that identify as bisexual are categorised as heterosexual.

**Sexual health/GUM attendance:** The number of sexual health/GUM clinic attendees per annum, from 2009 to 2014, for England. Data were provided in 5 year age bands, from 15 to 70+ years. Attendees over 70+ years were categorised into one age band due to low numbers in the over 70s.

**HIV testing:** The number and proportion of people offered and accepting a HIV test per annum (test coverage), from 2009 to 2014, for England. Data were provided in 5 year age bands, from 15 to 70+ years. Adults over 70+ years were categorised into one age band, again due to low numbers in the over 70s and the need to protect anonymity. Testing data was also provided by gender.

**HIV diagnosis:** The number of people reported as being newly diagnosed with HIV in England, from 1998 to 2013. Data were provided in 5 year age bands, from 15 to 80+ years. Adults over 80+ years were categorised into one age band. For some years, HIV diagnosis figures were very small for certain age groups. To protect anonymity, when numbers were less than 5 this was reported as <5. For diagnosis data, numbers were also presented by ethnicity.

### 3.7.5 Data analysis

Firstly, descriptive statistics were used to summarise the data. Bar charts and line graphs were created to examine the age distribution of sexual health/GUM attendance; HIV test coverage (offer and acceptance); and HIV diagnosis. Further graphs were created e.g. by sexual risk group and ethnicity.

The numbers of women who have sex with women (WSW) attending sexual health/GUM services were too low for meaningful analysis [0.2% of total attenders in 2014], and this group was therefore not separately assessed.

For each year, Spearman's rank correlation tests were used to measure associations between age and the likelihood of 1) sexual health/GUM service attendance; 2) offer of HIV testing; 3) acceptance of HIV testing; 4) HIV testing being both offered and accepted; 5) HIV diagnosis. In supplementary analysis, these associations were measured by sexual risk group. Logistic regressions were also performed, by age and sexual risk group, to explore the likelihood of HIV test offer; the acceptance of test offer; and a test being conducted.

Analyses, particularly regressions, were limited by the data format. Data received from PHE are presented in cells (e.g. numbers of MSM aged 50-54 receiving an offer of HIV testing) rather than at the individual patient level, and several important patient characteristics are not reported (e.g. socioeconomic status, geographical location). It was therefore not possible to adjust for all potential confounders.

Data management and analysis was performed using Excel and SPSS Version 23.0.

### 3.7.6 Ethical approval

This research was granted ethical approval by the HSRGC at the University of York.



### 3.8 Cross-sectional surveys for HCPs

Through surveying HCPs working in general practice and in sexual health/HIV services, the intention was to:

- Explore the level of awareness and HCPs working in general practice and sexual health/HIV clinics demonstrate in relation to HIV and older adults.
- Investigate how aware and up-to-date HCPs are with current HIV testing guidelines.
- To explore how able HCPs feel in discussing HIV with service users and offering someone a HIV test, and whether this is affected by the age of the service user.
- To examine whether general practices or sexual health/HIV clinics offer any particular services/clinics directly targeting older adults, or provide HIV information, e.g. in the form of leaflets/posters, specifically aimed at this age group.

#### 3.8.1 Why choose a descriptive cross-sectional survey design?

Cross-sectional surveys are used to capture snap-shots of information from samples of a population at fixed time points (Bowling, 2009). With this research design, it is intended that assumptions based on survey findings can be inferred to the wider population of interest (Bowling, 2009). For this research, the sampled populations were HCPs employed in two settings: general practice and sexual health/HIV services. It was anticipated that findings from the study (survey responses), if powered sufficiently, would more widely represent the attitudes, knowledge and viewpoints of HCPs working within these healthcare services. The cross-sectional survey design is considered most appropriate to examine prevalence (Mann, 2003); in this instance this related to perceptions, judgements and awareness surrounding HIV and the provision of HIV services for adults aged 50+ years compared to younger adults.

Questionnaires were used as the data collection tool to perform the surveys. The questionnaires are descriptive, as they intend to provide a depiction of the sample participants; however, they can also be used to highlight statistical associations between responses (Bowling, 2009). Although other means of data collection could have explored the aims of this research, such as interviews (face-to-face or via telephone), a questionnaire design was chosen as it has the capabilities of achieving a high number of participants (Bowling, 2009; Mann, 2003), over a relatively short amount of time (Gillham, 2007). This would not have been feasible with other design methods, particularly as only one researcher conducted data collection. A further advantage to performing a questionnaire, over other

methods, is the low cost associated with this type of research (Bowling, 2009; Gillham, 2007; Mann, 2003); this was an important factor given the financial restrictions of the PhD project.

Another benefit of using questionnaires is the anonymity it can afford to participants (Gillham, 2007); it was considered that HCPs may not want their identity or workplace to be exposed. Stressing responder anonymity was a strategy used to encourage participation and the production of authentic responses. It was made clear in the PIS that the questionnaire was completely anonymous and data was not being collected for the purpose of highlighting individual sexual health/HIV clinics or general practices.

However, cross-sectional surveys are restricted and may consequently miss responses and opinions which cannot be voiced in the same way as through an interview or focus group situation (Gillham, 2007). This limitation was addressed through the inclusion of some open-ended questions; particularly when exploring individual perceptions and experiences. At the end of the questionnaire, participants were also invited to add any additional comments.

### 3.8.2 Delivering the surveys in an online format

The questionnaire for HCPs working in general practice was delivered via email, using only professional email addresses. For HCPs working in sexual health/HIV services, the electronic survey was advertised by sexual health/HIV organisations such as the British Association for Sexual Health and HIV (BASHH) (see section 3.8.6). An online format was used due to the high level of internet access and email usage expected amongst HCPs in addition to the benefits of comparably lower costs. It was also considered advantageous to use an online questionnaire as data is already collated in a format which is readily transferrable to analysis software; this increases efficiency and reduces the likelihood of data inputting errors (Wyatt, 2000). The survey software used ([www.surveymonkey.com](http://www.surveymonkey.com)) allowed for the transfer of collected responses directly to SPSS.

Although it was considered that internet access would be high amongst the samples, a potential problem associated with online surveys is inadequate response rates. Low responses rates have been highlighted as an issue for questionnaires in general, with a notable reduction in survey response rates over time (Bowling, 2009).

With this knowledge, attempts to maximise the survey response rate were made (*to be discussed*). Considering the time and financial restrictions associated with the PhD project, and the large number of individuals that could be potentially reached using online questionnaires, this means of data collection was justified as the most feasible.

### 3.8.3 Sample size requirement for each survey

It was calculated, with the assistance and expertise of a senior statistician at the University of York, that each questionnaire would require 385 respondents to perform inferential analysis. This number was determined as necessary in order to be able to identify any findings significant at the 5% level (where the likelihood that findings are due to chance are 1 in 20).

This figure is based on the assumption that, for any question within the survey, P (expected proportion who will answer in a certain way) will be between 0.1 (10%) and 0.9 (90%) (Naing, Winn, & Rusli, 2006). As we do not know the precise proportion of people who will answer in a certain way, it is considered acceptable to set P at 0.5 (50%) (Naing, Winn, & Rusli, 2006). This figure will provide the largest estimate of a required sample size, working on the assumption that P is between 0.1 and 0.9 (Naing, Winn, & Rusli, 2006).

The formula used is  $n = Z^2 \times P(1-P) / d^2$ :

**Z** = Z statistic for a level of confidence = 1.96 (for 95% Confidence level);

**P** (expected proportion) = 0.5 (assuming 50% answer in a certain way); **d** (precision) = 0.05

This formula produces a maximum sample size requirement of 385, when the prevalence of a yes/no participant response is 50% with a 95% confidence interval ranging from 45% to 55%.

### 3.8.4 Eligible participants

#### Survey for HCPs working in general practice

The following HCPs were invited to complete the survey: general practitioners; GP registrars; advanced nurse practitioners; senior practice nurses/advanced practice nurses and practice nurses. It was a requirement for all participants to be working in England.

These staff members were targeted as they are the providers of sexual health consultations in the general practice setting. These groups offer HIV testing and discuss test results; they also provide general care to individuals living with HIV. No other HCPs working in general practice were considered to be directly involved in these aspects of care.

#### Survey for HCPs working in sexual health/HIV services

HCPs invited to participate included: sexual health/HIV consultants; sexual health/HIV registrars; speciality and associate specialist (SAS) doctors in sexual health/HIV; sexual health/HIV nurse practitioners; sexual health/HIV specialist nurses. It was a requirement that HCPs taking part in the study were currently working within these roles in England.

These groups were targeted as they provide HIV tests and discuss test results in this healthcare setting; they also provide direct care and treatment to individuals living with HIV.

### 3.8.5 Survey development

The surveys (Appendix 12 and Appendix 13) were developed with the assistance of the PhD supervisors and other Health Sciences researchers, highly experienced in cross-sectional survey design and dissemination, at the University of York. The initial stage in survey development was to identify 'key topics' (Gillham, 2007), this was achieved through performing the literature review (*chapter two*) and discussions with my PhD supervisors. The questionnaires were purposefully created in a semi-structured design, including both multiple choice questions and open questions.

A Professor in Primary and Community Care at the University of York provided expert input on the survey for HCPs working in general practice. The comprehensibility and usability of the survey was tested through conducting a 'think-aloud' with this researcher. This 'think-aloud', in which the researcher talked through the questionnaire as he completed it, enabled its content and structure to be scrutinised from the perspective of the target audience. It also meant the time taken to complete the questionnaire could be tested.

The questionnaires were headed by the University of York logo, as it has been identified that this level of association may provide further legitimisation to the research and increase response rates (Gillham, 2007). The questions and structure of each questionnaire mirrored each other; this was a deliberate choice to allow for comparability between HCPs across both settings. The questionnaire for HCPs working in sexual health/GUM services included participant information before the questions, to provide responders with the study details to make an informed decision about taking part. The questionnaire for HCPs working in general practice included a PIS as an attachment to the email (Appendix 14).

### 3.8.6 Survey distribution/advertisement

#### Survey for HCPs working in general practice

It was intended for the survey to be distributed to general practices within the main CCG coverage areas associated with the interviews with service users in the qualitative study. R&D assurance was requested and granted from CCG R&D departments in regions associated with these sites. This equated to 19 CCG coverage areas. To reach eligible participants, it was intended that after obtaining email addresses from CCGs, the survey would be emailed to general practice managers for circulation to the target audience (see Appendix 15).

### Survey for HCPs working in sexual health/HIV services

As work email addresses were not considered readily available for HCPs working in sexual health/HIV services, it was decided to advertise the survey through organisations with high levels of membership by the target audience. The following organisations were approached and agreed to advertise the survey:

#### **British Association for Sexual Health and HIV (BASHH)**

The first organisation approached to advertise the survey was BASHH. This association included the survey in their newsletters for February, May and August (Appendix 16). BASHH newsletters are emailed to all members of the association. At the time of initially advertising the survey, there were around 1000 BASHH members; the majority of these were medical professionals or other HCPs (BASHH, 2016). As well as newsletters being sent directly to members, they also remain available on the BASHH website (<http://www.bashh.org/>) via a member's restricted access link. The survey, when advertised by BASHH, was only available to association members.

#### **NAM**

The charity NAM, an organisation heavily involved in the dissemination of knowledge surrounding HIV/AIDS (NAM Publications, 2016), was approached and distributed a survey link via twitter from @aidsmap (22nd April and 29<sup>th</sup> June 2015). This twitter account at the time of writing has more than 5,500 followers; however, it cannot be ascertained how many of these meet the criteria of potentially eligible study participants.

A link to the survey was also included on the NAM Facebook page on 29<sup>th</sup> June 2015. Around 3,300 people 'like' this page at the time of writing; however, again it is unclear as to how many potential participants access this form of social media. In addition, NAM included the survey in Aidsmap news bulletins on 20th April, 5th May and 29<sup>th</sup> June and also in the HIV update on 29th April (Appendix 17).

#### **British HIV Association (BHIVA)**

The advertisement was included by the British HIV Association (BHIVA), 'the leading UK association representing healthcare professionals in HIV care' (BHIVA, 2016) in an edition of their electronic newsletter, *Members Matters*, on 21<sup>st</sup> July 2015. It is reported on the website that the organisation has more than 1,000 members (BHIVA, 2016). BHIVA serves as an advisory body, involved in the making of health policy in relation to HIV service provision (BHIVA, 2016).

### ***Terrence Higgins Trust (THT)***

The survey was sent to the Terrence Higgins Trust (THT) on June 26<sup>th</sup> 2015 for distribution amongst eligible potential participants working at the organisation. There are currently around 400 people in employment for the charity (THT, 2017a), although it is not clear how many may be eligible participants. This charity is involved in raising HIV awareness and improving the treatment and support given to those affected by HIV; the THT was established in 1982 in memory of Terry Higgins, one of the first people to die in the UK as a result of AIDS (THT, 2017a).

### ***Faculty of Sexual and Reproductive Healthcare (FSHR)***

The survey was advertised on the FSHR website from July 2015 (Appendix 18). The FSHR also advertised the study in their September newsletter. The FSHR, a part of the Royal College of Obstetricians and Gynaecologists, has a high level of UK membership; reporting 16,000 healthcare professional members that are involved in sexual/reproductive health services (FSHR, 2016).

### ***National HIV Nurses Association (NHIVNA)***

The advertisement was included in the National HIV Nurses Association (NHIVNA) newsletters on 30<sup>th</sup> April 2015 and 28<sup>th</sup> May 2015 (Appendix 19). NHIVNA is 'the leading UK professional association representing nurses in HIV care' (NHIVNA, 2016). There are currently around 350 members in total from the UK and Ireland (NHIVNA, 2016).

#### **3.8.7 Survey recruitment and data collection**

##### **Survey for HCPs working in general practice**

1) The email addresses of general managers were sought by the following means:

- Requesting GP practice manager email addresses from CCGs.
- Locating GP practice manager email addresses via the NHS Choices website or on websites for general practices.
- Telephoning GP practices to request GP practice manager email address or, if this was not available, a generic practice email which could be addressed to the practice manager (either named within the email or headed 'to the attention of the GP practice manager').

- Locating generic GP practice email addresses through the NHS Choices website or on websites for general practices.

2) Emails were sent to practice managers at the selected GP practices, providing study information and containing attachments to R&D approval letters. A link to the questionnaire and an attachment to the PIS were also included within the email.

3) Practice managers were asked to circulate the email to eligible potential participants working within the GP practice, as an invitation to take part in the survey research. To try and encourage the circulation of the survey and promote a good response rate, attempts were made to ascertain the names of the GP practice manager so that this email could be personalised. This strategy has been shown to enhance response rates (McPeake, Bateson & O'Neill, 2014). Participants who decided to take part were then able to complete the online questionnaire anonymously.

4) A further email was sent to practice managers for distribution amongst eligible HCPs approximately 3-4 weeks after the study opened. The email reminded those who had not taken part in the study about the opportunity to complete the questionnaire if they wished to do so. It served only to prompt individuals about the study who may have forgotten about the questionnaire or missed the original email. Only one reminder email was sent. A reminder was sent as it has been identified that this strategy is linked to higher survey response rates (Cook, Dickinson & Eccles., 2009; McPeake, Bateson & O'Neill. 2014).

The questionnaire was open to participants for at least four-five months, to allow time to try and achieve a sufficient response rate.

#### Survey for HCPs working in sexual health/HIV services

To reach the target sample, the survey was ultimately advertised by five sexual health/HIV organisations (see section 3.8.6). Originally only BASHH had been approached; however, over time further organisations were utilised to maximise response rates.

It was decided that the survey should be advertised numerous times, depending on response rates, and should be open to participants for at least four-five months.

The advert developed for inclusion by the organisations was made brief and inviting; it was purposefully kept to below 250 words (Appendix 16). Within the text it was made clear that the study was funded and sponsored by the University of York, as association with a leading organisation gives credence to research and may enhance participation (Gillham, 2007). A systematic review of postal surveys has also identified that questionnaires sent by universities

are more likely to receive responses than those from other organisations; therefore, it was considered important to stress the study funder (Edwards et al., 2009).

#### 3.8.8 Data analysis

Descriptive statistics were used to describe and provide a summary of the data. Bar charts and frequency tables were created to summarise the responses to each question within the survey. Percentages and proportions were also calculated for survey responses. It was not possible to perform inferential statistics due to the low response rates to both surveys (to be discussed in chapter four).

#### 3.8.9 Ethical approval

Both surveys were granted ethical approval by the HSRGC at the University of York.

To conduct the survey for HCPs working in general practice, research assurance was also granted by the CCG Research & Development (R&D) departments for each CCG area included in the study. This second level of ethical approval was required for this survey as NHS HCPs were involved in the study and were being contacted via their workplace email addresses for recruitment.

### 3.9 Summary

A pragmatic mixed-methods design was chosen for this research project to enable a comprehensive exploration of the acceptability and accessibility of HIV services to adults aged 50+ years. This chapter has discussed each of the methods used, providing a rationale for their inclusion.

The following chapter will outline the participants recruited to interviews (both service users and HCPs), highlighting sites of recruitment and participant characteristics, and also discuss survey response rates and respondent characteristics.







## Chapter 4: Participant characteristics and recruitment sites

### 4.1 Introduction

Following on from chapter three, which provided an outline of the methods used in this project, this section provides an overview of recruitment outcomes for the qualitative interviews and cross-sectional surveys. It provides a summary of survey respondent and interview participant characteristics, and an overview of interview recruitment sites. It addresses poor survey recruitment, particularly to the survey for HCPs working in general practice, and highlights factors potentially contributing to this.

### 4.2 Interview recruitment sites

Service user recruitment took place at sites A, B and C; three out of the five sites that granted approval for this research. Service users were almost entirely recruited from study site A, where HIV prevalence was highest. One participant was also recruited via charity advertisement of the study. HCP recruitment took place at sites A and D, the two sites that approved this study; the same numbers of HCPs were recruited from each site.

Table 5 provides an overview of HIV prevalence, HIV test coverage, and late HIV diagnoses in the local authorities corresponding to each recruitment site. Sites A (8.16 per 1000 people) and B (2.03 per 1000 people) are both classified as having a high HIV prevalence (PHE, 2016c). Due to high HIV prevalence ( $\geq 2$  per 1000 people), it is recommended that all new GP registrants and general medical admissions in the areas of Site A and B should be offered a HIV test (BHIVA, BASHH, BIS, 2008). Site C and D both have a HIV prevalence of less than 1 per 1000 (PHE, 2016c).

Table 5 shows that for the recruitment sites, the proportion of late HIV diagnoses increases as HIV prevalence decreases. Late HIV diagnosis is lowest for site A; this may be linked to the high levels of test coverage in GUM settings in this area (Table 5). STI acquisition rates also appear to be associated with HIV, with high HIV prevalence in areas where STI rates are also highest (table 5); a trend identified more broadly in national data (PHE, n.d.A).

For each site, further demographic details have been provided (table 6). Levels of deprivation have been compared as sexual health and HIV prevalence are linked to deprivation (HPA, 2012). For the recruitment sites, the sites with highest HIV prevalence (A and B) have highest deprivation.

Ethnicity has also been broken down for each area as it is well-documented that patterns of HIV acquisition differ by this factor; as previously highlighted, black African men and women

are disproportionately affected by HIV (Skingsley et al., 2015; NICE, 2011a). The area of Site A is ethnically diverse and contains the highest proportion of black people (8.2%) when compared to the other sites (ONS, 2012b). The least ethnically diverse sites (C & D) are those with lowest HIV prevalence.

Finally, the age of the population in each area has been considered, highlighting the proportion of adults aged 50 years and over. Site A has the highest proportion of younger people, only a quarter of the population in this area are aged 50 years and over. Sites of lowest HIV prevalence (C and D) have the highest proportion of adults over 50 years old (ONS, 2016).

#### 4.3 Interview participants

12 service users took part in the study (Table 7). The majority of service users were male, white British, identified themselves as MSM and had been diagnosed with HIV at age 50-53 years. The oldest service user was aged 68 years at diagnosis. 1 heterosexual female and 1 heterosexual male took part in the study. The majority of interviews lasted 45 to 90 minutes.

12 HCPs took part in the study (Table 8). The interviews with HCPs ranged in length from around 30 to 70 minutes. 7 HCPs were female and 5 were male. HCPs were recruited from nursing, medical and psychology backgrounds. The majority of HCPs had worked in sexual health/HIV services for at least 10 years.

Recruitment took place from June 2015 to July 2016 for service users, and September 2015 to January 2016 for HCPs.

Table 5: Overview of study sites from which participants were recruited (PHE, n.d.A)

SITE	HIV prevalence rate (diagnosed) per 1,000 people (15-59 year olds) – 2015	HIV test coverage in GUM settings, total (%) – 2015	% of diagnoses between 2013-2015 classified as late (in adults aged 15-59 years)
A	<b>Rate:</b> <u>8.16</u> (95% CI 7.73 to 8.61) <b>Count:</b> 1,339 people (London - Rate: 5.83 (95% CI 5.77 to 5.89); Count: 32,962)	<u>71.4%</u> (95% CI 70.8% to 72.1%) <b>Count:</b> 13,746 (London: 72.2% (95% CI 72.1% to 72.3%); Count: 321,137)	<u>24.2%</u> (95% CI 18.7% to 30.4%) <b>Count:</b> 54 people (London: 33.5% (95% CI 32.3% to 34.7%); Count = 2,020)
B	<b>Rate:</b> <u>2.03</u> (95% CI 1.83 to 2.24) <b>Count:</b> 385 people (North East – Rate: 0.98 (95% CI 0.93 to 1.03); Count: 1,499)	<u>57.6%</u> (95% CI 56.8% to 58.4%) <b>Count:</b> 8,590 people North East: 61.3% (95% CI 60.9% to 61.6%; Count: 41,364)	<u>45.2%</u> (CI 33.5% to 57.3%) <b>Count:</b> 33 people (North East: 45.1% (95% CI 39.4% to 51.0%); Count: 134)
C	<b>Rate:</b> <u>0.95</u> (95% CI 0.76 to 1.18) <b>Count:</b> 82 people (Yorkshire and Humber region - Rate: 1.32 (95% CI 1.28-1.36); Count: 4,171)	<u>68.6%</u> (95% CI 66.8% to 70.4%) <b>Count:</b> 1,788 people (Yorkshire and the Humber region: 62.0% (95% CI 61.7 to 62.3); Count: 68,283)	<u>58.3%</u> (95% CI 27.7% to 84.8%) <b>Count:</b> 7 people (Yorkshire and Humber region: 48.2% (95% CI 44.6% to 51.8%); Count: 364)
D	<b>Rate:</b> <u>0.65</u> (95% CI 0.52 to 0.81) <b>Count:</b> 84 people (Yorkshire and Humber region - Rate: 1.32 (95% CI 1.28-1.36); Count: 4,171)	<u>49.3%</u> (95% CI 48.2% to 50.4%) <b>Count:</b> 4,064 people (Yorkshire and the Humber region: 62.0% (95% CI 61.7 to 62.3); Count: 68,283)	<u>68.8%</u> (95% CI 41.3% to 89.0%) <b>Count:</b> 11 people (Yorkshire and Humber region: 48.2% (95% CI 44.6% to 51.8%); Count: 364)
England Values	<b>Rate:</b> <u>2.26</u> (95% CI 2.24 to 2.27) <b>Count:</b> 73,123	<u>67.3%</u> (95% CI 67.2% to 67.3%); <b>Count:</b> 998,503 people	<u>40.3%</u> (95% CI 39.5% to 41.1%); <b>Count:</b> 5,628 people

Table 6 Further demographic details for recruitment sites

SITE	Population number (Mid 2015 estimate) <sup>1</sup>	Proportion of population aged 50 years and over (Mid 2015 estimate) <sup>1</sup> (1dp)	Ethnicity, 2011 <sup>2</sup> (1dp)	Deprivation score, 2015 <sup>3</sup>	STI diagnosis rates (excluding Chlamydia in people aged <25 years) per 100,000 people aged 15-64 years, 2015 <sup>4</sup>
A	241,059	25.4%	66.3% White; 8.2% Black; 16.1% Asian; 5.6% Mixed; 1.6% Arab; 2.3% Other.	25.0	1,963 (95% CI 1,897 to 2,031) (London: 1,606 (95% CI 1,596 to 1,616))
B	292,883	30.2%	85.6% White; 1.8% Black; 9.7% Asian; 1.5% Mixed; 0.9% Arab; 0.5% Other.	28.3	1,023 (95% CI 979 to 1,068) (North East: 652 (95% CI 640 to 664))
C	157,016	43.6%	96.3% White; 0.7% Black; 1.5% Asian; 1.1% Mixed; 0.1% Arab; 0.2% Other.	10.4	469 (95% CI 427 to 515) (Yorkshire and Humber region: 617 (95% CI 609 to 626))
D	206,856	35.0%	94.3% White; 0.6% Black; 3.4% Asian; 1.2% Mixed; 0.3% Arab; 0.2% Other.	12.2	722 (95% CI 678 to 768) (Yorkshire and Humber region: 617 (95% CI 609 to 626))
England values	54,786,327	36.0%	85.4% White; 3.5% Black; 7.8% Asian; 2.3% Mixed; 0.4% Arab; 0.6% Other.	21.8	815 (95% CI 812 to 818)

<sup>1</sup> ONS (2016); <sup>2</sup> ONS (2012b); <sup>3</sup> PHE (n.d.B); <sup>4</sup> PHE (n.d.A)

Table 7: Characteristics of service users (adults diagnosed with HIV at age 50+ years)

Participant no.	Sex	Age at diagnosis	HIV prevalence in the local authority of recruitment	Sexual risk group	Approx. time after diagnosis that interview took place	Who initiated HIV test?	Where tested?	Stage of disease at diagnosis	Previous history of STI/HIV testing
1	M	67	High	Undisclosed	7 months	HCP	Hospital - inpatient	Unclear	Reports previous sexual health check – infrequent tests.
2	F	55	High	Heterosexual	11 months	HCP	Hospital - A&E	Early diagnosis	Reports one previous sexual health check – unsure whether tested for HIV
3	M	53	High	MSM	12 months	HCP	Private GP	Late diagnosis	Previous sexual health checks – frequent tests in younger years.
4	M	51	Low	Heterosexual	1 year and 2 months	HCP	Hospital -ICU	Late diagnosis	No prior history of sexual health checks.
5	M	50	High	MSM	9 months	Self-initiated	Sexual health clinic	Early diagnosis	Reports having regular sexual health checks (approx. every 18 months) but not HIV testing.
6	M	51	High	MSM	4 months	Self-initiated	Sexual health clinic	Early diagnosis	Reports having regular sexual health checks (3-4 times per year)
7	M	50	High	MSM	2 years	Self-initiated	Sexual health clinic	Early diagnosis	Previous HIV test was 10-15 years prior to diagnosis.
8	M	53	High	MSM	5 months	HCP	Hospital - ICU	Late diagnosis	Reports previous sexual health checks - not in recent years (2 tests in past)
9	M	53	High	MSM	4 months	Self-initiated	Sexual health clinic	Early diagnosis	Reports having regular sexual health checks (3-4 times per year)
10	M	57	High	MSM	2 years and 8/9 months	HCP	Hospital - inpatient	Late diagnosis	No prior history of HIV testing.
11	M	52	High	MSM	3 months	Self-initiated	Sexual health clinic	Early diagnosis	Reports having regular sexual health checks (approx. every six months)
12	M	68	-	MSM	4 years and 8 months	HCP	Hospital - inpatient	Late diagnosis	Reports having previous sexual health checks.

Table 8: Characteristics of HCPs

Participant no.	Sex	HIV prevalence	Job role	Years spent working in sexual health/HIV services
1	F	High	HIV specialist nurse	10-15 years.
2	M	High	Associate Specialist in HIV	20+ years.
3	M	High	HIV nurse	Less than 5 years.
4	F	High	Clinical psychologist	Unclear
5	F	Low	HIV lead nurse	20+ years.
6	F	High	HIV research nurse	15+ years
7	M	Low	GUM specialist nurse	Less than 5 years.
8	M	Low	HIV consultant	20+ years.
9	M	Low	HIV lead nurse	20+ years.
10	F	Low	Speciality doctor in GUM	20+ years.
11	F	High	Nurse practitioner working in HIV	15-20 years.
12	F	Low	Consultant in GUM	10 years.



#### 4.4 Respondents to survey for HCPs working in sexual health/HIV services

54 eligible respondents began the questionnaire; for completion rates for each section of the questionnaire see Figure 7. The demographic details for the 12 survey respondents who answered section one but were excluded from data analysis are presented in Appendix 20. The remaining 42 respondents were included in the analysis; the characteristics of these HCPs are presented in Table 9. The majority of respondents were female (69.0%), aged 35-54 years and working in sexual health. A high proportion of respondents were sexual health consultants (40.5%). There was an even split in respondents from low (< 2 per 1000 people) and high ( $\geq 2$  per 1000 people) HIV prevalence areas.

The advertising of the survey through a variety of organisations (e.g. BASHH and BHIVA), using several online mediums (e.g. Twitter and organisation websites), meant it was not possible to determine the survey response rate. Due to the small sample size, considerably lower than that required for inferential analysis (see section 3.8.3), statistical tests could not be used to infer findings to HCPs working across England in sexual health/HIV services.

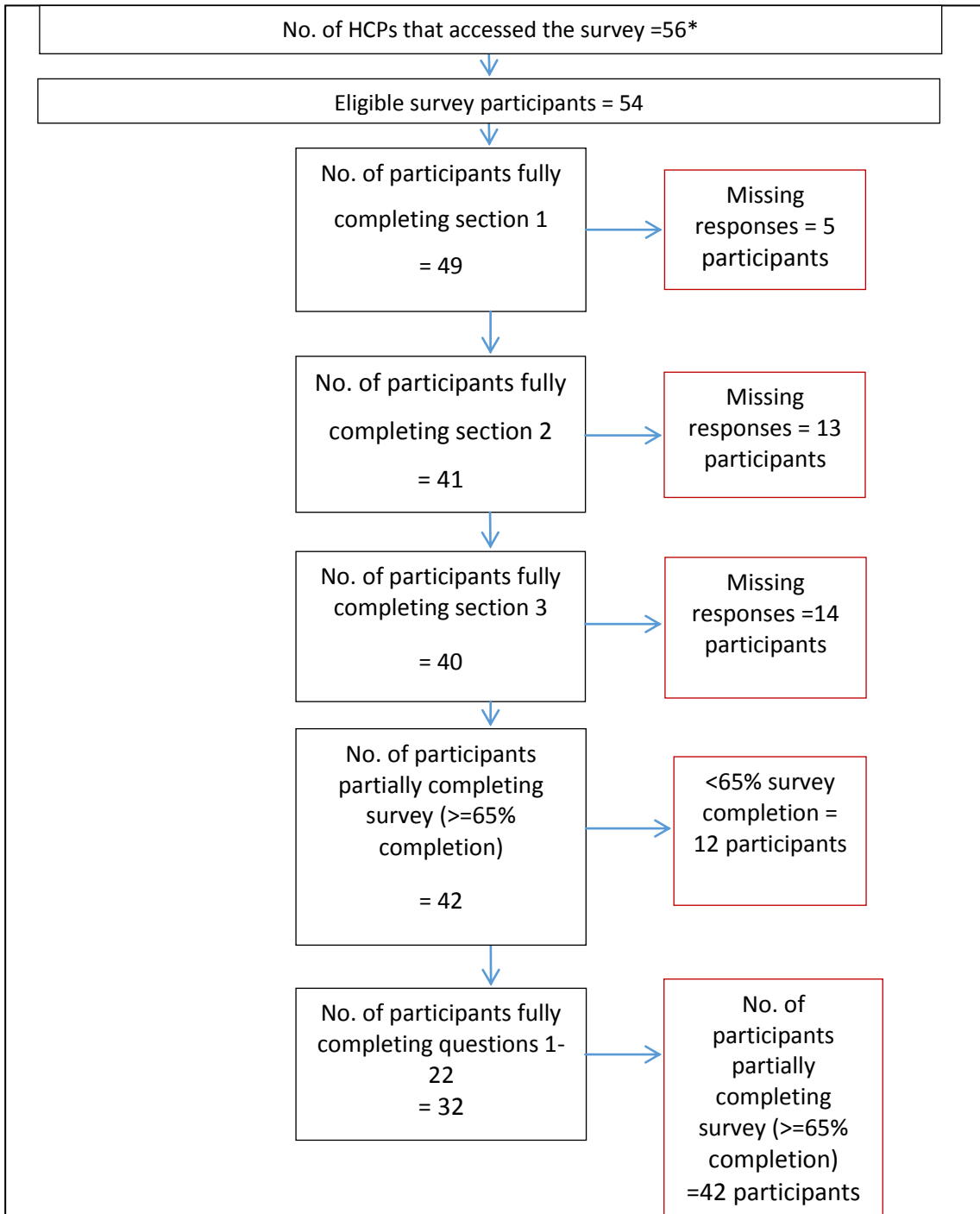


Figure 7: Completion rates for each questionnaire section – survey for HCPs working in sexual health/HIV services

\* 1 person was ineligible, based on their professional role; 1 person accessed the questionnaire but did not answer any questions.

Table 9: Characteristics of survey respondents

	Number	% (1dp)
<b>Sex</b>		
Male	13	31.0%
Female	29	69.0%
<b>Age group</b>		
25-34 years	4	9.5%
35-44 years	13	31.0%
45-54 years	17	40.5%
55-64 years	6	14.3%
65+ years	2	4.8%
<b>Professional role</b>		
Specialist sexual health consultant	17	40.5%
Specialist HIV consultant	1	2.4%
Specialist sexual health registrar	1	2.4%
Specialist HIV registrar	1	2.4%
Sexual health SAS doctor	8	19.0%
Sexual health nurse practitioner	1	2.4%
HIV nurse practitioner	2	4.8%
Sexual health specialist nurse	4	9.5%
HIV specialist nurse	4	9.5%
Other	3	7.1%
<b>HIV prevalence in workplace setting</b>		
< 2 per 1000	20	47.6%
2 - 4 per 1000	11	26.2%
> 4 per 1000	9	21.4%
Information not provided	2	4.8%

#### 4.5 Respondents to survey for HCPs working in general practice

Only 10 eligible respondents began the survey, an insufficient level of participation to enable any meaningful analysis to be performed. In hindsight, the low response was perhaps an unsurprising result for research involving general practice.

A Medline and CINAHL search, identifying UK surveys published over the past three years and targeting HCPs in general practice, found low response rates were reported for each study (20%-48%) (Demou et al., 2014; Gage et al., 2012; Hothersall, de Bellis-Ayres, & Jordan, 2012; Perry, Dowrick, & Ernst, 2014; Willoughby et al., 2013). Although many factors have been identified as affecting survey response rates, it does appear that there may be a reluctance for HCPs working in general practice to become involved in questionnaire based research.

In part, the low response rate in general practice may be due to a particularly heavy workload in this setting. A recent survey by the British Medical Association has indicated that more

than 70% of GP participants considered their workload to be 'unmanageable or unsustainable', with 60% of respondents reporting to 'always' work beyond their contracted hours due primarily to workload pressures (British Medical Association (BMA), 2015). Their workload has increased since the implementation of the *Health and Social Care Act (2012)*. In addition to workload, which may also have been a barrier to survey completion by HCPs working in sexual health/HIV services, the following section highlights some other potential barriers to survey completion.

#### 4.6 Why did the surveys achieve low response rates?

##### 4.6.1 Sampling strategy

**HCPs working in sexual health/HIV services:** The sample can be classified as a 'convenience sample'; one which has been targeted due to a commonality e.g. accessing BASHH newsletters; accessing websites, twitter and Facebook pages etc. It may be that this sample is not representative of the targeted population (Gillham, 2007). It was not known exactly how many eligible potential participants had access to the survey or the distribution of these people based on age, gender, job role or geographical distribution etc. The sampling strategy may have also contributed towards the low response rate to the survey, as we cannot be certain how many of the target audience were actually reached using this approach. It may therefore have compromised the validity of the survey (Braithwaite et al., 2003).

**HCPs working in general practice:** The process of reaching eligible HCPs was convoluted and difficult. It was unexpectedly challenging and time-consuming to locate the generic email addresses of general practices, let alone general practice managers. The first attempt in trying to find these details was to contact the CCGs for which permission had been granted to conduct the research. Each CCG was asked if it would be possible to access a list of GP practice managers and their contact details, or if this was not possible if they could circulate the survey to practices within the area on the chief investigators behalf. The second approach was to use the NHS choices website to try to identify GP surgeries/GP practice managers contact details. This method provided inconsistent results. Although GP practices provide ample forms of contact: telephone, fax, postal address, far fewer advertised email as a means of receiving communication; if they did this was via a scripted form for completion online.

As a third approach, GP practices were telephoned individually and email addresses were requested from receptionists. The vast majority of practices were willing to provide a generic email address for their surgery; fewer were willing to provide details to directly contact the manager.

The need to rely on practice managers to distribute the survey and study information to eligible members of staff meant it was not possible to ascertain how many potential participants had received the research invitation. Unarguably, it would have been a much smoother process to approach potential participants directly; however, it was not feasible to obtain this number of contact details, with this information not being readily available. It was not always clear whether or not CCG's, that had stated they would forward the invitation on to GP practice managers within their CCG area, or the GP practice managers themselves had done this or not. An agreement to do this was always reliant on faith.

It was also not possible to know whether participants had successfully received the questionnaire e.g., whether or not email addresses were accurate. A certain number of emails will have been marked as spam and never seen by the intended recipient.

These factors all compromised the validity of the survey and almost certainly affected the number of responders.

#### 4.6.2 Access to computers

Although a high volume of the NHS workforce access computers on a daily basis, this access may be restricted by factors such as needing to share a computer. It cannot be certain that HCPs have equal access to computers in both settings and across job roles. HCPs working in general practice would only be able to complete the questionnaire in a work environment as it was sent via professional email. HCPs working in sexual health/HIV services would have been able to complete the questionnaire outside of their workplace.

#### 4.6.3 Apathy towards survey completion: 'Not another questionnaire!'

A major challenge to the successful completion of questionnaire research involving HCPs is difficulties achieving an adequate level of study participation. This has been well documented in general practice, in part due to the inundation of staff members in this setting with questionnaire-based studies (MacPherson & Bisset, 1995). This was broadly considered to be the experience of doctors (Wedderburn & Rickenbach, 2011):

*'Ask any doctor and most will say that they are fed up with the constant barrage of questionnaires arriving in their inboxes on a weekly basis. Most receive two or more a week, from a wide variety of sources'*

This situation is also likely to be similar for nursing staff.

#### 4.6.4 Perceived topic importance

It has been found that survey completion is improved when participants have an interest in the area under exploration and perceive the topic as salient (Bowling, 2009). It may have been the case that GP practice managers and eligible participants did not view the topic as important to them. For example, one GP practice manager replied to the survey invitation email and declined to disseminate the survey, as they did not consider it applicable to their practice.

It would be expected that HCPs employed in sexual health/HIV services should perceive the research topic as important. High response rates have been achieved in surveys surrounding sexual health/HIV from HCPs or commissioners involved in this area of work (Hartney et al., 2014).

#### 4.7 Summary

In preparation for the reporting of empirical findings, this chapter has provided a clear overview of participant characteristics and recruitment site information. Unfortunately, survey response rates were low, particularly for HCPs working in general practice. Factors that may have contributed to the low survey response rates, such as heavy HCP workloads and research apathy, have been explored.

In reading the following sections (chapters five, six and seven), this chapter will serve as a reference point to assist in the understanding and interpretation of the research findings. In these results chapters, alongside verbatim interview quotations and survey responses, a participant descriptor will be given. For service users, transmission group (e.g. heterosexual male, MSM) and age at diagnosis will be highlighted (Dx). For HCPs, gender and professional role will be outlined. HIV prevalence in the area of recruitment (prev.) will be provided for both service users and HCPs. Participant numbers, included with each quotation, refer to those highlighted in chapter four (Table 7; Table 8).







## Chapter 5: Journey to testing

### 5.1 Introduction

Using the *Model of Pathways to Treatment* (MPT) as a framework for data analysis (Walter et al., 2012; Figure 3), this section of the results explores the journey to testing experienced by adults diagnosed with HIV at age 50+ years. It draws upon and integrates findings from:

- Qualitative interviews with adults diagnosed with HIV at age 50+ years (referred to hereafter as service users);
- Qualitative interviews with HCPs working in sexual health/HIV services and providing care for adults aged 50+ years at risk of or diagnosed with HIV;
- A survey of HCPs working in sexual health/HIV services and providing care for adults aged 50+ years at risk of or diagnosed with HIV;
- An analysis of attendance and HIV testing data for all sexual health/GUM clinics in England by age, gender and sexual risk group (MSM; heterosexual males; heterosexual females).

The chapter concentrates on the following aspects of the MPT: detection and appraisal of bodily change(s); perceiving a reason to discuss symptom(s) with a HCP; health-seeking; healthcare consultation(s) prior to diagnosis; and the time to testing. It begins with an exploration of the pathway to initial HCP access, considering the processes leading to this contact.

### 5.2 Pathway to first HCP contact

As outlined in Figure 8, one service user had their first encounter with health care services when admitted to hospital as an emergency, following a collapse. This person had not felt unwell prior to collapsing, or perceived any indication to test for HIV. By contrast, the other service users had all actively decided to access general practice or sexual health/GUM services for help. To gain an understanding of the different health-seeking pathways experienced by service users, social cognition models have been drawn upon in this section to explore the role of self-perceptions in the decision to access health services (Becker, 1974; Rosenstock, 1966).

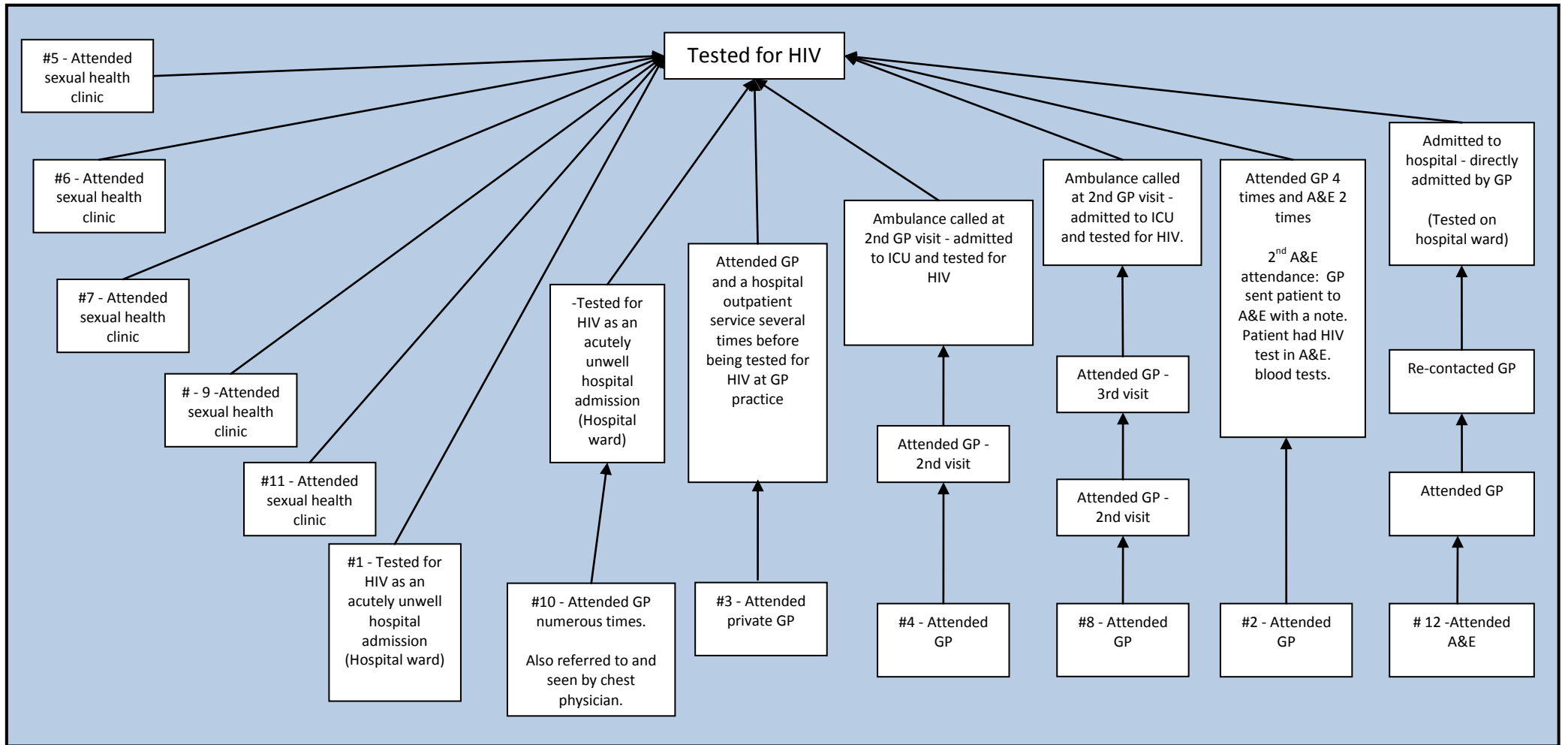


Figure 8: Health care access by service users prior to testing for HIV

### 5.2.1 Symptom recognition and interpretation

The identification of symptoms and their interpretation as requiring attention, the first stages of the MPT, are often an 'internal cue' to health-seeking (Janz & Becker, 1984; Mechanic, 1962). When symptomatic at their first contact with a HCP, service users often presented with symptoms that were varied and non-specific in nature; these included cough, headache and stomach problems. On experiencing symptoms, service users drew upon their knowledge on health and illness to explain these changes. This included knowledge of symptomatology as well as knowledge of the risk factors for particular conditions. In most cases symptoms were initially explained in terms of commonplace conditions, or normalised as due to ageing:

*'... I'd got what I thought was just a small chest infection um and I'd got a cough...' [Service user #8: MSM, Dx 53 years, high prev.]*

*'I suppose people sort of think oh you're feeling more tired that well that's just with you know, if you're ageing or I just you know, can't shake this cold, that's cos you know I'm getting older. All these sorts of things when actually these are things that potentially could be er associated with HIV' [HCP #11: Female nurse practitioner in HIV, high prev.]*

Although the majority of service users had symptoms at the point of accessing health services, four MSM were diagnosed at an early stage of disease and were asymptomatic at presentation.

### 5.2.2 Decision to access health services

As widely reported in the help seeking and illness cognition literature, in the presence of symptoms, these alone are often not sufficient to prompt action (Becker, 1974; Leventhal, Meyer & Nerenz, 1980; Leventhal, Nerenz & Steele, 1984; Ogden, 2012; Zola, 1973). Similarly, engagement in HIV risk behaviours (e.g. condomless sex, or sharing needles) may also not be enough to encourage health service attendance for testing. In considering symptomatic and asymptomatic service users, the following also affected the decision to access a HCP.

#### 5.2.2.1 *Symptom severity and impact*

For symptomatic service users, health-seeking was prompted when symptoms affected their ability to perform day-to-day activities, causing significant disruption to their lives:

*'... [I had] a cough on my chest, [a] constant cough and then I'm out of breath. If I'm talking I'm out of breath. If I were talking like this I'd be out of breath and coughing again...' [Service user #4: Heterosexual male, Dx 51 years, low prev.]*

When symptoms were experienced with greater severity, and occurred over a longer period of time than previously endured, this also prompted health-seeking:

*'...I developed a very, a very strong flu. And it was, actually it was the worst flu I can remember, it just wouldn't go away for two weeks. Um, no I, I, I spoke, I spoke to a friend of mine who's a doctor who specialising in these kind of infections and he said well have you had an HIV test yet...'*

*[Service user #11: MSM Dx 52 years, high prev.]*

As service users struggled to cope with symptoms, the need to isolate an underlying cause and receive symptom relief became increasingly urgent. This resulted in service users attending HCPs multiple times, looking for answers:

*'... eventually I went back [to the GP] and said I can't deal with it anymore...'* *[Service user #2:*

*Heterosexual female, Dx 55 years, high prev.]*

#### 5.2.2.2 Sanctioning of health service access

Symptom appraisal was often influenced by discussions with family and friends, with individuals seeking the knowledge available within their informal networks in order to make sense of their experiences. For example, on suspecting his flu-like symptoms may have been caused by a STI, one respondent received advice from a clinician friend to attend sexual health/GUM services. The recognition of symptoms by others, even without suggesting a cause, appeared to heighten the need to access a HCP. The encouragement of friends and family to access health services has previously been labelled the 'lay referral system' (Friedson, 1960).

*'... on this Monday I went for a meal with my two sisters and they said I've not seen you like this for a long time [participant's name]. She said you were; I saw you walking up the road to go into [name of the restaurant] for a meal with em; she said you're puffing a panting walking up the road (inaudible words). I said right, I'll go to the hospital, I'm going to the doctor tomorrow, said I'll go and get checked out, said I've got an appointment at the doctors tomorrow and I'm going 'cos I can't get my breath...'* *[Service user #4: Heterosexual male, Dx 51 years, low prev.]*

*'I don't go to the doctor unless I'm really ill and it was [partner's name] that convinced me to because he said I don't think you realise how much you are coughing'* *[Service user #8: MSM, Dx 53 years, high prev.]*

One HCP considered that in general, men were more likely than women to require encouragement from family members or friends to access health services:

*'...it just, isn't something that men do, is it? Certainly not until they absolutely have to usually and, you know, somebody's nagging them or something's happened....' [HCP #6: Female HIV research nurse, high prev.]*

### 5.2.2.3 Knowledge of HIV

In the absence of symptoms, health-seeking decisions were based on 'external cues' to action such as knowledge about HIV. Generally, adults aged 50+ years were considered by HCPs to have lower levels of HIV knowledge than younger people. 81% of HCP survey respondents (n = 34) disagreed with the statement that the over 50s are well informed about the risk factors for HIV. In contrast, 41% disagreed with this statement when phrased for adults aged 15-49 years (n = 17) (Figure 9).

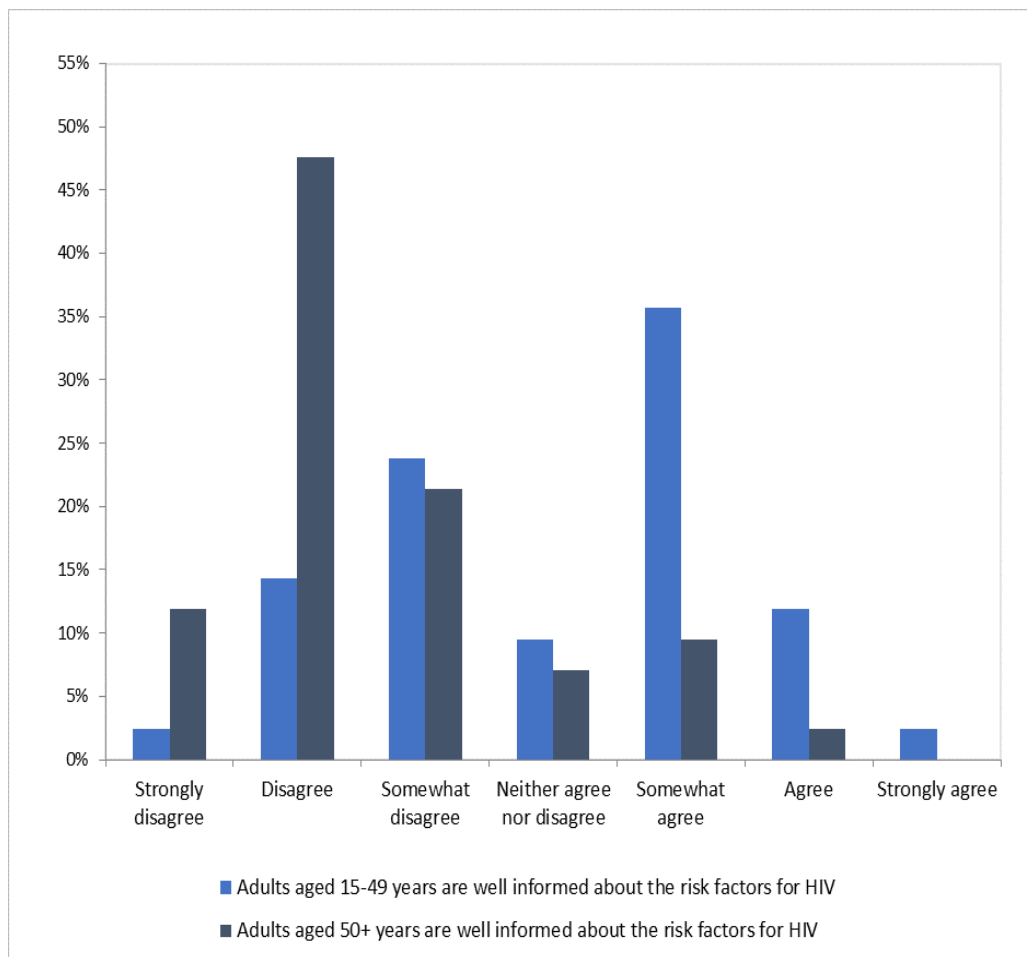


Figure 9: HCPs' perceptions of risk factor knowledge in younger and older adults (from HCP survey)

HIV and STI prevention messages were often felt to exclude adults aged 50+ years, through a youth focus and use of communication mediums associated with younger people:

*'... the sort of generations over fifty don't necessarily engage as much with social media advertising campaigns as opposed to 16-25 year olds who are much more likely to kind of encounter it online. Umm a lot of money goes into HIV kind of umm prevention I think on, online'*

*[HCP #7: Male GUM specialist nurse, low prev.]*

This was reported by interview and survey participants to leave a gap in knowledge surrounding the importance of practicing safer sex in older age:

*'...I mean there is that, the sort of evidence around men coming out of long term relationships, being married for thirty years and then divorcing and getting into new relationships and then just not necessarily reconnecting with the kind of, the safe sex message they had when they were like an adolescent or a like in their early twenties'* *[HCP #7: Male GUM specialist nurse, low prev.]*

*'I wouldn't have thought ermm...no I wouldn't have thought of it ermm being someone my age'*

*[Service user #2: Heterosexual female, Dx 55 years, high prev.]*

It was regarded that heterosexuals, particularly those not targeted by HIV campaigns (i.e. not of black African ethnicity or identifying as MSM), had received very little information about HIV/AIDS since the 80s. It appeared that HIV knowledge in this group was largely based on the 1987 'AIDS: Don't Die of Ignorance' campaign and 90s storylines in British TV soap operas and films, such as EastEnders (first episode in 1990) and Philadelphia (released in 1993), involving HIV positive characters. These reference points of knowledge are from a time prior to the development of effective treatment, this means that people may not be up-to-date in their knowledge of treatment advancements.

*'... if you think about it, that's probably the last time there was any sort of major health education or awareness raising certainly on a, on a large mass level. Everything now is more much*

*selective...'* *[HCP #10: Female GUM doctor, low prev.]*

A source of more recent knowledge of HIV in heterosexuals came from newspaper articles. Newspapers were considered to present inaccuracies surrounding HIV, and were perceived as sensationalist:

*'...the broadsheets and the tabloids, they're, they're there to sell headlines and um perhaps er, you know, not as knowledgeable as to sort of where we are and, and, and HIV'* *[Service user #7: MSM*

*Dx 50 years, high prev.]*

In contrast to heterosexuals, MSM were identified as much more likely to receive up-to-date and factual HIV information. MSM reported and demonstrated high levels of HIV knowledge; a finding corroborated by HCPs, and appeared better informed about HIV than heterosexual men and women. HIV knowledge in MSM came from belonging to the gay community, previous voluntary work with HIV charities, and personal experience in knowing someone with HIV:

*'[in the] gay community here [a high HIV prevalence area] .... you go to a bar, there's information leaflets. I mean you speak with friends, all ages, and diversity's there as well um and er, you know, all of the information is there, you know, to reach to all, a diverse group of gay people' [Service user #7: MSM, Dx 50 years, high prev.]*

MSM were considered more likely than heterosexuals to have accurate knowledge about the effectiveness of current HIV treatments, a further cue to routine HIV testing. This group were aware of the transition of HIV from a terminal to a chronic condition with the availability of ART.

*'.....there's a high percentage of guys that have HIV and live with it, you know, as another problem. I see it more as like a, diabetic type II these days than a life-threatening condition...'*  
*[Service user #9: MSM, Dx 53 years, high prev.]*

Extensive knowledge of HIV, including common symptomatology and perceived risk status, enabled one MSM service user to recognise his bodily changes as 'classic symptoms' of HIV infection. This person's awareness of HIV was based on caring for a partner who died early in the UK epidemic, prior to the development of effective treatment. First-hand knowledge of the disease was a crucial factor that prompted him to test:

*' I just noticed some, some of the classic symptoms and so it's mainly a rash and just feeling a bit poorly and er flu-like symptoms and, and I thought just putting those factors together er, you know, I should really go' [Service user #7: MSM, Dx 50 years, high prev.]*

#### 5.2.2.4 Perceptions of personal risk

In conjunction with HIV knowledge, perception of personal susceptibility to HIV was considered particularly low in groups not targeted by HIV prevention campaigns. This was expressed through survey responses, and in interviews with HCPs and service users. The continual representation of MSM in HIV campaigns served as an ongoing cue to health-seeking for this group and was linked to lower risk perception in heterosexual males:

*'... they think of it as a gay disease and that's, and that's how they look at it....' [Service user #6: MSM, Dx 51 years, high prev.]*

*'... there is still that culture that straight people thinks [HIV] only happens to the gay people' [HCP #3: Male HIV nurse, high HIV prevalence area]*

In interviewing a white heterosexual female service user, it was clear that she had never contemplated herself, or anyone she considered demographically similar to her, as at risk of HIV. HCPs acknowledged that service users receiving a late HIV diagnosis often did not belong to groups that would be broadly considered at risk of HIV, either personally or by HCPs:

*'We tend to see the more unusual....so if you think about, because if you're a certain demographic, say you're a white heterosexual female in her fifties/sixties, I've seen a lot of new diagnoses at that age and the reason is, is because it's unusual to be diagnosed. So I guess what that means for that person is they're not part of kind the...the usual groups and so perhaps that can sometimes be a bit strange for them, it also, and it also may be something they've never thought about .....often in our experience it's the...the unusual people that don't get offered a HIV test because nobody kind of thinks that could be what it is. So they tend to focus on the people traditionally that they would think has HIV....' [HCP #4: Female clinical psychologist, high prev.]*

As one survey respondent expressed it:

*'Staff think they are not at risk. Patients think they are not at risk' [Specialist sexual health consultant, female, 35-44 years old, low HIV prev.]*

For older adults, reduced personal risk perception and precaution efforts were reported after many years of living in fear of HIV/AIDS and taking measures to avoid infection - 'precaution fatigue':

*'I think we're probably gonna see er people like me that have grown up with HIV you know tended to be very, very careful about it you know for many, many years that in age and I think there's probably a lot of people like me that in age, with age you know your level of carefulness drops.'*  
[Service user #11: MSM, Dx 52 years, high prev.]

'Precaution fatigue' was also discussed by HCPs:

*'... these things [STIs and HIV] are often seen as risky when you were younger so it's that sort of, it's diff... it feels somehow different, somehow you're protected against it when you're older that you're not gonna get it...'* [HCP #4: Female clinical psychologist, high prev.]



One service user considered 'precaution fatigue' to be partly attributed to decreased concern about HIV due to the effectiveness of treatment. It was also felt that growing older 'makes you want to experience things' and engage in riskier behaviours.

#### 5.2.2.5 Stigma, fear and denial

HCPs were frustrated with the persistent stigma surrounding HIV and its impact on testing; however, this was not voiced by the interviewed service users as a factor directly affecting their journey to testing:

*'... if people have this attitude and stigma towards HIV it's not gonna pre...not gonna encourage them to test. They're not gonna go forward because they're gonna then be fearful of experiencing the discrimination or the stigma that's associated with being positive so how'd you get people to test ummm when actually there's only ever a negative attitude towards testing' [HCP #11: Female nurse practitioner, high prev.]*

HCPs discussed that some older service users avoided testing or denied their HIV positive diagnosis:

*'... sometimes you think they may have been tested and they ignored the result, they sort of buried it. There is, there's a denial, there is...you see some cases where there seems to have been some active denial even in the face of knowledge...' [HCP #8: Male HIV consultant, low prev.]*

Denial and fear were considered to stem from a lack of up-to-date knowledge on HIV (see section 5.2.2.3):

*'...as a nurse now you still kind of feel the kind of influence of it [‘Don't Die of Ignorance' campaign], and the fear that it created and the "I'd rather not know than test kind of attitude" which is yeah still ongoing unfortunately.' [HCP #7: Male GUM specialist nurse, low prev.]*

In light of this fear, it was felt that there may be a greater need to reassure the over 50s about the chronic, rather than terminal, prognosis now associated with a positive HIV diagnosis.

#### 5.2.2.6 Prior illness and health service access

A lack of prior health service use, or experience of morbidity, impacted on symptom interpretation and health-seeking. The context in which symptoms were experienced, where service users had no pre-existing morbidities, could either facilitate or hinder health seeking. For some, a particularly stoical approach to illness was demonstrated, with attempts made to

continue the trajectory of 'never being ill'. This reluctance to access health services and portrayal of invincibility was considered to be most associated with men:

*'Well, you see I've gone through life and yet I've been ill, I've ached and I've just got on with it. I'm not one who whinged or went to the doctors or anything. I just thought that's part of living, I'm aching. I'm hurting, I'm ill, I've got a cold or cough, I just carry on...'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

In contrast, for some the appearance of symptoms, when they had previously considered themselves as always healthy, prompted great concern and the need to seek immediate action. This variation in response highlights individual differences in illness cognitions.

#### 5.2.2.7 Advancing age

It was discussed that reaching 50 marked a significant turning point at which service users had started to give greater consideration about their own health and mortality. This was linked to noticing friends of a similar age starting to experience health problems, concern expressed by family members about their ageing, and also not having a HIV test for many years:

*'... when I got to 50 I went to the doctor and asked for an overall, you know, just check, check me over, my kids are saying I'm you know getting old, I'm just wanting an overall to check, well (I: an MOT (overlapping)) ...and I thought I'd been checked for everything...'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

*'...it was just when I was turning fifty years old and I hadn't been for umm a test for a good ten probably fifteen years and I thought turning fifty, you know, umm I don't quite feel right I'll go and have a, a test umm shortly after my 50<sup>th</sup> birthday which was at the beginning of umm January...'* [Service user #7: MSM, Dx 50 years, high prev.]

### 5.3 Diagnostic progress

For service users that attended a GP as their first health care contact, there were often multiple stages before HIV diagnosis, with back and forth attendances to the general practice (Figure 8). In some situations, service users that were diagnosed late were misdiagnosed and treated for different conditions in non-HIV specialist settings before being tested for HIV, despite presenting with clinical indicator conditions (BHIVA, BASHH, & BIS, 2008). In most instances, however, service users presented with symptoms that could be associated with a range of other more common health problems. In that case, unless attending a sexual

health/GUM clinic, HIV was unlikely to be considered as a probable diagnosis until a range of other avenues had been exhausted:

*'...when you think about it to be fair a lot of the symptoms for HIV can be, are not, they're not so obvious that they're kind of distinctive....understandably perhaps doctors can miss these things but I guess one of the things that they don't, it does, you do notice they do tend to actually be more likely to a test to certain people and not others so they must have certain prejudices to some extent in their own kind of thinking about HIV and who has it and who doesn't' [HCP #4: Female clinical psychologist, high prev.]*

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*INTERVIEWER: Was he [the GP] treating you for something different then? Did he think you had an infection or?*

*PARTICIPANT: Well he would, no, yes he would give me antibiotics at a push, and sometimes they helped a bit, for a short time. Ermm but it just wasn't, it wasn't....' [Service user #10: MSM, Dx 57 years, high prev.]*

The stage at which service users were diagnosed with HIV, a product of the time to accessing a HCP and to being tested for HIV after presenting to health services, was affected by many factors.

#### 5.4 HIV testing in health services

Four service users, identifying as MSM, were tested for HIV at their first point of HCP contact in sexual health/GUM services. These service users were all diagnosed at an early stage of disease. The remaining service users were tested in hospital settings, largely following a number of primary and secondary care visits. Of those admitted to hospital, two services users were tested in intensive care units and were acutely unwell at diagnosis (see Figure 8). All service users tested in non-HIV specialist settings, aside from one, were diagnosed at a late stage of disease. Service users discussed non-linear journeys to diagnosis, involving missed opportunities for testing in non-HIV specialist settings. HCPs (survey and interview participants) also highlighted their wider awareness of testing delays in non-specialist settings.

In terms of a national perspective, detailed testing data are largely unrecorded by hospital inpatient units or general practice; however, data are available from across sexual

health/GUM services in England to explore access and test coverage by age in this setting. These data highlight that although sexual health/GUM services are primarily accessed by younger adults (Appendix 21), the number of attendees aged 50+ years is rising. From 2009 to 2014, the number of attendees aged 50+ years increased by 59.3%, from 50,917 to 81,136. Higher numbers of men aged 50 years and over access sexual health/GUM services than women in this age group; the reverse is found for younger adults. In 2014, there were approximately 57% more male sexual health/GUM attendees aged 50+ years than females in this age group (n = 49,553 males; n = 31,589 females).

Despite growing access by older adults to sexual health/GUM services, there are discrepancies in HIV test coverage by age (proportion of attendees eligible for testing that are offered and accept a test). With advancing age, test coverage decreases substantially (Figure 10).

Coverage also varies in sexual health/GUM services by sexual risk group (Figure 10). In 2014, heterosexual females were least likely to be tested at any age, when compared to heterosexual males and MSM. With advancing age, the likelihood of being tested for HIV in 2014 dropped to just 37.3% in heterosexual females aged 70+ years, compared to 59.8% in heterosexual males and 80.8% in MSM in this age group.

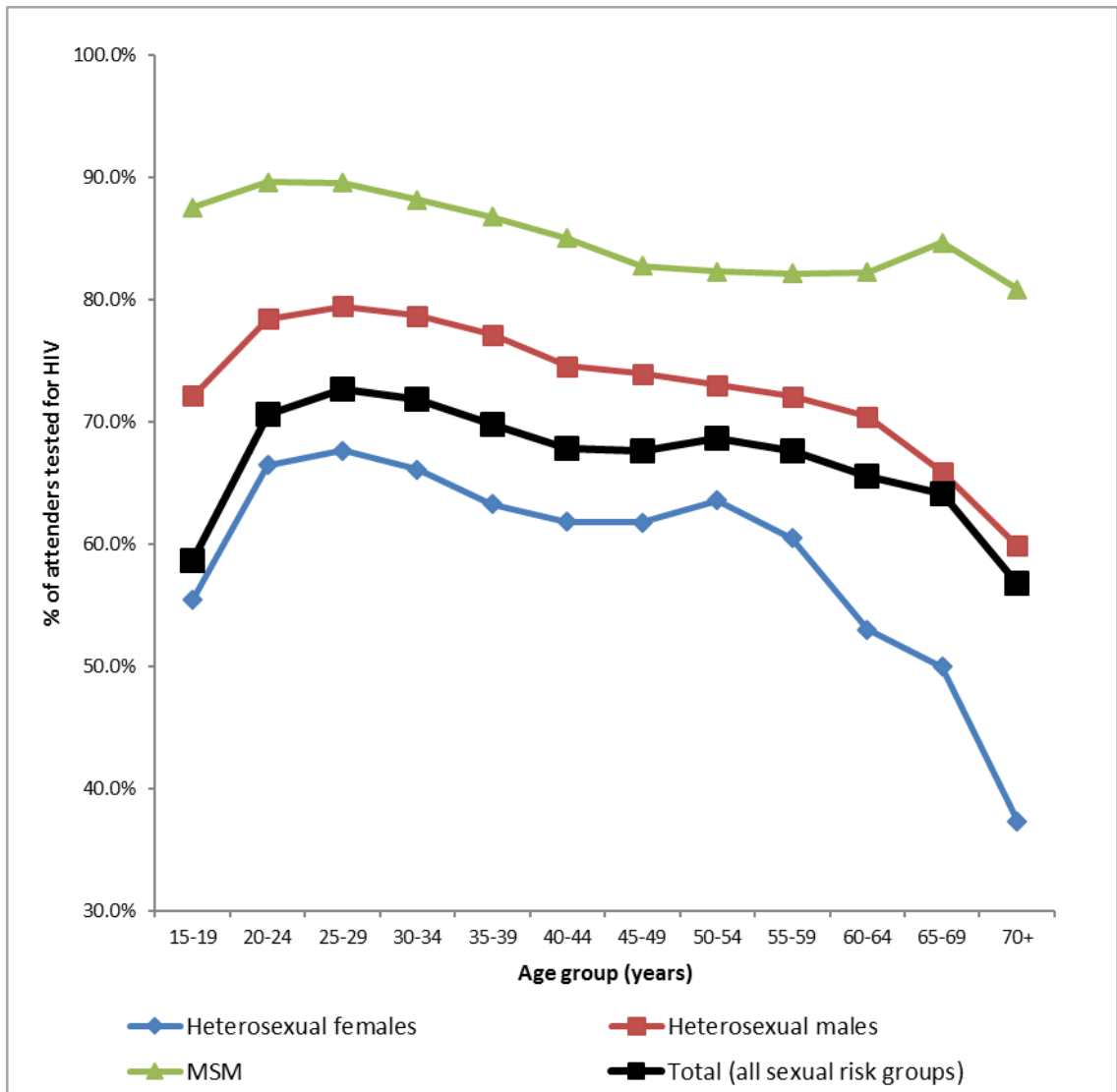


Figure 10: HIV test coverage in sexual health/GUM clinics by age and sexual risk group, 2014 – England.

Following logistic regression modelling, the odds of being tested for HIV were found to be significantly higher for eligible attendees aged 15-49 years compared to eligible attendees aged 50+ years for both genders (Table 10) and all sexual risk groups assessed (Table 11). The difference in the odds of being tested between age groups was greater for males than for females, but as seen in figure 10, males had a higher chance of being tested across all age groups.

Table 10: Likelihood of testing by age group, by gender (2014)

	<u>Males</u>		<u>Females</u>	
	<u>15-49 years</u>	<u>50+ years</u>	<u>15-49 years</u>	<u>50+ years</u>
<b><u>Number of attendees eligible for testing</u></b>	573,451	49,533	776,858	31,589
<b><u>Number of eligible attendees tested</u></b>	450,680	35,918	483,997	18,331
<b><u>% tested (1dp)</u></b>	78.6%	72.5%	62.3%	58.0%
<b><u>Odds ratio (95% CI)*</u></b>	1.37 (1.34-1.40)	--	1.20 (1.18-1.23)	--

\*Odds for ages 15-49 versus ages 50+

Table 11: Likelihood of testing by age group, by sexual risk group (2014)

	<u>Heterosexual males</u>		<u>Men who have sex with men</u>		<u>Heterosexual females</u>	
	<u>15-49</u>	<u>50+</u>	<u>15-49</u>	<u>50+</u>	<u>15-49</u>	<u>50+</u>
<b><u>Number of attendees eligible for testing</u></b>	460,604	36,115	92,528	11,408	729,261	29,623
<b><u>Number of eligible attendees tested</u></b>	356,834	25,569	81,253	9,394	467,441	17,701
<b><u>% tested (1dp)</u></b>	77.5%	70.8%	87.8%	82.3%	64.1%	59.8%
<b><u>Odds ratio (95% CI)*</u></b>	1.42 (1.39-1.45)	--	1.55 (1.47-1.63)	--	1.20 (1.17-1.23)	--

\*Odds for ages 15-49 versus ages 50+

For attendees aged 50 and over, the odds of being tested were greatest for MSM and lowest for heterosexual females (Table 12).

Table 12: Likelihood of testing by sexual risk group, ages 50+

	<b><u>Heterosexual males</u></b>	<b><u>MSM</u></b>	<b><u>Heterosexual females</u></b>
<b><u>Number of attendees eligible for testing</u></b>	36,115	11,408	29,623
<b><u>Number of eligible attendees tested</u></b>	25,569	9,394	17,701
<b><u>% tested (1dp)</u></b>	70.8%	82.3%	59.8%
<b><u>Odds ratio (95% CI)*</u></b>	--	1.92 (1.82- 2.03)	0.61 (0.59-0.63)

\*Odds compared with heterosexual males.

This national data suggests that there might be age-related barriers to being tested in sexual health/GUM settings. The analysis below explores whether these barriers relate to offer of testing by service providers and/or to acceptance of testing by attendees.

#### 5.5 Offer of HIV testing to adults aged 50+ years

National HIV testing for sexual health/GUM services highlights that testing is not offered to everyone, irrespective of age. In examining test offer data for sexual health/GUM clinics across England, it is clear that attendees (all eligible for testing) are less likely to be offered a HIV test with advancing age, with this trend particularly pronounced for heterosexual males and females (Figure 11).

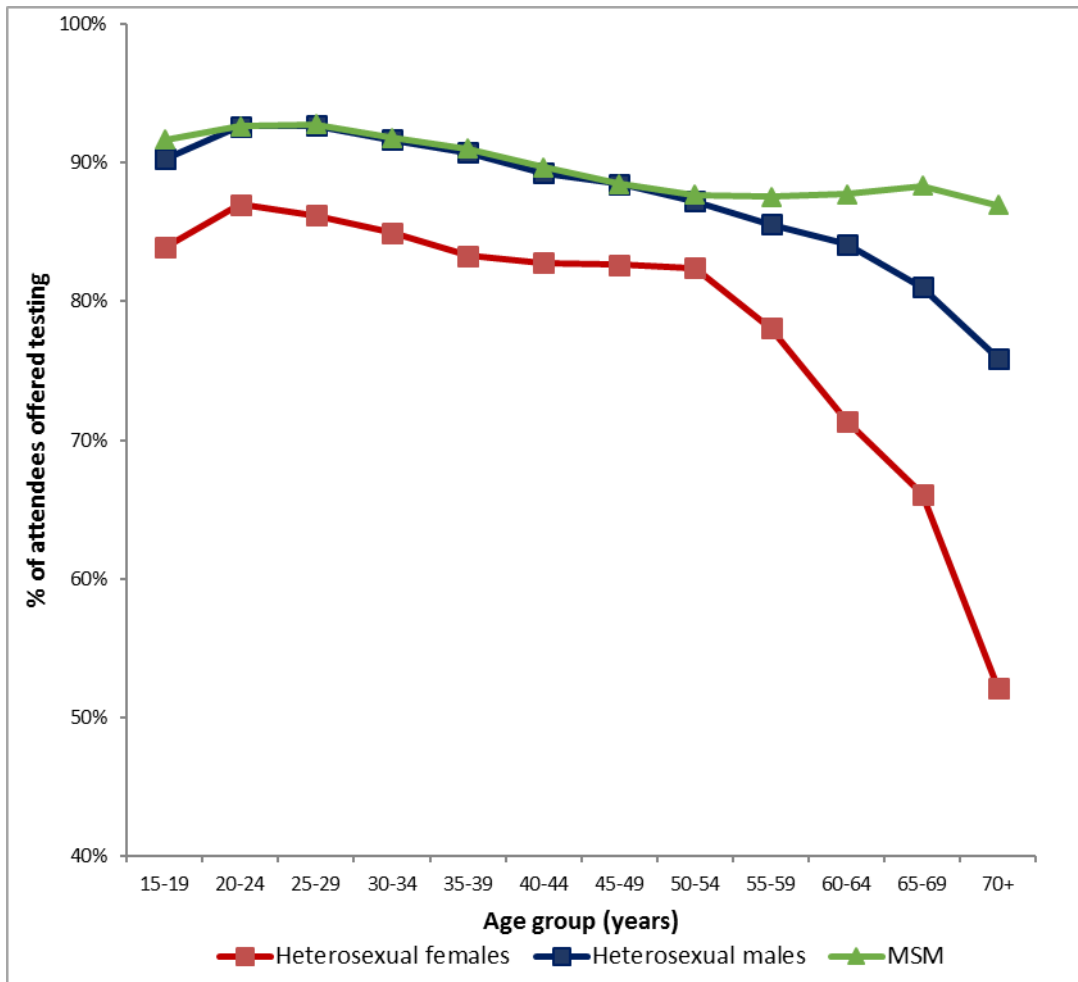


Figure 11: Proportion of sexual health/GUM clinic attendees offered a HIV test by age and sexual risk group, 2014 – England

In 2014, attendees aged 25-29 years had the highest likelihood of receiving an offer of HIV testing (88.0% overall in 2014), with the proportion of attendees receiving an offer declining with age. Only 70.3% of attendees in the over 70 age group were offered testing in 2014, 18 percentage points lower than for 25-29 year olds. The decrease in likelihood of offer was particularly pronounced for heterosexual women after the age of 50, falling to a low of 52.1% in the over 70s. Offer rates for heterosexual men and MSM in 2014 were very similar up to the age of 50-54, after which rates continued to fall for heterosexual men but remained stable for MSM. In the over 70 age group, offer rates for MSM – at 86.9% - were 11 percentage points higher than for heterosexual men and 34.8 percentage points higher than for heterosexual women.

Whilst these gaps in 2014 were large, they were even greater in previous years. Between 2009 and 2014 there were increases in the likelihood of offer for the 65-69 (69.8% to 77.1%) and 70+ (57.7% to 70.3%) age groups (Appendix 22). In comparison, for adults aged 15-24 years, the percentage of attendees offered testing declined during this time (87.7% to 82.1%).



For every year and in every risk group the association between age and offer of HIV testing was statistically significant ( $P < 0.001$  in all cases, Appendix 23) with increasing age associated with lower probability of being offered a test ( $R_s$  -0.80 to -0.99).

Following logistic regression modelling, the odds of being offered HIV testing were found to be significantly higher for eligible attendees aged 15-49 years compared to eligible attendees aged 50+ years for both genders (Table 13) and all sexual risk groups assessed (Table 14). The odds of being offered a test between age groups was similar for males and females (Table 13).

*Table 13: Likelihood of being offered a HIV test by age, by gender*

	<b><u>Males</u></b>		<b><u>Females</u></b>	
	<b>15-49 years</b>	<b>50+ years</b>	<b>15-49 years</b>	<b>50+ years</b>
<b><u>Number of attendees eligible for testing</u></b>	573,451	49,533	776,858	31,589
<b><u>Number of eligible attendees offered a HIV test</u></b>	521,949	41,862	645,693	23,957
<b><u>% offered (1dp)</u></b>	91.0%	84.5%	83.1%	75.8%
<b><u>Odds ratio</u></b> <b><u>(95% CI)*</u></b>	1.84 (1.79 to 1.89)	--	1.86 (1.81 to 1.91)	--

\*Odds for ages 15-49 versus ages 50+

Table 14: Likelihood of being offered a HIV test by age, by sexual risk group

	<u>Heterosexual males</u>		<u>Men who have sex with men</u>		<u>Heterosexual females</u>	
	<b>15-49</b>	<b>50+</b>	<b>15-49</b>	<b>50+</b>	<b>15-49</b>	<b>50+</b>
<b><u>Number of attendees eligible for testing</u></b>	460,604	36,115	92,528	11,408	729,261	29,623
<b><u>Number of eligible attendees offered a HIV test</u></b>	422,188	30,707	84,782	10,002	622,514	23,094
<b><u>% offered (1dp)</u></b>	91.7%	85.0%	91.6%	87.7%	85.4%	78.0%
<b><u>Odds ratio</u></b>	1.94	--	1.54	--	1.86	--
<b><u>(95% CI)*</u></b>	(1.88 to 2.00)		(1.45 to 1.64)		(1.81 to 1.91)	

\*Odds for ages 15-49 versus ages 50+

For attendees aged 50 and over, the odds of being offered a HIV test were greatest for MSM and lowest for heterosexual females (Table 15).

Table 15: Odds of being offered a HIV test by sexual risk group, ages 50+

	<u>Heterosexual males</u>	<u>MSM</u>	<u>Heterosexual females</u>
<b><u>Number of attendees eligible for testing</u></b>	36,115	11,408	29,623
<b><u>Number of eligible attendees offered a HIV test</u></b>	30,707	10,002	23,094
<b><u>% offered (1dp)</u></b>	85.0%	87.7%	78.0%
<b><u>Odds ratio</u></b>	--	1.25	0.55
<b><u>(95% CI)*</u></b>		(1.18 to 1.33)	(0.53 to 0.58)

\*Odds compared with heterosexual males.

Through interview and survey responses, the following barriers to test offer were identified.

#### 5.5.1 HCP expertise and willingness to test

In contrast to the evidence from national testing data in sexual health/GUM settings, HCPs (in interviews and surveys) discussed that testing is universally offered to all attendees in sexual health/GUM settings, aside from when:

*'... [they have] already tested appropriately from the history taken e.g. past screen and no new partner, blood donor...' [SAS doctor – GUM, HIV, CaSH; female; 65+ years old; low prev.]*

The majority of survey respondents (95%; n =39) stated that they offer HIV testing to everyone and feel very comfortable or completely comfortable in discussing HIV and offering testing to both younger and older people. Although levels of comfort declined slightly in relation to adults aged 50+ years (e.g. 93% of survey respondents felt completely comfortable in offering a HIV test to someone aged 15-49 years, compared to 88% to someone aged 50+ years).

Just over a third of survey respondents felt that there were additional barriers to offering a HIV test to someone aged 50+ years than a younger person; however, these barriers were discussed as affecting testing in non-HIV specialist settings. It was considered that the approach used to discuss sexual health might require adaptation for older adults. There was a clear need to be open-minded and ask about sexual risk, even when people appear to be in monogamous and 'safe' relationships, and to stress the routine nature of STI/HIV testing. This approach may be considered more challenging and require a greater amount of time, something which was considered a barrier by surveyed HCPs to non-HIV specialists.

*'... you have to be careful not to be caught out by it, so if you've been seeing somebody that's older umm I always ask them about their, try to ask them about their sexual health a lot of them find that really difficult but I always say it's part of our routine questioning, it doesn't matter who you are, where you're from, I will always ask you are you with your current partner or whatever and have you had any new partners, do you think you need a sexual health screen. I always ask them.... only because at times I've thought oh you know they'll be absolutely fine, they're in this monogamous relationship so they tell me and then something comes...and you think whoa!' [HCP #5: Female HIV Lead nurse, low prev.]*

Service users expressed greater confidence in the ability of HCPs working in sexual health/GUM settings to provide HIV testing than GPs, or other non-HIV specialists. A minority

of HCPs expressed the belief that GPs would prefer for people to access a sexual health/GUM services, as it was not their responsibility to test:

*'I do believe that there's an old guard of people who wouldn't feel comfortable about talking you know about sexually transmitted diseases or HIV, to any patient. They'd believe it was somebody else's job. Oh go to the clap clinic, go to the GU clinic...'* [HCP #2: Male associate specialist in HIV, high prev.]

Interestingly, none of the service users expressed that GPs should have raised the discussion of sexual health and had not considered discussing their sexual health or sexuality with a GP. This was linked to the limited relationships developed between service users and their GP; most had not attended general practice for many years.

*'Unless you start a conversation like that yourself, you, you don't really expect em to sort of...asking me "who are you sleeping with at the moment?" (Laughs)'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

*'... she'd never mentioned before, about sexual health...'* [Service user #5: MSM, Dx 50 years, high prev.]

It was considered that GPs may lack the competency and confidence to provide testing. Survey respondents considered that HCPs, particularly GPs and nurses, may feel less comfortable about discussing sexual health and HIV with their older patients:

*'.....I mean you know my, my GP will talk to me about anything but if I feel that. But I think that she's, she is definitely a GP that says that you know there are certain places you should go where, where expertise are better and you know er she'd rather you do that and see an expert than you get to go from her just in case she doesn't pick something up...'* [Service user #5: MSM, Dx 50 years, high prev.]

*'There is generally a reluctance to discuss HIV/STI with people as they get older'* [Male specialist nurse practitioner, 45-54 years old, low prev.]

It was considered by HCPs (surveyed and interviewed) and service users that GPs would only become interested in testing if it became financially incentivised:

*'I think if you're trying to roll out testing in GP practices there are only really two ways of doing it. One is to insert people into the practice who want to do it or to pay them. I mean it's the classic,*

*you know, pay them for every positive result and you'd have...you'd have a massive increase in testing. It's sad but that's the way it works...' [HCP #2: Male associate specialist in HIV, high prev.]*

*'GPs in [place name - high prev. area] were advised by GUM to offer everyone a blood test for HIV at new registration to the practice and as a test when taking bloods for other investigations. This I believe is not happening. Is it being incentivised?' [Female sexual health SAS doctor, 45-54 years old, high prev.]*

#### 5.5.2 Not considered at risk

Interview and survey responses, as well as national HIV testing data, indicate that HCPs are more likely to offer testing to groups targeted by HIV prevention and testing campaigns. This occurs even within sexual health/GUM services, despite the recommendation to offer testing universally (BHIVA, BASHH, & BIS, 2008). Advancing age reduces the likelihood of being considered at risk of HIV, with the misconception that older adults do not engage in high risk behaviours for HIV:

*'.....some people do think older people don't have sex, well they are having sex....so it is an area that needs to be addressed.' [HCP #1: Female HIV nurse specialist, low prev.]*

One service user mentioned HIV to his GP, however, this potential diagnosis was dismissed without any assessment of his sexual history or risk:

*'I mentioned, I said that my dad had er; my dad had um suggested it [HIV]. And he [the GP] sort of says well, I mean at the time I had, I hadn't told him I was gay you see umm and he went 'oh I'm, I'm sure something would have shown up in your bloods, blood count or something'. But er he didn't, I mean obviously he's not an expert and... I mean he is a generally a good doctor but he failed, he did fail I think on that you know' [Service user #10: MSM, Dx 57 years, high prev.]*

It was also reported that the misattribution of ageing as the cause of HIV-related symptoms, identified as a barrier to older adults accessing services (see section 5.2.1), was also a barrier to HCPs offering a HIV test.

For adults not belonging to targeted groups, advancing age compounded their likelihood of not being considered at risk. HCPs considered older heterosexual females, particularly of white ethnicity, as least likely to be offered testing. MSM were considered most likely to be offered testing. These are findings reflected in the testing data:

*'...so if you're say a gay man in your fifties....and...the doctor, your GP knew that, well most sensible GPs would say well have you had a HIV test recently, if they were coming in sick....' [HCP #4: Female clinical psychologist, high prev.]*

*'So she was sixty odd, so she had missed all of those opportunities cos nobody thought this white, she's Irish woman could be a possibly at risk of HIV....' [HCP #1: Female HIV nurse specialist, low prev.]*

### 5.5.3 Inexperience in accessing sexual health/GUM services

It is indicated, through national data and interview and survey responses, that attendance at sexual health/GUM services is more common in MSM than heterosexual men and women. The majority of interviewed MSM reported previous, sometimes frequent, STI/HIV testing in sexual health/GUM clinics.

*'...I've been a regular visitor of the [sexual health clinic name] .... and you know I tend to get tested very, very regularly, so every six months....' [Service user #11: MSM, Dx 52 years, high prev.]*

Routine HIV testing for MSM, alongside testing for other STIs, was expressed as culturally ingrained; however, this was not the case for older heterosexuals:

*'...if you are not active on the gay scene, as in out there, if you're not ummm, you don't know as many people as I do then yeah it, you're gonna...the difficulty is, it's getting through that door, not everybody checks regularly...' [Service user #6: MSM, Dx 51 years, high prev.]*

*'... the incidence of umm heterosexual men o-over fifty coming to clinic for an asymptomatic screen umm it's probably, I'd probably kind of anticipate it to be, to be quite low. It's normally kind of response to a symptom of a, another STI new gonorrhoea or warts or herpes or whatever.' [HCP #7: Male GUM specialist nurse, low prev.]*

### 5.5.4 Concerns about confidentiality

Interviewed HCPs and survey respondents reported that service users have concerns about anonymity and confidentiality in attending general practice for sexual health discussions and testing. This was linked to their familiarity with the GP and other staff at the practice. A lack of anonymity was also considered to make the interaction between a GP and service user more 'difficult', with HCPs worried about causing embarrassment or offense:

*'I think in general practice, I, I can totally sympathise and see the difficulties GPs because I think it's two-fold. I think um they probably know their patients well and, whereas very often we just see*

*somewhere for a one off check-up so it is a little bit more kind of anonymous and um, you know, there isn't that sort of on-going relationship um and also I think people coming here are expecting. They're coming to, a, a sexual health clinic so they are kind of expecting to be asked certain questions and be offered certain tests whereas they won't be going to their GPs so they probably would be more shocked so I do sympathise. I think it is probably more difficult in general practice to get on to this type of testing' [HCP #12: Female consultant in GUM, low prev.]*

#### 5.5.5 Stigma

Stigma was considered in relation to accessing sexual health/GUM services, and was acknowledged as a problem faced by younger as well as older people:

*'...e-even younger people, it's, it is getting better but it's getting slowly, even, even younger people umm you know, don't like the idea of coming to the clinic and see it as a stigma rather than as a, coming for a routine STI test as the sensible thing to do...' [HCP#10: Female GUM doctor, low HIV prevalence]*

It was expressed by HCPs that the stigma associated with sexual health/GUM settings was linked to the environment itself, rather than the care provided, although improvements in the appearance of these settings were apparent. It was considered advantageous to incorporate sexual health/GUM or HIV clinics within the main body of a hospital, to normalise this setting alongside other hospital departments:

*'... it's not as if like in some sexual health clinics you'll find they're sort of far away.... where nobody's gonna see you going in....and I think it would have been so easy for [hospital name] to take the [HIV clinic name] and put it somewhere at the back.... but they haven't done that. They've put the, you've got the sign up, you've got, know where it goes to and that in a way is.... a very positive statement, them saying well yes we know the people that are going into this clinic are suffering from HIV but there is no shame of that, they're coming to get treatment like anybody else comes to get treatment for any other virus or whatever....' [Service user #5: MSM, Dx 50 years, high prev.]*

#### 5.5.6 Geographical location

All service users that reported previous sexual health/GUM clinic attendance, or self-initiated testing in these settings, lived in high HIV prevalence areas. Several service users felt that it would be easier to access a sexual health clinic in an urban, high HIV prevalence area than a rural, low prevalence area. This was discussed in terms of travel time.

*'It also depends on where you are in the country.... if you were living in London or Manchester or Birmingham, a bigger city.... you may not go for regular screening.... I used to live you know two minutes down the road and I used to come up here every three months.....I came up here and walked, went to the walk- in, but if you're out, if you're in smaller places that would be more difficult' [Service user #6: MSM, Dx 51 years, high prev.]*

It was also considered that the limited choices of where to seek sexual health care in rural or suburban low prevalence areas might create greater concerns regarding confidentiality:

*'[Place name - high prevalence] is very different, different, because you can usually work and live in two different places and therefore sometimes it means that you, you can separate your life a lot easier but er, if you, you know live in a small village in [place name] quite often you work nearby and your social life revolves around there and you live there so you kind of, it's all linked' [HCP #5: Female HIV lead nurse, low prev.]*

It was clear that this concern could lead to some people travelling further away from their home for testing. This carries cost and time implications and could serve as a testing barrier:

*'I can think of a particular umm.... older man at one of our clinics, ermm, who lived in a rural community and used to come to the clinic...he wouldn't give his GP details and I don't think we even had a telephone number. He admitted to having sex-, he was, he was married as far as, er I was fairly certain he was married and he lived, you know, with his wife in a, a small, I say in a small rural community of some sort, er, some miles from our clinic. He deliberately chose a clinic which was, which was out of his area...' [HCP #10: Female GUM doctor, low prev.]*

It was also considered that it would be less embarrassing for older people to attend sexual health/GUM clinics in high rather than low HIV prevalence areas. This was due to the wider age range of attendees in these settings, a result of higher levels of STIs and HIV:

*'.... the majority are young people who I would guess attend sort of the more suburban sexual health clinic, you know, probably here in [high prev. area] you'd have gay men of all ages....' [HCP #1: Female HIV specialist nurse, high prev.]*

MSM that attended sexual health/GUM services to self-initiate testing perceived this environment to be readily accessible. This was linked to the friendliness of HCPs working in this setting:

*'In my book already you know this is a fantastic institution. They make it very easy to come and test yeah. So they really accommodate you and they're friendly and they're nice and they take*



*their time to chat and explain and er, you know, develop a relation to them to some extent'*

*[Service user #11: MSM, Dx 52 years, high prev.]*

### 5.5.7 Older age

Although not expressed by the interviewed service users that had self-initiated HIV testing in sexual health/GUM clinics, the majority of HCPs considered that this setting is youth focused:

*'...any older person might feel uncomfortable. Also ermm they don't like to be in the waiting with a lot of very, we don't have a lot of very silly you people but sometimes people come in as a group and can giggle and er cause a bit of minor mayhem and be quite unpleasant...'* *[HCP #10: Female*

*GUM doctor, low prev.]*

When surveyed, 80% of HCPs felt that sexual health/HIV clinics were more accessible to younger than older adults (Figure 12).

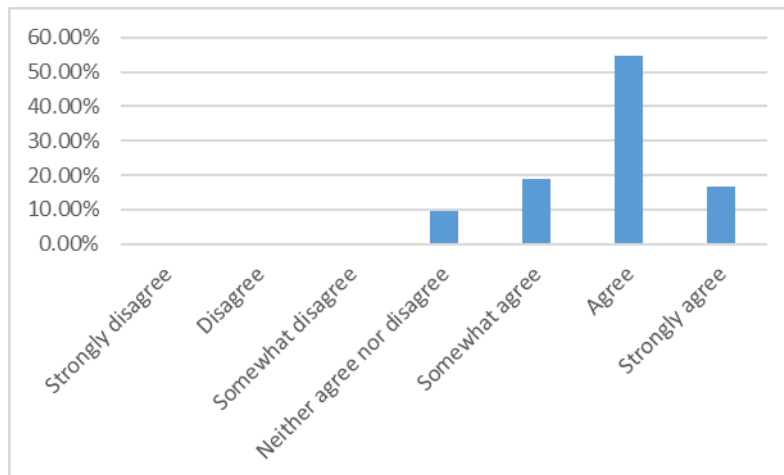


Figure 12: HCP's agreement with the statement 'I think that younger adults wanting to discuss HIV risk feel more able to use a sexual health/HIV clinic than older adults' (HCP survey)

Survey respondents reported that older adults might feel 'embarrassed to come and sit next to giggling teens' and may instead prefer to access their GP. One service user, diagnosed on a hospital ward, also considered sexual health/GUM to alienate older adults:

*'... the GU clinic is absolutely horrible for older people because it is so focused on young men and women going for all kinds of tests for all kinds of sexually transmitted diseases and you're just another one of them.'* *[Service user #12: MSM, Dx 68 years, high prev.]*

The impression of sexual health/GUM clinics as more accessible to younger adults was not associated with the care provided by HCPs; it was linked to the environment itself:

*'... the information is all geared to young people. It's all about sexual health, it's not about an older person living with HIV' [HCP #5: Female HIV lead nurse, low prev.]*

*'...you know, the television is either on radio one or umm you know a music channel and that, I, you can strongly imagine that older people, not all but most, would probably not want that...'*

*[HCP #9: Male HIV Lead nurse, low prev.]*

It was considered to be 'within the culture' of younger people to attend sexual health/GUM services. One HCP, aged over 50 years herself, stated that she personally would sooner visit her GP with a sexual health problem:

*'I mean I, I'm not in the first flush of youth and I have to say if I had a sexual health issue I wouldn't be coming here. I'd rather go to my GP because I would feel more comfortable...'* [HCP #5: Female

*HIV Lead nurse, low prev.]*

Several HCPs perceived that sexual health services are accessible to any age group. It was stated that employees in these services may pay more attention to older people; however, this description almost presents older attendees as a novelty:

*'... actually the receptionists like to, the sort of slightly odd cases, well you know, there's always another young kid wanting a check-up. There's always another girl or another boy coming but when somebody different comes, somebody older, they actually, the receptionists like that...'* [HCP

*#8: HIV consultant, low HIV prev.]*

Other HCPs also considered their sexual health/GUM clinics to be accessible to all; however, they struggled to recall older, particularly asymptomatic, attendees to their service:

*'I would say that the majority of our older patients tend to come through because they've been diagnosed elsewhere in general they wouldn't necessarily come here. They might then come here as contacts or partners of people who are diagnosed umm, you've got, you know, certainly I would say that the overwhelming majority of our population, our, our service users are younger people'*

*[HCP #9: Male HIV Lead nurse, low prev.]*

This impression of services as more youth orientated was justified by HCPs as a product of self-selection, due to younger people being the largest group of sexual health/GUM clinics attendees. Some of these justifications were based on stereotypical impressions about age and engagement in 'risky behaviours', and also economic evaluations. HCPs expressed the need to target finite resources on the group most affected by STIs/HIV:

*'... making ourselves kind of accessible to young people is like the priority....and it's probably to the detriment of remaining sort of umm welcoming to the kind of over fifties I think because there tends to be a bit of a contrast there in terms of what is, what'd be appealing to a young person and what would be appealing to an older person.... That's just you know because you need to look at every, epidemiology of public health and you think well where do we focus our resources?' [HCP #7: Male GUM specialist nurse, low prev.]*

#### 5.6 Acceptability of HIV testing to adults aged 50+ years

Although discussed in retrospect, service users expressed no opposition to accepting a HIV test. The consensus was that HIV testing should be more readily offered, in a variety of settings, and performed alongside other blood tests.

*'[it's] something that I think they should do when they check you for diabetes and anything....and if it's negative, it's negative. It's like all the other things they check you for, if you're negative then it's not a problem and if it's positive then you do wanna know...' [Service user #4: Heterosexual male, Dx 51 years, low prev.]*

HCPs discussed high levels of test acceptance by sexual health/GUM attendees, irrespective of age. Test offer was perhaps considered more agreeable to older adults than HCPs anticipated:

*'One feedback we had from an old man about eighty-two was "this is the most exciting thing that's happened to me" (both laugh) but they are quite...yes there doesn't seem to be, the block is with the practitioner I think.' [HCP #5: Female HIV Lead nurse, low prev.]*

Analysis of national sexual health/GUM service testing data shows that HIV test acceptance in these settings is broadly similar across all age groups and for all sexual risk group (Figure 13). In 2014, overall attenders in the 55-59 and 65-69 age groups were most likely to accept the offer of testing, with acceptance rates lowest in the 15-19 age group.

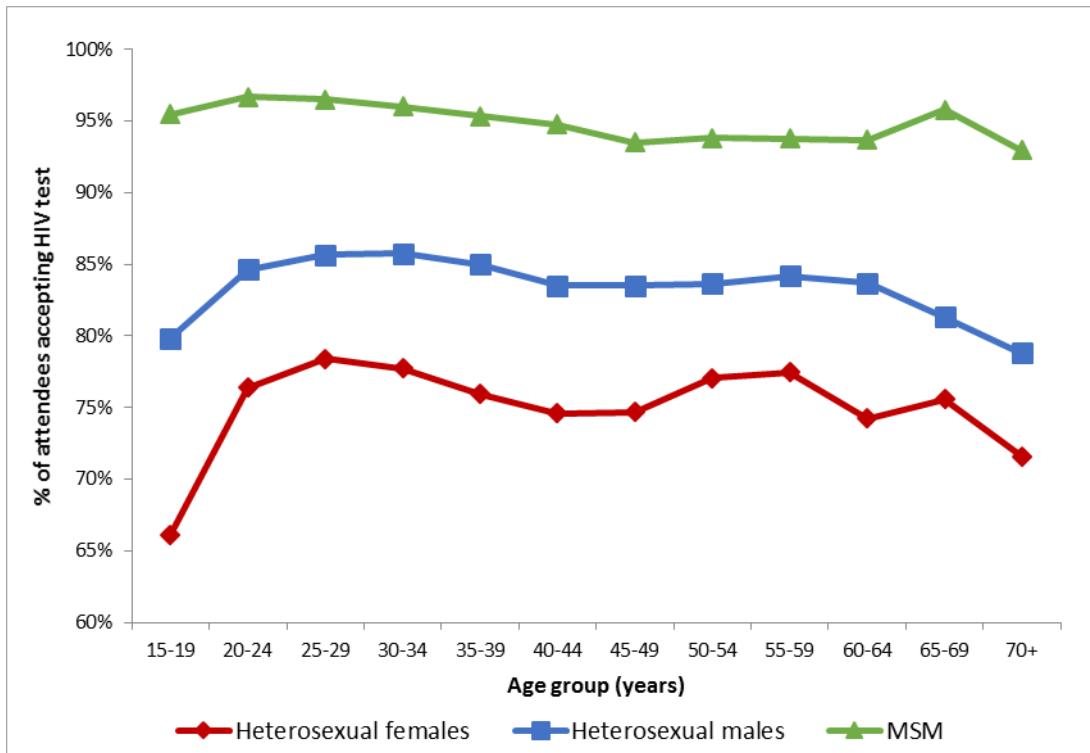


Figure 13: Proportion of sexual health/GUM clinic attendees accepting a HIV test by age and sexual risk group, 2014 – England.

Given the much lower rates of acceptance in the 15-19 age group and the relatively high rates of acceptance for attendees in their 50s, the association between age and acceptance of testing is not as clear as for offer of testing. The linear association is only statistically significant in every year for MSM ( $p < 0.05$  in all cases, Appendix 23), with increasing age associated with lower probability of testing ( $R_s$  -0.600 to -0.954). However, in 2014, the difference between uptake rates in the 20-24 and over 70 age groups for MSM was only 3.8%, and acceptance rates in every age group were over 90%.

Logistic regression modelling was again performed, this time to explore the odds of test acceptance by attendees aged 15-49 years compared to attendees aged 50+ years by gender (table 16) and sexual risk group (table 17).

Table 16: Likelihood of accepting a HIV test offer by age, by gender

	<u>Males</u>		<u>Females</u>	
	15-49 years	50+ years	15-49 years	50+ years
<b><u>Number of eligible attendees offered a HIV test</u></b>	521,949	41,862	645,693	23,957
<b><u>Number of eligible attendees accepting a test offer</u></b>	450,680	35,918	483,997	18,331
<b><u>% accepted (1dp)</u></b>	86.3%	85.8%	75.0%	76.5%
<b><u>Odds ratio</u></b> <b><u>(95% CI)*</u></b>	1.05 (1.02 to 1.08)	--	0.92 (0.89 to 0.95)	--

\*Odds for ages 15-49 versus ages 50+

Table 17: Likelihood of accepting a HIV test by age, by sexual risk group

	<u>Heterosexual males</u>		<u>Men who have sex with men</u>		<u>Heterosexual females</u>	
	15-49	50+	15-49	50+	15-49	50+
<b>Number and eligible attendees offered a HIV test</b>	422,188	30,707	84,782	10,002	622,514	23,094
<b>Number of eligible attendees accepting a test offer</b>	356,834	25,569	81,253	9,394	467,441	17,701
<b>% accepted (1dp)</b>	84.5%	83.3%	95.8%	93.9%	75.1%	76.6%
<b>Odds ratio</b> <b>(95% CI)*</b>	1.10 (1.06 to 1.13)	--	1.49 (1.36 to 1.63)	--	0.92 (0.89 to 0.95)	--

\*Odds for ages 15-49 versus ages 50+

Table 18: Odds of accepting a HIV test by sexual risk group, ages 50+

	<b><u>Heterosexual males</u></b>	<b><u>MSM</u></b>	<b><u>Heterosexual females</u></b>
<b><u>Number and eligible attendees offered a HIV test</u></b>	30,707	10,002	23,094
<b><u>Number of eligible attendees accepting a test offer</u></b>	25,569	9,394	17,701
<b><u>% accepted (1dp)</u></b>	83.3%	93.9%	76.6%
<b><u>Odds ratio (95% CI)*</u></b>	--	1.10 (1.06-1.13)	0.30 (0.30 to 0.31)

\*Odds compared with heterosexual males.

These findings suggest that, in sexual health/GUM settings, older MSM and heterosexual males are less likely to accept a HIV test than their younger comparators; this is particularly the case for MSM. For heterosexual females, attendees aged 50 and over are slightly more likely to accept testing than their younger comparators.

However, the strongest determinant of test acceptance is sexual risk group. For older attendees, compared with heterosexual males the odds of test acceptance are higher for MSM (odds ratio = 1.10) and lower for heterosexual females (odds ratio = 0.30) (Table 18).

## 5.7 Discussion

### 5.7.1 Non-specific symptoms, older age and HIV

A major barrier to the early detection of HIV is the absence of symptoms, or a lack of concerning symptoms, until potentially several years after infection (BHIVA, BASHH, & BIS, 2008). The majority of service users reported no symptoms prior to diagnosis, or symptoms for which HIV was not considered a cause.

Clinical indicator conditions to prompt HIV testing, outlined by the BHIVA, BASHH & BIS (2008), appear ineffective in triggering HIV testing (Damery et al., 2013; Hsu et al., 2013; Sudarshi et al., 2008). This is considered a result of presenting conditions often being associated with a range of other health problems (Damery et al., 2013).

A particular barrier to testing for older adults is that symptoms of HIV, such as tiredness and weight loss, may be attributed to 'normal' ageing (Grabar, Weiss, & Costagliola, 2006; Siegel, Schrimshaw, & Dean, 1999; UNAIDS, 2002; Wooten-Bielski, 1999). This may lead to delays in accessing health services, and to HCPs offering a test. Service user age was also reported as a barrier to HCPs discussing sexual health/HIV with older people. This is in concordance with previous research that reports GP embarrassment and worries about causing offence in discussing sexual health with adults aged 50+ years (Gott, Hinchliff, & Galena, 2003), and that HCPs are less likely to take a sexual history and discuss sexual health/HIV with older people (Farrell & Belza, 2012; Grant & Ragsdale, 2008; Lindau et al., 2006; Loeb et al., 2011; Maes & Louis, 2011; Skiest & Keiser, 1997; Slinkard & Kazer, 2011).

### 5.7.2 Not ticking the right boxes

It has been found that HCPs have a greater tendency to explain symptoms as due to conditions that are common or topical (Foot, Naylor & Imison, 2010; Triplet, 1992). HCPs have been found more likely to provide a diagnosis of conditions that most readily come to mind (*availability heuristic*) (Bornstein & Emler, 2000; Poses & Anthony, 1991) and to be influenced by factors beyond patient's symptoms e.g. a person's characteristics, lifestyle choices and behaviours (*representativeness heuristic*) (Bornstein & Emler, 2000; Brannon & Carson, 2003). The national guidelines actively encourage bias in HIV testing due to this representativeness heuristic, with the focus on testing certain groups (AHPN., n.d; BHIVA, BASHH, & BIS, 2008; Fowler et al., 2011; NICE, 2011a; NICE, 2011b; THT, n.d). The focus on MSM appears to have inadvertently increased the risk of late HIV diagnosis in the heterosexual population (Delpierre et al., 2007). Middle-aged white females were highlighted as a group considered

particularly at risk by HCPs. This has been identified in epidemiological studies (Smith et al., 2010) and in further qualitative studies:

*'I'm in a minority, because HIV is a minority in itself, I'm heterosexual, and, being white ... I'm not sure what the statistics are. But it feels like a minority within a minority within a minority. You're one of a kind. There are not many people in this situation' (White heterosexual female in her 60s, living with HIV (long-term diagnosed); Excerpt from Rosenfeld et al., 2015).*

The term candidacy is used by Dixon-Woods et al describe 'the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services' (2006). For adults diagnosed at a late stage of disease, this was associated with the individual not considering themselves as at risk of HIV, in addition to their HCPs. Even within sexual health/GUM settings, where opt-out HIV testing should be in place (BHIVA, BASHH, & BIS, 2008), it was identified that adults not targeted in HIV testing and prevention campaigns were less likely to be offered a test.

HCPs and service users were sympathetic to the position of GPs, required to serve as a 'jack of all trades' and to have a broad knowledge of medical conditions; therefore, diagnosing HIV was recognised as an understandably challenging in this setting.

### 5.7.3 Health seeking on turning 50

For a few service users, reaching midlife prompted greater concern over their health and encouraged them to test for HIV. Health concerns were expressed personally and by family members, as it was acknowledged that health conditions are more prevalent with advancing age (Barnett et al., 2012; DH, 2012). At around the age of 50 years onwards, in the UK people are invited for cancer screenings (Cancer Research UK, 2014; Cancer Research UK, 2015), and an NHS Health Check (NHS Choices, 2016a). It is also recommended that older people regularly have cholesterol checks and blood pressure measurements (NHS Choices, 2015b; NHS Choices, 2015c). For services users, it appeared that turning 50, and the health checks associated with older age, were cues to greater consideration of their health in general. This was further enforced when service users were aware of friends and family, of a similar age, experiencing health problems.

### 5.7.4 HIV knowledge

Adults aged 50+ years are generally reported to have lower levels of HIV knowledge than younger people (Gott, 2001; Henderson et al., 2004; Mack & Bland, 1999; NAT, 2014b), particularly older white heterosexual females (Grant & Ragsdale, 2004; Ross, Humble, &



Blum, 2013). Recent newspaper articles have highlighted the shock of middle-aged white heterosexual women in testing positive for HIV:

*'I just didn't know anything about it - I just thought you got it in Africa. I didn't know a white person had ever got it' (White heterosexual woman, diagnosed with HIV at age 40 years; Excerpt from Freeman, 2012)*

It was considered that at any age, adults targeted in HIV prevention and testing campaigns had higher HIV knowledge than other groups. Interviewed MSM displayed greater awareness and accuracy in their knowledge of HIV than heterosexuals and were considered by HCPs to be better informed about HIV. Awareness of HIV transmission routes has been identified as high in MSM; a recent survey, including 1415 participants aged 55-90 years found that 96.8% of MSM were aware that HIV could be transmitted through unprotected passive anal intercourse (Hickson et al., 2016).

High levels of knowledge in MSM are largely from belonging to the gay community, in which information about STIs and HIV is shared. As a group highly at risk of HIV, MSM are extensively targeted in STI/HIV prevention and testing campaigns (Gay Men Fighting AIDS (GMFA), 2012; NICE, 2011b; THT, n.d). This is particularly evident in high HIV prevalence areas (LGBT Foundation, 2017; London HIV Prevention Programme, n.d).

Although no black Africans participated in this research project, it has previously been found that HIV knowledge in this group is higher than in the general public. 96% of participants in a survey of black African men and women were aware of the risk of HIV transmission through unprotected sex (Bourne, Reid, & Weatherburn, 2014). In the general public, only around 80% were aware that HIV could be transmitted via this route (NAT, 2014b). This again indicates the impact of targeted HIV prevention and testing messages.

#### 5.7.5 'Precaution fatigue'

With advancing age, for some interviewed MSM their perception of HIV risk had diminished. Weinstein has previously identified that people may display unrealistic optimism towards their health if they have lived for a long time without developing illness (1982). After years of living in fear of HIV and taking precautions, some service users had developed 'precaution fatigue' and become complacent about their HIV risk. Linked to these interview findings, test acceptance data also identified that MSM aged 50+ years are less likely to accept a HIV test than younger MSM (see section 5.6).

Through interviews, it was reported that fear surrounding HIV had diminished in older MSM as they were aware of the development of increasingly effective treatments. By contrast, it was considered that younger adults may be unaware of HIV given the lack of national prevention campaign since the 80s, and that this may result in a lack of precaution taking in this group. Although literature is unavailable for the UK, a study conducted in France found that younger adults had become less afraid of HIV and this was linked to a decline in condom use (Beltzer et al., 2013).

#### 5.7.6 Lack of incentive to test for HIV in general practice

HIV is not included within the Quality and Outcomes Framework (QOF); the only sexual health related measure included in the QOF relates to contraception (General Practitioners Committee, NHS Employers, & NHS England, 2016). It was considered by several HCPs that GPs would only become interested in testing for HIV if this became financially incentivised, something which has been recommended by NAT (2009a; 2012).

NAT argue that in general practice, late HIV diagnosis should be classed as a 'significant event' and lead to a review of services (2012). Cancer diagnosed late is considered a 'significant event', which can be investigated by the Care Quality Commission (Royal College of General Practitioners (RCGP), 2016). NAT argue that this should also be the case for HIV.

#### 5.7.7 Geographical location/HIV prevalence and testing

It has been found that receiving a late HIV diagnosis may be more likely in low HIV prevalence areas (prevalence of HIV < 2 per 1000 population) (Ratcliffe et al., 2011). This suggests that HCPs in high prevalence areas, particularly London, may more readily offer testing, as per national recommendations (BHIVA, BASHH, & BIS, 2008). It also indicates that awareness of HIV and willingness to test may be greater in these areas. Regional variation has also been identified in figures for MSM; the proportion of MSM that have ever tested for HIV was found to be highest in London (89.4%) and lowest in the Midlands and East of England (70.5%) (Hickson et al., 2016).

However, the relationship between HIV prevalence and late diagnosis is skewed by London. Chadborn (2005) highlighted that the proportion of late diagnoses is much higher outside the capital, and this is evident from Table 19, which shows that the lowest proportion of late HIV diagnoses was in London, which is also an area of very high HIV prevalence. Outside the capital, there is no clear relationship between HIV prevalence and rates of late diagnosis (Spearman's  $R = +0.1$ ), and other characteristics of the Regions may therefore be more important.

Table 19: HIV prevalence and the proportion of late HIV diagnoses by region, England (PHE, n.d)

Region	HIV prevalence (diagnosed rate per 1000 people aged 15-59 years) - 2015	Proportion of HIV diagnoses classed as late, 2013-2015 (CD4 <350cells/mm <sup>3</sup> within 91 days of diagnosis)
East Midlands	1.42	51.2%
East of England	1.43	51.4%
South East	1.77	43.6%
South West	1.13	41.1%
London	5.83	33.5%
North East	0.98	45.1%
North West	1.78	46.3%
West Midlands	1.66	45.5%
Yorkshire and the	1.32	48.2%

#### 5.7.8 Sexual risk group, age and service acceptability

Although the number of older people accessing sexual health/GUM clinics has increased (Fish et al., 2012) sexual health/GUM clinics still appear to be youth focused. The continued efforts to target younger people have been justified by the high volume of younger adults attending these services, and the greater numbers of STIs in this population.

In previous studies, older people have been found to favour seeking sexual health advice from their GP, rather than sexual health/GUM services (Gott, 2001); however, the only service users that self-initiated STI/HIV testing did so at a sexual health/GUM clinic. For these service users, who all identified as MSM, testing in sexual health/GUM settings appeared to have become habitual. Annual testing is recommended for MSM (NICE, 2011b) and appears to be adopted by the majority of this group; 68.2% of MSM were identified within a survey conducted in 2014 to have been tested for HIV in the previous year, with almost three quarters testing in sexual health/GUM clinics rather than general practice (Hickson et al., 2016).

#### 5.8 Summary

- Older adults, particularly heterosexual men and women, appear less likely to self-initiate HIV testing. At any age, MSM appear more likely than heterosexuals to attend sexual health/GUM services for routine sexual health screening.
- Sexual health/GUM clinics are largely perceived as youth focused.

- With advancing age, sexual health/GUM attendees are less likely to be offered HIV testing. Low test offer in sexual health/GUM settings is especially marked for heterosexual women.
- Test acceptance in MSM and heterosexual males at age 50+ years is lower than in their younger counterparts. This suggests that with advancing age, personal perceptions of HIV risk may decline. For MSM, this relates to the development of 'precaution fatigue'; a lessening of precaution efforts and diminished perception of personal risk after years of living in fear of HIV, and not becoming infected, has created a false sense of safety.
- For older attendees, the likelihood of both being offered a HIV test and accepting a test is increased in MSM and reduced in heterosexual females, compared with heterosexual males. Variations in testing rates for different risk groups are likely to reflect the perceptions of risk of both health care providers and clinic attendees.
- A major barrier to the early detection of HIV is the lack of specific symptoms associated with the disease. This is accentuated in older people, for whom symptoms may be misinterpreted as related to ageing.
- HIV knowledge was necessary but not sufficient to encourage the self-initiating of testing. HIV awareness was highest in MSM, a result of the extensive HIV prevention and testing initiatives aimed at this group. Heterosexual men and women appear to have lower HIV knowledge.
- Belonging to a low risk group (e.g. not black African or MSM) seemed to inadvertently place white heterosexuals at greater HIV risk. Older white heterosexual women were particularly unlikely to be offered and accept HIV testing.
- Barriers to testing include: fear, stigma, limited HCP knowledge about HIV, and a lack of incentives to test. Testing barriers are not just related to age but also to other factors such as sexuality, gender, and geographical location.





## Chapter 6: HIV diagnosis and treatment

### 6.1 Introduction

Following an exploration of journeys to HIV testing for adults aged 50+ years in chapter five, this section of the results focuses on diagnosis and start of treatment; subsequent events in the *Model of Pathways to Treatment* (MPT) (Scott et al., 2013; Walter et al., 2012; Figure 3). This chapter will draw upon and integrate findings from:

- Qualitative interviews with adults diagnosed with HIV at age 50+ years (service users);
- Qualitative interviews with HCPs working in sexual health/HIV services and providing care for adults aged 50+ years at risk of or diagnosed with HIV;
- A survey of HCPs working in sexual health/HIV services and providing care for adults aged 50+ years at risk of or diagnosed with HIV;
- An analysis of HIV diagnosis data for England (1998 to 2013) by age, sexual risk group and ethnicity.

The chapter will explore initial reactions to testing positive for HIV and the impact of receiving a late HIV diagnosis. It will also look at the transition from diagnostic to HIV treatment services, experiences of disclosing a positive HIV status, and of taking antiretroviral therapy (ART). Firstly, it will provide an examination of HIV diagnosis data.

### 6.2 An age-related shift in new HIV diagnoses

In England, the total number of reported new HIV diagnoses increased from 2597 cases in 1998 to a peak of 7270 in 2005; an almost threefold increase over 7 years (Figure 14). Since 2005, the total number of reported new diagnoses per annum has gradually decreased (Figure 14).

In younger adults (15-49 years), new diagnoses have followed the same pattern as total cases, with a steady decline since 2005 (Appendix 24). Rates of new HIV diagnoses in younger age groups, calculated using mid-year population estimates, have largely decreased (particularly in adults aged 25-29 years and 30-34 years) or remained stable (Appendix 25).

By contrast, new HIV diagnoses in adults aged 50+ years have increased, from 217 cases in 1998 to 884 in 2013 – a fourfold increase (Figure 14). In 2013, 16.1% of new HIV diagnoses in England were in the 50+ age group; compared to 8.1% in 1998, reflecting a clear age-related

shift in the HIV epidemic. HIV diagnosis rates, calculated using mid-year population estimates, have largely increased across all 50+ age groups (Figure 15).

In adults aged 50+ years new HIV diagnosis rates decrease with increasing age, with the highest rates in the 50-54 age group and lowest rates in the 80+ age group (Figure 15). The majority of HIV diagnoses in older adults are therefore in those aged 50-59 years, and the increase in diagnosis rates between 1998 and 2013 was greatest for this age range. However, in recent years (2012, 2013) even age groups for which diagnosis rates have previously been extremely low (75-79 years and 80+ years) have experienced a rapid relative increase. This has occurred for all sexual risk groups (Appendix 25 to 28).

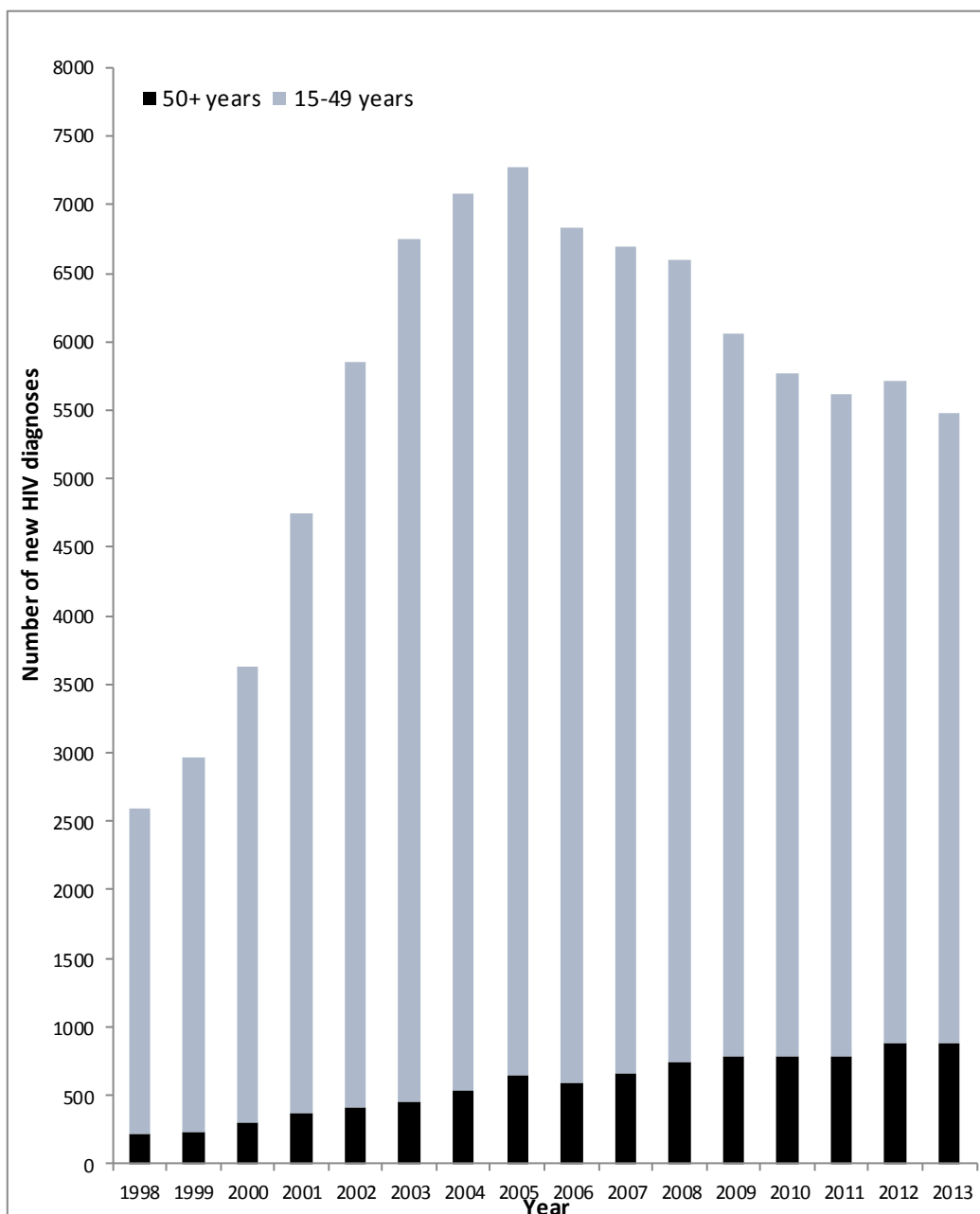


Figure 14: New HIV diagnoses per annum in adults aged 15-49 years and 50+ years, England (1998 to 2013)



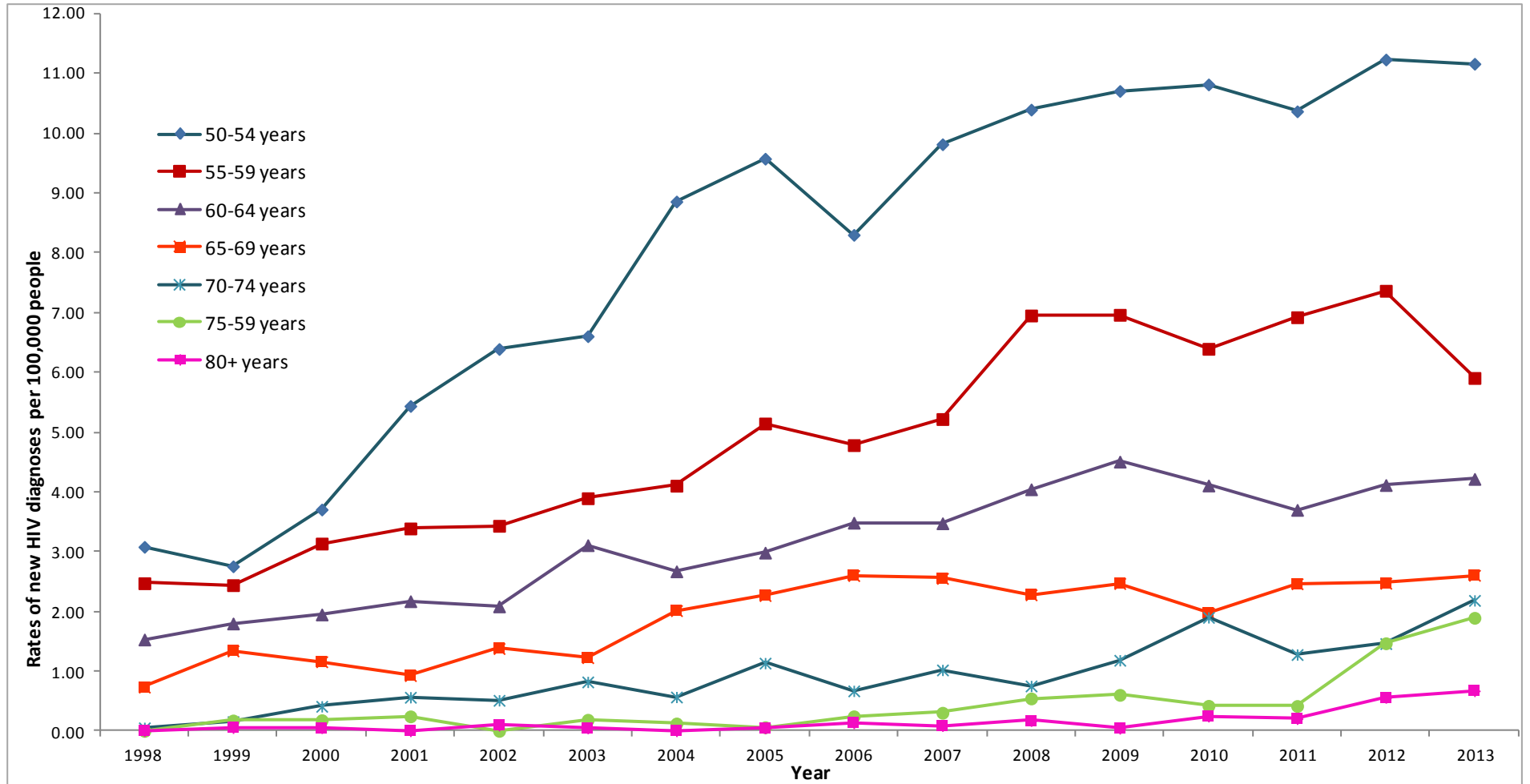


Figure 15: Rates of new HIV diagnoses in older age groups (50+ years), England (1998 to 2013)

The proportion of adults aged 50+ years that are newly diagnosed with HIV has increased across all sexual risk groups (Appendix 29). This has also been the case for adults aged 40-49 years, indicating that an age-shift in the epidemic begins around this age. The largest proportional increases over time in this age group were in heterosexual men and women (Appendix 29). Older adults account for a high proportion of heterosexual males diagnosed with HIV; over a quarter of heterosexual males diagnosed with HIV in 2013 were aged 50+ years (Table 20). However, the highest numbers of new HIV diagnoses in adults aged 50+ years in 2013 were in MSM (Table 20).

Table 20: New HIV diagnoses in adults aged 50+ years by sexual risk group, England 2013

	<u>Number of new HIV diagnoses in adults aged 50+ years</u>	<u>% of all new HIV diagnoses that occur in adults aged 50+ years</u>
<b>MSM</b>	272	10.2%
<b>Heterosexual males</b>	226	25.9%
<b>Heterosexual females</b>	181	16.4%

Several HCPs (survey respondents and interview participants) discussed witnessing an increase in new HIV diagnoses in adults aged 50+ years in their place of work:

*'We have >50 patients who have been diagnosed with HIV at an age of 50 or older. HIV in >50y is seen more commonly more than 15y ago.'* [Survey respondent: Female specialist sexual health consultant, 35-44 years, low prev.]

In contrast to sexual health clinic attendees (section 5.5.7), HCPs reported that a large proportion of HIV service attendees are aged 50+ years; reflecting both an increase in people ageing with HIV as well as new HIV diagnoses at this age:

*'.... I've got lots of patients who are older so I work with, I've got a seventy-five-year-old that I'm working with at the moment, I've got umm, quite a few in their fifties, quite a few actually now, and also some in their sixties as well so it, it's really varied. I'd say, as a team we still probably get a peak around the forties/fifties mark umm but some of those are people that have had HIV for a long time and some are new.....'* [HCP #4: Female clinical psychologist, high prev.]

### 6.3 '... you're gonna tell me I'm HIV, aren't you?'

Given the emerging increase in new HIV diagnoses in older adults, it is important to explore the competency of HCPs in delivering positive test results to someone in this age group as well as to younger people. The majority of service users expressed no complaint about how they were informed of their positive result and praised how the diagnosis was managed:

*'...I can't knock the care and the....the honesty that...they give you. You know, so it's all, from my point of view it's all positive for here.'* [Service user #8: MSM, Dx 53 years, high prev.]

However, one service user reported particularly poor communication from HCPs in a hospital setting and on receiving his results was not aware that a HIV test had been performed:

*'...she [doctor] said 'well now (participant's name) you've been told about your diagnosis and I've come to see what I can do to um reassure you' and I said 'well sorry I haven't been told anything at all'. So she [said] '...well what do you mean?' and I said 'I haven't been told anything about any diagnosis about what's wrong with me'..... So she said 'ah right', well she said er 'we you know that you have um Cryptosporidium which is a, you know, parasitical um infection in, in your um gut'. I said 'no I don't know that but I guessed that, that's what it might be'. And she said 'you know that you were tested for HIV?' and I said 'no, I didn't know that' and she said 'you didn't give consent?' and I said 'no, nobody ever mentioned HIV to me once since I came in here. I've had blood taken several times; I know I've had a whole lot of tests but nobody mentioned HIV'.....'*  
[Service user #12: MSM, Dx 68 years, high prev.]

This service user felt there was lack of care and communication from HCPs throughout his hospital stay, which he interpreted as discriminatory. As this person was uninformed of when the HIV test was performed, he felt that the poor care he received was due to HCP awareness of the diagnosis before him:

*'...the doctors didn't tell me anything at all about what their progress. I had er internal examinations, I had er heart examinations and all kinds of things but the doctors on the ward told me nothing at all. And the nurses on the ward mostly didn't speak to me. And then I've always wondered if they had information long before me about my diagnosis because of their attitude towards me'* [Service user #12: MSM, Dx 68 years, high prev.]

Another service user reported receiving his diagnosis over the telephone, something which he considered inappropriate, particularly as he was alone when contacted. This service user also found that the GP informing him of his diagnosis lacked confidence and competency in providing his results:

*'I got to know through the telephone, which is not a perfect situation..., ermm, and, and...I....I, I think he felt more uncomfortable speaking about it...er than, than me actually....'* [Service user #3: MSM, Dx 53 years, high prev.]

#### 6.4 Transition to treatment services

Although the majority of service users had experienced a smooth and efficient transfer from diagnostic to treatment services, examples of fragmented care were highlighted by HCPs and a service user. These were considered by HCPs to be a consequence of changes to HIV service commissioning in the UK (APPG HIV/AIDS, 2016; NAO, 2016; NAT, 2014a).

One service user, who was symptomatic at discharge from hospital following diagnosis, reported a long delay between testing positive and attendance at HIV treatment services. This was described as due to failings from the referring hospital ward:

*'I asked what will happen next and they said well you go home and you wait and in 2-3 weeks you'll get a letter with an appointment for the [hospital name] Infectious Diseases department. And that is exactly what happened. I went home, er, I was in a state of, I was really traumatised and everything and anxious.....I still had awful symptoms....and er after about 3 weeks I got an appointment to go to the [hospital name] and then things changed, and things were very different from then on so that is how er, how it all came about.'* [Service user #12: MSM, Dx 68 years, high prev.]

This appeared to be an exceptional case as the majority of service user discussed the transition to HIV treatment services as quick and efficient; however, the slow transition for this service user left him feeling particularly vulnerable. A further criticism, from a different service user, was that insufficient information about HIV was provided before consultation at the treatment clinic:

*'The only thing I've found a bit strange going through the whole process was the time between being diagnosed and actually starting with a proper er consultation there's very little information about the next steps which I found it a little bit strange and.....the terminology of the CD4 and....the viral loads. When you come into your first meeting they start throwing all this information at you but you're not really explained....'* [Service user #9: MSM, Dx 53 years, high prev.]

Although the transition from testing to treatment services was reported as well-organised by the vast majority of service users, it was pointed out by one HCP that in other NHS Trusts this

care pathway may not be as smooth. It was highlighted that disruptions to the transfer of care were occurring following the changes to sexual health and HIV service commissioning:

*'...trying to get that clear kind of seamless pathway from testing in sexual health to umm seeing a HIV nurse specialist, I've been told that you know in HIV it's like, it can be quite difficult....' [HCP #7: Male GUM specialist nurse, low prev.]*

## 6.5 Initial responses to diagnosis

The reactions of adults aged 50+ years to receiving a positive HIV diagnosis were varied, reflecting differences in the impact of diagnosis in the context of people's lives. This section will explore reported responses to diagnosis.

### 6.5.1 Relief

Some service users spoke of their relief at finally detecting the cause of their symptoms, and at not being diagnosed with a condition they considered worse than HIV, such as cancer or meningitis:

*'I just thought well when I was ill and I'm thinking the worst....could be cancer, could be something that, that is gonna kill me off and that was quite frightening but when I realised that this was something that hopefully you could, you could live with if you got the medications sorted then I thought well that's okay then' [Service user #4: Heterosexual male, Dx 51 years, low prev.]*

Family members and friends also reiterated this relief:

*'She said mum, that's.....You can live with that. Better than...you know...it could have been all sorts of things' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

### 6.5.2 Shock or surprise

For symptomatic service users, discovering HIV as the underlying cause of their symptoms was often reported as a shock. This response was particularly evident in people that had not considered themselves as at risk of HIV. For one service user, shock surmounted from the disbelief that she could have been exposed to HIV, as she had always been in long-term, monogamous, relationships and did not belong to a group in society that she associated with HIV:

*'.....everyone sees it as a nasty thing...nasty people have it um, yeah...it was...it was a shock' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

The GP caring for this service user also expressed shock at her diagnosis, highlighting that from a HCP perspective this person was also not considered at risk of HIV. As a white, middle-aged, heterosexual woman, this person did not belong to a group targeted in HIV prevention and testing efforts.

*'...she [the GP] actually called me and said how shocked...you know, everyone was. When I come back that day and they told me...they said...I just said god I, where has this come from? You know, and they said well we are just as surprised as you' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

Shock was also expressed by one service user who considered his risk of contracting HIV to have been lower at this stage in his life, due to a reduction in risk taking behaviour, than at a younger age:

*'Yeah, it was unexpected, there were other...other times in my life where I would have got less surprised but in that particular period I was like not ermm yeah thinking of that as a possibility because I...I had a test before er that was er negative and after that ermm I kept, I didn't really have any special reasons for thinking that I'd put myself in risk.' [Service user #3: MSM, Dx 53 years, high prev.]*

### 6.5.3 Confusion

For other service users, that had expressed much higher levels of HIV awareness and belonged to groups targeted by HIV prevention campaigns, the diagnosis was not necessarily considered a shock but it was described as unexpected. This stemmed from confusion surrounding symptoms and HIV; it was perceived that someone with HIV would experience symptoms much sooner than they had:

*"Cos it confused me, I wasn't bothered about being HIV positive but what confused me was how could I, when I've been with my partner now for four years and he's the only one I've been with..." [Service user #8: MSM, Dx 53 years, high prev.]*

*'I assumed that once you contracted HIV you would know more or less not, not immediately but within a couple of weeks you'd start to feel a bit off-ish and, and, and it would build' [Service user #8: MSM, Dx 53 years, high prev.]*

### 6.5.4 Stigma and shame

Only one person openly expressed shame at her diagnosis and associated heavy stigma with the disease:

*'It's wrong and it's horrible' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

*'Like I say you think junkie, you know gay and prostitutes. It was the worse three things you could be named' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

This person had low levels of HIV knowledge before diagnosis, and had not considered herself as being 'at risk' of HIV (see section 6.5.2). She also appeared to hold strong prejudices towards certain groups in society based on their lifestyle and sexual orientation; the association of these groups with HIV compounded her feelings of stigma (UNAIDS, 2003). This quotation emphasises the internalised stigma felt by this service user after diagnosis, even after being reassured and fully informed about the routes of HIV transmission:

*'...I went through a stage where my youngest daughter had her first baby in January and I felt I was a danger to him and could I go near him, could I...I had all these things. I'm so close to my grandchildren that I thought am I gonna hurt him, am I safe to do this and that. I wouldn't let one of them drink out the same cup and my daughter said mum calm down, they're...you're completely safe...' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

It was acknowledged that greater stigma might be felt by people diagnosed with HIV who do not belong to groups targeted in sexual health/HIV prevention and testing efforts:

*'.....it is a kind of still sometimes considered unfortunately to be...an infection that only kind of MSM individuals will acquire...and that's....sort of double stigma I think of you know umm homosexuality and HIV kind of still kind of persists really....' [HCP #9: Male HIV Lead nurse, low prev.]*

For these people, there appeared to be a greater need to accept that HIV can affect anyone, and to dispel previously held perceptions of the disease:

*'...I know I'm not a junkie or you know...I know I'm not and it can happen to normal people, so yeah, you have to [accept that] 'cos otherwise you'd think you know you would just go downhill otherwise [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

In particular, a middle-aged white heterosexual woman diagnosed with HIV would become part of a small minority of people living with the disease. As shown in Figure 16, in contrast to males the majority of new HIV diagnoses in females aged 50+ years in England between 2009 and 2013 were in black Africans. This trend is also found in adults aged 15-49 years (Appendix

29). Attending HIV treatment services when you fall within this small demographic was found to enhance perceptions of stigma:

*'...I don't see middle aged women like me in there, they're...they're coloured women' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

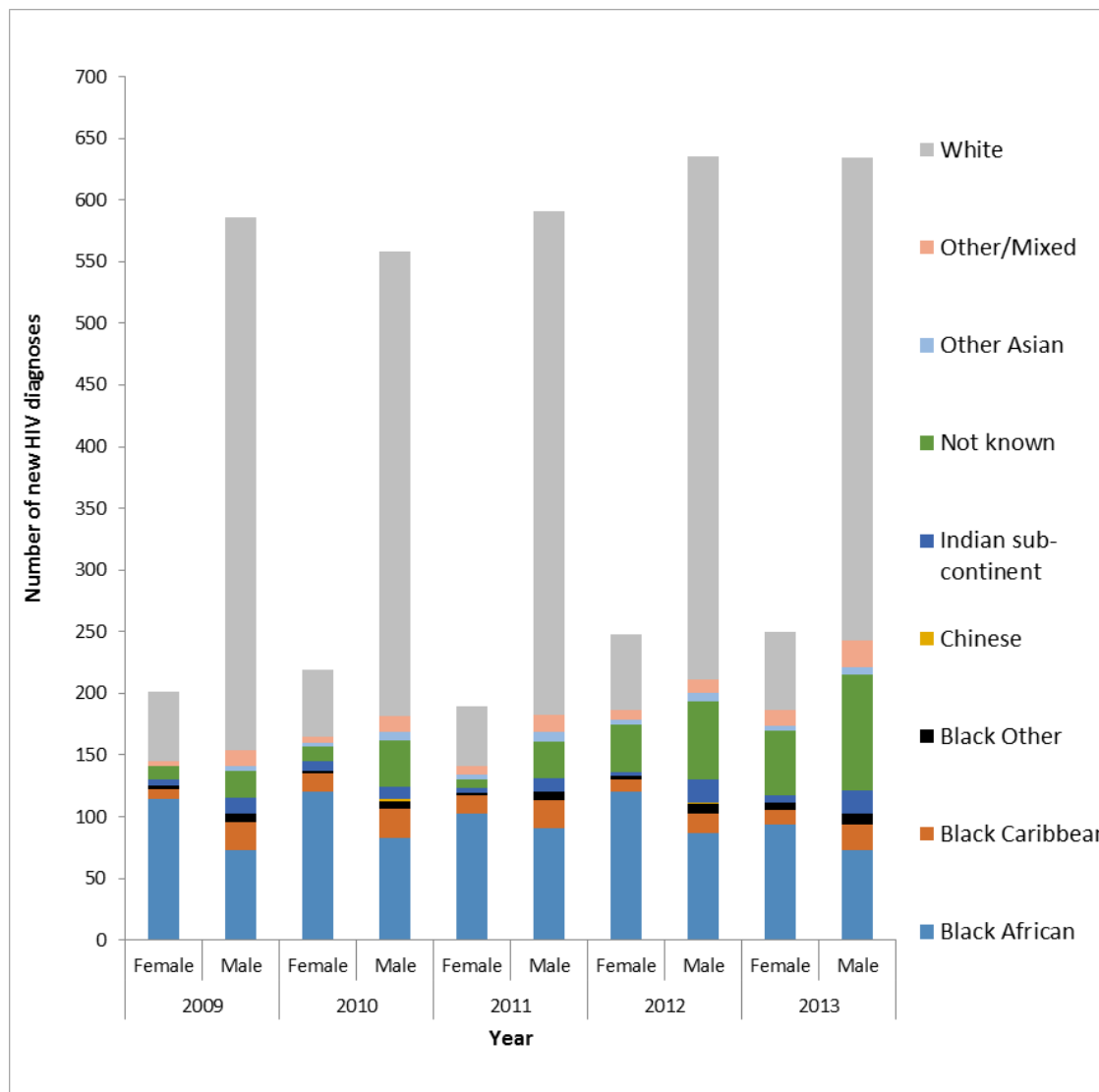


Figure 16: New HIV diagnoses in adults aged 50+ years by gender and ethnicity, England (2009 to 2013)

### 6.5.5 Disappointment

Some service users expressed disappointment at contracting HIV despite having extensive knowledge and awareness of the disease:

*'Disappointed with myself really 'cos I only have myself to blame for it, you know, I can't place the blame anywhere else...'* [Service user #9: MSM, Dx 53 years, high prev.]



One service user laughed off the following comments; this appeared to be an attempt to mask his frustration:

*'...for me the biggest upset was that given that I'm so educated about HIV, I still managed to get it (laughs). That is one of my biggest upsets of all' [Service user #11: MSM, Dx 52 years, high prev.]*

#### 6.5.6 'Taken relatively in their stride'

It was reported by HCPs that some service users were remarkably calm and accepting when given their HIV diagnosis. This was linked to the diagnosis not being a shock, when service users were particularly well-informed about HIV and had knowingly engaged in high risk behaviours:

*'....if they had an inkling of what they were doing, you know having unsafe sex or going to sex parties at the age of fifty-five. If then they get positive I think probably it's taken relatively in their stride....' [HCP #2: Male associate specialist in HIV, high prev.]*

This type of reaction was also linked to an awareness of the optimistic prognosis in living with HIV:

*'....when I got tested this time and it turned out to be positive the...doctor was like you're not screaming and shouting and....I'm like no well, why? And he said well were you expecting it then? So I'm not, I wasn't expecting it but I know it's not a death sentence anymore so I'll take my medication and I'll live with it....' [Service user #8: MSM, Dx 53 years, high prev.]*

#### 6.5.7 Suicidal ideation

One service user, someone that was already living with bipolar disorder, expressed suicidal thoughts at diagnosis. This feeling appeared to be exacerbated by the stigma he felt at this time from HCPs during his hospital admission (see section 6.4):

*'At that point I was ready to jump out the window, which is way high up in the hospital this room. And to be honest if I'd ever got the window open I really, seriously thought I might have jumped out of it.' [Service user #12: MSM, Dx 68 years, high prev.]*

#### 6.5.8 Fear

Several service users, particularly those that were acutely unwell at diagnosis, expressed immediate concerns about their prognosis:

*'And I said 'well, what do you mean? I'm not gonna die yet?' she [doctor] said 'no, no, no, of course not' [Service user #12: MSM, Dx 68 years]*

HCPs also considered that in general older adults may demonstrate greater fear about their prognosis, due to a lack of HIV knowledge:

*'...I think...the older people show more fear.....I think the younger people have, show less fear.... I think you know not to, again pigeon hole or stereo...but I think the younger tend to have a bit more 'Well I can just take a pill and I'll be alright'.... whereas the older people don't quite think in the same manner I don't think.'* [Service user #11: MSM, Dx 52 years, high prev.]

One service user, diagnosed at a late stage of disease, reported his panic about acquiring an opportunistic infection:

*'...it totally freaked me out because suddenly like when your immune system is so low I was afraid of everything, I was like washing the carrots like ten times you know like I didn't dare to eat in restaurants or....like I was totally freaked out....didn't really know how to handle it.'* [Service user #3: MSM, Dx 53 years, high prev.]

## 6.6 Late HIV diagnosis

As identified in chapter one, in comparing the proportion of late HIV diagnoses nationally for all broadly defined age groups (15-24 years; 25-34 years; 35-49 years and 50+ years) there is a distinct association between increasing age and greater risk of receiving a late HIV diagnosis (CD4 count <350cells/mm<sup>3</sup> within 91 days of diagnosis) (PHE, 2016a). From their experience, HCPs also found that late HIV diagnoses disproportionately affect older age groups:

*'...really we see the late diagnosis are in their 40s, 50s, 60s really and ermm we do, we do have a, you know a large proportion of my work is people who are that age.'* [HCP #1: Female HIV specialist nurse, high prev.]

Late HIV diagnosis at an older age was associated with greater morbidity and mortality risk than in younger people:

*'.....their immune reconstitution is not as good....they're less able to tolerate serious illness.....it's amazing how sick some young person can be and survive, whereas inevitably if you've been, say you've been a smoker or you...you've got a bit of cardiovascular disease and then you get suddenly serious infection, you are less likely to survive than somebody whose fit and athletic.....I think the...the first, well I always call the first twelve weeks which is before you can get effective therapy into somebody and bring their viral load down, the first twelve weeks are more dangerous for older people than for younger people....'* [HCP #2: Male associate specialist in HIV, high prev.]

In the interviews, seven service users reported or indicated receiving their diagnosis at a late stage of disease. All service users that received a late HIV diagnosis had their healthcare encounters leading to testing with non-HIV specialists (e.g. in general practice or secondary care), where it has previously been considered that HCPs may lack knowledge, confidence and competency in offering HIV testing (see section 5.5.1). The following factors, as outlined in section 5.4 were associated with late HIV diagnosis: belonging to a low risk group that is not targeted by HIV prevention and testing efforts; living in a low HIV prevalence area, in which HIV testing is recommended on clinical indicator conditions and risk (see section 2.3.1); non-specific HIV symptoms; lack of personal HIV knowledge and awareness; low personal risk perception; and 'precaution fatigue'.

For some service users, attending general practice as the first healthcare contact was associated with a lengthy time to diagnosis:

*'I'd been to the GP loads of times yeah. Yeah and he just, well he'd...he'd just kept saying well there's nothing wrong with your bloods and I, and, but if you're not ticking the right boxes you're not gonna to get to the right....you know, get to the bottom of things are you, you know'* [Service user #10: MSM, Dx 57 years, high prev.]

This situation had also been witnessed by HCPs:

*'One lady who is seventy er two I think it's very sad case, she kept going to her GP ermm with a variety of symptoms from diarrhoea, she had no end of colonoscopies and investigations, to chronic cough and literally she went to so many different doctors, specialities and it wasn't 'til she developed PCP that she was actually diagnosed and told this, you know, you have HIV. Sad'* [HCP #1: Female HIV specialist nurse, high prev.]

#### 6.6.1 A 'double trauma'

Receiving a late HIV diagnosis was described as more traumatic than being diagnosed at an early stage of disease, as the person then had to cope with being told the diagnosis, an urgent need to start treatment, and often severe symptoms:

*'...if you have the patient whose just got diagnosed, he's got a very low CD4 and has to start treatment that's a lot of stuff to form, to deal with.'* [HCP #6: Female HIV research nurse, high prev.]

As a consequence of advanced disease, the majority of service users that were diagnosed late experienced serious health problems at the time of testing. These were sometimes life-threatening:

*'...before they put me into the induced coma they didn't know themselves what they were gonna find so the coma was like we're gonna have to do this so we can try and see what's going off and then when I came out of that because it was like, well, we're not expecting him to live to see the week out and I pulled round.'* [Service user #8: MSM, Dx 53 years, high prev.]

The major health problems associated with late HIV diagnosis were associated with lengthy hospital stays and slow immune system recovery:

*'...they really took nearly a year to get me back on my feet to start the antiretrovirals because my um, my viral load was very, very high and my CD4 count was, well way below 200. So I was in a high risk um level there.'* [Service user #12: MSM, Dx 68 years, high prev.]

For several service users there were substantial financial implications due to the inability to work during recovery:

*'I've sort of used anything savings that I had to get things sorted out so that I've got somewhere, and er things to live, so I...I'm in, a bit in debt now....'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

In turn, a lack of money was reported to affect the ability to socialise. This compromised psychological wellbeing:

*'I used to look forward to my daughter coming round once a week and I'd make her tea and I'd try and do that, try and do bits that I could. I watched so much TV and so many films but I thought it's not what I wanna be doing and I really wanted to get to the gym but you can't, I couldn't go out anywhere because I didn't have money to go for a coffee up town or for a walk or anything. Er, so you're just stuck in a house and that was the hardest thing, having no money and being stuck inside after having such an active life....'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

The strain of being so unwell at diagnosis could also destabilise intimate and romantic relationships, contributing to their end:

*'He just couldn't deal with it at all. And it was awful, you know. Somebody you've been with for 17 years, it's a long time. It just totally was not expected and he actually left while I was still being nursed in bed.'* [Service user #12: MSM, Dx 68 years]

#### 6.6.2 Anger and mistrust

Some adults diagnosed late, who did not belong to groups targeted by HIV prevention and testing campaigns, were reported by HCPs to be angered by delays to testing, considering this to be an injustice:

*'...the lady I was mentioning at the, the beginning yeah she, that's what she says, 'I don't see why I should have been discriminated against because I was a woman' er you know. That's what she says this directly she said if "I was a, if I was a homosexual she says then they would have diagnosed me far earlier you know I really don't think this is, that this is, this is, you know good and proper and should be put up with"'* [HCP #8: Male HIV consultant, low prev.]

This loss of trust in the diagnostic ability of HCPs, particular general practitioners, indicated future problems in these HCP-service user relationships:

*'...they've had that sort of journey which is perhaps slightly different from somebody who just walks in and says can I have a HIV test....it's sort of a different, different reaction in a way and also what comes with that is a lot of anger at professionals because they feel that that should have been thought about earlier...'* [HCP #4: Female clinical psychologist, high prev.]

#### 6.7 Disclosure

HCPs considered that someone's decision to disclose their HIV status was based on numerous factors, which were not necessarily related to age:

*'...I've got some patients who have never told anybody, so people who haven't even told their partners....but that's all sort of across the....all different ages.'* [HCP #1: Female HIV specialist nurse, high prev.]

The decision to disclose HIV status was determined through consideration of the following.

##### 6.7.1 'Need to know' basis

Someone's decision to discuss their HIV status was based on whether there was a perceived need for disclosure. It was considered necessary by the majority of service users to disclose their HIV status to sexual partners. For one service user, this was perceived as the most difficult aspect of testing positive:

*'...I was quite happy with the medical side and the psychological side but sort of the fact, you know, you're upsetting someone else who's close to you....' [Service user #7: MSM, Dx 50 years, high prev.]*

There was a sense of obligation to tell at least one family member:

*'...I basically will, I have...going to tell my sister on the principal that if my mother ever does find out ermm she'll kill me so if I've told a member of the family. I basically, she knows I've had support if I needed it...'* [Service user #6: MSM, Dx 51 years, high prev.]

But more widely it was considered of no benefit to tell other people:

*'...the case has not arisen to actually talk about it to people. And ermm so, I thought, I'll keep...I believe the phrase is a need to know basis....you know, I'm not actually one of those people who likes telling people their entire life history. Occasionally you meet somebody at the bus stop and you know all about them by the time the bus starts to arrive. Do I want to know all this? No I'm not that type of person and I never have been, it's my make-up you know.'* [Service user #1: Male, Dx 67 years, high prev.]

One service user highlighted, in regarding HIV as a chronic condition, that there was no real need to disclose his status. For this service user, his social group were aware of HIV and some of his friends were living with HIV; therefore, revealing his diagnosis would not carry the same 'impact' that it would to other people and their friends:

*'...you know if I had diabetes I wouldn't bore them with that, you know, or if I had this ailment or that would I bore them....some of my friends had revealed you know, disclosed to me there status and um er, you know, alright well and next subject please.... 'cos that's the way it is, er, you know, now with informed gay sort of middle-aged people....'* [Service user #7: MSM, Dx 50 years, high prev.]

#### 6.7.2 Self-preservation and fear of stigma

Fear of stigma was reported as a major barrier to HIV disclosure:

*'.....he's worried that if he finds out that he's got HIV he'll never see his grandchildren....'* [HCP #5: Female HIV Lead nurse, low prev.]

In one instance, fear of stigma had resulted in a service user creating a self-justification for non-disclosure to previous sexual partners in Thailand:

*'...I thought, just like me, some of the cases if they got it then something will happen, they'll get ill or something really and it will get diagnosed, they will get diagnosed. A lot of the girls should get regular, a lot of the girls get regular checks with doctors 'cos your average girl does don't they? Whether they work in a supermarket or anything, you know, they go and see the doctors, I would think so. They do over here, don't they, yeah?' [Service user #4: Heterosexual male, Dx 51 years, low prev.]*

This service user's decision to allow previous sexual partners to only find out their status once unwell is an interesting reaction given that this service user was acutely unwell and at risk of dying at the time of his diagnosis. The rationale for non-disclosure to his sexual partners in Thailand highlights his need for self-preservation, revealing the stigma associated with the disease and this person's fear of the personal consequences of people knowing his status:

*'...if I told somebody....they might pass it on, I don't know how you can trust em not to say 'oh well he said that so you might have it', rumours gone round and everybody in the town knows.....And I don't wanna spread gossip if it's not true and there's no, you know, if I'd have been there [in Thailand] and somebody was having a cold all the time or a cough or they were showing symptoms like I realised I had....I would say you need to go to the doctors and get checked out for everything....I'd....persuade em to do it for their own health.... If I saw somebody that I thought was ill and showing symptoms of, you know, an immunity breakdown in some ways....' [Service user #4: Heterosexual male, Dx 51 years, low prev.]*

### 6.7.3 Potential distress to confidant

Service users generally considered it of no benefit to disclose their HIV status to the majority of family members, particularly their parents. It was feared that disclosure would cause them unnecessary worry, due to their lack of HIV knowledge and the stigma surrounding the disease. It was considered that the adults older than them (the older old) would have less knowledge of the disease, a finding previously highlighted in national surveys (NAT 2014b).

*'...I don't see a need to do that. Definitely not, if you take your 85 year old mum she wouldn't, she would think it was the end of the world, she'd think I was dead. Er, and the rest of your brothers and sisters (puffs air), does it really make a difference? If anything, they may not understand it and make the wrong perception, yeah. It makes, it make no difference.....' [Service user #11: MSM, Dx 52 years, high prev.]*

In the event of stable HIV disease, which is highly probable given the availability of effective treatment, it was unnecessary to disclose a positive HIV status and cause upset:

*'....I've still got, one of my friends has got, whose perfectly sorted, got a job, he's fifty, forty-five/fifty, ummm been positive for twenty, almost twenty years. Parents don't know....the parents are eighty-six and eighty-five, what's the point in telling them? So it's only when the patient gets sick that it becomes an issue and luckily now that doesn't happen very often.'* [HCP #2: Male associate specialist in HIV, high prev.]

*'No, my parents are quite old. They don't need to know that sort of thing.'* [Service user #9: MSM, Dx 53 years, high prev.]

#### 6.7.4 Concerns about the impact on identity

It was indicated that for some, there were concerns about the impact of diagnosis on their outward identity. For example, one service wanted to assert his sexual orientation as heterosexual:

*'.....and you know and people say are you gay and I said well I'm nothing like gay, I've never been gay and I'm...nothing wrong with people, ermm I talk to people who are gay, I've had to do and I haven't had a problem with it over the years....And I'm, and I'm okay with that, and I'm good, I'm and I, I'm not, what's it...homophobic. I keep laughing when I hear that, that Peter Kay video where he says I'm not homophobic, I'm not scared of my own house....But I've never been gay, I don't wanna be gay, I've no intention of being...'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

There were also concerns that disclosure would result in someone becoming 'labelled', with HIV becoming a defining feature of someone's identity:

*'....I haven't told anyone with the exception of my partner and medical and my dentist, you know, that I've been diagnosed. Er because you, you always think, well you label, I think there's a tendency to label someone as HIV positive 'cos, you know, cos I've done it myself before, you know, I was diagnosed. I went my friend, HIV positive, Pete or Jo or.... um John or whatever....'* [Service user #7: MSM, Dx 50 years, high prev.]

#### 6.7.5 Responses to disclosure

Responses to disclosure were generally reported by service users as positive, although this is perhaps unsurprising given the selectivity of disclose. Service users chose to inform only those they felt would respond in a reassuring and supportive manner:



*'...he [patient's brother] was fine. He, he's, well as long as you're alright, you take your tablet, don't whinge, and I'm like well I wasn't whinging I was just saying ' [Service user #8: MSM, Dx 53 years, high prev.]*

*'...when I was diagnosed I disclosed to all my family and they were really only supportive.... all of my family were 100% supportive.' [Service user #12: MSM, Dx 68 years]*

However, there will still experiences of stigma following disclosure, irrespective of a person's age:

*'.....I have a patient for example, he's 49, he's just been diagnosed....8 months ago, he told his brothers and sister, they are perfectly fine, supportive, 100% but he's not allowed to touch the nephews and nieces or kiss them or anything....you see what I mean....' [HCP #3: Male HIV nurse, high prev.]*

## 6.8 Treatment

At the time of interview, all service users were taking antiretroviral therapy (ART) and reported their disease as stable. The benefits of taking ART were quickly reported after commencing treatment:

*'...I felt all this is happening, you know, I've got skin problems, I've got regular sore throats and is this it for the rest of my life. Is this as good as it gets? And of course as soon as I go on the medication, get the medication everything's so much better.' [Service user #7: MSM, Dx 50 years, high prev.]*

Most had started treatment soon after diagnosis, as per HIV treatment guidelines (Waters et al., 2016); two service users were enrolled on clinical trials.

### 6.8.1 Adherence

All service users reported good adherence to ART, often stating that taking their medications had formed part of a routine, in line with other daily rituals such as brushing their teeth, waking up and getting ready for bed etc.

*'...that's been no problem at all, I mean adherence has been....yeah I'm, I'm pretty organised sort of, annoyingly so...' [Service user #7: MSM, Dx 50 years, high prev.]*

HCPs also generally reported that adults aged 50+ years had better ART adherence than younger service users:

*'.....the older person is more likely to be reliable than the younger person in terms of taking their treatment.'* [HCP #2: Male associate specialist in HIV, high prev.]

Particular systems had been put in place by some service users, and HCPs, to prompt medication taking:

*'I've got an alarm on my phone and I take them on the dot'* [Service user #2: Heterosexual female, Dx 55 years, high prev.]

*'I've got one of those organisers where once a week I sit down and I get all my tablets out and I write, move and put against the days umm and I get the whole lot organised'* [Service user #8: MSM, Dx 53 years, high prev.]

One service user treated on a one tablet a day regime, expressed the disruption he felt at one point in needing to take an additional form of medication:

*'...just two times is like fucking up your life and I was at ermm, often have to be at dinner parties, like er...er...business dinners, and you sneak out to the bathroom you know like and.....with your pills and ermm continue like the dinner conversations...it's a bit artificial...'* [Service user #3: MSM, Dx 53 years, high prev.]

This service user was not used to taking medications and had a particularly busy lifestyle. In general, it was perceived that adults aged 50+ years had a less 'chaotic' way of life, which made ART adherence easier:

*'No older people are more consistent, more reliable. And I think that's driven by, that's driven by chaos and drug taking and, you know, so the younger kids are....well they're not...yeah. I'm fifty-five now, if you'd have tried to get me to have a normal life when I was thirty, you know I was all over the place whereas now I know that I'm gonna have a cup of tea at seven in the morning and I'm gonna have a little sherry wine at nine o'clock at night (both laugh) and I...and I can guarantee that most of the time I won't be running round until three o'clock in the morning'* [HCP #2: Male associate specialist in HIV, high prev.]

Adherence to ART appeared to be easier if service users were already taking medications for other health conditions:

*'...because I was on several medications daily, to me it is just another medication and I have to remember to take the pills so and so on and so forth...'* [Service user #1: Male, Dx 67 years, high prev.]

*'....they're (older adults) much more um adherent.....if they're taking blood pressure pills or something, they'll take their antiretrovirals with it [HCP #5: Female HIV lead nurse, low prev.]*

It was also considered more acceptable or 'normal' to take some form of medication in older age:

*'...okay I have to take a tablet for the rest of my life but most people do for some reason be it diabetes or whatever, you know.....' [Service user #8: MSM, Dx 53 years, high prev.]*

*'.....if you are my age sort of age daily medication is a fact of life. I suspect. You know, unless you are very lucky.' [Service user #1: Male, Dx 67 years, high prev.]*

### 6.8.2 Dominated by diagnosis

One service user's life had become particularly dominated by her diagnosis. Although it had been over a year since testing for HIV, this person was struggling to come to terms with stigma and shame (see section 6.5.4) and the shock of diagnosis (see section 6.5.2).

*'....it's always you know in my head 'cos of what I've got and it's wrong and it's horrible and it's I've had to that...I think of that all the time' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

This was reinforced by the need to take medications every day, and was expressed in the strictness of her ART adherence:

*Service user #2: I've got an alarm on my phone (INTERVIEWER: have you?) and I take them on the dot (INTERVIEWER: yeah) so yeah*

*INTERVIEWER... Sounds like you are very organised?*

*Service user #2: So ermm...yeah...wh...in the beginning it was like, oh what if I go out and my alarm goes off. All those sorts of things..... if you're out somewhere and you know like 8 o'clock is coming and you're gonna have to take it and where...depends where you are or...whose there, you know, and you go off and take it. That hasn't happened that often 'cos now I'm used to taking it, I'll take it just before I go out so I haven't got that worry umm and then maybe it's a bit late and I'm like 'Ahh god it's late'.....They [HIV clinicians] always ask you if you've missed anything and no I'm on the dot....' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

### 6.8.3 Side-effects

HCPs reported that, with the continuous development and refinements of ART, there are now fewer side-effects associated with treatment:

*'...the newer treatments are much better tolerated and have fewer side-effects....' [HCP #2: Male associate specialist in HIV, high prev.]*

*'...it took quite a few years to work out the right way to combine the drugs and of course at the same time the, the new cleaner drugs were coming along so by 2000 we were much more on the ball and by 2005 we had it up to um, a reasonably fine art.' [HCP #8: Male HIV consultant, low prev.]*

The majority of service users reported no side-effects linked to taking ART. One service user reported an exacerbation of his Bipolar disorder with the transition to a new medication; however, this resolved with medication re-adjustment. Aside from this service user, few others discussed experiencing side-effects:

*'...I've got a permanent horrible taste in my mouth that's, I've had, I've had a few dreams you get back dreams and stuff with it. They...they're not that bad and they're not that often so that's alright...and then just feeling yuck basically' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

*'...you can feel it sometimes, er where you feel that you ermm, you lose your appetite a bit or you feel like intoxicated almost a bit like where you feel like if you switch off the light you will like glow in the dark (both laugh) ermm but no' [Service user #3: MSM, Dx 53 years, high prev.]*

It was voiced that there are difficulties in distinguishing symptoms of HIV from the side-effects of taking ART, or ageing. These were experienced by HCPs and services users.

*'[I'm] still very tired but yeah.....I'm, the medication I'm getting on really well, I've got no um problems with that really. I'm going through the menopause at the same time as well so I don't want to confuse medication, what that's doing to those...symptoms as well....It is a bit confusing which is...which is making me like it.....' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

*'...how do I know what...my fatigue is, how do I know what this is and it's that sort of thing of not being able to necessarily ummm make sense of all of our other symptoms that we have it, where do they kind of, what's causing this, you know is it, cause they might have HIV, they might also*

*have some arthritis, they might also have some ummm you know heart problems or you know lots of things that are sort of happening and I think you see that more in an older cohort just by the nature of bodies....' [HCP #4: Female clinical psychologist, high prev.]*

## 6.9 Discussion

### 6.9.1 Response to diagnosis

Initial responses to diagnosis in adults aged 50+ years are comparable to those more broadly identified in the literature overview (chapter two), across age groups. Shock and disbelief were expressed by individuals that had not perceived themselves to be at risk of infection, a response highlighted in previous studies (Anderson & Doyal, 2004; Anderson et al., 2009; Anderson et al., 2010; Doyal, 2009; Doyal & Anderson, 2005; Doyal, Anderson & Papparini, 2009; Flowers et al., 2006; Hult, Maurer, & Moskowitz, 2009; Papparini, Doyal, & Anderson, 2008; Stevens & Hilderbrant, 2006; Stevens & Tighe Doerr, 1997). Shock was linked to associating HIV with 'other' people, having low personal risk perception, and not belonging to a group targeted by HIV prevention and testing campaigns.

*'I think of, like, I don't know, prostitutes and backstreets and everything but, em, like I know that anyone can get them ...but it's still sort of ...you know "nice girls don't" or whatever' (Female participant, family planning clinic attendees; excerpt from Scoular, Duncan & Hart, 2001)*

Other identified themes, such as fear (Anderson et al., 2010; Flowers et al., 2011; Foreman & Rathaille, 2015), relief (Anderson et al., 2010; Hult, Maurer, & Moskowitz, 2009) and suicidal ideation (Anderson et al, 2010; Flowers et al, 2006; Stevens & Tighe Doerr, 1997) were also identified in studies involving younger people diagnosed with HIV.

It appears that women may consider their diagnosis as more shameful than men; this has been reflected more broadly in the literature, with women expressing high levels of stigma and shame in relation to the diagnosis of STIs and HIV (Dixon-Woods et al, 2001; Mulholland & Van Wersch, 2007; Stevens & Hilderbrant. (2006). Shame appears to be exacerbated in older age, due to misconceptions surrounding ageing and asexuality (Gott, 2005).

### 6.9.2 HIV disclosure, stigma and identity

Disclosure of HIV status was generally considered on a 'need to know' basis. This was linked to the stigma surrounding the disease (also highlighted in section 2.9.1 and 5.5.5), with concern about the impact of HIV on outward identity, and how disclosure would affect someone's treatment by friends and family (Carricaburu & Pierret, 1995). The labelling of someone as HIV positive and the continued reference to their status as a defining feature, was described as reducing people living with HIV 'from a whole and usual person to a tainted, discounted one' (Goffman, 1963). For the interviewed heterosexual male, there were also concerns about being labelled as homosexual and stigma associated with sexual orientation.

Disclosure was also restricted due to not wanting to cause distress to the confidant, or be negatively judged. There was a particular reluctance to disclose to parents, as it was considered unnecessary to cause them distress in the event of stable and uncomplicated disease. This may also be experienced by younger people in disclosing their status to parents; however, as advancing age is associated with lower HIV knowledge, particularly in adults aged 75+ years (NAT, 2014b), it was considered more challenging to inform this group of a positive result.

Disclosure was largely considered necessary to sexual partners, with a sense of both legal and moral obligation to do this. For one service user, the decision not to disclose his HIV status to previous sexual partners was rationalised on the belief that these partners would ultimately test anyway, either routinely or once symptomatic. This appeared to be an act of self-deception and preservation, to justify non-disclosure and avoid any detriment to self.

#### 6.9.3 Stage of HIV infection and test location

All self-initiated tests were conducted in sexual health/HIV clinics, by MSM; HCPs in this setting were perceived by self-initiated testers to have greater expertise than general practitioners and other non-HIV specialists (see section 5.5.1). This belief is widely reported in existing literature (Balfe & Brugha, 2009; Llewellyn et al., 2012). Interviewed HCPs voiced that they were aware of GPs lacking expertise in STI/HIV testing, and also GPs referring their attendees to sexual health/HIV clinics for testing (Cassel et al., 2003).

Late HIV diagnosis was associated with multiple attendances to general practice, or hospitals; a finding supported by the literature (Wohlgemut, Lawes, & Laing, 2012). HCPs considered that late HIV diagnosis was more likely for heterosexuals, particularly at an older age (Burns et al., 2008; Manavi et al., 2004; Noble et al., 2016; Smith et al., 2010). In 2015, 55% of heterosexual males and 49% of heterosexual females were diagnosed late; compared to 30% of MSM (PHE, 2016a).

Diagnosis at a late stage of disease, and the health complications linked to this, was associated with greater 'biographical disruption' (Bury, 1982), to be discussed in chapter seven.

#### 6.9.4 Entry to treatment services and commencing ART

Transition to HIV treatment services was largely experienced as efficient by service users, although this requires greater monitoring at a national level (APPG on HIV/AIDS, 2016).

Similarly to the wider HIV positive population, older adults reported minor side-effects in taking ART. Over time ART has become increasingly refined, reducing the likelihood of serious side-effects.

Older people also reported good ART adherence, which was reiterated by HCPs. This was considered in terms of life stage, with older adults describing less chaotic lives with advancing age which meant they did not miss doses. It was also considered that ART adherence was easier if someone was already taking other medications. This corroborates with existing literature that shows adults aged 50 years and over have better ART adherence than younger people (Barclay et al., 2007; Hinkin et al., 2004; Sherr et al., 2008b). A major strength of these studies is the use of objective adherence measures e.g. electronic measuring of medication bottle opening, rather than relying on self-reports. It is well recognised that many factors influence adherence to medication (Bolszewicz et al., 2015), in older people a factor associated with decreased ART adherence is a decline in cognitive ability (Barclay et al., 2007; Hinkin et al., 2004). Service users did not report this as an issue; however, HCPs had worked with older adults to promote ART adherence with cognitive decline e.g. through service user visits, use of dosette boxes etc.

#### 6.10 Summary

- Rates of new HIV diagnoses in England are increasing in older adults, while they are decreasing in younger people. On closer examination, the age-related shift in the epidemic appears to begin from the age of 40+ years. The majority of HIV diagnoses at age 50+ years are in MSM, followed by heterosexual males and heterosexual females;
- Compared to younger people, a higher proportion of HIV diagnoses in older adults are in heterosexuals;
- The majority of new HIV diagnoses in males aged 50+ years are in white people, while most diagnoses in females aged 50+ years are of black African ethnicity;
- The transition between testing for HIV and accessing treatment, referred to within the MPT as the pre-treatment interval (Scott et al., 2013), was mainly reported by interview participants as prompt and smooth, aside from in the case of one service user;
- Older adults are more likely to be diagnosed at a late stage of disease than younger people. Late diagnosis is linked to: not belonging to a traditional 'at risk' group, vague HIV symptoms, and presentation to a non-HIV specialist;



- Responses to diagnosis mirror those reported by younger people (shock; relief; disappointment; shame; stigma). There is an indication that women may feel greater levels of stigma and shame at diagnosis;
- Disclosure decisions were based on concerns about stigma and identity; unnecessarily worrying the confidant; and the perceived necessity of disclosure;
- Adherence to ART was reported as better in older people than younger adults. This was linked to life stage, with adults aged 50+ years considered to have less chaotic lives, making adherence more straightforward. Taking other medications was also associated with easier treatment adherence.



## Chapter 7: Ongoing care and life after diagnosis

### 7.1 Introduction

This section of the results explores the experience of living with HIV after receiving a positive diagnosis at age 50+ years. The chapter concentrates on journeys after treatment initiation, looking beyond the final stage of the *Model of Pathways to Treatment* (MPT) (Walter et al., 2012; Figure 3) e.g. at further experiences with health services, the impact of HIV on lifestyle, and adaptation to diagnosis. It will draw upon and integrate findings from:

- Qualitative interviews with adults diagnosed with HIV at age 50+ years (service users);
- Qualitative interviews with HCPs working in sexual health/HIV services and providing care for adults aged 50+ years;
- A survey of HCPs working in sexual health/HIV services and providing care for adults aged 50+ years.

Firstly, it will explore service user encounters with HIV clinicians and non-HIV specialists after diagnosis.

### 7.2 Trust in HCPs

Exceptional relationships, based on trust, were reported between service users and HCPs working in HIV services. The level of trust expressed by service users in their HIV clinicians, less commonly reported in their interactions with non-HIV specialists such as GPs, produced a positive effect on service user health and wellbeing. The establishment of trust with HIV clinicians was associated with the following.

#### 7.2.1 Continuity of care

Service users reported seeing the same HCPs at each attendance to HIV services. This continuity of care enabled the development of familiarity and trust between HIV clinicians and service users:

*'... you see your cohort of patients so they know they're seeing the same doctor. They get that continuity of care and I think actually they like that...you can understand that...it is nice to have someone that you feel like knows you and you know them' [HCP #12: Female GUM consultant, low prev.]*

It was clear that friendships had developed between HIV clinicians and service users, turning HIV service attendance into something that could be considered enjoyable:

*'... you end up almost becoming friends and you do become friends and forgetting how you know each other that (laughs) you know the lines end up blurring which umm has certainly happened and you know it's not a problem umm but yeah it's er, it is nice and that's I think from working in a HIV field is one of the attractions is that, it is a chronic illness you're dealing with patients that you know, they know you' [HCP #11: Female nurse practitioner in HIV, high prev.]*

*'...it's not sort of a, a dirge coming here, it's not something not to look forward um er it's a, a dare say is quite an enjoyable experience....' [Service user #7: MSM, Dx 50 years, high prev.]*

### 7.2.2 HIV clinicians as 'substitute GPs'

In comparison to attendance at HIV services, it was described by HCPs and service users as increasingly difficult to see the same clinician at each general practice visit:

*'...at my GP service...they're not rude but they are just so ...so under pressure, you know, and ermm the fact that you don't see the same doctor every time and it is next to impossible to do so whereas you see every... all the people you see here...including (says people's names) on the desk you know, so they are almost old friends' [Service user #1: Male, Dx 67 years, high prev.]*

*'.....getting into the general, to see your GP is a nightmare....' [Service user #6: MSM, Dx 51 years, high prev.]*

Given the challenges reported in accessing their GP, some service users had instead started to regard their HIV clinicians as 'substitute GPs'. The GP role, as described by Safran (2003), is to oversee and provide overall health management for patients; while specialist clinicians, such as those working in HIV services, concentrate on particular diseases. However, while general practice is described as increasingly overwhelmed, there appears to be a blurring of responsibilities between HIV clinicians and GPs:

*'... some of my patients because they're coming to us for it anyway, they'll come and they'll come with their list of everything that needs doing and we'll do it all together...' [HCP #9: Male HIV lead nurse, low prev.]*

HCPs discussed their roles as extending beyond HIV management, with this quotation appearing to describe responsibilities traditionally more associated with a GP:

*'... I see very much my role is about, it's not just about the sickness and the HIV, it's about their general health. It's about them losing weight, it's about them not, you know, not smoking. It's about, you know, all of those things. Not getting depressed and ermm and looking, and being*

*independent and, and....looking after themselves and so and I sort of feel that my roles quite a lot about that as well really.' [HCP #9: Male HIV Lead nurse, low prev.]*

### 7.2.3 Expertise and competency

Service users were extremely trusting of HCPs working in HIV services due to their ability to provide competent HIV treatment and management:

*'...they just know what they are doing; they know exactly what they are doing. Once they, once you know, I mean the next day I was called in and dealt with, so it, they're just they're just you know amazing really' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

When questioned, survey users either agreed (68%) or strongly agreed (38%) that they had received sufficient training to discuss HIV risk with younger people (n = 41); only one person disagreed with this statement when phrased for adults aged 50+ years. By contrast, GPs and other non-HIV specialists were often perceived by service users to lack the knowledge and the confidence to effectively care for people with HIV:

*'.....the thing is I feel like some patients coming say 'oh my GP told me don't give me any, not even an antibiotic because he's scared to interfere with it [HIV]', you know, you can go through that Liverpool pathway website<sup>2</sup> that you can put the medication of antiretroviral and whatever and it shows if it interfere or not. Me I've been there twice, three times a month sometimes and it is supposed to give you a green light, it means that it's fine, it's supposed to give you a red light, don't give it, or yellow light, maybe, maybe not. 80% of them give a yellow light...hello! What are you supposed to do? So it's not really helpful, so the GPs they panic and they send it to consultant.'*  
*[HCP #3: Male HIV nurse, high prev.]*

*'... well I mean well that GP actually asks me to run things by them.... for example me er....triglycerides high and my GP says oh er I really need to increase your Atorvastatin<sup>3</sup> but you would need to ask the [hospital name] first. I said [Dr's name] just give us em, they'll be alright. I said it's the other er, it's Simvastatin<sup>4</sup> that's a problem with Ritonavir<sup>5</sup>....so I will run it by [Dr's name]....but I'm sure it's right....' [Service user #10: MSM, Dx 57 years, high prev.]*

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<sup>2</sup> The Liverpool drug interactions website provides a 'HIV drug interaction checker': <http://www.hiv-druginteractions.org/>

<sup>3</sup> Taken to lower cholesterol

<sup>4</sup> As above

<sup>5</sup> Antiretroviral medication

It was reported that service users would commonly be referred to HIV specialists irrespective of their reasons for healthcare seeking:

*'.... I do think there is this feeling from not only GP's but non-HIV related specialists that it's all so complicated that they can't think about it and they can't do even the basics.... I would send somebody along to.....a surgeon with a basic gall bladder, you know, stones in the gall bladder. As soon as they saw HIV and all the different complicated things they are on it's like 'ooo you know I can't think about that'....' [HCP #2: Male associate specialist in HIV, high prev.]*

However, it was also widely acknowledged by HIV clinicians that they lacked the up-to-date knowledge required to be treat other conditions, and therefore do not have the skills to serve as 'substitute GPs' (section 7.2.2):

*'.....if we do like lipids and you know cholesterol and things like that I would send that back to the GP because they manage that.....I said to er somebody the other day, you know, we don't know enough, we don't know the new drugs coming on.... we're good at HIV but this is bread and butter to the GPs .....it's really important there's a cohesive approach, especially as people get older'*  
*[HCP #5: Female HIV lead nurse, low prev.]*

Due to the additional issues faced by older adults with HIV, it was considered essential by HCPs for GPs to be strongly rooted in providing and co-ordinating care:

*'Correspondence with GPs is crucial. Also, there remains an important question about the co-ordination of care in this group. Who is the primary clinician - GP or HIV clinic? I would argue that it should be GP.'* *[Specialist sexual health consultant, male, 35-44 years old, low HIV prev.]*

Despite the need for good GP and HIV clinician relationships, the quality of these was varied and role responsibilities were poorly defined:

*'... the interaction between hospital and GP is so unclear as to be really rather ermm spectacularly dysfunctional I would call it.... So you have some GP's who are actually very good, they'll ring you up or you know send emails or whatever and then you have those that really take absolutely no interest....'* *[HCP #2: Male associate specialist in HIV, high prev.]*

Concerns about the expertise and competency of GPs, alongside a lack of consistency in care led to some service users questioning the need to disclose their HIV status to non-HIV specialists:

*'...does my GP need to know? I, I don't know, the GP system in the UK is a funny one because the GPs always change; you never know who you are seeing next yeah? You go through a lot of hands and I don't think all GPs have the right education about what it means to be HIV positive' [Service user #11: MSM, Dx 52 years, high prev.]*

#### 7.2.4 Stigma and concerns about confidentiality

A lack of HIV knowledge in HCPs working beyond specialist settings was also linked to experiences of stigma and discrimination, or worries about being treated differently:

*'... I thought he [the dentist] came across as being a little bit nervous. And I don't think he'd been sort of exposed to patients, too many patients, and he was sort of a little bit umm....'What are the symptoms of AIDS then?' And, and what ermm 'oh you've got a little mark is that KS you've got or your mouth?' ....it was just, you know, I've still got a relatively strong immune system so I just think, you know.... I may have totally read that incorrectly ermm but, you know, I mean I just sensed that there wasn't the knowledge there or there was a bit more nervousness than there should have been....' [Service user #7: MSM, Dx 50 years, high prev.]*

Concerns surrounding possible stigma also led to some service users questioning the need to disclose their HIV status to non-HIV specialists:

*'...does my GP need to know? I, I don't know, the GP system in the UK is a funny one because the GPs always change; you never know who you are seeing next yeah? You go through a lot of hands and I don't think all GPs have the right education about what it means to be HIV positive' [Service user #11: MSM, Dx 52 years, high prev.]*

*'... I could just imagine the...the person being really freaked if you would [disclose], just because of the other ermm clients...' [Service user #3: MSM, Dx 53 years, high prev.]*

For one service user, disclosure of his HIV status to non-HIV specialists had led to a serious confidentiality breach, resulting in a breakdown of trust. A paper this service user presented to his NHS Trust was published online without permission, printing his HIV status and recognisable personal details, making him vulnerable to stigma and discrimination:

*'You just googled my name and up came the paper. I was absolutely horrified and it sent me into a great state of... state of shock, er and of course huge upset in my family er, and people close to me, huge upset.... I never made actually a formal complaint, what I did was ring up the information department and they said 'oh no, it's fine' and I said 'but you never, never asked me' 'and if you had I would've said no' [Service user #12: MSM, Dx 68 years]*

Where trust was created between non-HIV specialists and service users, this was achieved by HCPs taking the time to provide helpful reassurance. To offer helpful reassurance, HCPs needed to demonstrate HIV knowledge and empathy e.g. to recognise the impact of stigma in living with HIV:

*'He [the dentist] said, it's gonna make absolutely no difference to your.... you know, your treatment um sorry forget all the horror stories about being the last one in, in the, you know, and er, er you know it just doesn't happen' [Service user #7: MSM, Dx 50 years, high prev.]*

#### 7.2.5 'Enhanced' care in HIV services

The care provided by HIV services for adults diagnosed with HIV at age 50+ years appears to be superior, in many ways, to that largely experienced by older adults. The 'enhanced care' received by this group is largely a result of the dramatic changes in HIV prognosis, without the same degree of change in how people living with HIV are managed. This HCP acknowledges that HIV services are now under increased financial strain and demands to provide only 'essential' care:

*'... part of the perception we have is that we've developed this phenomenally effective ermm model in HIV and we've gone from everybody dying to, you know, my clinics full of people who've got minor problems or psychological, psychiatric problems.... and we've built up a lot of things that aren't routine care and now because it's being as it were pressurised we are being asked to dumb down the service to what everybody else gets...' [HCP #2: Male associate specialist in HIV, high prev.]*

The care provided by HIV services can firstly be considered 'enhanced' due to the high levels of health monitoring received by people with the disease e.g. in terms of blood tests, blood pressure checks, weight measurements etc. This increases the likelihood of prompt detection of additional health problems:

*'... you're being monitored. I mean I....one of my boys just got diagnosed with prostate cancer at the age of fifty-five now he, I was doing PSAs<sup>6</sup> on him more regularly because his father had died of prostate cancer so the fact that he was HIV positive with a family history of something which was then monitored perhaps a little bit more frequently than it would have been, led to a diagnosis which he might not have had if he'd have just gone to his GP and said oh my father died of prostate cancer. They'd say so what and they wouldn't bother doing any extra testing so it ..... there's almost secondary benefits you know' [HCP #2: Male associate specialist in HIV, high prev.]*

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<sup>6</sup> PSA = Prostate-specific antigen; an elevated PSA indicates possible prostate cancer.



It was also found that service users received additional 'check-ups' between appointments, through direct contact with HIV clinicians. In one instance, a HIV clinician had given his personal contact details to his patients:

*'I get emails or phone calls from different people just to check I'm okay in between appointments and stuff and they don't have to do that' [Service user #6: MSM, Dx 51 years, high prev.]*

Service users were also reported to be seen more frequently than guidelines recommend:

*'I have a whole group of patients I see every month or every six weeks which is completely against what the NHS says, oh you should be trying to get to see them all every six months. Now I know all the patients I can see every six months and they're all already being seen every six months.....'*  
*[HCP #2: Male associate specialist in HIV, high prev.]*

The additional health monitoring and contact with HCPs cemented the trust between service users and clinicians, and provided service users with extra reassurance:

*'I actually feel...more confident....with my health and my outlook now than I have before 'cos...I actually know where I am health wise and er, you know, and it's not just the HIV issue, it's, it's all aspects of my health... if er anything um, er sort of happens to me health wise it's gonna get caught quickly...so that gives me probably more confidence than I've ever had rather than sort of waiting for it and, yeah, until something's too late....'* *[Service user #7: MSM, Dx 50 years, high prev.]*

HCPs working in HIV services were viewed, and considered themselves, as advocates for their service users, acknowledging that this is not the situation for older adults in general:

*'...I think there's an awful lot of older people in the.... general population who have nobody to advocate for them.'* *[HCP #2: Male associate specialist in HIV, high prev.]*

Due to the 'enhanced' care received, it was anticipated that the life-expectancy of someone diagnosed with HIV at an older age could exceed that predicted before diagnosis; this was supported by the perception that the impact would be greater for men:

*'it would not surprise me at some stage, you know, a guy in my position whose life-expectancy would probably be even better because I'm now going for the regular health checks that I'd never have gone for before, so I'll pick up other things that, you know, and if there's good, strong adherence and, you know, an awareness of the need to have a healthy lifestyle, I, I, I mean who knows where it's going'* *[Service user #7: MSM, Dx 50 years, high prev.]*

*'I heard the other day that, especially for male patients, they tend to live longer than a non-positive male patient because when you have a positive patient the positive patient is monitoring and screened for everything' [HCP #3: Male HIV nurse, high prev.]*

### 7.3 Challenges for HIV clinicians

Although service users perceived HIV services positively, primarily due to the consistency and expertise of care in this setting, meeting the needs of adults diagnosed with HIV at age 50+ years was considered challenging by HCPs for the following reasons.

#### 7.3.1 '...the ageing population gives us a lot more curveballs'

Due to the greater likelihood of additional health problems with advancing age, older adults were broadly considered more challenging to treat:

*'So you're, you're not having to look just at the HIV things in the over fifty population, you're also looking at whatever else they've got going on.'* [HCP #11: Female nurse practitioner in HIV, high prev.]

In starting ART, it was considered that older people may be at a disadvantage due to pre-existing health issues:

*'...from an ageing, an older person, their, you're starting with a baseline of an older liver and....older.... kidneys, so when you're looking to start treatment those are the things you need to take into consideration as well. There's the, their actual ageing physiology ... and they may be sort of starting with a, more compromised baseline than a younger person.....'* [HCP #11: Female nurse practitioner in HIV, high prev.]

There were also concerns about possible medication interactions:

*'There might be other things going on....they'll very often be on a number of drugs so that if you do introduce an antiretroviral or change a drug you've got to be more aware of interactions. I mean that's certainly true in the older age group, you've got more drugs to have to think about....'* [HCP #12: Female consultant in GUM, low prev]

HCPs acknowledged the need for longer consultation times with adults aged 50+ years, due to the complexity of their health and social care needs:

*'...I mean I spend more time and more effort with my older patients than I do with my younger. I mean today I've seen ummm....one, two, three....three people over sixty and I spent more time and*

*I concentrated more on those three than I did with the five or six I saw below thirty-five.’ [HCP #2: Male associate specialist in HIV, high prev.]*

*‘.... we might.....be maybe more involved with the older people as they get older, as they develop more problems....we do referrals to social services....I have you know involved like Age UK for certain older, you know people as they get older, you know in their 60s and they might be very isolated whereas before they were working, you know, then they retire, they don’t really have family or friends so they do become quite isolated. I think but I would say maybe that could happen with any...anybody.’ [HCP #1: Female HIV specialist nurse, high prev.]*

### 7.3.2 Protecting ‘exceptionalism’ or accepting ‘normalisation’ in HIV care

HCPs working in HIV services appear remarkably protective of their service users, and maintaining the scope within their role to provide exceptional and ‘enhanced’ care. This was particularly expressed by clinicians that had worked in HIV medicine from the 80s onwards, when there was no effective treatment for the disease. It was highlighted by one HCP through the paternal phrasing he used in referring to male service users as ‘my boys’.

*‘...oh it was terrible, the early days were awful, ’85 to ’95 it was er very tragic. Wards full of very advanced cases, you know, people dying left, right and centre. People going blind as well, terrible things.....’ [HCP #8: HIV consultant, low HIV prev.]*

Contradictory to its transformation to a condition largely regarded as chronic, HIV was still not necessarily considered in this light. One HCP expressed concerns about future changes he predicted to HIV commissioning:

*‘...and although I absolutely agree with the normalisation of HIV, it’s still not normal and it’s still stigmatised and we still haven’t got over that. Ummm, and my concern is that....I think probably what will happen, certainly in the next five to ten years is that HIV will come....out of specialist commissioning and we’ll come under the CCGs so then patients will have no choice and they will have, like a diabetic patient, apart from their diagnosis or any complex changes they will have to be looked after by their GP.....and then I imagine what will then happen is then that the GP has to refer in just like a GP does, you know. So, and so, it would be lovely if that could be that but I’m not quite sure that anyone’s ready for that.’ [HCP #9: Male HIV Lead nurse, low prev.]*

This quotation emphasises a perceived threat to the care and wellbeing of patients, and also to the current role of HIV clinicians. This HCP is questioning his readiness to compromise the strong professional relationships he is able to develop with service users and the personal satisfaction this brings:

*'.....in HIV we still have that luxury....and that's what I've always enjoyed about it.....you know... 'cos otherwise you'd work in A&E or something....' [HCP #9: Male HIV Lead nurse, low prev.]*

### 7.3.3 Geographical location and resource availability

HCPs working in low HIV prevalence areas discussed the need to be particularly adaptable, and have a wider range of knowledge, due to the limited services available for patient referral. This was largely expressed with regards to older adults, who were generally reported to have more complex health and social needs than younger people. This HCP voiced differences in the requirements of his role in a low compared to a high HIV prevalence area, from experience in both settings:

*'...what's very nice about coming up here is when I was in [place name - high HIV prev. area], you know, you had a big team so you know, so we, we had a CAB advice worker coming in so I didn't have to worry too much, and we had a psychologist, you know, so we had a dietician, you know, so you just referred whereas I think...for me I have got a...a greater sort of awareness of a holistic approach because I haven't had those people, those people don't exist....' [HCP #9: Male HIV Lead nurse, low HIV prevalence area]*

This HCP also discussed difficulties in referring patients to mental health services, and general problems in making referrals due to changes in the commissioning of services:

*'Well psychologists is impossible, cos there's hardly any provision....I think one of the biggest problems that I think we've had over the last few years is where everything's been re-organised...so all the providers have all changed...whereas I used to have everybody's number in my mobile.....I used to know their names but I don't know who they are now...part of the problem now with this commissioning and re-commissioning means that you go through that cycle every three to five years again where everyone's got to develop a new relationship...so that's gonna be a big challenge I think' [HCP #9: Male HIV lead nurse, low HIV prevalence area]*

In high HIV prevalence areas, an abundance of resources were available:

*'....about the social issues we have community nurses, also to look into that we have our counselling departments to look after that.....we have a Tuesday afternoon for positive patients with er liver problems, we have er the [name] coming on Fridays to provide therapy to our patients who may suffer from any type of bones or muscle disorder.....we also have, believe me or not, sacrocranial therapy on a Thursday afternoon, offering to our patients, which is amazing, we have*

*our psychotherapists as well, err we have a psychiatric as well on a Wednesday and on a Monday.'*

*[HCP #4: Female clinical psychologist, high prev.]*

However, it was acknowledged that even in high prevalence areas, resources were being downscaled as a consequence of improvements in HIV treatment and prognosis:

*'.....as people have got better those have been withdrawn as not necessary.... years ago we would have social worker or we would have a dietician or a physiotherapist, now those as...as defined HIV services no longer exist....' [HCP #2: Male associate specialist in HIV, high prev.]*

In low HIV prevalence areas, it was also challenging to provide support groups that were acceptable to everyone. There were simply not enough attendees to enable the funding of services for particular groups:

*'Because we're a relatively small service umm it's, we have discussed this occasionally over the years, umm we haven't got enough, we probably haven't got enough patients within the specialised groups to make a specialised clinic viable really. And like, you know, paying for a member of staff just to see a small number of....patients at a certain time.....may not be economically viable.....we're too small a service really... it's easier to do with large city....sexual health services where they've got a big population and have got enough patients to run) specialised clinics I think.'* *[HCP#10: Female GUM doctor, low HIV prevalence]*

Where support groups were provided by HIV clinics, survey respondents highlighted that these were usually for MSM or younger people (usually <19 years, <21 years or <25 years). Due to the low numbers of people living with HIV, it was also difficult to match patients and organise peer support:

*'....I think it, it's, it's not as easy, whereas maybe in a bigger city and you know in the bigger service maybe in [place name – high prevalence] it's slightly easier to look at how you get peer support....' [HCP #9: Male HIV Lead nurse, low HIV prevalence area]*

This was particularly the case when patients belonged to low risk groups:

*'.....she didn't meet the, the stereotype tick box.....I think for her, another issue was that.... 'cos she lived outside of London as well so you know what are the services like for someone like her?.....she doesn't meet the criteria to fall into the gay men's support group or the African support group she's this sort of middle class white woman hanging on her own....' [HCP #11: Female nurse practitioner in HIV, high prev.]*

#### 7.3.4 Providing services for universal or targeted access

Unlike sexual health/GUM services (section 5.7.8), HIV services were regarded as accessible and acceptable to anyone:

*'...I mean I was surprised....it was just so laid back, everyone was treated exactly the same, regardless of your age, whatever.... it's just a nice place to be, which is what it should be...'*

*[Service user #8: MSM, Dx 53 years, high prev.]*

*'.... I don't think they look at age.... they look at the person and they look at what their needs are and that's what you need, you know, that's the whole point....'* *[Service user #6: MSM, Dx 51*

*years, high prev.]*

Although a few service users had found support groups for people living with HIV helpful, some felt that they did not 'fit in' with those available. This service user found that the division of support groups by gender and routes of HIV transmission was detrimental, and lead to the exclusion of some people.

*'I did go there for a bit but it wasn't really for me... It was too gay for me can you believe, because I'm a gay man, it was too gay for me. But I wasn't the only person, quite a few people in [place name] felt the same way.... all these people came together for me and the gay people all, all kind of were a clique. And people who were not part of that clique either left or, or didn't go anymore or some of them felt excluded.'* *[Service user #12: MSM, Dx 68 years]*

Heterosexuals, particularly women, appeared most likely to be excluded:

*'Everything was so gay. All men, there were no women....and the so called counsellor was such a Queen, you know. It was er, it wasn't a pleasure to go to a group. And there were no women's groups or anything and there were no mixed groups, only a men's group. And the reason for that when I asked was that's all they could get funding for....'* *[Service user #12: MSM, Dx 68 years]*

#### 7.3.5 Communication

It was considered that adults aged 50+ years were less likely to raise problems during consultations, in comparison to younger people. This meant that HCPs adapted their approach to communicating with older adults:

*'.....with the older ones I think you often have to prompt them more because there's a lot of the 'Oh I don't want to bother you'.....or even they 'Oh, I've forgotten I did go into hospital last week or two weeks ago ummm the doctor said I'd got you know some problem with my hip and I then,*

*so you have to dig a bit deeper so you end up spending more time with your older patients.’ [HCP #2: Male associate specialist in HIV, high prev.]*

*‘...I know that they won’t complain, I know that they always the most patient ones.’ [HCP #3: Male HIV nurse, high prev.]*

With younger adults, the challenge was to keep people connected to the service and adherent to ART:

*‘....so I rather think it is different because I’m just absolutely focused on keeping youngsters engaged..... I don’t really see that in the over fifties and obviously they’ve got maturity and experience of life ...’ [HCP #6: Female HIV research nurse, high prev.]*

#### 7.4 Impact of HIV on lifestyle and identity

When asked about the medium and longer term impacts of testing positive for HIV at an older age e.g. in terms of day-to-day life, relationships, work and wellbeing, the following factors were discussed. The heterogeneity of these responses highlights service user individuality and differences in the context of people’s lives.

##### 7.4.1 Context of diagnosis

Once diagnosed and well managed with ART, for the most part HIV was not expressed as a prime concern for older adults with HIV:

*‘So it, it’s I can’t see that it’s gonna affect any...my life in any way negatively but again you know there’s some people who it does affect and I understand that every person’s different [Service user #4: Heterosexual male, Dx 51 years, low prev.]*

*‘...life goes on and as long as I take my tablets.....there’s no difference between me and Joe Bloggs.’ [Service user #8: MSM, Dx 53 years, high prev.]*

This was due to the advancements in treatment:

*‘I think there’s a, less of a, an anxiety because you have effective therapy now. HIV has become....really rather pedestrian and rather boring. Once you can diagnose somebody you can pretty well confirm that they’ll....be okay unless they have a serious opportunistic infection at the beginning.’ [HCP #2: Male associate specialist in HIV, high prev.]*

HIV was particularly not regarded as a major concern for people living with the disease in the following contexts.

#### 7.4.2 Living with other health problems

Living with HIV in addition to other health problems was reported as an extra burden for service users by some HCPs:

*'...I think getting older anyway in our society is quite difficult....if you throw HIV in as well it's another sort of chronic health thing to manage and you ummm...yeah you've got a sense of kind of also having other health problems, possibly coming up....and then sort of managing all of that whereas when you are younger perhaps you don't have the burden of all of that so much....' [HCP #4: Female clinical psychologist, high prev.]*

However, in the presence of other symptomatic chronic conditions, service users considered these to be of much greater concern than HIV:

*'...at the moment the thing that is bothering me the most is arthritis which has got nothing to do, well I don't think it has got anything to do with it [HIV]...' [Service user #1: Male, Dx 67 years, high prev.]*

This was also identified by HCPs in their older patients:

*'I can think of, you know, a couple of people with MS, where you know they don't care about their HIV at all....' [HCP #6: Female HIV research nurse, high prev.]*

For one service user that tested positive for hepatitis C at the same time as HIV, the former diagnosis was reported to have a far more negative impact. This service user was particularly concerned about telling people about his hepatitis C:

*'...I will tell them that I've got liver problems, I won't necessarily tell them it's hep C because hep C people jump to conclusions and they pre-judge. If you've got hepatitis that's fine because you could have caught it all sorts of different ways, if you've got hep C there's the, you know the main key issues of how you can get it....The problem with, in the gay community, in the gay and bisexual community, hep C is....is the new taboo, the new stigma and that's within our own community ermm so basically ermm it's not a problem to be HIV, fine, it's not a problem to be ermm undetectable...' [Patient #6: White MSM diagnosed with HIV at age 51 years, high HIV prevalence area]*



At the time of interview, this service user was unable to obtain treatment for his hepatitis C, fuelling psychological distress and fears surrounding transmission. Hepatitis C appeared to hold much greater stigma than HIV.

#### 7.4.3 Financial and housing difficulties

Other aspects of people's lives, aside from those related to their health, were also reported to be of greater concern than their HIV diagnosis. One service user's life had been turned upside down at the time of diagnosis with the threat of going to prison, losing his job and his home:

*'...then I was moved up to er, up to the [name of clinic] ermm now the problem was, was the fact is that umm I was due in court on umm in the morning of the [date of first appointment at HIV clinic] and so I told, can I be here at 4'oclock in the afternoon....and I said well if I'm not in prison yes, um yeah so ummm. It was, it's been of...a bit trying.....' [Service user #6: MSM, Dx 51 years, high prev.]*

The service user recounted the night his was diagnosed with HIV:

*'...I ended up having nowhere to sleep that night and so I didn't, I stayed up outside, basically I...I had a shed but behind the council flats I used to live in which was storage so I basically spent all night tidying stuff and looking at stuff.... so the night I was probably needed somebody to be there ermm I was on my own.' [Service user #6: MSM, Dx 51 years, high prev.]*

In light of the more traumatic events in his life, being diagnosed with HIV and attending HIV services was not expressed as a problem:

*'.....this is actually an easy part of my life' [Service user #6: MSM, Dx 51 years, high prev.]*

*'...it's been a rollercoaster, er but if it's focusing on this part of it, this part of it is actually going swimmingly...' [Service user #6: MSM, Dx 51 years, high prev.]*

#### 7.4.4 Peer reassurance

When service users knew other older adults living with HIV, and saw them managing successfully, this was reassuring:

*'... the HIV.....because I've known what's going on because I've got friends who I'm pretty sure have got reasonably, you know, have good lives as long as you are looking after yourselves....fine....that [HIV] was not a problem....' [Service user #6: MSM, Dx 51 years, high prev.]*

The support provided by knowing others with HIV also reduced the stigmatising effect of the disease. It appeared that MSM were more likely to know someone else with HIV, and have peer support, than heterosexuals from groups considered at 'low risk' of HIV. In high prevalence areas it was also more likely for people to have peer support (see section 7.3.3).

#### 7.4.5 Impact on lifestyle and behaviours

For one service user, receiving his diagnosis made him more aware of his advancing age, prompting him to take greater care of himself:

*'I probably needed something to sort of slow me down, so this has done.... so it was probably a wake-up call...'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

It also prompted one service user to stop taking recreational drugs:

*'...age of forty five I got into er house music and started tacking Ecstasy and having a whale of a time (laughs). Um but I've never taken it since I was diagnosed...'* [Service user #10: MSM, Dx 57 years, high prev.]

HCPs had witnessed older people taking greater care of their health after diagnosis, something which was not reported for younger people:

*.....this happens as well if you witness with elderly patients, they tend to go to that extremely healthy lifestyle, almost over the top which I....a bit weird but they just have that wonderful, yes, the way of coping, you know. But you know if they happy and if it works why not.'* [HCP #3: Male HIV nurse, high prev.]

Prior to diagnosis, service users had often not considered their health or mortality. One service expressed the way his family had viewed him as 'invincible' before diagnosis:

*'.....they've seen a flaw in my resilience now, you see, so they, they do check now and again but they just thought oh dad's never ill....All their lives, never been in hospital, never been sick in bed. I've had the odd cold, the odd cough, sore throat. I've had dislocated shoulders, broken ribs and everything and I just carry on....'* [Service user #4: Heterosexual male, Dx 51 years, low prev.]

In addition to the diagnosis serving as a wake-up call to prompt greater health awareness, it also encouraged service users to evaluate their lives in a broader sense and 'seize the day':

*'.....they can then sort of think of well what do I want out of life? And it can be quite a reflective time to some extent. It can be a time where ermm you might, you know we have people who go*

*you know I might take some time off and go and travel you know or do something different....'*

*[HCP #4: Female clinical psychologist, high prev.]*

It also heightened the importance of family and partners, strengthening these bonds:

*'It's definitely brought me and [partner's name] a lot closer together and we're, we're planning on getting married which we were only talking about it. It had come up in conversation before but nothing definite and now it's a definite thing um so yeah I, I do look at things in a, a different light....it's definitely brought us closer together'* *[Service user #8: MSM, Dx 53 years, high prev.]*

#### 7.4.6 Psychological benefit

For one service user that had struggled with chronic depression prior to diagnosis, and had previously refused HIV testing due to concerns about the effect this might have on his mental health, testing positive actually had a beneficial impact:

*'It hasn't impacted on my mental health as I thought it would do, you know, ermm it's actually possibly made me er stronger than, than it has had that detrimental feeling'* *[Service user #5: MSM, Dx 50 years, high prev.]*

In testing for HIV, this service user had addressed a concern he had been avoiding for many years and gained control over his health. This is similar to the comfort discussed by other male service users in achieving a better understanding of their own health (7.2.5). A further service user described their clinicians as providing a 'psychological cushion' [Service user #1].

#### 7.4.7 Exposure of 'closeted' sexuality

Several interviewed HCPs and survey respondents reported that for older married men in heterosexual partnerships it was a common occurrence for their HIV diagnosis to also force a revelation of their 'double lives' as MSM:

*'...I had a patient who I suppose was in his early sixties, late fifties/early sixties, but for him the HIV wasn't the issue but for him the fact that we had now discovered that, and his wife had discovered that he had been having sex with men was much bigger issue than the HIV.....I think...that's what's difficult for a lot of our older patients is that suddenly what they've portrayed out there is not quite right, and particularly if they live in small communities.'* *[HCP #5: Female HIV Lead nurse, low prev.]*

This situation was reported as a particularly challenging for heterosexual partners, having a major impact on their identity as well as the person diagnosed:

*'.....that's their world that, you know that, this is their story this is what they have and then all of a sudden that's just blown to smithereens....'* [HCP #5: Female HIV Lead nurse, low prev.]

#### 7.4.8 Stigma

The greatest concern about living with HIV was reported as the stigma still associated with the disease:

*'...I think the big issue for me is er, you know, is er stigma and I haven't quite worked out whether it's um me imposing that stigma on myself or, whether there is still, there is still that stigma out there, you know, with my age group, you know, it. You know it's a two-way thing isn't it...'* [Service user #7: MSM, Dx 50 years, high prev.]

Stigma was felt even within the gay community, voiced by some as surprising given the high levels of HIV knowledge expected in this group:

*'.....people can be quite rude and quite brutal, you know.....in the broader sort of gay community, certainly the society and certainly the nation, you know, I still feel it's still quite an issue.'* [Service user #7: MSM, Dx 50 years, high prev.]

It was considered that stigma may be worse depending on where you live, increasing in low prevalence areas beyond big cities:

*'I'm not sure what it's like in the provinces though and I'm sure attitudes aren't as tolerant everywhere in the UK as they are in er in....[place name – high prevalence] or in certain parts of [place name – high prevalence] should I say'* [Service user #7: MSM, Dx 50 years, high prev.]

Stigma was found to impact broadly across peoples living, affecting their relationships, work and ability to travel.

#### 7.4.9 Relationships

For one service user, being diagnosed with HIV created mistrust and anxiety in her relationship. She was uncertain as to whether her partner, found to have transmitted the infection to her, had been fully aware of his HIV positive status before their relationship started. For this service user, being diagnosed with HIV meant she could not even contemplate the idea of having a different partner in the future:

*'...it made me feel well at least we'll be stronger because we know we can't, we're not gonna go anywhere else...not that I would but I know I'd make it work even more now because, if we had a*

*little problem, because of the situation...'* [Service user #2: Heterosexual female, Dx 55 years, high prev.]

This quotation highlights the intense stigma this service user felt surrounding her HIV diagnosis. It indicates fear of rejection as a barrier to forming another intimate relationship and consequently a resignation to stay in her current partnership no matter what.

This service user also displayed feelings of resentment that her partner had contracted HIV before her and transmitted the infection but had not become ill or needed to take medications:

*'...I had an issue with him not having treatment and me having it...'* [Service user #2: Heterosexual female, Dx 55 years, high prev.]

*'I get these days where I'm, I can't bear to look at him and then I get days where I love him so much I could cry'* [Service user #2: Heterosexual female, Dx 55 years, high prev.]

Further service users also expressed uncertainty about developing new sexual and romantic partnerships, again reporting concerns about stigma:

*'... you can go on gay chat rooms, you know Gaydar apps or what have you, you know, some of the things people say about um.... if you're HIV positive you're almost an outcast, a leper.... amongst young and old.... people can be quite rude and quite brutal...'* [Service user #7: MSM, Dx 50 years, high prev.]

One service user identified that before diagnosis, he subconsciously felt stigma towards HIV and dating someone with the disease:

*'... if someone probably you know six months ago would have told me he is er he has HIV but he is undetectable I still wouldn't have touched him to some extent, you know what I mean.... Er and now, now that I myself am in that similar situation I understand much better that actually, what it actually means, you know, it's like um .... the stigma, I probably still had somewhere in the back of my mind when I was negative I think to some extent has, has gone.'* [Service user #11: MSM, Dx 52 years, high prev.]

Questions were raised around if and when someone should disclose their status, creating anxieties around acceptance:

*'... the HIV hasn't been a, an issue for me. I mean it's not. I suppose if I was going to get into a, er a relationship then you know, I'll have, I'd have to question you know when do I tell the person?'*

*[Service user #5: MSM, Dx 50 years, high prev.]*

#### 7.4.10 Work

Several patients had modified their working roles after diagnosis; this was mainly reported as due to concerns about experiencing stigma.

*'I've cut down my hours and I've left like days like this so I can do appointments without anybody...without saying oh can I have this day off cos I've got an appointment...'* *[Service user #2:*

*Heterosexual female, Dx 55 years, high prev.]*

Disclosure to work colleagues was not common, unless firm friendships and trust had been established, due to fears around confidentiality:

*'... I don't wanna tell anybody at work.... how can I put this and be polite? They're not, some of them aren't the brightest in the bunch and they probably don't understand about HIV and.... they do talk to people and you, you never know what they're gonna come out with. You know, I mean I've, I've had arguments in the shop because so and so's told so and so, and so and so's told so and so and you think well why did you do it – 'oh, I never thought about it, I just said have you heard about...' –and I think it could get to, if I go in and say the reason why I've been off is blah, blah, blah, you know, one of them will say, say to a, a customer, have you heard why [participant's name] been off so long 'cos he's got AIDS. 'Cos that's the way they would understand it and then that's the way it would come out. It wouldn't be he's HIV, he's got AIDS and that's the way their mind works so...'* *[Service user #8: MSM, Dx 53 years, high prev.]*

In addition to stigma, symptoms (e.g. tiredness) had also modified people's working hours.

One service user also expressed concerns about HIV transmission at work:

*'...the only thing that I get a bit worried about is my professional life is I work in the food industry as a, er a chef mostly. And um, um, and, you know, if you cut yourself it's a lot more serious now.*

*So I just try really hard to be extra careful in that area'* *[Service user #9: MSM, Dx 53 years, high HIV prevalence prev.]*

#### 7.4.11 Travel

One service user voiced the impact of diagnosis on their ability to travel. Travel was strongly linked to this service user's work, and although travel restrictions have been lifted in some countries he felt that stigma and discrimination were still commonplace:

*'...I mean suddenly I have a different.....different situation travelling. I mean I don't want to go to Singapore but then I would have people to er buy my medicine in Singapore but I don't want to go er through the customs and being busted and being sent home. I won't put myself at risk for being humiliated in that way. I simply skipped going to Middle East because of that reason and it's only until recently that China and Korea and a lot of other countries actually ermm was okay under pressure from the....the world community but like Health Executive. It doesn't mean that you wouldn't get trouble in the customs if they would go through your luggage' [Service user #3: MSM, Dx 53 years, high prev.]*

#### 7.4.12 Ageing with HIV

The vast majority of service users expressed an optimistic outlook towards ageing with HIV. The perception was that with good ART adherence living with HIV would not prove to be any more problematic:

*'...as long as I've got eyes and hands that work I'll be alright but that's an ageing thing anyway er....I'm of a way of thinking now that er, something else is gonna get me, not the AIDS, you know. Age, something else will catch up with me and it won't be the AIDS....' [Service user #4: Heterosexual male, Dx 51 years, low prev.]*

It was also considered to be advantageous that older people with HIV had extensive experience of the health system, given the level of care received in HIV services (see section 7.2.5):

*'.....they already know about having scans, they already know about you know looking at information, consent forms.....so they do have an advantage over the general population who may be presented in a time great of stress with something that.... completely new....so I think that knowledge of the system and what's important, even just going to collect your pills every time.... here's that constant feedback which is advantageous.' [HCP #2: Male associate specialist in HIV, high prev.]*

Only one service user voiced particular concerns about ageing with HIV:

*'I mean, if you just look up in the internet it's quite scary...to...to, read about the ermm prospects of being diagnosed more than fifty because it all says oh then you will have a lot of problems....'*  
*[Service user #3: MSM, Dx 53 years, high prev.]*

It was also discussed that symptoms of ageing and HIV may again be difficult to differentiate; this have previously been highlighted as a barrier to diagnosing HIV in adults aged 50+ years (see section 5.7.1):

*'.....at my age I'm gonna get aches and pains and things....so you've gotta remember that...It's not because of what you've got, you're gonna have that anyway' [Service user #2: Heterosexual female, Dx 55 years, high prev.]*

The relative optimism of the service users towards ageing with HIV may be linked to their age and also their physical health, as the majority were only in their early fifties and few had additional health problems. It appeared that not everyone had considered the impact of ageing with HIV. For some service users, it also appeared that optimism may have developed as a coping mechanism. One service user expressed the belief that HIV treatments would improve even further during their lifetime:

*'I also assume there's gonna be another, a further development in, in medication. My friends who are in the industry they assure me that in four of five years' time that I'll be having a vaccination every four or five months and that's it. So from that perspective you know it looks, it looks all very manageable' [Service user #11: MSM, Dx 52 years, high prev.]*

## 7.5 Adaptation and resilience at an older age

When service users were asked to speculate on the impact of receiving a HIV diagnosis at 50 years and over compared to a younger age, several participants perceived that older age had provided them with greater resilience and ability to adapt.

This was attributed to gaining years of life experience, and having achieved many important identity forming milestones (e.g. first job, first relationship) by the time of diagnosis.

*'...I think mentally it's probably even easier if you're a certain age. 'Cos you're probably more mature um so you know you're probably more mature in dealing with this....Um and then you know, you probably have more support structure... You're just more settled yeah in life....I can imagine it's much more difficult to cope with when you are in the middle of your life. You're building up your life, you're developing and you're growing in a career and, I don't know, wanting a relationship. And I was to some extent given my age, lucky that I have made a career behind me and that I have a long term partnership. So that made it to some extent even easier....' [Service user #11: MSM, Dx 52 years, high prev.]*

Resilience had been developed following the experience of other hurdles and life challenges:



*'....I do think umm, by the time you've got to that age, you know, you're used to overcoming or coming to terms with.....crap that happens to you really.'* [HCP #6: Female HIV research nurse, high prev.]

At a younger age, it was considered that someone's lifestyle may hinder their adaptation to illness. It was generally regarded that younger people's lives were less structured and more unsettled:

*'.....the young lads coming in, they are so umm, oh, they are so immature and their lifestyles so chaotic...'* [HCP #6: Female HIV research nurse, high prev.]

Adaption at any age appeared to be associated with gaining HIV knowledge and understanding of HIV:

*'I'm a relatively logical person so no, once I, it took me, it didn't take me very long to really cope with it because you know once I understand how it works, I understand the treatment, I understand what it means to be treated basically, you know. It was, became a very normal part of my life very quickly.'* [Service user #11: MSM, Dx 52 years, high prev.]

## 7.6 Discussion

### 7.6.1 'Secondary benefits' of a HIV diagnosis

Service users were confident in the expertise and competency of HIV clinicians in managing their disease, and felt they would be treated without stigma in this environment. Most service users had not achieved this type of trusting relationship with GPs or other non-HIV specialists, affecting their decision to disclose their HIV status with these HCPs.

Adults diagnosed with HIV at an older age reported some 'secondary benefits' as a result of their diagnosis. Compared to the older population in general, this group were considered to receive higher levels of health monitoring through frequent blood tests, weight measurements, blood pressure checks, and clinician contact. It is recommended that people with stable HIV are followed up 6 monthly in clinic, with specific checks performed at each attendance (Angus et al., 2016a). Adults taking ART, with an undetectable viral load and a CD4 count  $>350$  cells/mm<sup>3</sup>, should have their full blood count checked yearly, and additional blood tests e.g. to check kidney and liver function, performed every 6-12 months (Angus et al., 2016a). It was considered that this degree of monitoring would promote the early detection of risk factors and symptoms of further disease.

Older adults with HIV reported seeing the same HIV clinicians at each consultation; however, in the wider population this is not experienced in accessing general practice. Currently, only around a third of patients are consistently, or almost consistently, able to see their preferred GP (NHS England, 2016d). Other chronic conditions such as diabetes and depression, which are commissioned by CCGs and do not receive specialist commissioning, are predominantly managed in general practice (Goodwin et al., 2010). The implication here is that for other chronic conditions, older adults may have difficulties in accessing the same HCPs at each consultation. Consistency in care is crucial to establishing patient trust (von Bültzingslöwen et al., 2006), satisfaction (Becker, Drachman, & Kirscht, 1974; Fairhurst & May, 2006; Roberge et al., 2001; Saultz & Albedaiwi, 2004), problem identification and goal setting (Freeman & Hughes, 2010).

The time allocated to GP consultations, on average lasting approximately 8-10 minutes (NHS Choices, 2016b), is also arguably insufficient to allow patients the opportunity to present their concerns (BMA, 2016) or to develop the trust required to support information sharing.

Routine appointment times in HIV services are longer; for example, Chelsea and Westminster NHS Foundation Trust state that most of their consultations last 15-30 minutes (2016), at Barts Health NHS Trust appointments last approximately 20 minutes (2016).

The use of HIV clinicians as substitute GPs, given the consistency of care and time allocated to appointments in this setting, is unsurprisingly reported more widely in the literature:

*‘General practice is a cornerstone of healthcare in the United Kingdom. GPs are routinely involved in managing the health of millions of people across the country. This is not, though, the case for most people with HIV and AIDS. As Dr Ewen Stewart of the RCGP noted, “a lot of patients are not getting their primary care in primary care. They are getting it all at the hospital clinic.”’ (Fowler et al., 2011, p.66)*

The consistency in care, coupled with the high levels of monitoring provided in HIV services, is comparable to that experienced by clinical trial participants, who are found overall to achieve better outcomes than non-trial patients (DH, 2010). In examining the life-expectancy of adults with HIV by sexual risk group, a recent study has found that MSM with HIV have higher life expectancies than men in the general population; 69.3 years at age 20 in MSM living with HIV in Canada or the USA, compared to 59.7 years (Canada) or 57.0 years (USA) for men in the general population at age 20 years (Samji et al., 2013). This is the first study to have explored life-expectancy by sexual risk group, instead of examining people with HIV as a collective. As these findings are for the study period 2006-2007, and the researchers found life expectancies had increased consistently in comparing the study periods 2000-2002, 2003-2005, this would indicate that life expectancy may currently be higher than that reported by Samji et al (2013).

Although ART is the major factor that has led to life-expectancy increases in people living with HIV, recent advancements can also be partially attributed to broader health management. Men in particular were considered to experience improved health after diagnosis. This was linked to a reluctance to attend health services and a lack of consideration about their health before diagnosis. Further literature has shown the men are more likely to delay health-seeking; this is linked to the perceived conflict between societal depictions of 'masculinity' and healthcare engagement (Galdas, Cheater, & Marshall, 2005; Galdas, 2013).

#### 7.6.2 Catch-22 situation for HCPs

It appears that GPs are in a catch-22 situation where they are expected to be able to provide care for adults with HIV, without having the experience or education needed for this role. If HIV clinicians are serving almost as ‘substitute GPs’ for people living with HIV, then the GP role in HIV care becomes questionable. In addition, HIV clinicians are in danger of being expected to fulfil a GP role, without the expertise required to provide generalist care.

Frustration at this situation and the potential compromises to care have been expressed by people living with HIV and additional morbidities, such as diabetes:

*'I even had one consultant tell me I had to keep my diabetes separate from my HIV and my GP would have to deal with it. The trouble there is GP's don't know enough about HIV.'* (Rodgers, 2016)

It appears that the responsibilities of GPs and HIV clinicians in caring for adults with HIV require clarification (Namiba & Anderson, 2010). If HIV clinicians are to adopt more of a GP role, then this will require additional training; if GPs are to become more involved then they will require greater HIV knowledge.

This is even more paramount with an ageing population. Living with a long-term condition (LTC) is common in older adults, 14% of adults younger than 40 years live with a LTC, compared to approximately 40% of adults aged 50-59 years and 58% of adults aged 60+ years (General Lifestyle Survey 2009 cited in DH, 2012). People living with HIV have been found to experience a greater burden of chronic conditions (Kendall et al., 2014); in the over 50s, this has been estimated at double that found in the general population (Power, Bell, & Freemantle, 2010). Modifiable risk factors for further diseases are reported as higher in adults with HIV than the general population, such as smoking (Lesley et al., 2016).

As other chronic conditions, such as cardiovascular disease, are commissioned by CCGs and cared for by general practice there is a possibility for disjointed care (APPG on HIV/AIDS, 2013). To ensure quality care, GPs must therefore have high levels of HIV knowledge and awareness and effective communication must exist between HIV clinicians and GPs (APPG on HIV/AIDS, 2013).

As there are increasing calls for GPs to provide HIV testing and care for people living with HIV (BHIVA, n.d), it is difficult to imagine how the skills and experience needed for this will develop without a greater transfer of care to GPs. Although several HCPs expressed the desire to keep HIV services as 'exceptional' (see section 7.3.2), this potentially restricts the ability to 'normalise' testing and promote early diagnosis. As highlighted in section 5.7.2, symptoms are more likely to be explained by HCPs as due to common or topical symptoms (Foot, Naylor & Imison, 2010; Triplet, 1992). Therefore, it can be considered that HIV is more likely to be contemplated as a possible diagnosis when HCPs are already caring for people with HIV, and the disease is on their radar.

### 7.6.3 Identity and Adaptation

There are several theories surrounding identity disruption in the event of a chronic condition, and adaptation after diagnosis (Bury, 1982; Charmaz, 1995; Giddens, 1979; Karp 1994; Parsons, 1951). This diagnosis of a chronic condition has been found to impact on relationships, lifestyle, and future goals (Bury, 1982; Charmaz, 1995).

*'... illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted.'* (Bury, 1982)

The personal meanings attributed to a chronic condition, alongside the social context of diagnosis, have an impact on identity (Bury, 1991). Bury reports that these meanings relate to the significance e.g. personal perceptions and connotations surrounding the condition, and the consequences of diagnosis e.g. influence on the ability to work (1991). In order to adapt to living with a chronic condition, this may require a reconstruction of identity (Charmaz, 1987) and 'biographical work' (Corbin & Strauss, 1987).

It was speculated by service users that diagnosis at an older age may have better equipped them to adapt; however, when unpicked, this appears to be more closely linked to life stage and context (Bury, 1991; Price, 1996). Older adults that had already experienced significant biographical disturbance, e.g. in terms of their health, employment or relationships, considered HIV as less disruptive. In other research, older people with HIV reported their age to have resulted in the wisdom, from past life experiences and crisis points, to adapt (Siegel, Raveis, & Karus, 1998). In this situation, it is argued that being diagnosed with a chronic disease is more of a 'biographical continuation' or part of the 'biographical flow' than a disruption (Harris, 2009).

Most service users discussed their situation in positive terms, and for them HIV had become normalised within their biographies. For the majority of service users, also identified by Alexias, Savvakis, & Stratopoulou (2016), HIV was not the defining feature of people's lives. For service users with financial difficulties or additional morbidities, particularly if symptomatic, these were more salient than well-managed HIV. This has been reiterated by HCPs more broadly; for example, people with type 2 diabetes have a shorter life expectancy than those with successfully treated HIV (Diabetes UK, 2010; May, Gompels & Sabin, 2012).

*'As a doctor I can tell you that, medically speaking, I'd rather have HIV than diabetes. While this might sound shocking or surprising, the facts speak for themselves: the prognosis for those with type 2 diabetes is much worse than for those with HIV.'* (Pemberton, 2014 cited in Innes, 2014)

Once effectively controlled with ART, it was expressed that living with HIV would only present significant disruption in the event of forming new intimate relationships, or the development of severe symptoms – a finding previously identified in people living with HIV (Anderson et al., 2010; Wouters & De Wet, 2015). Distinguishing the cause of symptoms, whether they are linked to HIV, other co-morbidities, or ageing has been previously reported as a concern for older people living with HIV (Enriquez, Lackey & Witt, 2008; Rosenfeld, Ridge & Von Lob, 2014). For several service users, there were positive effects associated with diagnosis, such as the adoption of healthier lifestyles. This has previously been identified in people living with HIV (Alexias, Savvakis, & Stratopoulou, 2016).

Prior to the advent and refinement of ART, someone diagnosed with HIV would almost certainly develop symptoms associated with either, or both, HIV treatment and HIV/AIDS. Coping with these visible physical changes, and the stigma attached to HIV, has been reported as particularly challenging (Alexias, Savvakis, & Stratopoulou, 2016; Carricaburu & Pierret, 1995). As HIV treatment has become increasingly effective, with a reduction in side effects, visible symptoms are no longer commonplace; therefore, service users were mainly adapting to internalised issues such as stigma.

Stigma surrounding illness has been shown more broadly to influence illness adaptation and coping abilities, this has been reported for cancer (Chambers et al., 2012) and in mental health (Holmes & River, 1998). The only service user that voiced major difficulties in adapting to living with HIV held particularly stigmatising views of the disease, and did not belong to a group targeted by HIV prevention and testing campaigns.

By contrast, MSM generally appeared to experience less internalised stigma. Carricaburu & Pierret (1995) found that MSM diagnosed with HIV experienced a collective identity, through belonging to a group disproportionately affected by HIV, which helped them to positively adapt. Awareness of personal risk, which was considered more likely in MSM, has also been linked to easier adaptation to diagnosis (Anderson et al., 2010). The greater HIV knowledge in MSM, awareness of ART effectiveness and peer reassurance were all beneficial to adaptation.

Bury (1982) discusses the importance of being able to 'mobilise resources' e.g. social support and financial security, in adaptation. The majority of service users reported a good social network, with at least one person aware of their HIV status; however, for some their diagnosis had created distance in their relationships. In terms of financial security, one service user discussed the detrimental effect of not being able to work due to illness.

#### 7.6.4 Persistent stigma

*'It's amazing that despite the advances in treatment, people's attitudes are still exactly the same'*

[Female living with HIV, aged 48 years; excerpt from HIV Stigma Survey UK, 2015]

It was considered that most of the general public has limited knowledge about HIV. HIV knowledge is closely linked to attitudes towards the disease; those with lower levels of knowledge are more likely to stigmatise those living with HIV (NAT, 2014b). Only 45% of people were found by NAT to correctly identify how HIV is transmitted, without citing any incorrect acquisition routes (2014b). Inaccurate HIV knowledge is most associated with adults aged 50+ years, declining with advancing age in this group (NAT, 2014b).

Adults aged over 75 years are most likely to display an unsympathetic view towards people with HIV (NAT, 2014b). For example, 44% of respondents aged 75+ years to the NAT survey in 2014 agreed with the statement *'I don't have much sympathy for people with HIV if they were infected through unprotected sex'* compared to 21% of adults younger than 75.

Several interview participants considered stigma to remain dominant; however, most reported this as felt rather than enacted stigma. Stigma was also found within the gay community, although to a lower extent; a finding also reported by Smit et al (2012). Fears of rejection and concerns about disclosure are commonly reported by people living with HIV, serving as barriers to developing relationships (Anderson & Doyal, 2004; Anderson et al., 2008; Doyal, Anderson, & Papparini, 2009; HIV Stigma Survey UK, 2015). One service user felt as though she could not have a new intimate/sexual relationship after her diagnosis.

Several service users expressed uncertainty as to whether other HCPs, such as dentists, needed to be informed about their diagnosis; highlighting concerns about disclosure. For some people living with HIV, attending additional healthcare services such as the dentist is still associated with stigma and poor care provision (Elford et al., 2008; Sharp & Hudson, 2010; HIV Stigma Survey UK, 2015). In the latest HIV Stigma Survey, 39% of respondents (people living with HIV) were worried about being treated differently by their dentist due to their diagnosis; 14% avoided seeking dental care (2015). This appears to be something that can be encountered by anyone living with HIV, irrespective of age. Confidentiality breaches are still a concern, and although rare can have a severe impact (Halliday, Campbell & Elgot, 2015).

Felt stigma can be tackled through peer support, and creating the opportunity for people living with HIV to discuss their status and experiences of stigma (NAT, 2016). The media

presentation of HIV, in a predominately negative light, is considered to fuel stigma (NAT, 2016). To reduce stigma, recommendations are for HIV media coverage to increase and for the disease to be presented accurately (NAT, 2010b; NAT, 2016).

#### 7.6.5 Restriction on freedom to travel

Despite having no identified public health benefit (UNAIDS, 2009), there are still numerous countries that impose travel and residency restrictions based on HIV status (Deutsche AIDS-Hilfe (DAH), European AIDS Treatment Group (EATG) & International AIDS Society (IAS), n.d). Although there has been considerable progress (UNAIDS, 2015), there are still countries that refuse entry to anyone diagnosed with HIV (e.g. Brunei and Russia), or require evidence of a negative HIV test to be granted permission to stay longer than 3 months (e.g. Singapore) (DAH, EATG, & IAS, n.d). HIV travel and residency restrictions cause considerable personal harms and result in the avoidance of HIV testing and treatment access (UNAIDS, 2009).

Several patients, all MSM, discussed travel in their interviews; however, they voiced a lack of willingness to travel to the most restrictive countries due to their lack of acceptance of homosexuality, in addition to their HIV travel and immigration policies (International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA), 2016).

#### 7.6.6 Living with HIV and working

PLWHIV are legally protected in the workplace by the *Equality Act 2010*. The majority of respondents (58%) to a survey of gay men living with HIV reported that their diagnosis 'had no impact on their working life at the moment' (NAT, 2009). Employment satisfaction has been reported as similar in HIV negative gay men to those living with HIV (NAT, 2009).

In this survey, it was found that 30% of respondents reported the need to take 1-3 days off work in the past year to attend clinic appointments (NAT, 2009). Service users reported the need to maintain a flexible working pattern, to ensure the ability to attend clinic appointments without the need to disclose their HIV status to employers. Several service users had reduced their working hours after diagnosis. This finding was reported by 21% of NAT survey respondents (2009).

Disclosure of HIV status to someone at work, reported by 62% of survey respondents, was generally received positively (77%) (NAT, 2009). For those that did not disclose their status the most common reason was 'no need', worries about confidentiality and being treated differently (NAT, 2009). For participants that had disclosed their HIV status to someone at work in the Stigma Index survey, 63% felt the response was supportive (2015).



### 7.6.7 Geographical location and access to services

It has been suggested that the quality of health care in general is lower in rural areas (Watt, Franks & Sheldon, 1994) and also that health care choice is more limited (Rosen, Florin & Hutt, 2007). In relation to sexual health, services have been described as 'patchy' across regions with variability in 'availability, quality and choice' (DH, 2001a). In addition, mental health services for people living with HIV are considered more easily accessible inside London (NAT, 2010c). HIV clinicians working in low prevalence areas reported the need to be highly adaptable to meet the needs of their service users, when services might not be available for referral.

HIV charities are also largely concentrated around London (Gay Men's Group (GMG), n.d; Positive East, 2013; Positively UK, 2016) and other high HIV prevalence cities (George House Trust, n.d), offering support groups and workshops. Support groups and workshops for people living with HIV at age 50+ years were only identified in London (Living Well, 2016; THT, 2014). Given the high prevalence of HIV in London, it was also considered easier to provide face-to-face peer support in this area (Positively UK, 2014).

### 7.7 Summary

- HIV services were described positively. For some service users, HCPs working in HIV services had almost become 'substitute GP's; this was linked to consistency of care, clinician expertise and contact time;
- A strong trusting bond had formed between HIV clinicians and services users, which for the most part did not exist between service users and their GP;
- For some older adults, particularly males, being diagnosed with HIV was associated with some 'secondary benefits' related to better health monitoring and clinician contact;
- There is a blurring of responsibilities between HIV clinicians and GPs. This is problematic as HIV clinicians lack the generalist knowledge of GPs, and GPs lack HIV knowledge. To care for other chronic conditions, such as cardiovascular disease and diabetes in people living with HIV, roles must be clarified. GPs and HIV clinicians must receive the knowledge and experience required to care for this group of patients. Action must be taken to avoid fragmentation and provide effective care for service users;

- In areas of high HIV prevalence it was easier for HCPs to make service user referrals to additional services e.g. psychological support. This was due to a higher number of services, considered to be a consequence of greater demand;
- With adherence to ART, service users were largely optimistic about ageing with HIV. Ageing with HIV presented some uncertainties, such as the cause of symptoms;
- HIV is not considered to be a prime concern for people living with HIV in the presence of other chronic conditions such as arthritis or diabetes;
- Stigma remains the most challenging aspect of living with HIV; however, service users most commonly expressed this as felt rather than exacted stigma. Stigma was expressed as a barrier to travelling, working and forming new intimate/sexual relationships.





## Chapter 8: Discussion and conclusions

### 8.1 Introduction

This chapter summarises the key findings of this mixed-methods study exploring the accessibility and acceptability of HIV services in the UK to adults receiving a positive HIV diagnosis at age 50 years and over. It then provides an overview of the strengths and weaknesses of this research, focusing on each method used in the thesis. Finally, the chapter proposes areas for future research and presents recommendations for policy-makers and sexual health/HIV service providers to ensure equity in service accessibility and acceptability.

### 8.2 Key findings

This thesis has explored the journey experienced by adults diagnosed with HIV at age 50+ years through the following stages: the pathway to HIV testing (chapter five); HIV diagnosis and treatment (chapter six); and ongoing care and life after HIV diagnosis (chapter seven). These stages mirror components of the *Model of Pathways to Treatment* (MPT) (Scott et al., 2013; Walter et al., 2012; Figure 3), as outlined in chapter one, and also extend beyond this framework to explore life after diagnosis. Key study findings will be discussed alongside the MPT where applicable, using labels within the model as headings. In accordance with the MPT, contributory factors will be outlined at each stage of the model and differentiated as patient, healthcare provider and system, or disease related (Scott et al., 2013).

#### 8.2.1 Symptom detection and appraisal

Service users were often diagnosed with HIV following complex, non-linear, routes to testing; exploring these has enabled a better understanding of factors affecting HIV detection.

A commonly reported barrier to early HIV detection, which occurs irrespective of age, is the lack of disease specific symptoms until someone has reached an advanced stage of HIV infection (BHIVA, BASHH & BIS, 2008). Although the majority of service users had experienced symptoms prior to testing these were attributed to more common conditions. HCPs and service users also considered that symptoms linked to HIV could be misinterpreted as related to ageing (Grabar, Weiss & Costagliola., 2006; Siegel, Schrimshaw & Evans, 1999; UNAIDS, 2002; Wooten-Bielski, 1999).

The ability to recognise symptoms as HIV-related was found to be greater in MSM, which is in part a product of targeting HIV prevention and testing messages at this group (Fowler et al., 2011; HPE, n.d; NICE, 2011b; THT, n.d).

The only service user that recognised his symptoms as HIV-related had high levels of HIV knowledge. This was a result of his prior involvement with HIV charities, experience in caring for a previous partner with HIV, and belonging to the 'gay community' in which information sharing around HIV appears to be common. This service user also lived within a high HIV prevalence area, which was linked to greater exposure to people living with HIV and more intensive HIV awareness raising efforts. In general, older adults were reported to lack HIV knowledge.

### 8.2.2 Decision to access health services

In conjunction with existing research into health-seeking behaviour, symptoms alone were not necessarily sufficient to prompt health service access (Brannon, Feist & Updegraff, 2013). For most service users their first healthcare contact was with a GP, highlighting their pivotal position to promote early HIV detection. Service users that attended their GP were symptomatic but had not considered HIV to be a cause of their symptoms. The majority of people that are diagnosed at a late stage of infection in the UK have attended general practice multiple times in the year prior to testing, indicating missed opportunities to test (Burns et al., 2008).

Health-seeking was prompted by increasing symptom severity, which impacted on the ability of service users to perform their usual activities of living; the visibility of symptoms to others; and the sanctioning of health service access by family members.

Perceived susceptibility to an illness is widely regarded as a driver to health-seeking (Rogers, 1975; Rosenstock, 1966); however, the majority of service users had not considered HIV as a possible diagnosis. This was due to a lack of HIV knowledge and personal risk perception, which in turn can largely be considered a consequence of poor health promotion; with the absence of a national HIV campaign since the 80s (Fowler et al., 2011).

Higher levels of HIV knowledge were found in MSM, associated with the targeting of this group in HIV prevention and testing messages (Fowler et al., 2011; HPE, n.d; NICE, 2011a; THT, n.d). MSM were generally considered more likely to attend sexual health/GUM services than heterosexuals, and to request routine sexual health screening. The only people to access sexual health/GUM clinics at the first point of healthcare contact were MSM. Only one service user accessed sexual health/GUM services based on the recommendation of a sexual partner. Two service users attended for routine screening and the final sexual health/GUM attendee due to symptoms. For those attending sexual health/GUM services for testing, the benefits of knowing about their HIV status outweighed the costs (Rosenstock, 1966).

For several MSM, their perception of personal HIV risk and measures to protect themselves against HIV had diminished with advancing age, an occurrence which I have termed 'precaution fatigue' (see section 5.7.5). A lessening of precaution efforts and diminished perception of personal risk after years of living in fear of HIV, and not becoming infected, has created a false sense of safety.

### 8.2.3 Diagnosis and start of treatment

The majority of service users reported or indicated receiving their diagnosis at a late stage of disease. All service users that received a late HIV diagnosis had their healthcare encounters leading to testing with non-HIV specialists (e.g. in general practice or secondary care). Attendees to sexual health/GUM services were all diagnosed at an early stage of disease; this was only the case for 1 person diagnosed in a non-HIV specialist setting. Late diagnosis was linked to greater disruption to the lives of service users, in terms of their relationships, work and health.

Presentation to non-HIV specialists with vague symptoms was associated with late HIV diagnosis (section 5.7.1), with clinicians more likely to attribute symptoms to more topical or common conditions. It was considered by HCPs working in sexual health/HIV services that HCPs working in general practice may be reluctant to discuss sexual health and offer HIV testing, particularly with the advancing age of patients. This is reported in previous research (Gott, Hinchliff, & Galena, 2004), although this requires further up-to-date exploration from the GP perspective. It was also regarded that non-HIV specialists may not consider older adults at risk of HIV. Belonging to a group considered at low risk of HIV was associated with late HIV diagnosis, particularly for white heterosexual women in advancing age. This was due to a lack of HIV knowledge and risk awareness, on the part of service users and clinicians.

Even within sexual health/GUM clinics, where universal testing is recommended (BHIVA, BASHH & BIS, 2008), there was a significant association between advancing age and decreased likelihood of someone being offered a HIV test; this was particularly evident for heterosexual women.

Initial responses to diagnosis e.g. shock; disbelief; shame and stigma (section 6.5) generally reflected those also reported in the wider literature by younger adults. Disclosure of HIV status was largely determined on a 'need to know' basis, with consideration of the impact on relatives and potential stigma.

For MSM, diagnosis was not necessarily a shock although the timing, in older age, was expressed by some as 'unexpected'. The only interviewed female service experienced great

shame and internalised stigma, this was associated with not belonging to a group considered 'at risk' of HIV.

After diagnosis, for most service users treatment was promptly initiated; however, it was recognised that changes to HIV service commissioning (section 1.4) have caused disruption to treatment referral in some areas. Treatment was generally well tolerated and older adults were described as having better ART adherence than younger people.

#### 8.2.4 Ongoing care and life after diagnosis

It was expressed by HCPs that there were some 'secondary benefits' associated with their diagnosis. This was voiced in terms of: better health monitoring, consistency in care, and the expertise and competency of HCPs working in HIV services. HIV services provide an exceptional level of care for older adults living with HIV, resulting in HIV clinicians almost becoming 'substitute GPs'. This was associated with the earlier detection and treatment of future problems. There may be some detrimental effects to this relationship though, as HIV clinicians do not share the same knowledge as GPs. GPs and HIV clinicians are both important in providing the best care for people with HIV, particularly in the presence of comorbidities, and therefore this relationship is crucial. Service users generally did not have as strong a relationship with their GP as HIV clinicians; this was associated with concerns about stigma and confidentiality, and GP expertise.

As long as their disease was stable, and well-controlled by ART, the majority of service users reported that their diagnosis was not a dominant aspect of their lives, particularly in the presence of other symptomatic conditions and social issues. However, there were concerns about starting a new sexual relationship after diagnosis. HCPs discussed that other chronic conditions may become particularly problematic in older service users.

Older adults generally professed a better ability to adapt to their diagnosis than younger people. This was discussed in terms of greater life experience, with older adults having already experienced various challenges and identity forming milestones such as gaining their first job etc. Resilience enabled a smoother adaptation to diagnosis.

#### 8.2.5 Factors that impact on HIV service accessibility and acceptability to adults aged 50+ years

The following over-arching factors were found to impact on the accessibility and acceptability of HIV services to adults diagnosed with HIV at age 50+ years, and were considered to increase the likelihood of late HIV diagnosis in older adults. These factors affected the



pathway to HIV diagnosis and treatment, healthcare service access after diagnosis, and the broader experience of living with HIV.

#### *8.2.5.1 Sexual risk*

Belonging to a group targeted by HIV prevention and testing campaigns (e.g. MSM) was associated with prompt HIV detection. In MSM, this was partly due to the higher levels of HIV knowledge experienced by this group compared to heterosexual men and women. This was identified through interviews with service users and HCPs, and is supported in broader surveys of MSM (Hickson et al., 2016).

This greater knowledge appeared to be the result of the targeting of MSM in STI/HIV prevention and testing (BHIVA, BASHH, & BASHH, 2008; GMFA, 2012; NICE, 2011b; THT, n.d). This is particularly evident in high HIV prevalence areas (LGBT Foundation, 2016; London HIV Prevention Programme, n.d). HCPs were found more likely to offer MSM a HIV test in sexual health/GUM settings, and MSM aged 50+ years were more likely to accept testing than older heterosexual men and women.

Although stigma was experienced irrespective of sexual risk group, it was indicated that higher internalised stigma was associated with belonging to a low risk group.

#### *8.2.5.2 Geographical location*

Living in a high prevalence area was associated with greater choice in health service access e.g. regarding where to go for HIV testing. In general, high prevalence areas were considered to be better resourced than low prevalence areas e.g. in terms of services available for patient referral.

It was considered by HCPs that living in a high HIV prevalence area was linked to a greater likelihood of knowing other people living with HIV, and receiving peer support. This was found to be particularly the case for MSM within the gay community, as this group are disproportionately affected by HIV.

#### *8.2.5.3 Stigma*

Stigma has featured as a major and recurring theme throughout this thesis, as a factor adversely affecting access to services for HIV testing (see chapter 5), the response to being diagnosed with HIV and disclosure decisions (chapter 6), experiences of working life, travel, health service access, and relationships (chapter 7).

### 8.2.6 Summary of findings

This study has found that adults diagnosed with HIV at age 50+ years experience an 'enhanced' level of care after diagnosis, which may place them at certain advantages to the general population in terms of additional health monitoring. However, there are major barriers to the early detection of HIV in older age. This is primarily due to the stereotypes surrounding who is 'at risk' of HIV, created through the almost exclusive targeting of HIV prevention and testing strategies at younger people, particularly MSM and black African heterosexuals.

Although there is no denying some of the service user benefits associated with this 'enhanced care', it can also be argued that unless HIV is managed in the same way as other chronic conditions (i.e. predominantly by the GP), it will not be regarded as such. This appears to contribute to the stigma associated with the disease, upholding HIV as something to be considered 'exceptional' rather than 'normal' like diabetes or arthritis. Until HCPs in non-specialist settings are given greater responsibility and the resources to provide care for people with HIV, GPs and other non-HIV specialists cannot gain the competency and confidence needed to care for this group.

### 8.3 Strengths and limitations of the research

The main strength of this study is that it addresses a distinct gap in the literature. This is the first research project to have provided an in-depth exploration of the journey to HIV testing and treatment for adults diagnosed with HIV at age 50+ years in the UK. In using a mixed-methods approach, this study has provided a more comprehensive examination than achievable through a single qualitative or quantitative approach. It has allowed for the greater explanation of findings, and the triangulation of methods for their corroboration. For example, survey data indicating that older adults feel more comfortable in accessing their GP to discuss sexual health than sexual health/GUM clinics was corroborated, and explained, with interview responses. Findings from national sexual health/GUM data were also appraised alongside interview and survey responses.

This project, as with any other, also has its limitations. The main limitation is that the 'GP voice' is clearly absent from the research; despite attempts to involve HCPs working in general practice in the study (see section 3.8). HIV care in general practice is instead reported by service users and sexual health/HIV clinicians and not from the GP perspective.

While conducting this study, there have been major changes in the commissioning of sexual health and HIV services. The prevention and testing of STIs, including HIV, is now largely

commissioned by local authorities, while HIV treatment and care is commissioned by NHS England (NAO, 2016; NAT, 2014). These changes have placed greater strain on HIV services, requiring extensive re-organisation for some Trusts, and it was felt that the recruitment of interview participants (both service users and HCPs) was affected by this.

With regards to each method used in the study, the following are some of the identified strengths and limitations.

### 8.3.1 Survey of HCP working in sexual health/HIV services

A major limitation of the survey was the low number of respondents (see section 4.4) despite efforts to widely distribute the survey via advertisement with key sexual health/HIV organisations in the UK (section 3.8.6). This meant the study was insufficiently powered to perform any inferential statistics (section 3.8.3). A strength was the proportion of surveys sufficiently completed (78%) to allow for descriptive analysis. In addition, there were a high number of in-depth responses to open text questions. In the future, further strategies to increase the number of survey respondents should be considered (see 4.6).

### 8.3.2 Analysis of PHE data

#### ***Datasets***

The comprehensiveness of each dataset is a major strength, with the reporting of national figures by gender, sexual orientation and the smaller age ranges as requested. There are potential limitations to the datasets due to data reporting. For example, the reporting of new HIV diagnoses is voluntary and therefore under-reporting is likely. In addition the accuracy of datasets is dependent on the quality of clinicians' recording and PHE's collation of data. However, data accuracy is unlikely to relate to patient factors such as age and sexual status, and reported relationships between these factors and offer and uptake of HIV testing is unlikely to be biased. There may also be delayed reporting; data for the most recent years is therefore likely to change (PHE, 2013a). Due to the confidential nature of reporting, it is also possible that entries may be duplicated if service users access multiple testing sites (PHE, 2013a).

#### ***Analysis***

Following the descriptive analysis of sexual health/GUM attendance, testing and diagnosis data, associations were measured between age and these variables using Spearman's rho.

Although Spearman's rho was considered the most appropriate test to use, given that the analysis involved only ordinal data (Bland, 2000), there are drawbacks to using this test. A

weakness in performing the analysis using Spearman's rho is that it only looks at the rank order of data; it does not consider the degree of variation in the data. For example, the value of  $R_s$  may be the same for two datasets but the range of these may vary greatly. This is clearly evident for MSM in this study. Although there is a statistically significant, strongly negative, linear relationship between age and test acceptance in MSM, the proportion of MSM accepting a test is high at any age (ranging from 86.9% to 92.8%) and MSM are consistently more likely to test than the other sexual risk groups. This highlights the need to interpret  $R_s$  values with caution. In addition, Spearman's rho only serves to identify an association, allowing acceptance or rejection of the null hypothesis, but it does not report the strength of a relationship (Bland, 2000).

### 8.3.3 Qualitative interviews

#### 8.3.3.1 *Service users*

The ability to recruit 12 people to this study and conduct in-depth interviews, despite this being a relatively 'hard-to-reach' and stigmatised group, was a major strength; particularly in light of the major changes to sexual health/GUM services (section 8.3).

A limitation of the interview study was the lack of diversity in service user characteristics. The majority of participants were aged 50-53 years at diagnosis; at the lowest end of the age range for study eligibility. Therefore, little insight was gained into the experience of receiving a diagnosis beyond this age. The under-representation of older adults in research has been widely highlighted as an issue (McMurdo et al., 2011), and studies specifically focusing on older people living with HIV have primarily recruited adults in their fifties (Emlet, 2006; Power, Bell & Freemantle, 2010). Service users were also predominantly MSM, again this is reported widely in research involving people living with HIV (Power, Bell & Freemantle, 2010), and only one female was recruited to the study. A difficulty in recruitment from low HIV prevalence areas, particularly outside of London, limits the applicability of findings beyond high prevalence areas. However, in the majority of national studies around half of those recruited are based in London (Power, Bell & Freemantle, 2010).

Overall, patterns in service user recruitment largely reflect wider trends in the HIV epidemic; new HIV diagnoses in older adults are largely in people in their fifties, and MSM are most affected by HIV. The HIV epidemic in the UK is also mainly concentrated in London.

## 8.4 Recommendations for HIV prevention and testing

This section outlines recommendations for policy-makers and sexual health/HIV service providers to encourage the prompt detection of HIV in adults aged 50+ years. Several of these recommendations also aim to tackle the stigma associated with HIV by increasing HIV knowledge (NAT, 2014b) and presenting accurate media coverage of HIV (NAT, 2010b; NAT, 2016).

### 8.4.1 Increase HIV knowledge in non-HIV specialists

To reduce the proportion of late HIV diagnoses, there is widespread recognition that HIV knowledge requires improvement in non-HIV specialists, including GPs (Kall et al., 2012). The development of training for non-specialists has been recommended (Harris & Khatri, 2015) and BHIVA have suggested the benefit of enhanced GP training (Angus et al., 2016b). One programme implemented at general practices in a high prevalence area of London demonstrated significant increases in HIV testing post-intervention (Pillay et al., 2013); however, the effectiveness of this training has not been tested elsewhere. Mandatory GP training on HIV has also been successfully implemented in Manchester (Namiba & Anderson, 2010).

NAT also recommend that late HIV diagnosis is categorised as a 'significant event', prompting review (2012). This is currently performed for late cancer diagnoses (RCGP, 2016) and unexpected or avoidable deaths (NHS England Patient Safety Domain, 2015).

### 8.4.2 Increase HIV knowledge in the general population

There is a clear need to increase HIV awareness and knowledge in the general population, not just those considered 'at risk' based on their sexual orientation:

*'...[the] general population don't know shit about it and it's like ermm there could be more information on that' [Service user #3: MSM, Dx 53 years, high prev.]*

A national HIV campaign has not been implemented since the 1980s; arguably this has impacted on the perception of HIV risk in the general public (Fowler et al., 2011).

HIV knowledge in older heterosexual men and women was found to be based largely on early HIV campaigns and mass media depictions of HIV, from the late 80s and early 90s. A report conducted by NAT to investigate the funding allocated to HIV prevention highlights a dramatic decrease over time in monetary allowance (NAT, 2015). Given the advancements in HIV treatment since this time, knowledge gained from these depictions is now inaccurate and the public are greatly in need of an update on the advancements in HIV:

*'...you don't see as much about HIV and about how well things are developing and how well the drugs are doing.....You don't see as much positive stuff in the news as you do about other....conditions where...similar, developments have been made....' [Service user #5: MSM, Dx 50 years, high prev.]*

Service users expressed the need to include older people within these campaigns:

*'...any future campaigns ought to be, to spell it out a bit more and for all ages.....you know, you still can catch things like that....' [Service user #1: Male, Dx 67 years, high prev.]*

In preparing HIV campaigns, the medium for their delivery also requires great consideration to ensure the message are accessible to older adults, as well as younger people. As one clinician highlighted, prevention messages are now often delivered via phone apps, which may not be accessed by all age groups. This warrants exploration.

*'..... the kind of the campaigns are very much, particularly the Chlamydia screening campaigns are very much kind of Smartphone focused and about kind of dating apps.....that, I just....I don't know whether you know.....a fifty year old would be engaging with necessarily..' [HCP #7: Male GUM specialist nurse, low prev.]*

Aside from through national campaigns, it was also considered that HIV awareness and knowledge were raised through accurate depictions of HIV in television, film and media reporting. For example, a recent storyline in Emmerdale, a British soap opera, sought to raise HIV awareness in older people. This storyline, featuring a white heterosexual woman diagnosed with HIV in her fifties (Brown, 2014), resulted in wide media coverage and discussion (Magnanti, 2014; Palmer, 2014). Although the impact of this storyline on HIV testing has not been evaluated, television is regarded as useful medium to raise awareness:

*"A well-researched storyline in a national soap is worth any number of health campaigns" (Will Harris, Head of Media at the Terrence Higgins Trust; excerpt from Strudwick, 2014)*

Storylines featuring younger men with HIV have also featured in the British soap operas EastEnders and Hollyoaks; these have correlated with an increase in HIV testing (Ross & Scott, 1993). However, the impact of these storylines in HIV prevention has not been evaluated. An issue with television campaigns, as with national HIV campaigns, is that their impact is considered short-lived (Nicoll et al., 2001; Ross & Scott, 1993); therefore, efforts must be sustained.

The discussion of HIV by high profile figures has also been shown to raise public consciousness around HIV. The day that Charlie Sheen disclosed his HIV positive status correlated with 'the greatest number of HIV-related Google searches ever recorded in the United States', of which 1.25 million included terms such as testing and symptoms (Ayers et al., 2016). Although these searches do not necessarily reflect behaviour changes or access to testing services, they indicate a rise in public consciousness around HIV. The 'Charlie Sheen Effect' has also been evident in the UK:

*"As the UK's leading HIV and sexual health charity, Terrence Higgins Trust website had its busiest day ever on 17 November, with almost 20,000 page views. The most popular covered 'Stages of HIV infection', 'Getting Help Now' and 'What are HIV and AIDS?'" (Alex Sparrowhawk, Membership Officer of Terrence Higgins Trust; excerpt from BBC News, 2016)*

The live streaming of Prince Harry being tested for HIV also increased demand for HIV testing, serving to normalise the process (Davis, 2016). More broadly, health disclosures by celebrities have been effective in increasing screening rates and awareness raising (Casey et al., 2013; Lancucki et al., 2012):

*'If you look at the uptake of cervical screening after...Alma on Coronation Street<sup>7</sup> died, I mean it was huge....and after Jade Goody<sup>8</sup>....but you just think maybe that's, you need a campaign like that....' [HCP #5: Female HIV Lead nurse, low prev.]*

#### 8.4.3 Re-evaluate the effectiveness of HIV testing guidelines

According to current guidelines, HIV testing in the UK should be universally offered in:

*'GUM or sexual health clinics; antenatal services; termination of pregnancy services; drug dependency programmes; and healthcare services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma' (BHIVA, BASHH & BIS, 2008).*

Opt-out HIV testing is also recommended in general practices and hospitals in areas of high HIV prevalence ( $\geq 2$  in 1000 population aged 15-59 years), for new GP registrants and hospital admissions (BHIVA, BASHH & BIS, 2008). The evidence to support the UK guidelines is based on economic modelling performed in the USA (Branson et al., 2006; Paltiel et al., 2005; Walensky et al., 2005), indicating that testing is cost-effective in areas where HIV prevalence is equal or greater to 2 per 1000 people (HPA, 2011).

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<sup>7</sup> British soap opera;

<sup>8</sup> British television personality who died from cervical cancer in 2009, aged 27 years.

However, recent studies have identified that expanded testing may prove more efficient. Frequent testing of populations at high risk of HIV infection (MSM; people who inject drugs; people from high HIV prevalence countries), and one time whole population testing has been found cost-effective in economic modelling performed for the UK (Long et al., 2014). One time HIV testing has also been modelled as effective in France (based on an undiagnosed HIV prevalence of 0.1%) and Portugal (based on an undiagnosed HIV prevalence of 0.16%) (Yazdanpanah et al., 2010). In 2014, undiagnosed HIV prevalence in the UK was estimated at 0.3 per 1000 population aged 15+ years (Skingsley et al., 2015), suggesting that more widespread testing may be cost-effective in the UK. HCPs also questioned the UK testing guidelines:

*'...the money we spent...as a trust and as a local community...on late diagnosis would have been enough to test every 18 to 65 year old, and given us change. So there is.....and if you look at antenatal screening that's been successful cos it's been normalised as this is what we do. So I think, the start, of my feeling is....is that the screening process is wrong for everybody. We just need to move away from this 2% and just do it and then....even the French study showed that even if you do every adult once in their lifetime it raises their awareness and actually it's cost-effective....'* [HCP #5: Female HIV Lead nurse, low prev.]

There is a still a great need for HIV testing to become normalised. HCPs and service users considered that incorporating opt-out HIV testing, alongside other blood tests and healthcare check-ups, would increase uptake:

*'.....there's a huge issue about...the actual framework in which we test. And I think, if I was it.....every time a woman had a cervical smear, every three years, I'd offer an HIV test....and every time you did a well man's check for men in the GP surgery I'd just offer it there....'* [HCP #5: Female HIV Lead nurse, low prev.]

The guidelines actively encourage testing in a prescribed way, and for judgements to be made purely based on ethnicity and sexual orientation. In doing so, these groups become stigmatised and people not considered 'at risk' at greater likelihood of late HIV diagnosis.

#### 8.4.4 Increased surveillance of HIV testing and diagnosis

To gain greater insight into testing in non-specialist settings, it is recommended that HIV test coverage (test offered and accepted) be recorded within a national surveillance system (Elmahdi et al., 2014). This would be particularly beneficial in high HIV prevalence areas, where new registrants to general practice and all hospital admissions should be offered HIV



testing (BHIVA, BASHH, BIS, 2008). Surveillance would enable the identification of disparities in performance at practice and hospital level, and at regional levels.

The increased documentation of positive results would also enable more effective planning for the epidemic, through an understanding of local HIV prevalence.

#### 8.4.5 Ensure a smooth transition from testing to treatment services

One service user had a particularly lengthy delay between testing for HIV, and referral to treatment services, highlighting the need for effective communication between diagnostic and treatment services. Also at this stage, it is important to ensure effective communication with service users. It was discussed by one service user that he would have preferred greater information at this stage, for example an information sheet defining the terminology surrounding HIV e.g. CD4, viral load etc.

*'There could be a really good document to actually tell you.....I've taken most of the information from here [treatment clinic] but a little easy crib sheet would be really helpful for when you're going through that initial process.'* [Service user #9: MSM, Dx 53 years, high prev.]

Although, it is well recognised that the degree of information people want is variable, this information could be provided for those that would like it.

## 8.5 Recommendations for HIV treatment and management services

This section recommends a number of potential alterations to the model of care for HIV in the UK. This primary intention of these suggested changes is to optimise the treatment and care received by adults diagnosed with HIV at age 50+ years. However, it is also considered that they will be beneficial more broadly to people living with HIV, will promote HIV testing and ultimately reduce the stigma surrounding HIV.

It is intended that the proposals discussed in this section are evaluated and approved by stakeholders (including GPs, HIV clinicians, and service users), prior to being recommended to policy-makers.

### 8.5.1 Provide defined roles for HIV clinicians and GPs in providing care

As highlighted in chapter seven, there appears to be a blurring of responsibilities and a lack of clarity regarding the GP and HIV clinician role in caring for adults with HIV. Both sets of HCPs are currently essential to the provision of care for these service users, particularly in the presence of other chronic conditions, which are more prevalent with advancing age. HIV clinicians are specialists in HIV treatment and management; while GPs have the expertise to provide generalist medical care, across a wide range of health problems.

It can be argued that GPs should have greater involvement and responsibility in caring for adults living with HIV (Ford-Young & Kulasegaram, 2013; Madge et al., 2011; THT, 2017b), to ensure the best care for these service users. As acknowledged by HCPs in this thesis, there are elements of care HIV clinicians are being asked to provide that extend beyond their remit of knowledge but are 'bread and butter' to GPs (section 7.2.2). It can be considered detrimental to service users not to involve GPs in providing care, particularly when comorbidities exist, as they have a different scope of knowledge to HIV clinicians (section 7.3.1). Lack of clarity surrounding roles also increases the potential for mistakes and omissions.

Long term, it is anticipated that greater GP involvement in caring for people with HIV would help to dispel some of the stigma surrounding HIV. The management of HIV in an environment where other chronic conditions are treated would help to promote the 'normalisation' of the disease. Currently, the 'exceptionalism' of HIV treatment and care sets the disease apart from other chronic conditions.

### 8.5.2 Promotion of HIV testing in GP practices

Increased GP contact and involvement in the care of people living with HIV would enhance their awareness of HIV more generally. As highlighted in section 5.7.7, HCPs are more likely to

explain symptoms as caused by common or topical conditions (Foot, Naylor & Imison, 2010; Triplet, 1992) which come to mind quickly (Bornstein & Emler, 2000; Poses & Anthony, 1991). Heightened involvement in caring for people with HIV, making the disease more visible, would encourage GPs to more readily consider HIV within the diagnostic process.

As discussed in chapter seven, the strength of HIV clinician and service user relationships is based on trust; established through expertise, consistency in care, and frequent health monitoring. To achieve this type of relationship between GPs and services users, these strengths need to be carried forward into general practice. This could potentially be achieved in several ways; the following have been highlighted by Namiba & Anderson (2010):

- Placing a GP within HIV services as a long-term measure;
- Placing a GP within HIV services as a short-term measure before their return to general practice. This would enable a more gradual familiarisation between service users and GPs, and time to install service user confidence in GPs.

These options could also be considered:

#### 8.5.3 Clinics specifically tailored to meet the needs of older people living with HIV.

One HIV clinic, in London, has been developed specifically for people living with HIV at age 50+ years (Waters et al., 2012). Although reported as well received by service users (Waters et al., 2012), it is unclear whether this clinic is cost-effective or provides better care than age inclusive clinics. One HCP questioned the need for such a service:

*'...I said "well why do you feel you need an over 50s clinic? Why doesn't everybody get individualised care that's appropriate to their needs?" And she said "well it just wouldn't get done"....and I just thought that's....really telling isn't it.....that somebody wouldn't get....their blood pressure or not get urinalysis done, do you?' [HCP #9: Male HIV Lead nurse, low prev.]*

The development of clinics exclusively for older people arguably also transfers the care of people living with HIV further from GPs, reinforcing the impression of HIV clinicians as 'substitute GPs' as they provide an even greater role in healthcare (7.5.2).

#### 8.5.4 Greater involvement by HIV clinicians with GP practice

HIV clinicians could be utilised to train HCPs working in general practice and provide real-life examples of caring for adults diagnosed with HIV. This could involve discussion around approaches to offering HIV tests and how to respond to positive results.

HIV clinicians, following GP practice involvement, could serve as a point-of-contact for general enquiries from practices within their area regarding HIV testing and care. The development of these relationships aims to promote the sharing of information between GPs and HIV clinicians.

#### 8.5.5 Consistency in care in general practice

This could be promoted through having a named GP (BMA, 2016) for people that have disclosed their HIV positive status in general practice.

#### 8.5.6 Defined roles allocated to GPs

Certain roles could be specifically allocated to GPs. For example, an area indicated for improvement in HIV services, from an audit conducted by BHIVA in 2015, was the monitoring and management of cardiovascular disease and smoking cessation (BHIVA Audit and Standards Sub-Committee, 2015). This could be performed by GPs, who are traditionally involved in these aspects of care in the general population.

#### 8.5.7 Transfer of uncomplicated HIV care to general practice

In cases of uncomplicated and well-controlled HIV, over time it is highly probable that a larger proportion of responsibility for caring for people with HIV could be transferred to general practice. In a similar way to diabetes care (Goodwin et al., 2011; Murphy, 1997), people with stable HIV could be predominantly treated in general practice, with the re-referral or continuous management of more complex cases in specialist HIV services.

To manage service users with HIV, roles for GPs or nurses with special interests in HIV could be developed. GPs with special interests have undertaken training and gained knowledge in a particular clinical speciality in order to take 'referrals for patients who may otherwise have been sent directly to a secondary care consultant' (Malik, 2006). In the event of stable, well-controlled disease, it appears reasonable that GPs and specialist nurses could monitor HIV according to BHIVA guidelines (Angus et al., 2016a). This should be regarded as a long-term plan that would require a slow transition, to ensure that general practices are properly resourced, and stakeholders feel confident in this shift in care.

Anticipated barriers to greater transfer of HIV care to GPs are service user and clinician concerns, and whether GPs have the infrastructure to take up this additional care. Service users must be assured that their confidentiality will be maintained in general practice (General Medical Council (GMC), 2009).

## 8.6 Recommendations for future research

Future projects should explore the current model of HIV care in the UK. The King's Fund has recently initiated research on the 'key risks and opportunities that those involved in planning future HIV services nationally and locally should consider' (2016). Importantly, this King's Fund project involves stakeholders and HIV service users.

Despite attempts to gain the perspective of general practitioners in this thesis, there were major recruitment issues (section 4.6). As GPs were identified as key to promoting earlier HIV detection in older adults, and for providing care, it is crucial that any future research in this area includes these HCPs. Further research should also strive to recruit service users beyond high HIV prevalence areas, particularly outside of London. HIV research is often London-centric, a consequence of the concentration of HIV in this city; however, the experience of those living in lower prevalence and more rural areas should also be sought.

Further recommendations are to consider ways to recruit heterosexuals, particularly women, to gain ethnic diversity in recruitment, and to recruit older adults across a wider range of ages. One way this could be achieved is through an expansion in the number of recruitment sites, in order to gain access to a greater number of potential participants. To be effective, this would require greater funding and more than one study researcher. Sampling could also become more purposive to recruit under-accessed groups.

## 8.7 Recommendations for further data analysis

It is considered that in the preparation and production of a future paper, a narrative analysis of the rich data generated in this thesis could be produced. Narrative analysis is defined as 'an approach taken to interview data that is concerned with understanding how and why people talk about their lives as a story or a series of stories.' (Earthy & Cronin, 2008). Narrative analysis considers the context in which stories are told, in addition to the content of the stories (Earthy & Cronin, 2008). Narrative analysis has historically been used in research exploring the experience of living with a chronic illness (Bury, 1982; Frank, 1995; Williams, 1984).

In contrast to thematic analysis, narrative analysis looks at stories as a whole, instead of breaking data into themes and sub-themes. This approach could be taken using the data already generated in this thesis, as service users discussed their experiences in the form of a story, or a journey, to the point of testing for HIV and living with HIV after diagnosis (Earthy & Cronin, 2008). A narrative analysis could be used as an addition to the thematic analysis already conducted to provide greater insight into why service users discussed certain topics,

and also to look at how these topics were discussed. This would complement the insight already achieved through thematic analysis into the content of service user interviews.

## 8.8 Dissemination of findings

To date, findings from this thesis have been presented at several academic conferences and to HCPs working in sexual health/HIV services. Presentations have been given to HIV specialist nurses in Yorkshire and Humber; the HIV specialist team at York Sexual Health Centre; the 22<sup>nd</sup> Annual Conference of the British HIV Association (Bell et al., 2016a); the British Association for Sexual Health & HIV conference 2016 (Bell et al., 2016b); the Society for Social Medicine 60<sup>th</sup> Annual Scientific Meeting (Bell et al., 2016c); and the 9<sup>th</sup> European Public Health Conference.

## 8.9 Conclusion

The findings from this thesis suggest that HIV testing services (e.g. sexual health/GUM clinics and general practice) could improve their accessibility and acceptability to adults aged 50+ years. Sexual health/GUM services are largely perceived as youth focused, and GPs as lacking the expertise to provide testing. With advancing age it appears that service users are less likely to be offered a HIV test, even within sexual health/GUM settings where testing should be universally offered, particularly if they do not belong to a group targeted in HIV prevention and testing efforts.

In general, MSM appear more likely to access STI/HIV testing services due to higher HIV knowledge and personal risk perception, and also prior attendance at sexual health/GUM services. This was considered to be a result of the extensive targeting of MSM in HIV prevention and testing campaigns. This appears to be a factor in the greater likelihood of test offer and early HIV diagnosis in MSM.

Once diagnosed, HIV treatment services were found to provide exceptional care, associated with benefits including better health monitoring, clinician expertise, and consistency of care. However, the continuing 'exceptionalism' surrounding HIV may not be helpful in reducing HIV stigma or promoting HIV awareness in the general population. It is therefore recommended that gradually, following an investment in GP education and service user engagement, a greater proportion of HIV care is assigned to GPs. This would be particularly advantageous to older adults due to the higher likelihood of comorbidities in this cohort, which extend beyond the HIV clinicians remit of knowledge but are routinely managed by GPs.







**Appendix 1: Summary of literature on healthcare seeking behaviour, risk perception, attitudes towards STI/HIV testing, and STI/HIV testing experiences**

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
<b>Interview studies</b>					
Balfe & Brugha. (2009). What prompts young adults in Ireland to attend health services for STI testing?	30 people (21 women; 9 men).  Recruited from various healthcare settings which provide STI testing (e.g. general practice, family planning clinics, and sexual health/GUM clinics).	18-29 years.	Semi-structured interviews.  24 telephone interviews. 6 face to face interviews.  Thematic analysis.	Republic of Ireland.	<b>Aim:</b> ‘to identify and explore why young adults (18–29 years) in Ireland attended specialist and community health services for STI testing; the factors that supported/undermined their decisions to seek STI testing; and any factors that led to delay in seeking STI testing’ <b>Findings</b> Why the decision to test? - symptomatic - requirement of employer - engaged in unprotected sex - commitment to a monogamous relationship (not wanting to use condoms) - following a period of engaging in ‘risky’ sex  <b>Prompts to testing</b> - health promotion campaigns - awareness of STIs through watching television, particularly soap operas - friends have previously been for testing - friends have had STIs  <b>Reasons for testing delay</b>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<ul style="list-style-type: none"> <li>- stigma</li> <li>- embarrassment- worried about being judged by healthcare professionals</li> <li>- not feeling at risk, not displaying symptoms</li> <li>- difficulties in accessing clinics: busy, long waiting times, needing to travel to clinic, opening hours</li> <li>Other findings</li> <li>- sexual health/GUM services considered to have greatest expertise and afford anonymity</li> <li>- positive experience of attending clinic (concerns about stigma and judgement dispelled)</li> </ul> <p><b>Considerations/limitations</b></p> <ul style="list-style-type: none"> <li>- Study took place in Republic of Ireland; here people have to pay for GP services, although sexual health/GUM clinics are free. This may be a barrier to those wanting to test but not wanting to access sexual health/GUM clinics.</li> <li>- Telephone interviews vs. Face to face.</li> <li>- How many participants tested positive?</li> <li>- How many had accessed sexual health services before?</li> </ul> <p>- refers to Giddens 'protective cocoon' –</p>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					feeling of invincibility Giddens, A. (1991), Modernity and self-identity. Self and society in the late modern age
Burns et al., (2007). Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilization of HIV health and social care services by African migrants in Britain.	'key informants' - working with black Africans living with HIV		Semi-structured interviews.		<b>Aim:</b> '... to identify the current key issues influencing service uptake by HIV positive Africans.'  <b>Findings</b>  Barriers to testing: stigma and fear of prognosis, concerns about confidentiality, health seeking behaviour - would only attend a health service in Africa if felt unwell, institutional racism, difficulties in navigating health services, not aware of GUM clinics, lack of HIV testing outside of antenatal or GUM services.  - Stigma despite high HIV prevalence in Africa.  - Knowledge of prognosis based on experience in Africa.
Defty et al. (2010). GPs' perceived barriers to their involvement in caring for patients with	125 GP participants.		Questionnaire.	South of England.	<b>Aim:</b> 'To explore GPs' current perceptions of barriers to their involvement in managing patients with HIV'.

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
HIV: a questionnaire-based study.					<p><b>Findings</b></p> <p>Barriers include:</p> <ul style="list-style-type: none"> <li>- time restrictions;</li> <li>- lack of experience;</li> <li>-insufficient training;</li> <li>- poor communication between care providers;</li> <li>- Problems in determining the cause of symptoms, unsure if symptoms are HIV-related.</li> <li>-insufficient financial reimbursement.</li> </ul> <p>- 93% of participants felt able to manage non-HIV related health problems in people with HIV.</p>
Dixon-Woods et al. (2001). Choosing and using services for sexual health: a qualitative study of women's views	37 female GUM and/or family planning clinic attendees.	15-53 years	Qualitative interviews.  Constant comparative method.	East Midlands, England.	<p><b>Aim:</b> 'To explore women's accounts of choosing and using specialist services for sexual health'</p> <p><b>Findings</b></p>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<p>Prompts to access services:</p> <ul style="list-style-type: none"> <li>- symptoms</li> <li>- concern about own sexual behaviour</li> <li>- concern about a partner's sexual behaviour</li> <li>- partner has symptoms</li> <li>- routine check</li> </ul> <p>Specialist services in comparison to general practice were associated with:</p> <ul style="list-style-type: none"> <li>- higher levels of expertise</li> <li>- more comfortable environment</li> <li>- anonymity of accessing service where you are unknown</li> <li>- easier to get an appointment at specialist services than general practice</li> <li>- GP considered more judgemental</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<p>- Concern about STI diagnosis going on medical record if attends general practice.</p> <p>- Need to overcome stigma, embarrassment of attending services.</p> <p>Decision to access GUM based on - awareness of these services; referral by a healthcare professional; advised by a friend etc.</p>
Dowson et al. (2012). Why some men present late for HIV testing: a qualitative analysis.	17 MSM CD4 <200 at diagnosis Diagnosed within the previous year	Range 33 to 67 years Median = 41 Aged 50+ year = 4	Semi-structured interviews. Framework approach used for data analysis.	Brighton	<p>Barriers to earlier HIV testing: stigma and fear of prognosis; perceived low risk; HIV testing should be offered by general practitioners, sexual health clinics are perceived as less convenient and more embarrassing; reassured by feeling 'healthy'</p> <p>- Awareness of how HIV is transmitted.</p> <p>- Lack of awareness of the dramatic improvements in HIV prognosis. Current impression of HIV is still that of HIV in the '80s.</p>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<ul style="list-style-type: none"> <li>- Lack of knowledge that someone could have HIV and be asymptomatic.</li> <li>- targeting particular risk groups creates stigma.</li> <li>- Ongoing need to normalise testing.</li> <li>- General practitioners could be incentivised to offer testing.</li> </ul>
Evans & Cross (2007). Community sexually transmitted infection services are good enough: a qualitative study of clients' experiences.	<p>16 people diagnosed with an STI.</p> <p>Attendees at community STI service</p> <p>Majority symptomatic.</p>	Majority aged <25 years.	Semi-structured interviews.	Lewisham, London, England.	<p><b>Aim:</b> 'To explore the experiences of clients using a community STI service for testing and treatment'.</p> <p><b>Findings</b></p> <p>Facilitators to testing: proximity of the testing venue, ease at booking appointments, short waiting times, opening times, easy to find, friendly and non-judgemental service providers, services available by gender.</p> <p>Barriers: confidentiality, stigma. Once accessed services are found to be acceptable.</p>
Evans & Farquhar (1996). An interview based approach to seeking user	76 previous, current or potential GUM	Age of participants not	Semi-structured interviews.	Bristol, England.	<b>Aim:</b> 'To assess user and potential user views on the appropriateness, nature and quality of genitourinary medicine (GUM)

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
views in genitourinary medicine.	<p>attendees.</p> <p>10 community informants.</p> <p>11 healthcare professionals.</p> <p>Mixed sample: African-Caribbean people; homeless people; MSM; WSW; PLWHA; sex workers.</p>	reported.	Thematic analysis.	Dept. Of GUM at Bristol Royal Infirmary.	<p>provision in Bristol, UK...'</p> <p><b>Findings</b></p> <p>Not much information available about the GUM department. Not well known. MSM highlighted as a group that were aware of the dept.</p> <p>Access to clinic often prompted by a friend's recommendation.</p> <p>Anxiety associated with going to the clinic.</p> <p>Concerns about being recognised.</p> <p>Concerns about treatments.</p> <p>Concerns about confidentiality.</p> <p>Long waiting times.</p> <p>Some participants (mainly females and African-Caribbean men) wanted separate sex waiting areas/entrances/receptions.</p> <p>Once accessed, clinic found to be friendly and non-judgmental.</p> <p>Many people living with HIV would like</p>



<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					inpatient and outpatient HIV services to be integrated; mixed opinions about further integration of sexual health with HIV.
Flowers, Duncan & Knussen. (2003). Re-appraising HIV testing: an exploration of the psychosocial costs and benefits associated with learning one's HIV status in a purposive sample of Scottish gay men.	MSM with various HIV testing experiences.	Interview participants: 21-45 years (Median age 33 years)  Focus group participants: 22-49 years (Median age 35 years)	18 in-depth interviews (individual).  Participants recruited via gay bars; sexual health charities.  - 2 participants living with diagnosed HIV.  4 focus groups (19 participants). Participants recruited from community support groups.  - 10 focus group participants living with diagnosed HIV.  Interpretative phenomenological	In-depth interview participants from Glasgow and Edinburgh.  Focus group participants also recruited from the Highlands and the West Coast.	<b>Aim:</b> 'This study explored contemporary understandings of the psychosocial costs and benefits associated with learning one's HIV status within a purposive sample of Scottish gay men. It seeks to provide insight into the psychosocial factors associated with decision-making processes relating to the HIV antibody test'.  <b>Findings</b>  - prompted to have a HIV test for 'peace of mind' (negative result expected).  - testing negative may trigger positive behaviour changes i.e. practising of safer sex.  - Contrastingly, negative test may lead to a false sense of security and further engagement in unsafe sex.  - prompted to test as the 'not knowing' becomes more unbearable than 'knowing a

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
			analysis.		<p>positive result'</p> <ul style="list-style-type: none"> <li>- fear of a positive result may be a barrier to testing; ability to cope if diagnosed with HIV (difficulties in managing antiretrovirals, frequent clinic attendances and blood tests)</li> <li>- denial may be a barrier to testing</li> <li>- worried about HIV transmission</li> </ul> <p><b>Considerations/limitations</b></p> <ul style="list-style-type: none"> <li>- age of the study</li> </ul>
Gilbart et al. (2006). Late diagnosis of HIV infection among individuals with low, unrecognised or unacknowledged risks in England, Wales and Northern Ireland.	<p>286 participants (diagnosed with HIV between 1986 and 2003)</p> <p>'...newly diagnosed individuals who, after follow-up, still have either no evidence of 'high-</p>	<p>Median age of adults with symptoms at diagnosis = 39 years (men); 30.4 years (women)</p>	<p>Semi-structured in-depth interviews.</p> <p>Conducted by June 2003.</p> <p>Participants identified from new HIV diagnosis data for England, Wales and Northern Ireland.</p>	<p>Participants from England, Wales and Northern Ireland.</p>	<p><b>Aim:</b> to 'describe the characteristics of these individuals who are diagnosed late during the course of their HIV infection, with a comparison to those diagnosed more promptly'.</p> <p><b>Findings:</b></p> <ul style="list-style-type: none"> <li>- 55% had symptoms of HIV at diagnosis</li> <li>- higher proportion of people diagnosed late were male</li> <li>- people diagnosed late were more likely to have acquired their infection through</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
	risk' exposure, no partners with a 'high-risk' exposure, exposure outside the UK or partners from a country with a high HIV prevalence.'				heterosexual transmission in the UK (almost 50% became infected through this route).
Holgate & Longman. (1998). Some Peoples' Psychological Experiences of Attending a Sexual Health Clinic and having a Sexually Transmitted Infection	8 attendees attending a sexual health/GUM with an STI	Age of attendees not reported.	Action research.  Each participant was interviewed twice.  Thematic analysis.  Triangulation of findings with research diary and photographs.	? Surrey.	<b>Aim:</b> 'This study considers aspects of the experiences of a group of people attending a sexual health clinic and receiving the diagnosis of a sexually transmitted infection (STI)'  <b>Findings</b>  - most attendees referred by their GP  - concerns about being judged  - stigma  - concerns about what will happen at the clinic  - anxieties about testing positive for an STI, the impact of this  - shame

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<ul style="list-style-type: none"> <li>- embarrassment</li> <li>- not wanting to disclose their STI to others</li> </ul> <p><b>Considerations/limitations</b></p> <ul style="list-style-type: none"> <li>- Look at Stockwell (1984) – ‘unpopular patient’ includes those to which stigma is attached. This could include adults with an STI/HIV.</li> <li>- small sample size</li> <li>- age of the study</li> </ul>
Leenaars, Rombouts & Kok (1993). Seeking medical care for a Sexually Transmitted Disease: Determinants of delay-behavior.					<p>Abstract</p> <p><b>Aim:</b> ‘This study was conducted to identify determinants of delay-behavior in a sample of individuals with STD-related symptoms (<i>N</i> = 585)’</p> <p><b>Findings</b></p> <p>Health Belief Model – found to be inadequate in explaining delays in health seeking for symptomatic STIs</p> <p>Males, particularly MSM, least likely to</p>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<p>delay health seeking</p> <p><b>Prompts to health seeking</b></p> <ul style="list-style-type: none"> <li>- symptoms related to sexual behaviour</li> <li>- perceived necessity</li> <li>- information/knowledge about STIs</li> </ul> <p><b>Barriers to health seeking</b></p> <ul style="list-style-type: none"> <li>- stigma</li> <li>- shame</li> <li>- accessibility of testing clinic (e.g. walk-in hours)</li> </ul>
Llewellyn et al. (2012). Understanding patient choices for attending sexually transmitted infection testing services: a qualitative study.	65 people (58% males)  Previous or current service users (had used GUM services in the previous year).	Mean age in focus groups overall = 30 years (range 16-65 years)  Mean age in focus group for adults with HIV = 51 years (range 37 to 65)	10 focus groups.  1 group for people living with HIV.  1 group for overseas students.  Framework analysis.  Other eight groups reflected each sexual risk group (heterosexual	Brighton, England.	<p><b>Aim:</b> ‘...to establish which aspects of STI testing services are most important to previous or current service users’</p> <p><b>Findings</b></p> <p>Factors behind decision to access GUM services and not the GP for testing:</p> <ul style="list-style-type: none"> <li>- perceived expertise</li> <li>- perceived ability to carry out a wider range</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
		years)	males, heterosexual females, WSW, MSM) and two age groups (>24 years and ≤24 years)		<p>of tests in GUM</p> <ul style="list-style-type: none"> <li>- longer appointments</li> </ul> <p>Factors behind decision to access GP and not GUM services for testing:</p> <ul style="list-style-type: none"> <li>- greater anonymity, no one knows why you are sat in the waiting room</li> <li>- a good relationship may have already been established with a GP.</li> <li>- may be a more familiar environment.</li> </ul> <p>Negative aspects of GUM services:</p> <ul style="list-style-type: none"> <li>- too busy</li> <li>- environment is 'unpleasant', fuels stigma</li> <li>- concerns about confidentiality</li> </ul> <p>Younger adults more likely to perceive general practitioners as able to perform a wide range of STI tests.</p>
Mulholland & Van Wersch (2007). Stigma, sexually transmitted infections and attendance at the GUM	10 people (5 male, 5 female)	18-28 years Mean age = 22 years	Semi-structured interviews.	GUM clinic. North of England.	<b>Aim:</b> to address 'a gap in the literature regarding understanding of people's health care seeking behaviours in relation to sexually transmitted infections'

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
Clinic: an exploratory study with implications for the theory of planned behaviour.	Heterosexual participants only.		Themes considered alongside the Theory of Planned Behaviour.		<p><b>Findings</b></p> <p><u>Accessing services linked to:</u> perceived susceptibility; wanting to be free of infection (feeling 'dirty') – so can safely have sex; perception of personal risk; knowledge about STIs</p> <p><u>Barriers to accessing GUM:</u> stigma, embarrassment, anxiety, confidentiality; practical issues (not knowing clinic location, clinic opening hours), uncertainty about what happens at the clinic.</p> <p><b>Other findings:</b></p> <ul style="list-style-type: none"> <li>- not disclosing GUM attendance to anyone else</li> <li>- Different experience for women, compared to men.</li> </ul> <p>Women diagnosed with an STI labelled themselves as 'slags' and 'sluts'</p> <ul style="list-style-type: none"> <li>- Impact on personal identity of testing positive for an STI – social connotations surrounding STIs.</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
Normansell, Drennan & Oakeshott. (2015). Exploring access and attitudes to regular sexually transmitted infection screening: the views of young, multi-ethnic, inner city, female students	17 females recruited from further education college.	16-25 years.	Semi-structured interviews.	London, England.	<p><b>Aims:</b> 'The aims of this qualitative, community based study were to explore access and attitudes to STI screening in high risk, young, ethnically diverse female students recruited outside of the healthcare system'</p> <p><b>Findings</b></p> <p>Barriers: stigma, shame, long waiting times in clinics, not wanting to discuss sexual health with a general practitioner (perceived as more judgemental and lacking expertise)</p>
Prost et al. (2009). Feasibility and acceptability of offering rapid HIV tests to patients registering with primary care in London (UK): a pilot study.	47 participants.  Anglophone & Francophone.	Participants were aged between 18 and 55 years.	20 qualitative interviews.	London, England.	<p><b>Aim:</b> 'To assess the acceptability and feasibility of offering rapid HIV tests to patients registering with primary care in London, UK'.</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- opt-out testing found to be acceptable on registering with a GP;</li> <li>- need to increase HIV knowledge and risk perception;</li> <li>- need to ensure that tests are only performed with informed consent</li> </ul>



<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
Richardson et al. (2010). A pilot qualitative analysis of the psychosocial factors which drive young people to decline chlamydia testing in the UK: implications for health promotion and screening.	14 young people that declined Chlamydia testing in educational settings	16-24 years.	Semi-structured interviews.  Interpretative phenomenological analysis.	? Brighton, England.	<b>Abstract:</b>  <b>Aim:</b> 'The main objectives of this study are to investigate the psychosocial issues for young people who decline chlamydia testing as part of the national chlamydia screening programme in the UK and to consider the implications for future opportunistic screening.'  <b>Findings</b>  Barriers to testing include: stigma, embarrassment, uncertainty about the test procedure.
Scoular, Duncan & Hart. (2001). <i>"That sort of place ...where filthy men go ..."</i> : a qualitative study of women's perceptions of genitourinary medicine services'	17 women recently diagnosed with Chlamydia  (10 from a GUM clinic and 10 from a family planning clinic).	Aged 18-29 years.	Semi-structured interviews.  Thematic analysis.	Glasgow, Scotland.	<b>Aim:</b> 'to investigate the experience of stigma among young women recently diagnosed with an STI and to consider the implications of these experiences for optimising access to GUM clinics'  <b>Findings</b>  STIs associated with 'other' people within society, interview participants had not considered themselves at risk.  Limited awareness of STIs and STI risk in the general public.

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<p>Negative social and moral connotations of having a sexually transmitted infection.</p> <p>Fear of judgement, not wanting other people to know about clinic attendance.</p> <p>Stigma surrounding GUM clinics: ‘fear of the unknown’; concerns about being recognised; judgment by healthcare professionals, not wanting to be seen as entering the clinic.</p> <p>Greater stigma associated with a attending GUM clinic than a family planning clinic.</p>
Shangase & Egbe (2015). Barriers to accessing HIV services for black African communities in Cambridgeshire, the United Kingdom.	30 black African people (12 male, 18 female).	Age range from 21 to 65 years.  Participants mainly in their twenties or thirties.	Focus groups – one male and one female.  Theoretical framework: Kleihman’s model of health care systems.  Thematic analysis.  Data collected in 2009.		<p><b>Aim:</b> ‘To identify the barriers to accessing HIV services in the black African communities in Cambridge and Huntingdon’</p> <p><b>Barriers:</b></p> <p>Language &amp; cultural differences.</p> <p>Communication barriers between healthcare professionals and attendees.</p> <p>Modern vs. Traditional medicine.</p> <p>Awareness of services.</p>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
Sutcliffe et al. (2011). Comparing expectations and experiences of care for sexually transmitted infections in general practice: a qualitative study	49 people (29 females; 20 males)  38 (20 women; 18 men) recruited from GUM clinics (had attended GP prior to GUM)  11 (9 women; 2 men) recruited from general practice	Age range 16-43 years.  Mean age (Bristol GUM) = 24 years.  Mean age (Brent GUM) = 29 years.  Mean age (Bristol GP) = 17  Mean age (Brent GP) = 27	Semi-structured interviews.  6 general practices and 2 GUM clinics.	Brent, London & Bristol, SW England.	<b>Aim:</b> 'To explore the expectations and experiences of men and women who initially presented at their general practice with a suspected sexually transmitted infection in order to identify areas where change could improve service delivery'  <b>Findings</b>  - GP considered easier to access  - once accessed, GUM services found to be acceptable  - GPs do not provide enough STI information, do not possess expert knowledge  - not all STI tests performed by the GP  - stigma associated with going into a GUM clinic – anxious not to be seen  - GP seen to avoid discussing sexual health  - would prefer a formal referral from GP to GUM (e.g. letter, appointment)  <b>Considerations/limitations</b>  - difficulty in recruiting people that initially

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					attended general practice
Wayal et al. (2011). Home sampling kits for sexually transmitted infections: preferences and concerns of men who have sex with men	24 MSM GUM clinic attendees.	Six participants recruited from each of the following age groups:  ≤ 29 years, 30–39 years, 40–49 years, ≥ 50 years	Semi-structured interviews.  Data collected in 2006.	Brighton, England.	<b>Aim:</b> To explore ‘views towards the introduction of home sampling kits for STI into clinical practice’  <b>Findings</b>  - home sampling kits found to be acceptable;  - Participants would prefer to access kits from medical settings vs. social /commercial settings (concerns about maintaining confidentiality, stigma).  - Preference to be able to check for all STIs and HIV with a kit.
Questionnaire studies					
Ashby et al. (2012). HIV testing and acceptability in an inner city polyclinic.	Attendees to a London polyclinic.	Adults aged 16-65 years were eligible to take part.  Interquartile range age of adults tested =	Individuals offered testing within the polyclinic.  Collected data over ten 4 hour periods (at varying times to include busier and quieter	Hammersmith Hospital, London.	<b>Aim:</b> ‘...to investigate the expansion of our services to offer routine HIV testing to patients attending the trust polyclinic. The aims of this pilot were to assess uptake and patient acceptability of HIV testing within a polyclinic environment and to determine whether testing for HIV in this setting captures a previously untested portion of the local population.’

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
		22-43 years.  Median age = 31 years.	hours)		<b>Findings</b>  - HIV test acceptability (76%) (Majority had not tested for HIV before – 75%)  - service reported as acceptable by users
Cassell et al. (2003). Treating sexually transmitted infections in primary care: a missed opportunity?	Survey of first time GUM attendees (number =721)  45% men	Age of participants not reported.	Cross-sectional survey.	London, England.	<b>Aim:</b> ‘To explore patterns of primary care attendance, barriers to the use of primary care, and views on services in a population of first time genitourinary medicine (GUM) clinic attenders.’  <b>Findings</b>  - GP attendees symptomatic for slightly longer than those attending GUM directly (median 7.5 days vs. 5 days)  - 40.5% of attendees had seen their GP before accessing GUM  - 36.9% of attendees only found out about the GUM clinic through their general practice.  - Reasons for attending GUM (not GP): ‘speed and convenience’, GUM doctors are the experts.

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
Erwin et al. (2002). Pathways to testing and care by black African and white patients in London.	<p>Survey of adults living with HIV attending a HIV outpatient clinic (between July 1999 and March 2000).</p> <p>392 participants (64% white; 26% black African; 10% other ethnicities)</p> <p>Majority of white participants were male (92%)</p> <p>Majority of black African participants were female (60%)</p>	<p>Median age of black African participants = 34 years; age range 21 to 60 years.</p> <p>Median age of white participants = 38 years; age range 20-76 years.</p>	Survey.	<p>South London, England.</p> <p>(St. Thomas's Hospital)</p>	<p><b>Aim:</b> 'To examine factors associated with uptake of HIV clinic services by black African HIV positive people living in London.'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Black Africans had a lower perception of personal HIV risk, compared to white participants;</li> <li>- 28% of black Africans suspected they may have HIV before testing; compared to 45% of white participants</li> <li>- black Africans that suspect HIV were found to be more likely to delay testing (62% waited 12 months+ to test; compared to 31% of white people)</li> <li>- black Africans may face additional hardships e.g. financial, housing</li> <li>- barriers to testing: stigma, worried about impact on family; fear</li> </ul> <p><b>Considerations/limitations</b></p> <ul style="list-style-type: none"> <li>- does not report exposure routes</li> <li>- age of the research</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					- have not included age as a variable
Flowers et al. (2013). Has testing been normalized? An analysis of changes in barriers to HIV testing among men who have sex with men between 2000 and 2010 in Scotland, UK	Cross-sectional survey.	2000 survey – 8.4% aged equal to or greater than 45 years.  2010 survey – 12.6% aged equal to or greater than 45 years.	Participant recruited from commercial gay scene.	Glasgow, Scotland.	<b>Aim:</b> ‘This paper examines changes in barriers to HIV testing amongst gay men. We compared data collected in 2000 and 2010 to assess changes in HIV testing behaviours, in community-level perceptions of barriers to HIV testing, and in the relative contributions of barrier measures.’  <b>Findings</b>  - 30.6% increase in testing between 2000 and 2010.  - perception of the benefits of testing increased (statistically significant – $p < 0.001$ )  - testing perceived as more normalised (statistically significant – $p < 0.001$ )  - fear of testing positive and clinic barriers (e.g. opening hours, waiting times) had not significantly altered. These remain barriers to testing.
Hambly & Luzzi. (2006). Sexual health services – a patient preference survey	Survey of GUM attendees (number = 209)		Cross-sectional survey.  Data collected in 2004.	High Wycombe, Buckinghamshire, England.	<b>Aim:</b> ‘The aim of this survey was to determine whether attenders at the GU medicine clinic in south Buckinghamshire would be willing to see their general practitioner (GP) for sexual health services,

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					and what factors were important to them in making this decision'  <b>Findings</b>  - 59% would prefer to access GUM for testing and treatment; 30% would prefer to attend general practice for these service.
Mercer et al. (2013). Not so different after all? Comparing patients attending general practice-based locally enhanced services for sexual health with patients attending genitourinary medicine	Survey of patients attending GUM clinics (number = 933) and general practice-based locally enhanced services (number = 111).	Median age in GUM = 24 years.  Median age in GP-LESSH = 23 years.	Cross-sectional survey.  Data collected 2009-2010.  <i>Analysis</i> – data stratified by service accessed (GUM or GP-LESSH) and gender. CHI-squared tests were performed.	Cornwall, England.	<b>Aim:</b> To compare the characteristics and experiences of adults attending GUM clinics and GP practice based LESHH.  <b>Findings</b>  - GP-LESSH attendees took longer to access services and receive care  - GP-LESSH attendees less likely to report symptoms than GUM attendees (19.6% vs. 20.6%)  - the proportion of STI diagnoses in attendees to either setting were similar
Neale et al, (2008). Who attends primary care services prior to attendance at genitourinary services and what level of care	1000 first time attendees to GUM services in Cornwall between June and December 2006.	Age of participants not reported.	Cross-sectional survey.	Cornwall, England.	<b>Aim:</b> 'To determine the proportion of patients initially attending primary care services and describe the care received prior to attending genitourinary medicine (GUM) clinics'



<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
have they received?					<p><b>Findings</b></p> <ul style="list-style-type: none"> <li>-35% had attended GP prior to GUM</li> <li>- people aged 25+ years were more likely to attend their GP before GUM</li> <li>- 60% of women and 58% of men examined by GP</li> <li>- low levels of chlamydia testing, particularly in men</li> <li>- only 9% of people identified as having genital warts were treated by GP</li> </ul>
Reviews					
Bolsewicz et al. (2015). Factors impacting HIV testing: a review – perspectives from Australia, Canada, and the UK.	Review of 36 studies.  Published, peer-reviewed literature and national reports (2003-2013).			Studies based in the UK, Australia and Canada.	<p><b>Aim:</b> '...to identify and address barriers to testing'.</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- low perception of personal risk;</li> <li>- stigma;</li> <li>- fear of testing positive;</li> <li>- concerns about confidentiality;</li> <li>- reluctance of healthcare professionals to</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					offer tests; - older age
Davies, Gompels & May. (2015). Public and Healthcare Practitioner Attitudes towards HIV Testing: Review of Evidence from the United Kingdom (UK).	Review of 64 studies.  UK based studies, published between 1996 and 2014.  41 studies - public attitudes  23 studies – HCP attitudes	Studies not explored by age.	Broad search of electronic databases, hand searches, search of BHIVA conference reports.	UK based studies.	<b>Aim:</b> ‘To explore attitudes towards HIV testing in the United Kingdom (UK) from the public and healthcare practitioners (HCP) to more fully understand the barriers and motivators towards testing.’  <b>Testing barriers (service user):</b>  - low perception of personal risk;  - stigma;  - discrimination;  - concerns about confidentiality;  - concerns about disclosure;  - not being offered a test;  - poor HIV knowledge;  - don’t want to know/denial;  - fear  - Concerns about impact of testing positive

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<p>(effect on insurance; lifestyle etc.);</p> <p><b>Testing motivators</b></p> <ul style="list-style-type: none"> <li>- being offered a test;</li> <li>- feeling at risk;</li> <li>- having symptoms;</li> <li>- opt out testing;</li> <li>- perceived to be better to test and know HIV status;</li> <li>- availability of rapid testing;</li> <li>- accurate HIV knowledge;</li> </ul> <p><b>HCP barriers towards offering a test</b></p> <ul style="list-style-type: none"> <li>- fear of causing offense in offering a test;</li> <li>- concerns about confidentiality;</li> <li>- difficulties in discussing HIV;</li> <li>- lack of HIV knowledge;</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					<ul style="list-style-type: none"> <li>- lack of knowledge about clinical indicators and high risk groups;</li> <li>- lack of confidence and competency in testing;</li> <li>- lack of time;</li> <li>- uncertainty about managing a positive result;</li> </ul>
DeBlonde et al. (2010). Barriers to HIV testing In Europe systematic review.	24 peer-reviewed studies.		'Systematic review of the literature on HIV testing barriers in Europe'	Studies performed in Europe.	<p><b>Aim:</b> '...to better understand the barriers to HIV testing and counselling with the aim to contribute to the decrease of the number of undiagnosed people'.</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- low perception of personal risk;</li> <li>- lack of awareness of where to get tested;</li> <li>- GP reluctance to offer testing;</li> <li>- stigma;</li> <li>- fear of testing positive;</li> <li>- Concerns about confidentiality.</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
Kaai et al. (2012). Factors that affect HIV testing and counseling services among heterosexuals in Canada and the United Kingdom: An integrated review. <i>Patient Education &amp; Counseling</i> . 88 (1) 4-15.	27 studies.  Published and unpublished literature - 1996 to September 2010).			Studies performed in Canada and the UK.	<p><b>Aim:</b> 'To examine factors that affect the utilization of HIV testing and counseling (HTC) services among heterosexual populations in Canada and the U.K'.</p> <p><b>Barriers and prompts to testing</b></p> <ul style="list-style-type: none"> <li>-socio-demographic characteristics;</li> <li>-risk perception;</li> <li>- stigma;</li> <li>- knowledge about HIV;</li> <li>- clinician relationship;</li> <li>- health service opening hours;</li> <li>- Confidentiality.</li> </ul>
Cost-effectiveness of HIV testing					
Long et al. (2014). Expanded HIV testing in low prevalence, high income countries: a cost effectiveness analysis for the United Kingdom.					<p><b>Aim:</b> To estimate 'the effectiveness and cost-effectiveness of HIV testing in the United Kingdom (UK), where 25% of PLHIV are estimated to be undiagnosed'.</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- the one-time testing of everyone and the annual testing of MSM, injection drug users</li> </ul>

<u>Reference</u>	<u>Participant group/studies reviewed</u>	<u>Age of participants</u>	<u>Method of data collection and analysis.</u>	<u>Location of study</u>	<u>Aim and Findings</u>
					and people from high risk countries was found to be cost-effective.

## Appendix 2: Summary of literature on receiving a positive diagnosis and living with HIV - UK

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
Interview studies					
Anderson & Doyal. (2004). Women from Africa living with HIV in London: a descriptive study.	<p>62 black African women.</p> <p>Diagnosed with HIV for at least 6 months.</p> <p>Living in the UK for at least 6 months.</p> <p>58/62 diagnosed with HIV in the UK.</p> <p>1/3 of participants were asylum seekers.</p>	<p>Age range from 20 to 58 years.</p> <p>Median age 33 years.</p> <p>Two participants aged 46-50 years.</p> <p>Two participants aged 51-60 years.</p>	<p>In-depth, semi-structured interviews.</p> <p>Interviews performed in 2001.</p>	London, UK.	<p><b>Aim:</b> ‘ This study explores the illness biographies and daily lives of HIV-positive African women receiving treatment in London’</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Participants experienced financial and housing problems.</li> <li>- Response to diagnosis: shock (even in those that had symptoms), did not feel at risk as they associated HIV with ‘prostitution, multiple sexual partners and profound ill health’</li> <li>-Living with HIV: anxiety, uncertainty, worried about disclosure (to other members of the African community); self-isolation due to fears about disclosure; avoidance of sexual/intimate relationships; health problems related to HIV; impact on identity; majority of participants talked about stigma (particularly in the African community); most people discussed the importance of faith (belief in faith having the potential to heal)</li> </ul> <p><b>Considerations/strengths/limitations:</b></p> <ul style="list-style-type: none"> <li>- no interview extracts included to support</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					findings; - large number of participants
Anderson et al. (2008). HIV/AIDS-related stigma and discrimination: Accounts of HIV-positive Caribbean people in the United Kingdom.	25 Caribbean people living with HIV in London (21 diagnosed with HIV in the UK)  (10 MSM; 5 heterosexual males; 10 heterosexual females).	Two females aged 16-24 years; eleven males aged 25-44 years; five females aged 25-44 years; four males aged 45+ years; 3 females aged 45+ years)	In-depth, semi-structured interviews.	London, UK	<b>Aim:</b> 'This paper explores the effects of HIV/AIDS-related stigma and discrimination (HASD) on HIV-positive Caribbean people in the Caribbean and the UK'  <b>Findings</b>  - stigma considered to be rooted in fear of contagion, lack of knowledge about HIV, negative social associations linked to HIV (e.g. promiscuity and immorality), and homophobia  - stigma also generated by the religious belief that HIV is a punishment for sinful behaviour  <u>Felt stigma:</u> concern about other people's reactions to their HIV status (fear of violence, disclosure, being ostracised, rejection etc.)  - suicidal ideation  - depression  - internalised stigma – worried about transmitting HIV through touching or sharing utensils with someone



Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p><u>Enacted stigma (rarely reported)</u>: segregation of HIV positive persons things from those of HIV negative family members; unwarranted levels of cleaning; rejection (ultimately family members did accept the person living with HIV)</p> <p>Perceived healthcare discrimination – any symptoms treated as HIV related.</p> <p>Avoiding stigma and discrimination</p> <ul style="list-style-type: none"> <li>- careful evaluation of who to disclose status to (making sure it is to someone who will be supportive and accepting)</li> <li>- avoiding sexual/romantic relationships due to fear of rejection</li> <li>- limiting social interactions</li> </ul> <p>Positive aspects of diagnosis</p> <ul style="list-style-type: none"> <li>- makes those affected feel stronger</li> <li>- encourage safer sex</li> </ul> <p>* importance of family and faith in coping with HIV</p>
Anderson et al. (2009). Coping with HIV: Caribbean people in	25 Caribbean people living with HIV	Age not reported.	In-depth, semi-structured interviews.	London, UK.	<b>Aim:</b> to investigate ‘the coping strategies of HIV-positive Caribbean people’

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
the United Kingdom.	(10 MSM; 5 heterosexual males; 10 heterosexual females).  Living with HIV from 9 months-13 years.	? the same as reported in Anderson et al. (2008)			<p><b>Findings</b></p> <p>Initial response to diagnosis</p> <ul style="list-style-type: none"> <li>- shock</li> <li>- distress</li> <li>- 'biographical disruption'</li> </ul> <p><b>4 coping strategies</b></p> <ul style="list-style-type: none"> <li>- restricted disclosure</li> <li>- faith</li> <li>- submersion</li> <li>- positive reappraisal</li> </ul> <p><b>Facilitators to coping</b></p> <ul style="list-style-type: none"> <li>- social support</li> <li>- good response, and lack of stigma, from those disclosed to</li> <li>- feeling in good health</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					- HIV diagnosis considered as a chronic condition
Anderson et al. (2010). 'It took a piece of me': initial responses to a positive HIV diagnosis by Caribbean people in the UK.	25 Caribbean people living with HIV  (10 MSM; 5 heterosexual males; 5 heterosexual females).  Living with HIV from 9 months-13 years.	Age not reported.	Semi-structured interviews.	London, UK.	<p><b>Aim:</b> To explore 'diagnosis experience and immediate reactions to it'</p> <p><b>Findings:</b></p> <p>Reaching diagnosis:</p> <ul style="list-style-type: none"> <li>- Majority of participants did not self-initiate testing, only tested when became symptomatic.</li> <li>- Felt at low risk before diagnosis (HIV associated with MSM and promiscuity).</li> </ul> <p><b>Response to diagnosis:</b></p> <ul style="list-style-type: none"> <li>- Importance of the way a positive diagnosis is delivered.</li> <li>- Shock and denial</li> <li>- 'Biographical disruption'</li> <li>- Suicidal ideation</li> <li>- Biographical disruption</li> <li>- Acceptance</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p><b>Limitations highlighted in the paper:</b></p> <ul style="list-style-type: none"> <li>- Only includes clinic attendees, the sample may not represent those that have struggled most with receiving a positive HIV diagnosis.</li> </ul> <p><b>Other limitations not highlighted:</b></p> <ul style="list-style-type: none"> <li>- Age of participants not reported.</li> <li>- Wide time frame for some participants between the interview time period and when they were diagnosed. The length of this time period should be made clear</li> </ul>
Calin., et al. (2007). Disclosure of HIV among black African men and women attending a London HIV clinic.	45 black Africans living with HIV  (31 females; 14 males)  Mean age of UK residence = 15 years for males; 8 years for females.	Mean age of males = 44.  Mean age of females = 39.	Semi-structured interviews.  Content analysis.	London, UK.	<p><b>Aim:</b> 'to establish the determinants and outcomes of disclosure among black Africans in the UK'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Majority of participants had disclosed their HIV status to someone.</li> </ul> <p><i>Reasons for disclosure</i></p> <ul style="list-style-type: none"> <li>- wanting to make their sexual partner aware, as they may be at risk.</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>- partner has a right to know</li> <li>- close, trusting relationship has been established with person disclosed to</li> <li>- belief that disclosure would result in an understanding and supportive response</li> <li>- need to explain reason for poor health</li> </ul> <p><i>Reasons for non-disclosure:</i></p> <ul style="list-style-type: none"> <li>- fear of partner's reaction, may result in separation or mistrust</li> <li>- not wanting to create worry and concern (family may still consider a HIV diagnosis to be a death sentence)</li> <li>- concerned about the impact the disclosure may have on family members</li> <li>- concern about what responses may be – stigma, lack of understanding, fear of transmission</li> </ul> <p>Disclosure linked to greater social support, lower levels of stigma and less anxiety.</p>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
Chinouya & O'Keefe (2005). God will look after us: Africans, HIV and religion in Milton Keynes.	<p>17 African women and 5 African men living with HIV. All participants on antiretroviral therapy. 20 participants Christian, 2 participants Muslim.</p> <p>20 faith leader (18 men, 2 women; 18 Christian; 2 Muslim)</p> <p>Contracted HIV through heterosexual contact.</p>	Age range of adults living with HIV – 22 to 50 years.	<p>Data collected in 2003.</p> <p>Semi-structured interviews with adults living with HIV focused on 'coping with HIV, religion, service utilisation and family life'</p> <p>Focus groups with faith leaders focused on: 'the faith leaders' beliefs about HIV and how HIV was affecting their congregations; the role of religion in supporting those living with HIV; faith and sexual health issues, genders as well as gender relations within faith community settings'</p> <p>Thematic Framework analysis.</p>	Milton Keynes, England.	<p><b>Aim:</b> To examine 'how black migrant Africans in Middle England make sense of religion, in particular Christianity, in their daily lives when faced with a life-threatening condition, namely, the human immuno-deficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS)'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Religion cited as helping people to cope with living with HIV</li> <li>- However, stigma is also apparent within the places of worship (people living with HIV are concerned about disclosure and being judged by others)</li> <li>- only 2 people had disclosed their status to someone belonging to their place of worship</li> <li>- relationship with God particularly appears beneficial when people living with HIV have not disclosed their status to other people</li> <li>- praying for a cure</li> <li>- belief that their religion will prevent further transmission of their HIV</li> <li>- Diagnosis: almost all participants living with HIV</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>had presented with symptoms; majority of participants surprised by diagnosis; some prompted to test due to the awareness of a sexual partner testing as HIV positive; limited sources of social support (e.g. no support groups (considered to be a result of not being a big city)</p> <p>- Faith leaders feel they could become more involved in the HIV response (feel they have not been considered in this capacity); difficulty in discussing sexual health</p>
<p>Davis, Frankis &amp; Flowers. (2006). Uncertainty and 'technological horizon' in qualitative interviews about HIV treatment.</p>	<p>20 MSM living with HIV.</p> <p>10 participants from Glasgow; 10 participants from London.</p> <p>11 diagnosed after the advent of HAART (1996); 9 diagnosed before 1996.</p>	<p>Age range 28 to 55 years.</p> <p>Median age = 39 years.</p> <p>Mean age = 39.55.</p>	<p>Constant comparison method.</p> <p>Interviews conducted in Glasgow and London analysed together – major differences in responses not identified between locations.</p>	<p>Glasgow and London. UK.</p>	<p><b>Aim:</b> '...to provide an account of the impact of effective HIV treatment on HIV positive people's experience of the disease, their changed understanding of their bodies in relation to HIV medical technologies and the assimilation of this knowledge into their identities'.</p> <p>- Uncertainty about the future consequences of taking HAART.</p>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	4 treatment naive				
Dibb & Kamalesh. (2012). Exploring positive adjustment in HIV positive African women living in the UK.	12 African women living with HIV.  Participants diagnosed with HIV between 3 and 16 years prior to interview. Mean = 7 years.  All acquired HIV through heterosexual HIV transmission.	Age range 32 to 60 years.  Mean age = 46.5 years.	Interpretative phenomenological analysis.	London, England.	<b>Aim:</b> to address this question – ‘do HIV positive African women living in the UK positively adjust to living with HIV and, if so, in what way this adjustment may occur?’  <b>Findings</b>  Able to cope through the use of:  - Downward comparison  - Comparison with others living with HIV. Role models.  - adoption of healthier lifestyles  - greater appreciation of life, re-evaluation of priorities and ambitions  Taylor (1983) Adjustment of threatening events: A theory of cognitive adaptation. <i>American Psychologist</i> . 38 (11) 1161-1173.  Taylor & Lobel. (1989). Social comparison activity under threat: Downward evaluation and upward contacts. <i>Psychological Review</i> . 96 (4) 569-575.
Doyal. (2009). Challenges in researching life with HIV/AIDS: an			Intersectional approach	London, England.	<b>Aim:</b> ‘This paper presents findings from three studies of Black African migrants living with HIV in London’



Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
intersectional analysis of black African migrants in London.					<p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Diagnosis: shock; HIV stigma considered to be particularly strong within the African community; concern about life-expectancy; worried about disclosure; self-enforced social isolation to avoid disclosure</li> <li>- HIV services in the UK praised</li> <li>- housing and financial issues</li> <li>- MSM face additional stigma regarding sexual orientation</li> <li>- negative impact of status on sexual/intimate relationships</li> <li>- impact of HIV status on masculinity</li> </ul>
Doyal & Anderson. (2005). 'My fear is to fall in love again...' How HIV-positive African women survive in London.	62 black African women living with HIV.  Living in the UK for 6 months+  Living with HIV for 6 months+	Age range from 20 to 58. Majority of participants in their thirties.	Semi-structured interviews.  Data collected in 2001.	London, England.	<ul style="list-style-type: none"> <li>- concerns about transmitting HIV to any children they may have</li> </ul> <p><b>Response to diagnosis</b></p> <ul style="list-style-type: none"> <li>- shock at diagnosis</li> <li>- considered themselves to be 'innocent victims' (if HIV contracted during a relationship in which they have been faithful)</li> </ul> <p><b>Living with HIV</b></p>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	25 asylum seekers; 16 participants permitted to live in the UK for between 1 and 5 years; 1 participant a visitor; 2 participants illegal immigrants				<ul style="list-style-type: none"> <li>- fear of stigma</li> <li>- inability to work due to illness</li> <li>- 'biographical disruption'</li> <li>- cessation of 'normal' life</li> <li>- depression and anxiety</li> <li>- concern about disclosure of status</li> <li>- greater appreciation for life, gain perspective on what is important</li> <li>- fear about entering new sexual relationships</li> <li>- faith as a source of support</li> <li>- wanting to return to Africa but unable to leave the UK for fear of not being able to access ART</li> </ul>
Doyal, Anderson & Papparini. (2009). 'You are not yourself': exploring masculinities among heterosexual African men living with HIV in London.	<p>46 men.</p> <p>Born in Africa.</p> <p>Living in the UK for 6 months+</p> <p>Living with HIV for 6 months+</p> <p>Data collected in</p>	Aged 18+ years.		London, England.	<p><b>Aim:</b> 'This study used qualitative methods to explore the experiences of a sample of black African men who defined themselves as heterosexual and were receiving treatment for HIV and/or AIDS in London'</p> <p><b>Findings</b></p> <p><i>Reasons for testing</i></p>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	2004.				<ul style="list-style-type: none"> <li>- symptomatic</li> <li>- encouraged by a female to test</li> <li>- partner diagnosed as positive</li> <li>- reluctant to access health services without a female prompt</li> </ul> <p><i>Response to diagnosis/living with HIV</i></p> <ul style="list-style-type: none"> <li>- fear of dying</li> <li>- shock</li> <li>- robbed of a future</li> <li>- disclosure to a partner may result in separation</li> <li>- not wanting to disclose to some family members, fear of causing worry (particularly to those living in Africa)</li> <li>- financial challenges, pre-existing problems exacerbated e.g. through feeling too unwell to work, which may impact on identity as a man</li> <li>- disruption to some of gender 'norms' some African men may be used to</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>- loss of interest in sex</li> <li>- fear of transmitting HIV</li> <li>- adoption of safer sexual behaviour</li> <li>- concerns about the possibility of having a partner and children (worried about outliving any children)</li> <li>- loneliness</li> <li>- good relationship with their HIV clinicians (some concerns about waiting times, needing to call the clinic)</li> <li>- majority of participants adhered well to HAART</li> <li>- faith as a source of support for some</li> </ul>
Elford et al. (2008). Disclosure of HIV status: the role of ethnicity among people living with HIV in London.	1407 participants included in the analysis.		Questionnaire.  Data collected between June 2004 and June 2005.	London, England.	<p><b>Aim:</b> 'To examine HIV disclosure among people living with HIV in London'.</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- 88% of participant had disclosed their status to one person.</li> <li>- black African men and women least likely to disclose their status.</li> <li>- black African men and women least likely to</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					disclose their status to their partner.
Elford et al. (2008). HIV-related discrimination reported by people living with HIV in London, UK.	1385 participants included in the analysis.		Questionnaire.  Data collected between June 2004 and June 2005.	London, England.	<b>Aim:</b> '...to examine the extent to which people living with HIV in London reported being discriminated against because of their infection'.  <b>Findings</b>  - Almost 1/3 of participants had experienced HIV-related discrimination.  - Most of this discrimination (49.6%) occurred in healthcare settings (mainly by a dentist or a GP).
Flowers et al. (2006). Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK.	30 black Africans living with HIV (17 women; 13 men)	Aged between 21 and 46 years.	In-depth, semi-structured interviews.  Interpretative phenomenological analysis.	London, England.	<b>Aim:</b> 'The interviews focused upon experiential accounts of living with HIV'  <b>Findings</b>  - shock and distressed by diagnosis;  - disbelief at diagnosis;  - HIV not necessarily considered the 'most important' problem in people's lives (e.g. immigration status; accessing to treatment)  - stigma (felt and enacted)  - fear of disclosure  - self-enforced social isolation

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>- physical symptoms/side effects may lead to concern about HIV status disclosure;</li> <li>- impact of HIV on identity;</li> <li>- optimism after diagnosis (rarely reported);</li> </ul> <p><b>**Goffman (1963)</b></p>
Foreman & Rathaille. (2015) Not Just Another Long Term Chronic Illness – Social Work and HIV in Ireland	<p>15 people living with HIV in Ireland.</p> <ul style="list-style-type: none"> <li>- 9 Irish men;</li> <li>- 3 Irish women;</li> <li>- 2 African women;</li> <li>- 1 South American woman</li> </ul> <p>2 focus groups (9 social workers and members of HIV counsellors group)</p>		Semi-structured interviews	Ireland.	<p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- stigma/discrimination;</li> <li>- general public lack HIV knowledge and awareness;</li> <li>- fear of dying;</li> <li>- fear about disclosure;</li> <li>- self-isolation;</li> <li>- reduction in specialist support available to adults with HIV e.g. HIV specialist social worker;</li> <li>- lack of emotional support for adults newly diagnosed with HIV;</li> <li>- help of peer support;</li> <li>- HIV still not like other chronic health conditions due to the stigma it is associated with</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
Flowers, et al. (2011). Understanding the impact of HIV diagnosis among gay men in Scotland: An interpretative phenomenological analysis.	14 white MSM living with HIV.  All diagnosed between 1997 and 2003.  Data collected took place between 2003 and 2005.  Average time since diagnosis = 4 years.	Age range 22 to 54 years.  Mean age = 36 years.	Interpretative phenomenological analysis.	Scotland	<b>Aim:</b> 'to explore the impact of HIV diagnosis in-depth'  <b>Findings</b>  'Crisis, loss and challenges'  - uncertainty about prognosis  - 'identity crisis', loss of self  - anxiety  - paranoia that other people will be able to tell they are HIV positive  - distress  - grief, 'part of me died'  - suicidal ideation  'Integrating HIV with self and experiencing a sense of damaged reality'  - adjustment  - younger adults suggested to adjust more quickly than older adults (particularly when older adults have other health problems)  - isolation

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>- constrained by the disease</li> <li>- fear of rejection or actual rejection (by some people participants had disclosed to)</li> <li>- 'Adjustment and assimilation'</li> <li>- adjustment appeared easier for younger MSM, without symptoms, that had recently been diagnosed with HIV</li> <li>- need for acceptance from others, not appear different in the eyes of friends and family</li> <li>- greater appreciation for life</li> <li>- adoption of positive and healthy behaviours, aim to achieve life goals</li> <li>- optimism for future based on advances in treatment</li> </ul> <p><b>Limitations/strengths/considerations</b></p> <ul style="list-style-type: none"> <li>- when authors refer to older adults, which age group do they mean</li> </ul>
Ibrahim et al. (2008). Social and economic hardship among people living with HIV in London.	1604 participants included in the analysis.		Data collected between June 2004 and June 2005.	London, England.	<p><b>Aim:</b> 'To examine the social and economic circumstances of people living with HIV in London'.</p> <p><b>Findings</b></p>



Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>- black African men and women experienced greater financial difficulties, and were more likely to be unemployed.</li> <li>- Also issues associated with residency experienced by black African people.</li> </ul>
<p>Mazanderani &amp; Papparini. (2015). The stories we tell: Qualitative research interviews, talking technologies and the 'normalisation' of life with HIV.</p>	<p>76 participants:</p> <p>Two groups interviewed:</p> <ul style="list-style-type: none"> <li>- 35 PLWHA (diverse in terms of HIV transmission routes, ethnicity, race, gender)</li> <li>- 41 black African women living with HIV (from sub-Saharan Africa)</li> </ul>	<p>Age of participants not reported.</p>	<p>Semi structured interviews.</p> <p>Conducted between 2009 and 2010.</p>	<p>London, England.</p>	<p><b>Aim:</b> 'This paper focuses on one crucial aspect of this enactment: the contemporary 'normalisation' of HIV as 'just another' chronic condition – a process taking place at the level of individual subjectivities, social identities, clinical practices and global health policy, and of which social science research is a vital part. Through an analysis of 76 interviews conducted in London (2009–10), we examine tensions in the experiential narratives of individuals living with HIV in which life with the virus is framed as 'normal', yet where this 'normality' is beset with contradictions and ambiguities'</p> <p>Identified themes:</p> <ul style="list-style-type: none"> <li>- 'normalisation'</li> <li>- 'biomedicalisation'</li> <li>- 'discrimination'</li> <li>- acceptance of status achieved partly through comparison to others that are experiencing</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>poorer health</p> <ul style="list-style-type: none"> <li>- effective treatment has now made HIV medically manageable</li> <li>- HIV is largely regarded as a chronic condition in the UK (where PLWHA have access to HAART); however, there are challenges to the 'normalisation' of HIV. PLWHA still face financial difficulties, stigma and discrimination, and health complications etc. that serve as barriers to achieving a 'normal' life.</li> </ul>
Ndirangu & Evans. (2008). Experiences of African Immigrant Women Living with HIV in the U.K: Implications for Health Professionals.	<p>8 migrant African women living with HIV.</p> <p>(2 students; 4 asylum seekers; 2 people granted permanent UK residency)</p> <p>Living in the UK for between 1 and 5 years.</p> <p>Majority living with</p>		<p>Semi-structured interviews.</p> <p>Thematically analysed, using framework analysis.</p>	<p>Nottingham East Midlands, England.</p>	<p><b>Aim:</b> '(i) to explore African women's experiences of coping with HIV, and, (ii) to explore their views on the city's HIV services.'</p> <p><b>Findings:</b></p> <ul style="list-style-type: none"> <li>- concern about access to treatment if they return to Africa</li> <li>- negative social perceptions of women living with HIV, considered to be promiscuous</li> <li>- faith as a source of support</li> <li>- HIV services reported as good, preferred to accessing the GP.</li> </ul> <p><b>Strengths/limitations/considerations</b></p>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	HIV for between 1 and 4 years.				<ul style="list-style-type: none"> <li>- limitation: small number of participants</li> <li>- strength: one of only a few studies based outside of London</li> </ul>
Paparini, Doyal & Anderson. (2008). 'I count myself as being in a different world': African gay and bisexual men living with HIV in London. An exploratory study.	<p>8 black African MSM living with HIV.</p> <p>Participants born in sub-Saharan Africa. Participants had been living in the UK for between 2 and 17 years (average 10 years)</p> <p>Data collected between 2006 and 2007</p>	<p>Age range 27 to 43 years.</p> <p>Majority aged 30+ years.</p>	<p>Semi-structured interviews.</p> <p>Thematic analysis.</p> <p>Grounded theory approach.</p>	London, England.	<p><b>Aim:</b> To explore 'the experiences of a group of black African men who define themselves as gay and are living with HIV in the UK'</p> <p><b>Findings</b></p> <p><i>Reasons for testing</i></p> <ul style="list-style-type: none"> <li>- self initiated as part of routine sexual health check</li> <li>- concerned about partner's sexual behaviour</li> <li>- symptoms</li> </ul> <p><i>Response to diagnosis</i></p> <ul style="list-style-type: none"> <li>- 8 participants were shocked at their diagnosis</li> <li>- For 1 participant the diagnosis was not unexpected</li> <li>- fear of death (particularly in those diagnosed pre-HAART)</li> <li>- concerned about sexual partners.</li> <li>- difficulties and reluctance in disclosure to family</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>members (fear of reaction to sexual orientation and their HIV status, concern about worrying family members)</p> <ul style="list-style-type: none"> <li>- HIV impacts on social life</li> <li>- fewer sexual encounters after diagnosis (fear of outcome of status disclosure)</li> <li>- practising of safer sex</li> <li>- lack of support services directly aimed at this group</li> <li>- satisfied with healthcare services</li> <li>- importance of faith (although there may be concerns about homophobia within religious communities)</li> </ul> <p><i>Limitations/considerations</i></p> <ul style="list-style-type: none"> <li>- No quotations used to illustrate the conclusions drawn.</li> </ul>
Ridge et al. (2008). Like a prayer: the role of spirituality and religion for people living with HIV in the UK.	<p>44 adults living with HIV.</p> <ul style="list-style-type: none"> <li>- 9 black African heterosexual men;</li> <li>- 10 black African heterosexual</li> </ul>	Aged 18+ years.	<p>Semi-structured interviews.</p> <p>Thematic analysis.</p>	<p>Adults living in London, Brighton and Manchester</p>	<p><b>Aim:</b> To address the question 'How are spirituality and religion woven into the stories of people living with HIV, and how do these storylines influence coping?'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- importance of religion in helping to cope with</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	women - 24 gay men.  3 focus groups (2 groups of four black African women; 1 group of four black African men)				HIV; however, also a lot of stigma experienced in places of religious worship  - healing ability of God  - comfort in prayer  - positive thinking, living in the now (mindfulness)  - religion as a source of strength
Studies conducted in the USA, Australia or Europe					
Hult, Maurer & Moskowitz. (2009). "I'm sorry, you're positive": A qualitative study of individual experiences of testing positive for HIV.	50 adults recently diagnosed with HIV  (46 men; 4 women)  35 gay; 8 heterosexual; 5 bisexual  Mean time since diagnosis = 6.7 weeks	Mean age = 40.5 years.	Semi-structured interviews  Participants interviewed 7 times in the 18months following their diagnosis	San Francisco, California, USA.	<b>Aim:</b> 'to describe the experience of testing positive for HIV for people in the San Francisco Bay area'  Being informed of positive result:  - some healthcare professionals themselves were emotional when providing results  - some were impersonal  - some professed a judgemental attitude  - receiving result over the telephone not considered appropriate  - some healthcare professionals were comforting and calming, offering support and counselling

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p><b>Response to diagnosis:</b></p> <ul style="list-style-type: none"> <li>- shock</li> <li>- distress</li> <li>- numbness</li> <li>- relief in knowing (able to take action)</li> </ul> <p><b>Limitations/strengths/considerations</b></p> <ul style="list-style-type: none"> <li>- can study have any applicability to a UK context</li> <li>- one of only a few studies looking at the experience of being given a positive HIV diagnosis</li> </ul>
Roth & Nelson. (1997). HIV diagnosis rituals and identity narratives.	9 people living with HIV (8 male; 1 female)	Age range 28 to 50 years.	Narrative analysis.	Sydney, Australia.	<p><b>Aim:</b> 'to examine the patient's role in the production an HIV/AIDS diagnosis and subsequent construction of an HIV-positive self'</p> <p><b>Findings</b></p> <p><i>Receiving diagnosis</i></p> <ul style="list-style-type: none"> <li>- awkwardness of healthcare professionals in delivering the diagnosis</li> <li>- difficulties in understanding medical terminology used by healthcare professionals</li> <li>- felt to be inappropriate and impersonal to</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>deliver diagnosis over the telephone</p> <p><i>Response to diagnosis</i></p> <ul style="list-style-type: none"> <li>- development of a new identity, with HIV</li> <li>- for MSM living with HIV there is a strong sense of community (voluntary work, activism etc)</li> </ul> <p><b>Limitations/considerations</b></p> <ul style="list-style-type: none"> <li>- study conducted in Australia</li> <li>- pre-HAART study</li> <li>- not enough information about participants e.g. modes of HIV acquisition.</li> </ul>
Stevens & Hilderbrant. (2006). Women's responses to being diagnosed with HIV infection.	<p>55 women living with HIV.</p> <p>35% of participants diagnosed with AIDS.</p> <p>50% of participants with symptomatic infection.</p> <p>15% of participants asymptomatic.</p>		<p>Longitudinal (data collection started in 2000 and ended in 2003). 10 interviews performed with each participant at intervals over a two year period.</p> <p>Qualitative narrative interview design.</p> <p>Feminist narrative</p>	Wisconsin, USA.	<p><b>Aim:</b> 'to describe, from the perspective of women whose results were positive: (a) why they had been tested for HIV, (b) how they were told their diagnosis, (c) what their immediate reactions were, and (d) how they responded over time'</p> <p><b>Findings</b></p> <p>Most common reasons for testing</p> <ul style="list-style-type: none"> <li>- symptomatic</li> <li>- sexual partner diagnosed as positive</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	<p>475 interviews performed in total (550 would have been performed without attrition).</p> <p>Length of time since diagnosis ranged from 1 to 21 years (average = 7 years).</p>		approach.		<ul style="list-style-type: none"> <li>- part of antenatal screening</li> <li>- advised by healthcare professional</li> <li>- donated blood found to be positive</li> <li>- felt at risk</li> </ul> <p>Being informed of positive result</p> <ul style="list-style-type: none"> <li>- Inadequate support at diagnosis</li> <li>- Healthcare professionals not well informed about - HIV</li> <li>- Some participants given diagnosis over the telephone</li> </ul> <p>Immediate response to diagnosis</p> <ul style="list-style-type: none"> <li>- devastation</li> <li>- fear of dying</li> <li>- withdrawal</li> <li>- life is over</li> <li>- shock</li> <li>- had not considered themselves to be at risk of HIV</li> <li>- anger directed at sexual partners, blamed for</li> </ul>



Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>the HIV transmission</p> <p>Response to diagnosis over time</p> <ul style="list-style-type: none"> <li>- depression</li> <li>- submersion which either allows for the continuation of routine aspects of life, and the achievement of goals, or the adoption of unhealthy behaviours and lack of interest in fulfilment</li> <li>- shame</li> <li>- suicidal ideation</li> </ul> <p><b>Limitations/considerations</b></p> <ul style="list-style-type: none"> <li>- some participants were diagnosed before the advent of HAART</li> <li>- not clear when participants were diagnosed with HIV</li> <li>- study took place in the USA</li> </ul>
Schwartz, Block & Schafer. (2014). Oregon patients with HIV infection who experience delayed diagnosis.	<p>17 people living with HIV.</p> <p>All diagnosed with AIDS within 12 months of testing</p>		<p>Thematic analysis.</p> <p>Study conducted between 2009 and 2012.</p>	Oregon, USA.	<p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Low perception of personal risk was linked to:</li> <li>Being involved in long term relationships</li> <li>Lack of risk awareness despite engaging in risky</li> </ul>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	<p>positive for HIV.</p> <p>11 men 6 women</p> <p>All participants were White.</p> <p>53% of participants heterosexual; 24% as homosexual; 18% as bisexual. 1 person described themselves as 'confused'</p>				<p>sexual behaviours</p> <p>Having unprotected sex with people that 'look healthy'</p> <p>Only having risky sex on a few occasions</p> <p>Only associating HIV with certain groups, 'it was well known that most people didn't have HIV....They were either gay, or intravenous drug users, and I don't do either'</p> <p>Feeling of invincibility</p> <p>- Diagnosis</p> <p>After multiple presentations to healthcare professional and months/years of poor health.</p> <p>Delayed diagnosis due to not fitting the 'traditional 'risk categories''</p>
Stevens & Tighe Doerr. (1997). Trauma of discovery: Women's narratives of being informed they are HIV-infected.	<p>38 women living with HIV.</p> <p>47% diagnosed with AIDS.</p> <p>Data collected</p>	<p>Age range 31 to 55 years.</p> <p>Mean age = 41.</p>	<p>In-depth open-ended interview (interviews lasted 2 to 3 hours).</p> <p>Narrative analysis technique.</p>	San Francisco, California.	<p><b>Aim:</b> 'to describe women's subjective experiences of being informed of a positive HIV antibody test and, from their point of view, to explain the meaning and impact of discovering that one is HIV-infected'</p> <p><b>Findings</b></p> <p>- diagnosis a 'traumatic event'</p>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
	between 1993 and 1994 (pre-HAART era).				<ul style="list-style-type: none"> <li>- fears about their own life expectancy</li> <li>- fear of transmitting HIV to others</li> <li>- threat of death started to wane when people had lived with HIV for longer than they had thought possible</li> <li>- withdrawal from society</li> <li>- not wanting to enter romantic/sexual relationships</li> </ul> <p>Receiving a positive HIV diagnosis interpreted as an 'epiphany' (4), 'confirmation' (14), or 'calamity' (20 participants).</p> <p><u>Epiphany</u> – realisation of what is important, greater appreciation for life, push to reach goals, adoption of healthier behaviours</p> <p><u>Confirmation</u> – diagnosis was not a shock, 'something they had somehow already suspected', associated with knowing people affected by HIV/AIDS, associated with having symptoms they suspected were HIV related.</p> <p><u>Calamity</u> – shocked and distressed by diagnosis, had not felt at risk, had limited awareness of HIV/AIDS, for some this led to a denial of diagnosis, fear of dying, suicidal ideation, social</p>

Reference	Participant group	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>withdrawal, submersion</p> <p><b>Limitations/considerations</b></p> <ul style="list-style-type: none"> <li>- study took place before the advent of HAART</li> <li>- study took place in the USA</li> </ul>

### Appendix 3: Summary of literature on HIV, sexually transmitted infections, sexual health and older adults

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
Qualitative studies					
Altschuler & Katz (2015). "Of course it's relevant!" A focus group study of older adults' perceived importance of HIV/AIDS prevention education.	52 adults aged 50+ years.  40 females; 12 males.	Age range 50 to 82 years.	5 focus groups.  Thematic analysis.	California, USA.	<p><b>Aim:</b> to explore 'older adults' perceptions and opinions about the importance of HIV/AIDS prevention education and reasons for participation'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Stereotypical image of the asexual older adult is incorrect and therefore this group need to be made aware of STIs and HIV -</li> <li>'we're not dead yet'.</li> <li>- Participants wanted to be more informed about HIV.</li> <li>- Felt that workplace environment might be a good setting to learn more about HIV/AIDS (particularly as people are increasingly working into older age)</li> <li>- need to dispel the misconceptions surrounding HIV (the stigma)</li> <li>- difficulties in entering intimate/sexual relationships</li> </ul>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>Considerations/limitations</p> <ul style="list-style-type: none"> <li>- study conducted in USA</li> </ul>
<p>Bodley-Tickell et al. (2008). Trends in sexually transmitted infections (other than HIV) in older people: analysis of data from an enhanced surveillance system.</p>	<p>GUM attendees in West Midlands.</p>	<p>Median age of older GUM attendees = 50 years.</p> <p>Median age for older females = 49 years; age range 45-83 years.</p> <p>Median age for older males = 51 years; age range 45-82 years.</p>	<p>Epidemiological study.</p> <p>Analysis of regional GUM data (West Midlands GUM clinics):</p> <ul style="list-style-type: none"> <li>- attendees;</li> <li>- STI diagnoses (gonorrhoea, chlamydia, genital herpes, genital warts, and syphilis).</li> </ul> <p>Researchers</p>	<p>West Midlands, England.</p>	<p><b>Aim:</b> 'This study examines the distribution of selected sexually transmitted infections (STIs) in older people (aged ≥45 years) attending genitourinary medicine (GUM) clinics in the West Midlands, UK.'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Increase in adults aged 45+ years attending GUM (older people constituted 3.7% of GUM attendees in 1996, and 4.3% in 2003).</li> <li>- Increase in STI rates in older adults between 1996 and 2003.</li> <li>- 344 STI diagnoses in adults aged 45+ years in 1996; 780 in 2003.</li> <li>- In older adults, men aged 55-59 years were most likely to be diagnosed with an STI.</li> </ul> <p><b>Considerations/limitations</b></p>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
			measured infection episodes.		- only captures GUM clinic data, would be helpful to have data on testing outside of GUM settings; - age of the study
DeGrazia & Scrandis. (2015). Successful Coping in Urban, Community-Dwelling Older Adults with HIV.	40 participants.  5 participants diagnosed with HIV at age 50+ years (2 men; 3 women)	Participants aged between 50 and 69 years.  - Mean age = 55.5 years.	Interviews.  Focus groups.	USA.	<b>Aim:</b> to explore 'how urban, community dwelling older adults coped with HIV infection'  <b>Findings</b>  - at diagnosis participants reported anger at becoming infected; suicidal ideation.  - struggling with comorbidities.  - Financial difficulties (mainly related to paying for the treatment of additional healthcare problems).  Facilitators to coping: peer support; helping others; faith.
Elford et al. (2008). Over fifty and living with HIV in London.	1687 participants living with HIV (clinic attendees between June 2004 and June 2005).	140 participants were aged 50-59.  44 were aged	Survey.  Focus groups.	North East London, England.	<b>Aim:</b> 'To examine age at diagnosis, sexual behaviour and some social characteristics of people living with HIV in London who are over the age of 50 years, with particular reference to gay men.'

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
	187 participants were aged 50+ years.	60+ years.			<p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- New infections increasing in older adults.</li> <li>- 40.3% of participants aged 50+ years were diagnosed with HIV at an older age (older heterosexual black African men and women more likely to be aged 50+ years at diagnosis, 47.1% and 51.6% respectively; older gay men = 33.3%).</li> </ul>
Emlet. (2006). A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS.	88 participants.	<p>44 participants aged 20-39 years</p> <ul style="list-style-type: none"> <li>- age range 21 to 39 years.</li> <li>- mean age 34.66 years.</li> </ul> <p>44 participants aged 50+ years.</p> <ul style="list-style-type: none"> <li>- age range 50</li> </ul>	<p>Interviews.</p> <p>Data collected 2002/2003.</p>	Pacific Northwest, USA.	<p><b>Aim:</b>'...to examine the relationships between age, HIV-related stigma, and patterns of disclosure'.</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Older and younger adults reported similar levels of stigma.</li> <li>- Older people less likely to disclose their HIV status.</li> </ul>



Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
		to 71 years.  - mean age 55.45 years.			
Emlet. (2006). "You're Awfully Old to Have This Disease": Experiences of Stigma and Ageism in Adults 50 Years and Older Living With HIV/AIDS.	25 participants aged 50+ years and living with HIV.  Majority of participants were male = 68%;  Majority white (60%) or African American (36%)	Aged 50+ years.  Age range 50-72 years.  Median age = 56.1 years.	In-depth semi-structured interviews.  Interviews took place between November 2003 and December 2004.	Pacific Northwest, USA.	<b>Aim:</b> '...this study sought to examine whether older adults with HIV/AIDS experience both ageism and HIV stigma and how those experiences manifest in their lives'  <b>Findings</b>  - Experience of double stigma, due to age and HIV status.  - 17 participants reported experiencing double stigma.  - Participants discussed managing other co-morbidities.  - Internalised ageism.  - HIV stigma linked to fear of transmission;  - Concerns about confidentiality;  - Non-disclosure of status as a protective

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>barrier against stigma and discrimination.</p> <p>- Participants reported rejection; feeling isolated; being stereotyped (older people should know better; should not engage in 'risky' behaviours)</p> <p><b>Considerations/limitations</b></p> <p>- one of the first studies to look at experiences of stigma in older adults living with HIV</p>
Emlet. (2008). Truth and consequences: A qualitative exploration of HIV disclosure in older adults.	25 participants.  - 17 male (68%).	Participants aged between 50 and 72 years.  Mean age = 56.1 years.	In-depth semi-structured interviews.	Washington, USA.	<p><b>Aim:</b> To explore HIV disclosure in adults aged 50+ years.</p> <p><b>Findings</b></p> <p>- Reasons for non-disclosure: fear of response; stigma; fear of rejection; confidentiality previously broken.</p> <p>- Benefits of disclosure: support</p>
Enriquez, Lackey & Witt. (2008). Health concerns of mature women living with HIV in the Midwestern United	18 participants living with HIV.  Participants all living on	Participants aged between 41 and 68 years.	Semi-structured interviews.  Content analysis.	Mid Western, USA.	<p><b>Aim:</b> '...to better understand the health concerns of mature Midwestern women living with HIV'</p> <p><b>Findings</b></p>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
States.	a low income.	Mean age = 47 years.			<ul style="list-style-type: none"> <li>- concerns about future;</li> <li>- wanting reassurance about health (frequent screenings);</li> <li>- difficulties in differentiating symptoms related to HIV or aging.</li> <li>- uncertainties about ageing with HIV.</li> <li>- isolation.</li> <li>- importance of peer support.</li> </ul>
Gott et al. (1999). Delay in symptom presentation among a sample of older GUM clinic attenders.	GUM clinic attendees.	Participants aged 50+ years.	<p>Self-administered questionnaire.</p> <p>Patient notes.</p> <p>Logistic regression.</p>	Sheffield, Nottingham & Leicester, England.	<p><b>Aim:</b> To explore the ‘ (1) extent of delay behaviour, (2) reasons for delay behaviour and (3) variables predicting delay behaviour among a sample of genitourinary medicine (GUM) clinic attenders aged over 50 years’</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- 43.8% of older adults delayed GUM access for 2+ weeks after symptoms started.</li> <li>- Reasons for delaying clinic attendance: wanting to ‘wait and see’ if symptoms will subside; embarrassment; fear.</li> <li>- Older people found more likely to delay clinic</li> </ul>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					attendance than younger adults.
Gott. (2001). Sexual activity and risk-taking in later life.	319 respondents.	Adults aged 50+ years.	Postal questionnaire. Sent to adults aged 50+ years from four electoral wards in Sheffield.	Sheffield, England.	<p><b>Aim:</b> 'The primary study objective was to identify the prevalence of sexual activity and sexual risk-taking behaviour among a sample of older community-based adults. Secondary objectives included gathering data about past experiences of consultations regarding sexual health issues with general practitioners (GPs) and at genitourinary medicine (GUM) clinics, and exploring participants' STI and HIV/AIDS-related information needs'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Majority of respondents reported being sexually active (81.5%).</li> <li>- Males aged 50 to 60 years were found to be the main 'risk-takers'.</li> <li>- 3.8% of women and 11.1% of men reported more than one sexual partner in the 5 years prior to participating in the survey.</li> <li>- Only 60% of older adults with sexual health problems had sought healthcare.</li> </ul>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					- Majority of respondents felt they had received very little information about STIs/HIV.
Gott & Hinchliff. (2003). Barriers to seeking treatment for sexual problems in primary care: a qualitative study with older people.	23 women.  21 men.	Participants aged 50-92 years.  No. aged 50-59 years = 14 (eight men; six women)  No. aged 60-69 years =9 (six men; three women)  No. aged 70-79 years = 16 (six men; ten women)  No. aged 80+ years = 6 (five men; 1 woman)	Semi-structured interviews.  Participants recruited from one GP practice.  Framework approach.	Sheffield, England.	<b>Aim:</b> 'The aim of the present study was to identify barriers experienced by older people in seeking treatment for sexual problems.'  <b>Findings</b>  - 25 older people reported a sexual problem.  - No participants reported that a GP had discussed sexual health with them (even when GPs started patients on medications that may affect sexual function, or patient was diagnosed with a health problem that may affect sexual function).  - Older people find it difficult to discuss sexual health/sexual problems with their GP.  - Barriers: fear of judgement; stereotype of asexual older adult; problems with sexual function attributed to ageing; shame; embarrassment; fear.  - Awareness of genitourinary clinics needs to be raised.  - Some participants wanted to see a general

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					with similar characteristics to them i.e. gender, age;
Gott & Hinchliff. (2003). How important is sex in later life? The views of older people.	23 women. 21 men.	Participants aged between 50 and 92 years.	Quality of life measures.  Semi-structured interviews.  Participants recruited from one GP practice.  Framework approach.	Sheffield, England.	<b>Aim:</b> to explore '...how sex is prioritised in middle age and later life'.  - majority of participants considered sex as at least 'moderately' important;  - 7 people considered sex as 'not important'. This was attributed to: not wanting a new partner after being widowed; diminished interest in sex; sexual dysfunction; health problems; psychological barriers; partner not interested in sex;  - 15 people considered sex as 'very important' or 'extremely important'.  - A few participants reported improvements in their sex lives in older age.
Gott, Hinchliff & Galena. (2004). General practitioner attitudes to discussing sexual health issues with older people.	22 general practitioners.  - 13 men; 9 women.	Participants aged between 34 and 57 years.	In-depth semi-structured interviews.  Participants	Sheffield, England.	<b>Aim:</b> to explore 'how GPs perceive and manage later life sexual health problems...'  <b>Findings</b>  - Sexual health discussed more in terms of

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
			recruited from one GP practice.  Framework approach.		<p>younger adults.</p> <ul style="list-style-type: none"> <li>- GPs more likely to demonstrate a 'reactive approach' to sexual health in older adults. GPs more likely to wait for older adults to discuss sexual health, rather than initiate a conversation themselves.</li> <li>- Impression of older people as asexual.</li> <li>- Not perceiving older adults as at risk of STIs.</li> <li>- Feeling insufficiently trained to discuss sexual health with older people.</li> <li>- Worried about embarrassing or offending older people by discussing sex (although this concern is not based on actual experience of causing embarrassment or offence).</li> <li>- A 'minority' of participants considered older people having sex as 'unpalatable'.</li> </ul>
Grodensky et al. (2015). "I should Know Better": The Roles of Relationships, Spirituality, Disclosure,	15 women living with HIV.	Participants aged between 50 and 79 years.	In-depth semi-structured interviews.	South East, USA.	<b>Aim:</b> to explore '...specific challenges older HIV-infected women face in coping with the disease and its attendant stressors'.

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
Stigma, and Shame for Older Women Living With HIV Seeking Support in the South		Mean age = 57 years.			<p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- support from family, friends.</li> <li>- enforced social isolation due to fear of HIV disclosure, fear of response to disclosure (stigma).</li> <li>- greater shame at being diagnosed in older age</li> <li>- 'I should know better...'</li> <li>- negative impact on sexual/intimate relationships for many participants (e.g. due to fear of rejection, fear of transmission).</li> <li>- importance of faith.</li> </ul>
Grov et al. (2010). Loneliness and HIV-related stigma explain depression among older HIV-positive adults.	914 participants.	Participants aged between 50 and 78 years.  Median age = 54 years.	Survey.	New York City, USA.	<p><b>Aim:</b> to assess 'the role of perceived health, stigma, and loneliness in predicting depression among a community-based study of nearly one-thousand older HIV-positive adults in New York City' .</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>-39.1% of participants reported depressive symptoms.</li> <li>- depression strongly linked to stigma and</li> </ul>



Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					loneliness.
Lekas, Schrimshaw & Siegel. (2005). Pathways to HIV testing among adults aged fifty and older with HIV/AIDS.	35 participants aged 50+ years at diagnosis.	Participants aged 50+ years.	Interviews.  Data collected between 1996 and 1997.	New York City, USA.	<p><b>Aim:</b> 'To examine the barriers and facilitating factors to testing in this age group' (adults aged 50+ years)</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- Prompts to testing: symptoms; advised by healthcare professional, awareness of personal risk, family noticed poor health.</li> <li>- Barriers: denial; considering testing to be pointless when treatments were ineffective; lack of awareness; HIV considered to affect younger people.</li> </ul> <p><b>Considerations/limitations:</b></p> <ul style="list-style-type: none"> <li>- HAART only became available from 1996 onwards.</li> <li>- Majority of participants diagnosed before effective treatment became available.</li> </ul>
Masten. (2015). "A Shrinking Kind of Life": Gay Men's Experience of Aging with HIV.	15 MSM living with HIV.  Focus on ageing with HIV.	Eight aged 50-54 years; Four aged 55 to 59 years; two aged 60 to 64	Semi-structured interviews.	New York	<p><b>Aim:</b> 'To answer the following questions: How do gay men in late middle age construct the experience of aging with HIV/AIDS? What meanings do they attribute to aging? What role do themes from the literature play in gay men's</p>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
		years.	<p>Initial interview and follow up interview.</p> <p>Methods 'nested in a tradition of grounded theory'</p> <p>Conceptual frameworks:</p> <ul style="list-style-type: none"> <li>- Life stage theory</li> <li>- Theory on successful aging</li> </ul> <p>Data collection between 2004 and 2006.</p>		<p>experience of living with HIV/AIDS?'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- "shrinking kind of life", 'diminishing circles of social involvement</li> <li>- feeling isolated</li> <li>- stigma (associated with being gay, older and living with HIV, also may be associated with ethnicity)</li> <li>- experience of losing friends due to AIDS prior to the availability of effective treatment</li> <li>- physical challenges (uncertainty about whether physical problems are related to HIV, ageing, medication, other conditions)</li> <li>- physical problems impact on ability to work</li> <li>- financial insecurities</li> <li>- impact on identity</li> <li>- loss</li> <li>- survivor guilt</li> </ul>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>-fear of disclosure</li> <li>- reduced sexual encounters</li> <li>- less interest in the gay 'scene'</li> <li>- concern that their HIV status is visible to other, e.g. if they have lipodystrophy, 'the look of AIDS'</li> </ul> <p><b>Limitations/strengths/considerations</b></p> <ul style="list-style-type: none"> <li>- not clear at what time point the follow up interview took place</li> <li>- it is not made clear how long each participant has been living with HIV</li> <li>- consider when data collected</li> <li>- lipodystrophy associated with earlier HIV treatments, newer medications are less likely to cause it</li> </ul>
McCord. (2014). Attention HIV: older African American women define sexual risk.	7 participants.	Participants aged between 45 and 60 years.	Focus groups.  Thematic analysis.	USA	<p><b>Aim:</b> '...this study examined how a group of older African American women defined sexual-risk behaviour'.</p> <p><b>Findings</b></p>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>- lack of awareness of HIV in older people.</li> <li>- more natural for people that have just exited long term partnerships not to use condoms.</li> <li>- older people should know to practice safer sex.</li> <li>- difficulties in negotiating condom use.</li> </ul>
Nevedal & Sankar. (2016). The Significance of Sexuality and Intimacy in the Lives of Older African Americans with HIV/AIDS	43 people living with HIV.	Participants aged 50+ years.	<p>Semi-structured interviews.</p> <p>Participants recruited from infectious diseases clinics.</p> <p>Data collected in 2009.</p> <p>Thematic analysis.</p>	Mid Western, USA.	<p><b>Aim:</b> To explore 'older African Americans' experiences of living with HIV/AIDS'. using Becker's life course disruption theory.</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- For some participants, their sex life ended after diagnosis.</li> <li>- Difficulties in entering new intimate/sexual relationships.</li> <li>- Feeling damaged.</li> <li>- Fear of rejection.</li> </ul> <p>** Becker's life course disruption theory (1997)</p>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
Owen & Catalan. (2012). <i>'We never expected this to happen': narratives of ageing with HIV among gay men living in London, UK.</i>	10 MSM living with HIV.	Participants aged between 50 and 78 years.	Biographical narrative approach.	London, England.	- Challenges in adjusting to living with HIV, from thinking that your diagnosis would be terminal to the development of effective treatments.
Pratt et al. (2010). Human immunodeficiency virus (HIV) in older people.	Review.	Adults aged 50+ years.	Overview paper.	Focused on the UK.	<p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- suggests factors associated with increase in new HIV diagnoses in adults aged 50+ years: stigma; engagement in risky behaviour; advent of Viagra; increase in foreign travel; misconception that older people are asexual; HIV prevention not targeted at older people; low personal risk perception in older people; healthcare professional may not consider HIV as a possible diagnosis in older people.</li> <li>- side effects and drug interactions may be more prevalent in older adults with HIV.</li> </ul>
Psaros et al. (2015). Reflections on living with HIV over time: exploring the perspective of HIV-	19 female participants. Average time since diagnosis = 16.32 years.	Participants aged 50+ years. Mean age =	Semi-structured interviews.	Boston, USA.	<b>Aim:</b> '...to explore the experience of US women over 50 living with HIV to be understand how they make sense of their diagnosis and cope with their illness over time and during the aging

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
infected women over 50.		56.79 years.	Grounded theory. Content analysis.		process.’  <b>Findings</b>  - feeling uncertain about the future, ageing with HIV.  - concern about becoming treatment resistant.  - acceptance of diagnosis, downward comparison.  - engagement in healthier, more positive behaviours after diagnosis.  <b>Considerations/limitations</b>  - Focused on people that have aged with HIV.
Rosenfeld, Ridge & Von Lob. (2014). Vital scientific puzzle or living uncertainty? Professional and lived approaches to the uncertainties of ageing with HIV.	PLWH and aged 50+ years:  - 21 adults living with HIV for 10+ years.  - 55 adults living HIV for less than 10 years (22 MSM; 9 black African	Participants aged between 50 and 86 years.  Time from diagnosis ranged from 1	Grounded theory.  Semi-structured life history interviews.  Thematic	London, England.	‘The ageing of the HIV population is unfolding within the context of a politicised history of medical care, medical breakthroughs changing HIV from a fatal to a chronic illness, and a long-standing treatment partnership between medical professionals and HIV patients. This article draws on in-depth interviews with those living with HIV in later life (aged 50 and over), as well as those working with them, to uncover how these various actors understand the

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
	<p>heterosexual men; 11 heterosexual black African women; 8 white heterosexual men; 5 white heterosexual women)</p> <p><i>17 stakeholders:</i> healthcare professionals (6); non-clinical professionals working in HIV services (3); academics (2); policy makers (4); activists/advocates (2)</p>	to 28 years.	<p>analysis.</p> <p>'Modified constant comparison approach'</p> <p>Data collected over 2 years.</p>		<p>nature and consequences of this new phenomenon, and whether their understandings and approaches vary according to the individual's connection to it'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- uncertainties of ageing with HIV (identifying the cause of symptoms – part of ageing or due to HIV; concerned about premature ageing/premature death)</li> <li>- premature ageing thought to be a product of the length of time living with HIV and taking ART, and lifestyle (smoking, alcohol consumption etc more prevalent in PLWH)</li> <li>- clinicians have little experience in managing the health of adults ageing with HIV (as PLWH historically have not reached older age), this is uncertain territory for them as well as their patients</li> <li>- concern particularly among people that have been living with HIV for 10+ years</li> </ul> <p><b>Strengths/limitations/considerations</b></p>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<ul style="list-style-type: none"> <li>- researchers struggled to recruit recently diagnosed white heterosexual men and women</li> <li>- does not describe the sample of adults living with HIV for 10+ years</li> </ul>
Sankar et al. (2011). What do we know about older adults and HIV? A review of social and behavioral literature.	58 peer reviewed publications.	Older adults defined as aged 50+ years.	Systematic critical content review.  Literature from 1984 to 2010.	-	<p><b>Aim:</b> 'to assess the state of knowledge of the sociocultural and behavioral factors associated with aging and HIV...'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- 17% of studies compared older people to younger adults.</li> <li>- Older adults found to have better adherence to ART.</li> <li>- Older adults less likely to disclose their HIV status than younger people.</li> <li>- High levels of depression in older people with HIV.</li> <li>- Lower risk perception in older adults.</li> <li>- Older adults engage in risk behaviours, comparable to younger people.</li> </ul>



Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
Sherr et al. (2009). Clinical and behavioural aspects of aging with HIV infection.	778 participants.	Participants aged 18+ years.  12% of participants aged 50+ years.	Questionnaire.  Participants recruited from 5 HIV outpatient clinics.	London & South East, England.	<b>Aim:</b> 'This study examined age distribution and explored the impact of age on the experience of illness'  <b>Findings</b>  - higher proportion of adults aged 50+ years were male, in comparison to the younger age group.  - Older adults more likely to be adherent to treatment and report fewer side-effects.  - great psychological and physical burden reported in older adults.
Shippy & Karpiak. (2005). The aging HIV/AIDS population: Fragile social networks.	160 participants. (106 men; 54 women). (74% heterosexual).	136 participants aged 50-59 years (85% of participants).  24 participants aged 60+ years (15% of participants).	Survey.	New York City, USA.	<b>Aim:</b> to provide 'a detailed profile of this growing, aging cohort and their social networks.'  <b>Findings</b>  - 19% of participants said 'they would rely on themselves' and not others for support;  - 7% did not know who they could ask for support.  - 16% of participants felt they had no one to

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
					<p>'turn to for assistance'</p> <ul style="list-style-type: none"> <li>- 45% reported needing much more help.</li> <li>- 23% of participants found it difficult to access services, reporting that they 'feel out of place because of their age'.</li> </ul> <p><b>Considerations/limitations</b></p> <ul style="list-style-type: none"> <li>- age of the study, not an in-depth exploration.</li> </ul>
Siegel, Bradley & Lekas. (2004). Causal attributions for fatigue among late middle-aged and older adults with HIV infection.	100 adults living with HIV that had experienced 3+ illness or treatment side-effects in the 30 days prior to participation.	<p>Participants aged between 50 and 71 years.</p> <p>Mean age of participants = 55.7 years.</p> <p>82% aged 50-58 years.</p> <p>18% aged 60-</p>	<p>Semi-structured interviews.</p> <p>2 interview per participant (some conducted on the same day).</p> <p>Content analysis.</p> <p>Data collected between</p>	New York City, USA.	<p><b>Aim:</b> '...to better understand the symptom appraisal process among 100 HIV+ older adults (50+)...'</p> <p><b>Findings</b></p> <ul style="list-style-type: none"> <li>- 49 participants reported fatigue; 18% of these felt it was 'their most difficult symptom with which to live'.</li> <li>- most people with fatigue attributed it as a symptom of HIV (88%).</li> <li>- 30% of people also felt that their fatigue may also be linked to their age.</li> <li>- Medication also felt to cause fatigue.</li> </ul>

Reference	Participant group/studies reviewed	Age of participants	Method of data collection and analysis.	Location of study	Findings
		71 years.	November 2000 and February 2002.		<ul style="list-style-type: none"> <li>- Important that people living with HIV do not simply accept that HIV is the cause of their symptoms; fatigue should be investigated.</li> <li>- uncertainty surrounding cause of symptoms creates anxiety.</li> </ul>

#### Appendix 4: Literature search examples

<p><u>Search:</u> Living with HIV</p> <ul style="list-style-type: none"> <li>- Initial response to diagnosis.</li> <li>- Longer term impact of diagnosis.</li> <li>- Comparing diagnosis at older age to diagnosis at younger age.</li> <li>- Comparing the diagnosis of HIV at an older age to the diagnosis of other chronic conditions.</li> </ul>				
Databases searched: Ovid MEDLINE(R) 1946 to present; CINAHL, Google Scholar				
Database searched	Search terms (including and limits applied)	Number of results	Number of relevant results	Date of search
CINAHL	HIV or AIDS; UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland; Qualitative or interview; 'Living with HIV'	59	2 (already identified in previous CINAHL search) 18	21.07.2016
Ovid MEDLINE(R) 1946 to Present	HIV or AIDS; UK or United Kingdom or Britain or England or Wales or Scotland or North Ireland; Qualitative or interview; 'living with HIV'	18	6 (already identified in previous CINHAL search)	28.07.2016
Ovid MEDLINE(R) 1946 to Present	'living with HIV'; UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland;	45	5	28.07.2016

	Older or 'aged 50' or middle age*			
Ovid MEDLINE(R) 1946 to Present	'living with HIV'; USA or Europe; Older or 'aged 50' or middle age.	61	2 (already identified in previous CINAHL search)	28.07.2016
Ovid MEDLINE(R) 1946 to Present	"living with HIV"; UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland	112	10 (already identified in previous searches) 6	28.07.2016
CINAHL	(HIV or AIDS or HIV/AIDS or Human Immunodeficiency Virus) AND (UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland ) AND (qualitative or interviews or perceptions or experiences) AND "living with HIV"	72	13 (already identified in previous searches) 3	28.07.2016
CINAHL	(HIV or AIDS) AND (UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland) AND ('Living with HIV') AND (Qualitative or interview or perceptions or experiences) AND (50' or older or elderly or aged or old or senior)	6	1 (already identified in previous search)	28.07.2016
CINAHL	(HIV or AIDS) AND (UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland) AND ('Living with HIV') AND (50' or older or elderly or aged or old or senior)	15	3 (already identified in previous search)	28.07.2016

CINAHL	(HIV or AIDS) AND (USA or Europe) AND ('Living with HIV') AND (Qualitative or interview or perceptions or experiences) AND ('50' or older or elderly or aged or old or senior) Limits: since 2000	454	20	28.07.2016
Google Scholar	(HIV or AIDS or HIV/AIDS or Human Immunodeficiency Virus) AND (UK or United Kingdom or England) AND (qualitative or interviews or perceptions or experiences) AND "living with HIV" AND diagnosis Must include: United Kingdom or UK or England or Wales or Northern Ireland Limits: Since 2000	24	1	28.07.2016
Google Scholar	(HIV or AIDS or HIV/AIDS or Human Immunodeficiency Virus) AND (UK or United Kingdom or England) AND (older) AND ('living with HIV') Limits: Since 2000	39,700 – searched through first 200 results	5 (already identified in previous searches) 11	28.07.2016

Search: Journey to HIV testing

Initial response to diagnosis.

- Health/help seeking behaviour
- Where tested?
- Self-initiated or healthcare professional initiated testing
- Experience of testing
- Test location
- Comparing the routes to testing experienced by older adults in comparison to younger adults.

Databases searched: Ovid MEDLINE(R) 1946 to present; CINAHL				
Database searched	Search terms (including and limits applied)	Number of results	Number of relevant results	Date of search
CINAHL	(HIV and test*) AND (UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland) AND (qualitative or interview or perceptions or experiences)	152	15	28.07.2016
CINAHL	(STI or sexually transmitted) and (test*) AND (UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland) AND (qualitative or interview or perceptions or experiences)	59	3 (already identified in previous searches) 3	28.07.2016
Ovid MEDLINE(R) 1946 to Present	(HIV and test*) AND (UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland) AND (qualitative or interview or perceptions or experiences)	90	10 (already identified in previous searches) 3	28.07.2016
Ovid MEDLINE(R) 1946 to Present	(STI or sexually transmitted) and (test*) AND (UK or United Kingdom or Britain or England or Wales or Scotland or Northern Ireland) AND (qualitative or interview or perceptions or experiences)	51	5 (already identified in previous searches) 1	28.07.2016

## **Appendix 5: Interview topic guide for interviews with services users**

### **Influence of age on awareness of HIV prior to diagnosis**

*What did the individual know about HIV before their diagnosis?*

- Knowledge about transmission
- Knowledge about prevention
- Knowledge about treatment for HIV and prognosis
- Perception of personal HIV risk
- Does the individual associate HIV with particular age groups/particular 'at risk' groups within society
- Impact of age on HIV knowledge and awareness
- Impact of age on perceptions of HIV risk
- Thoughts about the media presentation of HIV – are specific age groups or exposure groups more targeted
- Thoughts about sexual health/HIV services – acceptability and inclusivity to all age groups.
- Has the individual's awareness of HIV and HIV risk changed over time
- Prior history of receiving a HIV test
- Knowing someone with HIV
- Any prior discussion about sexual health/HIV with a healthcare professional, relative's friends etc. How comfortable does the individual feel in these discussions? Has age had an impact on ability to discuss sexual health/HIV?

### **Influence of age on pathway to receiving HIV diagnosis**

*What was the individual's experience of being diagnosed with HIV? How did they come to receive a diagnosis?*

- Initiation of HIV test – self-requested or offered by a healthcare professional
- When and where diagnosed
- Thoughts about the HIV test location (GUM/ GP surgery/hospital setting etc.) and the way the test was delivered e.g. counselling, information received.



- Thoughts about the health care received leading up to, and at the time, of diagnosis
- Symptoms prior to diagnosis
- Encounters with healthcare professionals prior to diagnosis
- Length of time from feeling unwell to receiving HIV test
- Perceived influence of age on timing of test and healthcare received
- Any misdiagnoses prior to HIV diagnosis
- Discussions with relatives, friends etc. prior to receiving a HIV test – level of support and ability to disclose this to others. Influence of age on discussing having a HIV test with others.

### **Influence of age on experience of HIV services**

*What has your experience of HIV services been like?*

- Thoughts about attending GUM clinic or GP surgeries for appointments
  - Perception of the environment/ healthcare professionals
  - Is the environment somewhere you consider suitable for all age groups
  - Is the environment targeted towards certain 'at risk' groups or certain age groups
  - Does age impact on interactions with healthcare professionals
  - Any contact with other people (other people of a similar age) diagnosed with HIV
  - Convenience of sexual health/HIV services – opening hours, appointment availability
  - Level of support – availability and acceptability of support groups
  - Is the service able to meet the needs of younger and older adults?
- Thoughts about the healthcare received
  - Any areas which were particularly good?
  - Any areas which may need improvement?
- Impact of HIV diagnosis in day-to-day life – relationships, work, lifestyle
- Influence of age at diagnosis on the impact of HIV diagnosis

- Does the individual think that if they had been diagnosed with HIV under the age of 50 their experience would have been different? In what ways?
  - Healthcare received
  - Impact on relationships, work, lifestyle, well-being, ability to disclose HIV status, coping ability

### **Living with HIV – thoughts about the future**

*What are your thoughts about the future?*

- Influence of age at diagnosis on perceptions of the future
- Disclosure of HIV diagnosis to healthcare professionals, family, friends, work colleagues etc.
- Relationships
- Co-morbidities
- Taking medication

## **Appendix 6: Interview topic guide for interviews with HCPs**

### **Information about the individual/ their professional roles**

- Could you tell me a little bit about your role at the [workplace name]?
- What does your job involve on a day-to-day basis?
- How long have you worked in this role at the [workplace name]?
- How long have you worked in this area of healthcare (sexual health/HIV/infectious diseases)?
- Have you always been based in [geographical location] while working in this area of healthcare?

### **HIV service acceptability and accessibility to older adults**

- In the centre, what sort of age range of adults do you see?
- Do you think that the centre is geared towards any particular age group or 'at risk' group?
- In general, would you consider HIV/sexual health services to be more geared up to particular age groups or 'at risk' groups?
- How acceptable do you think the clinic is to older adults and younger adults?
- How acceptable do you think HIV/sexual health services in general are to older and younger adults? Is that impacted on by other factors e.g. HIV prevalence, geographical location
- What do you think about HIV prevention in the UK? Do you think it reaches all age groups?

### **Attitudes towards discussing HIV with older adults and offering a HIV test**

- Do you feel like there are barriers to offering someone a HIV test? If so, what do you consider these to be? Within the clinic or more widely.
- Do you feel like there are any additional barriers to offering an older adult an HIV test? If so, what do you consider these to be? Within the clinic or more widely.

### **Experiences of testing older adults for HIV and diagnosing older adults with HIV**

- Do you perform HIV testing as part of your day-to-day role?
- What is your experience in testing adults over the age of 50 years?
  - How often do you see older adults? Has this changed over time?
  - Is the response of older adults in any way different to that of younger adults when being tested/on receiving a positive diagnosis? (e.g. awareness of exposure beforehand, knowledge of risk, what are their perceptions regarding prognosis)
  - Is there any difference in age to who self-refers for a test or is tested based on healthcare professional recommendation?
- Do you find that older adults generally present at a later stage of disease to younger adults? Why do you think this is?

#### **Provision of sexual health/HIV services for older adults**

- Does your clinic/centre offer any services targeted at specific 'risk groups' or age groups
  - Any services specifically for older adults
- Do you consider the requirements of services to be any different for older adults compared to younger adults?
- Do older adults generally have different physical and psychological healthcare needs to younger adults?

#### **Questions to ask the psychologist**

- What sort of age ranges of referrals do you receive? Has there been a change in the ages of individuals using the service?
- Do the points of distress raised by older adults generally differ to younger adults?

**Exploring the experience of receiving a positive HIV diagnosis at age 50 years and over**

**Version 8.0, 10/09/2015**

We would like to invite you to take part in the above named multi-centre research study. The aim in conducting this study is to produce findings which can be used to help maximise the effectiveness of HIV services in meeting the needs of adults aged 50 years and over.

Before you decide whether to take part, please take your time to read the following information. Please feel free to contact us if you wish to take part or if you would like additional information, and to talk to others, such as friends or family members, before making your decision.

**What is the purpose of this study?**

The number of people aged 50 years and over being newly diagnosed with HIV is increasing in the UK. Many of these people receive a late HIV diagnosis, which increases their likelihood of poor health outcomes.

As the number of new HIV diagnoses in the over 50s is increasing, it is important to look at how accessible and acceptable HIV services are for people in this age group. The aim of this study is to explore the experiences of people over the age of 50 who receive a positive HIV diagnosis. We will look at:

- How participants reached the point of being tested for HIV
- Participants' experiences of health services prior to, and at the time of, testing positive for HIV
- What participants think about HIV services and what they expect of these services
- The impact of age on a participant's experience of receiving a positive HIV diagnosis.
- Participants' knowledge and awareness of HIV and AIDS prior to diagnosis.

It is intended that a minimum of 16 participants in total will be take part in the study. Participants will be approached to take part in the study from five research sites.

### **Who is doing the study?**

This study is part of a wider PhD project by Sadie Bell (chief Investigator), at the University of York. The chief investigator for this project is working in collaboration with Professor Tim Doran (Professor of Health Policy, University of York), Dr Joy Adamson (Deputy Director of the York Trials Unit, University of York) and Dr Fabiola Martin (Senior Clinical Lecturer in HIV Medicine at the Centre for Immunology and Infection (CII) and Hull York Medical School (HYMS), University of York). The study is being funded by the University of York.

### **Who can take part?**

You can take part in the study if you fulfil all of the following criteria:

- You have been diagnosed as HIV positive within the last 3 years
- You were 50 years of age or older at the time of diagnosis
- You were diagnosed as HIV positive in the UK.
- You can spare approximately 45 minutes to 1 hour of your time to take part in an audio-recorded interview.

### **Do I have to take part?**

No. Taking part in the study is entirely voluntary.

### **What will happen if I do NOT take part?**

Your decision NOT to take part will have no impact on your health care. Your clinic will not be informed if you take part or not.

### **What will be involved if I take part in this study?**

Volunteers to the study will be asked to sign a consent form as a written record of their decision to participate in the study. Participants will be given a copy of this consent form and the original form will be stored by the chief investigator.

Participants are asked to take part in one interview only. The interview will be performed by Sadie Bell (chief investigator) and take place at a setting of the participant's choice, either at the clinic/unit or at the participant's home address. If the interview takes place outside of your home address, the cost of your travel to the interview setting will be covered. The

interview will be audio-recorded. Hand-written notes may also be made by the chief investigator during the interview. The interview is expected to last approximately 45 minutes to 1 hour.

Data collected from the interviews will be analysed and the findings used as part of a PhD project.

### **What are the benefits of taking part?**

There are no expected personal advantages to taking part in this study. The reason for your participation would be to improve understanding of the effectiveness of services for people over 50 receiving a diagnosis of HIV. It is possible that sharing your experiences will be beneficial to you.

In addition, it is intended that the collective findings from all interviews will be informative to older adults at risk of HIV, as well as mature HIV carriers, health care providers and policy makers.

### **What are the disadvantages of taking part?**

There are no expected personal disadvantages of participation. It is possible that talking about your experience of being HIV positive may cause you emotional upset. You may stop the interview at any time and resume only if you wish to continue.

The researcher also reserves the right to stop the interview should she find it necessary.

### **Can I withdraw from the study?**

You can withdraw from the study at any time prior to interview, during the interview, and up to 1 month after the interview.

Once your consent has been withdrawn all the interview data you have provided will be destroyed and not used in any data analysis.

If you decide to withdraw from the study beyond 1 month following the interview, it will not be possible to remove the interview data you have provided. At this time, the interview data you have provided will have been analysed, alongside the interview data of all other participants, and therefore it will not be possible to extract your data from this analysis.

### **Will the information I give be kept confidential?**

Your information will be treated with strict confidence. All data will only be accessed by the researchers carrying out the study.

Interviews will be audio-recorded and transcribed electronically at the University of York. All audio-files will be deleted from audio-recording devices following transfer onto a University of York computer.

All data will be stored in a secure location at the University of York. Hand-written information will be stored in a locked cabinet at the University of York; electronic data will be stored on a password protected research computer at the University of York.

All of the information provided by participants will remain anonymous, with a pseudonym used in place of your real name to analyse the interview data. Any information provided which could lead to your identity being revealed will be removed, e.g. name, address etc. Any direct quotations reported in the study findings will be presented anonymously.

All personal data, apart from the consent form, will be deleted three months after the interview takes place.

Anonymised study data will be stored for five years after completion of the PhD.

### **What will happen to the results of the study?**

The results of the study will be reported for academic assessment as part of a PhD project. In order to raise awareness of policy makers, scientists, clinicians and the wider public the study results will be presented at conferences and submitted for publication in research journals.

A final study report will be provided to all participating clinics for the attention of clinic staff and patients.

### **Who has reviewed this study?**

This study has been granted ethical approval by three governing bodies:

Health Sciences Research Governance Committee at the University of York, the NHS Research Ethics Committee, and local hospital Research & Development departments at each study hospital.

### **If you would like to take part please contact:**



Ms Sadie Bell, a PhD student at the department of Health Sciences at University of York will obtain consent and conduct all interviews. Should you wish to take part, seek more information or share comments about the study please contact:

Sadie Bell

Health Sciences PhD Student, University of York

**Telephone number:** 07484 118974

**Email address:** slb521@york.ac.uk

**Work address:** Research Centre for the Social Sciences (RCSS), 6 Innovation Close, University of York, Heslington, York, YO10 5ZF, UK.

**Who do I contact in the event of a complaint?**

At the end of the interview, participants will be invited to present any concerns or complaints to Sadie Bell. Should a participant wish to raise a complaint outside of the interview, or to someone other than Ms Bell, the participant can contact:

Professor Tim Doran:

**Telephone number:** 01904 321524; **Email address:** tim.doran@york.ac.uk

**Work address:** Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK.

Dr Joy Adamson:

**Telephone number:** 01904 321378; **Email address:** joy.adamson@york.ac.uk

**Work address:** Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK.

Patient advice and liaison service (PALS)

The contact information for PALS will be provided by Sadie Bell to you.

***Thank you for taking the time to read this information sheet.***

**Appendix 8: Consent form for interviews with service users**

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**The Department of Health Sciences**

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**Exploring the experience of receiving a positive HIV diagnosis at age 50 years and over**

Consent from version: 7.0; 27/02/2015

Please read carefully and initial the boxes to confirm your agreement to the following statements	Initials
I have read the participant information sheet (version ...) for the above named research study. I have been given the opportunity to ask questions about the study, and any questions I have asked have been answered fully. I have been given sufficient time to make a decision about taking part in the study.	
I understand that my participation in the study is entirely voluntary and that I am free to withdraw from the study, without having to give a reason for withdrawing, at any time up to 1 month after the interview has taken place.	
I understand that the interview will be audio-recorded and hand-written notes may be taken by the chief investigator (Sadie Bell) during the interview.	
I understand that data collected from my interview, once anonymised, may be looked at by other researchers (Professor Tim Doran; Dr Joy Adamson; Dr Fabiola Martin) working alongside the chief investigator (Sadie Bell). I give permission for these people to have access to my data.	
I understand that any information I provide, including my personal details, will be treated confidentially. All information collected will be stored securely and will only be accessed by the researchers carrying out the study.	
The research records, such as this consent form, may also be examined by authorised people from regulatory authorities to ensure that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.	
I understand that the responses I provide during the interview may be directly quoted in published documents but that these quotations will be made anonymous.	
I agree to participate in this research study.	

Name of Participant: .....Participant Signature: ..... Date: .....

Name of Researcher: ..... Researcher Signature: .....Date: .....

Centre name: .....

**Contact Address:** Research Centre for the Social Sciences (RCSS), 6 Innovation Close, University of York, Heslington, York, YO10 5ZF.

When completed, 1 (original) to be kept by the chief investigator (for researcher file) and 1 for participant.

**Would you like to take part  
in research looking at older  
adults' experiences of  
receiving a diagnosis of HIV?**

**Were you aged 50 years or over when  
diagnosed with HIV?**

**Were you diagnosed with HIV within the last 3 years?**

**At the University of York, we aim to improve understanding  
of how effective health services are in meeting the needs of  
older adults with HIV**

**We would like to interview you about your experiences.  
Interviews will last approx. 45-60 minutes**

To take part, or seek more information about the study, please contact:

Sadie Bell (Health Sciences PhD Student, University of York)

Contact number: 07484 118974; Email address: slb521@york.ac.uk

Study information sheets are also available at this centre

## Appendix 10: PIS for interviews with HCPs

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### **Exploring service provision for older adults at risk of HIV and newly diagnosed with HIV**

**Version 1.0, 03/06/2015**

We would like to invite you to take part in the above named multi-site interview study. It is intended that study findings will contribute to a better understanding of HIV service provision for adults aged 50+ years at risk of HIV and newly diagnosed with HIV. The study will look to explore how accessible and acceptable HIV services are to this age group, from the perspective of healthcare professionals working in this medical speciality.

Before you decide whether to take part in the study, please take your time to read the following information.

#### **What is the purpose of this study?**

The aim of the study will be to explore service provision for older adults at risk of HIV and newly diagnosed with HIV, looking at healthcare professionals':

- Viewpoints surrounding HIV services and their accessibility and acceptability to older adults;
- Attitudes towards discussing HIV risk with older adults and offering a HIV test,
- Experiences of testing older adults for HIV and diagnosing older adults with HIV;
- Provision of sexual health/HIV services for older adults within their own clinical setting.

#### **Who is doing the study?**

This study is part of a wider PhD project by Sadie Bell (chief Investigator), funded by the University of York. The chief investigator for this project is working in collaboration with Professor Tim Doran (Professor of Health Policy, University of York), Dr Joy Adamson (Deputy Director of the York Trials Unit, University of York) and Dr Fabiola Martin (Senior Clinical Lecturer in HIV Medicine at the Centre for Immunology and Infection (CII) and Hull York Medical School, University of York).

### **Who can take part?**

You can take part in the study if you fulfil the following criteria:

- You are a healthcare professional working in sexual health/HIV services at one of the selected study sites.
- You can spare approximately 30 to 40 minutes of your time to take part in an audio-recorded interview.

### **Do I have to take part?**

No. Taking part in the study is entirely voluntary.

### **What will be involved if I take part in this study?**

Volunteers to the study will be asked to sign a consent form as a written record of their decision to participate in the study. Participants will be given a copy of this consent form and the original form will be stored by the chief investigator.

Participants are asked to take part in one interview only. The interview will be performed by Sadie Bell (chief investigator) at the clinic/unit at which you work. The interview will be audio-recorded. Hand-written notes may also be made by the chief investigator during the interview. The interview is expected to last approximately 30 to 40 minutes.

Data collected from the interviews will be analysed and the findings used as part of a PhD project.

### **What are the advantages/disadvantages of taking part?**

There are no expected personal advantages or disadvantages to taking part in the study. It is anticipated that there will be wider advantages to participating in the study as it intended that data collected will contribute to a better understanding of how accessible and acceptable HIV services are to older adults. These findings may then be used to help optimise the effectiveness of HIV services in providing for older adults.

### **Can I withdraw from the study?**

You can withdraw from the study at any time prior to interview, during the interview, and up to 1 month after the interview.

Once your consent has been withdrawn all the interview data you have provided will be destroyed and not used in any data analysis.

If you decide to withdraw from the study beyond 1 month following the interview, it will not be possible to remove the interview data you have provided. At this time, the interview data you have provided will have been analysed, alongside the interview data of all other participants, and therefore it will not be possible to extract your data from this analysis.

### **Will the information I give be kept confidential?**

Your information will be treated with strict confidence. All data will only be accessed by the researchers carrying out the study.

Interviews will be audio-recorded and transcribed electronically at the University of York. All audio-files will be deleted from audio-recording devices following transfer onto a University of York computer.

All data will be stored in a secure location at the University of York. Hand-written information will be stored in a locked cabinet at the University of York; electronic data will be stored on a password protected research computer at the University of York.

All of the information provided by participants will remain anonymous, with a pseudonym used in place of your real name to analyse the interview data. Any information provided which could lead to your identity being revealed will be removed, e.g. name, address etc. Any direct quotations reported in the study findings will be presented anonymously.

All personal data, apart from the consent form, will be deleted three months after the interview takes place.

Anonymised study data will be stored for five years after completion of the PhD.

### **What will happen to the results of the study?**

The results of the study will be reported for academic assessment as part of a PhD project. In order to raise awareness of policy makers, scientists, clinicians and the wider public the study results will be presented at conferences and submitted for publication in research journals.

A final study report will be provided to all participating clinics for the attention of clinic staff and patients.

**Who has reviewed this study?**

This study has been granted ethical approval by two governing bodies:

Health Sciences Research Governance Committee at the University of York and local hospital Research & Development departments at each study hospital.

**If you would like to take part please contact:**

Ms Sadie Bell, a PhD student at the department of Health Sciences at University of York will obtain consent and conduct all interviews. Should you wish to take part, seek more information or share comments about the study please contact:

Sadie Bell

Health Sciences PhD Student, University of York

**Telephone number:** 07484 118974

**Email address:** slb521@york.ac.uk

**Work address:** Research Centre for the Social Sciences (RCSS), 6 Innovation Close, University of York, Heslington, York, YO10 5ZF, UK.

**Who do I contact in the event of a complaint?**

At the end of the interview, participants will be invited to present any concerns or complaints to Sadie Bell. Should a participant wish to raise a complaint outside of the interview, or to someone other than Ms Bell, the participant can contact:

Professor Tim Doran:

**Telephone number:** 01904 321524; **Email address:** tim.doran@york.ac.uk

**Work address:** Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK.

Dr Joy Adamson:

**Telephone number:** 01904 321378; **Email address:** joy.adamson@york.ac.uk

**Work address:** Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK.

## Appendix 11: Consent form for interviews with HCPs

THE UNIVERSITY *of York*

The Department of Health Sciences

Trust logo affixed here

**Exploring service provision for older adults at risk of HIV and newly diagnosed with HIV**

Consent from version: 1.0; 03/06/2015

Please read carefully and initial the boxes to confirm your agreement to the following statements	Initials
I have read the participant information sheet (version ...) for the above named research study. I have been given the opportunity to ask questions about the study, and any questions I have asked have been answered fully. I have been given sufficient time to make a decision about taking part in the study.	
I understand that my participation in the study is entirely voluntary and that I am free to withdraw from the study, without having to give a reason for withdrawing, at any time up to 1 month after the interview has taken place.	
I understand that the interview will be audio-recorded and hand-written notes may be taken by the chief investigator (Sadie Bell) during the interview.	
I understand that data collected from my interview, once anonymised, may be looked at by other researchers (Professor Tim Doran; Dr Joy Adamson; Dr Fabiola Martin) working alongside the chief investigator (Sadie Bell). I give permission for these people to have access to my data.	
I understand that any information I provide, including my personal details, will be treated confidentially. All information collected will be stored securely and will only be accessed by the researchers carrying out the study.	
The research records, such as this consent form, may also be examined by authorised people from regulatory authorities to ensure that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.	
I understand that the responses I provide during the interview may be directly quoted in published documents but that these quotations will be made anonymous.	
I agree to participate in this research study.	

Name of Participant: ..... Participant Signature: .....

Date:.....

Name of Researcher: ..... Researcher Signature: .....

Date:.....

Centre name: .....

**Contact Address:** Research Centre for the Social Sciences (RCSS), 6 Innovation Close, University of York, Heslington, York, YO10 5ZF.

When completed, 1 (original) to be kept by the chief investigator (for researcher file) and 1 for participant.



## **Appendix 12: Questionnaire for HCPs working in sexual health/GUM clinics**

### **Cross-sectional survey to explore the provision of HIV prevention and testing services for older adults at GP practices and sexual health/HIV clinics**

We would like to invite you to take part in the above named research survey. It is intended that survey findings will contribute to a better understanding of how accessible and acceptable HIV services are, particularly to older adults.

Before you decide whether to take part, please take your time to read the following information.

#### What is the purpose of this survey?

The survey aims to explore the acceptability and accessibility of HIV services, focusing on older adults, in two healthcare settings: GP practices and sexual health/HIV clinics.

The purpose of this survey is to explore, within the sexual health/HIV clinic setting, healthcare professionals':

- knowledge and awareness of HIV and HIV testing guidelines;
- perceptions and awareness of HIV in older compared to younger adults;
- attitudes towards discussing HIV risk with older compared to younger adults;
- attitudes towards offering a HIV test to older compared to younger adults;
- provision of sexual health/HIV services for older compared to younger adults

#### Who is doing the survey?

This survey is part of a wider PhD project by Sadie Bell (chief Investigator), funded by the University of York. The chief investigator for this project is working in collaboration with Professor Tim Doran (Professor of Health Policy, University of York), Dr Joy Adamson (Deputy Director – York Trials Unit, University of York) and Dr Fabiola Martin (Senior Clinical Lecturer in HIV Medicine at the Centre for Immunology and Infection (CII) and Hull York Medical School, University of York).

#### Who can take part?

You can complete the survey if you are employed in England as a:

- sexual health/HIV consultant;
- sexual health/HIV registrar;
- sexual health/HIV SAS doctor;
- sexual health/HIV nurse practitioner;
- sexual health/HIV specialist nurse.

Do I have to take part?

No. Taking part in the survey is entirely voluntary. There will be no disadvantages or advantages to participating in the survey.

What will be involved if I take part in this survey?

You will be asked to fill in an online survey. The survey will take approximately 10 minutes to complete. You will only be required to complete one survey.

In completing the online survey, consent to participate is implied.

Data collected from the surveys will be analysed and the findings used as part of a PhD project.

What are the advantages/benefits and disadvantages/risks of taking part?

There are no personal advantages or disadvantages to taking part in the survey. It is anticipated that there will be wider advantages to participating in the survey as it intended that data collected will contribute to a better understanding of how accessible and acceptable HIV services are, particularly to older adults. These findings may then be used to help identify areas in which HIV services may require modification to optimise their effectiveness in providing for older adults.

Can I withdraw from the survey at any time?

When you have filled in each section of the survey, you will be asked to click a box to confirm that you consent for the questionnaire to be submitted. Once this box has been clicked, and the questionnaire submitted, it will not be possible to withdraw the information that you have provided. The data you provide will be completely anonymous and therefore cannot be traced to one individual and removed after submission.

If you decide to withdraw from the study, you can do this at any point prior to submitting the survey, simply by closing the survey page.

Will the information I give be kept confidential?

All the information you provide will remain anonymous, with a number used to label the survey data to enable analysis. No information will be provided by yourself that could lead to your identity being revealed, e.g. date of birth, name, address etc. Any direct quotations reported in the study findings, from open-questions within the survey, will remain anonymous. The local authority in which your workplace is located will not be reported in study findings, so as to avoid the identification of individual sexual health/ HIV services.

Questionnaire data will be electronically stored in a secure storage drive at the University of York. Electronic data will be password protected.

The data will only be accessed by the chief investigator and the supervisors for the PhD project (Professor Tim Doran, Dr Joy Adamson and Dr Fabiola Martin - University of York).

What will happen to the results of the study?

The results of the study will be reported for academic assessment as part of a PhD project. The results may also be presented at conferences and submitted for publication in research journals. It is intended that a link to a collective summary of survey findings will be added to the BASHH newsletter, once all data has been collected and analysed.

Who has reviewed this study?

The study has been reviewed by the Health Sciences Research Governance Committee at the University of York.

Who do I contact in the event of a complaint?

If you would like to make a complaint please contact:

\* Professor Tim Doran (PhD supervisor; Professor of Health Policy, University of York)  
Email address: tim.doran@york.ac.uk; Telephone number: 01904 321524; Work address:  
Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York,  
YO10 5DD, UK

\* Dr Joy Adamson (PhD supervisor; Deputy Director of York Trials Unit, University of York)  
Email address: joy.adamson@york.ac.uk; Telephone number: 01904 321378; Work address:  
Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York,  
YO10 5DD, UK

**If you would like more information, or have any questions or comments, about the study please contact Sadie Bell (Chief investigator)**

· Sadie Bell (PhD student – Health Sciences, University of York)

Email address: slb521@york.ac.uk; Work address: Research Centre for the Social Sciences (RCSS),  
6 Innovation Close, University of York, Heslington, York, YO10 5ZF

**Thank you for taking the time to read this study information, please click on the Next button below to start the survey**

**About you and the sexual health/HIV clinic in which you work**

In this first section of the questionnaire, we would like to ask you some questions about yourself and the sexual health/HIV clinic in which you work.

**1) Are you male or female?**

Male

Female

**2) What is your age?**

19 to 24 years old

25 to 34 years old

35 to 44 years old

45 to 54 years old

55 to 64 years old

65+ years old

**3) What is your role within the sexual health/HIV clinic?**

Specialist sexual health consultant

Specialist HIV consultant

Specialist sexual health registrar

Specialist HIV registrar

Sexual health SAS doctor

HIV SAS doctor

Sexual health nurse practitioner

HIV nurse practitioner

Sexual health specialist nurse

HIV specialist nurse

Other (please specify) .....

4) As an estimate, how many people have attended the sexual health/HIV clinic in the last year?<sup>9</sup>

5) Which local authority is the sexual health/HIV clinic a part of?<sup>10</sup>

6) The sexual health/HIV clinic is:

in a rural location

in a suburban location

in an urban location

7) Approximately how materially deprived is the area in which your clinic is located?



### HIV knowledge and awareness

In this section of the questionnaire, we would like to ask you some questions about your HIV knowledge and awareness.

8) Please rank these age groups in order of what you consider to be their HIV acquisition risk: 1 = lowest risk, 4 = highest risk.

15-24 years  25-34 years  35-49 years  50+ years

9) Please rank these age groups in order of what you consider to be their likelihood of receiving a late HIV diagnosis (CD4 count <350 cells/mm<sup>3</sup>): 1 = lowest likelihood, 4 = highest likelihood.

15-24 years  25-34 years  35-49 years  50+ years

10) Please rank these age groups in order of the number of people you think are being seen for HIV care: 1 = lowest number, 4 = highest number.

15-24 years  25-34 years  35-49 years  50+ years

11) I think that when offered, adults aged 45+ years are less likely to accept a HIV test in a sexual health/HIV clinic than adults aged 15-44 years.

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<sup>9</sup> A dropdown menu is provided which lists numerical ranges e.g. less than 2000 people, between 2000 and 4000 people etc

<sup>10</sup> A dropdown menu is provided which lists local authorities.

Yes [ ] No [ ]

Don't know [ ]

**12) I think that adults aged 45+ years are more likely to be offered a HIV test in a sexual health/HIV clinic than adults aged 15-44 years.**

Yes [ ] No [ ]

Don't know [ ]

**13) I think that HIV prevalence in my local authority:**

[ ] Is equal to or greater than 2 in 1000 population.

[ ] Is less than 2 in 1000 population.

[ ] Don't know.

**Discussing HIV risk and offering a HIV test to service users**

In this section of the questionnaire, we would like to ask you some questions about how able you feel in discussing HIV with service users and in offering HIV tests.

For this section: **Older adults will be defined as anyone aged 50+ years; Younger adults will be defined as anyone 18-49 years**

**14) How far do you agree with the following statements (please tick one response for each statement)**

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
Older adults are well informed about the risk factors for HIV							
Younger adults are well informed about the risk factors for HIV							
I think that all age groups feel able to use sexual health/HIV clinics to discuss the risk of HIV							
I think that all age groups feel able to use their GP surgery to discuss the risk of HIV							
I think that younger adults wanting to discuss HIV risk feel more able to use a sexual health/HIV clinic than older adults							
I think that younger adults wanting to discuss HIV risk feel more able to use a GP surgery than older adults							
I feel that I have had sufficient training to discuss the risk of HIV with older adults							
I feel that I have had sufficient training to discuss the risk of HIV with younger adults							

**15) How comfortable do you/would you feel....**

...in discussing risk of HIV with younger adults?



....in initiating a discussion about risk of HIV with younger adults?



....in offering a HIV test to a younger adult?



...in discussing risk of HIV with older adults?



....in initiating a discussion about risk of HIV with older adults?





...in offering a HIV test to an older adult?



**HIV services in your sexual health/HIV clinic**

In this final section of the questionnaire, we would like to ask you about your practice and HIV service provision in your sexual health/HIV clinic.

**16) I offer all attenders at the clinic a HIV test**

Yes [ ]

No [ ]

If no, what factors prompt a HIV test? .....

**17) As far as you can recall, in which age groups have you diagnosed HIV? (Please tick all boxes that are applicable)**

[ ] 15-24 year olds

[ ] 25-34 year olds

[ ] 35-49 year olds

[ ] 50+ year olds

[ ] All of the above age groups

[ ] I have not diagnosed anyone with HIV in the past year

**18) Have you experienced any barriers to offering someone a HIV test in your sexual health/HIV clinic?**

Yes [ ]

No [ ]

If yes, please state the barriers experienced.....

**19) In your opinion, are there any additional barriers to offering a HIV test to an older adult compared to a younger adult?**

Yes [ ]

No [ ]

If yes, please state these barriers.....

**20) Are you currently caring for someone with HIV in any of these age groups? (Please tick all boxes that are applicable).**

[ ] 15-24 year olds

[ ] 25-34 year olds

[ ] 35-49 year olds

[ ] 50+ year olds

[ ] Not currently caring for anyone with HIV

**21) Are there any clinic sessions provided at your workplace setting which are aimed at specific population groups? (E.g. men who have sex with men, younger adults)**

Yes [ ]

No [ ]

If yes, please specify

**22) Are there any leaflets provided at your clinic which are aimed at specific population groups? (e.g. men who have sex with men, younger adults)**

Yes [ ]

No [ ]

If yes, please state which and provide a brief description of this resource (e.g. title, authors)...

**23) Please feel free to provide any additional comments below about HIV service provision in your sexual health/HIV clinic or any issues related to HIV service provision for older people....**

### Appendix 13: Questionnaire for HCPs at GP practices

This survey is part of a PhD project, being conducted at the University of York. The survey aims to explore the acceptability and accessibility of HIV services, focusing on older adults, in two healthcare settings: GP practices and sexual health/HIV clinics. This survey is focusing on the GP practice setting.

The survey should only take approximately 10 minutes to complete. The responses provided will be completely anonymous and no information will be provided to enable the direct identification of GP practices.

It is hoped that this research will contribute to a better understanding of how accessible and acceptable HIV services are to older adults and to allow the opportunity for participants to raise any issues relating to HIV service provision for older people.

Thank you for your help in completing this survey.

#### **About you**

*In this section of the questionnaire, we would like to ask you a few questions about yourself*

##### **1) Are you male or female?**

Male

Female

##### **2) What is your age?**

19 to 24 years old

25 to 34 years old

35 to 44 years old

45 to 54 years old

55 to 64 years old

65+ years old

##### **3) What is your role within the general practice?**

General practitioner

GP registrar

Advanced nurse practitioner

Senior practice nurse/nurse practitioner

Practice nurse

Other (please specify) .....

4) As an estimate, how many people are registered at the general practice [ ]<sup>11</sup>

5) Which district is the general practice in? [ ]<sup>12</sup>

6) The general practice where I work is:

[ ] in a rural location

[ ] in a suburban location

[ ] in an urban location

7) Approximately how materially deprived is the area in which your general practice is located?



### HIV knowledge and awareness

*In this section the questionnaire, we would like to ask you some questions about your HIV knowledge and awareness*

8) Please rank these age groups in order of what you consider to be their HIV acquisition risk in the UK: 1 = lowest risk, 4 = highest risk.

15-24 years [ ] 25-34 years [ ] 35-49 years [ ] 50+ years [ ]

9) Please rank these age groups in order of what you consider to be their risk of receiving a late HIV diagnosis in the UK (CD4 count <350 cells/mm<sup>3</sup>): 1=lowest risk, 4=highest risk.

15-24 years [ ] 25-34 years [ ] 35-49 years [ ] 50+ years [ ]

10) Please rank these age groups in order of the number of people you think are diagnosed with HIV and being seen for care in the UK: 1 = lowest number, 4 = highest number.

15-24 years [ ] 25-34 years [ ] 35-49 years [ ] 50+ years [ ]

11) A HIV test taken 3 weeks after potential HIV exposure comes back negative. Do you think this means HIV infection can be ruled out?

[ ] Yes

[ ] No

[ ] Don't know

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<sup>11</sup> A dropdown menu is provided which lists numerical ranges e.g. less than 1000, between 1000 and 2000 etc.

<sup>12</sup> A dropdown menu is provided which lists districts in England.

**12) Would any of the following factors from a patient history trigger routine HIV testing?  
(please tick as many boxes as applicable)**

- Recurrent oral candidiasis
- Swollen lymph nodes
- Report of past injecting drug use
- Female who has been in sexual contact with a man who has had sex with a man
- Recent chlamydia diagnosis
- Unexplained weight loss
- Dementia
- Recurrent herpes zoster
- Bacterial pneumonia
- Symptoms similar to those of glandular fever
- Sexual contact with a person living in the UK from a country of high HIV prevalence
- Peripheral neuropathy
- Psoriasis
- Unexplained fever
- Abnormal cervical smear
- Unexplained anaemia
- Male who has had sexual contact with men
- Unexplained chronic diarrhoea
- All of the above
- None of the above

**13) I think that HIV prevalence in the district in which the general practice is located:**

- Is equal or greater than 2 in 1000 population
- Is less than 2 per 1000 population
- Don't know

**Discussing risk factors for HIV with patients and offering a HIV test**

In this section of the questionnaire, we would like to ask you some questions about how able you feel in discussing risk of HIV with your patients and offering HIV tests.

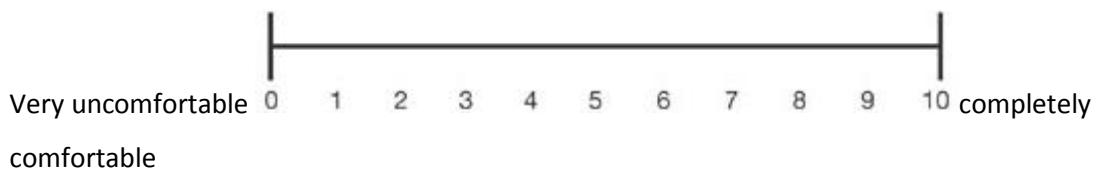
For this section: **Older adults will be defined as anyone aged 50+ years; Younger adults will be defined as anyone aged 18-49 years**

**14) How far do you agree with the following statements (please tick one response for each statement).**

	Strongly disagree	Disagree	Somewhat disagree	Neither	Somewhat agree	Agree	Strongly agree
Older adults are well informed about the risk factors for HIV							
Younger adults are well informed about the risk factors for HIV							
I think that all age groups feel able to use sexual health/HIV clinics to discuss the risk of HIV							
I think that all age groups feel able to use their GP surgery to discuss the risk of HIV							
I think that younger adults wanting to discuss HIV risk feel more able to use a sexual health/HIV clinic than older adults							
I think that younger adults wanting to discuss HIV risk feel more able to use a GP surgery than older adults							
I feel that I have had sufficient training to discuss the risk of HIV with older adults							
I feel that I have had sufficient training to discuss the risk of HIV with younger adults							

**15) How comfortable do you/would you feel....**

...in discussing risk of HIV with younger adults?



...in initiating a discussion about risk of HIV with younger adults?



...in offering a HIV test to a younger adult?



...in discussing risk of HIV with older adults?



...in initiating a discussion about risk of HIV with older adults?



...in offering a HIV test to an older adult?



**HIV services in your GP surgery**

In this final section of the questionnaire, we would like to ask about your practice and the HIV services available at your GP surgery.

**16) Have you ever tested anyone for HIV?**

Yes

No

**17) Have you ever used the UK national guidelines for HIV testing in practice? (British HIV Association (BHIVA), British Association for Sexual Health and HIV (BASHH) & British Infection Society (BIS), 2008)**

Yes

No

**18) Have you ever diagnosed anyone with HIV?**

Yes

No

**19) As far as you can recall, in which age groups have you diagnosed HIV? (Please tick all boxes that are applicable)**

15-24 year olds

25-34 year olds

35-49 year olds

50+ year olds

All of the above age groups

Unable to recall the age groups of anyone I have diagnosed with HIV

**20) As an individual, do you offer all new registrants to your GP practice a HIV test?**

Yes

No

Please explain why .....

**21) As far as you are aware, are you currently caring for someone with HIV in any of these age groups? (please tick all boxes that are applicable)**

15-24 year olds

25-34 year olds

35-49 year olds



50+ year olds

Unaware of caring for anyone with HIV

**22) Do you feel that there are any barriers to offering a HIV test in your practice setting?**

Yes

No

If yes, please state these barriers.....

**23) In your opinion, are there any additional barriers to offering a HIV test to an older adult compared to a younger adult?**

Yes

No

If yes, please state these barriers.....

**24) Please feel free to provide any additional comments below regarding HIV service provision in your GP practice or any issues related to HIV service provision for older people.....**

## Appendix 14: PIS for survey – HCPs working in general practice

THE UNIVERSITY *of York*  
The Department of Health Sciences

### **Cross-sectional survey to explore the provision of HIV services for older adults at GP practices and sexual health/HIV clinics**

We would like to invite you to take part in the above named multi-site cross-sectional survey. It is intended that survey findings will contribute to a better understanding of how accessible and acceptable HIV services are, particularly to older adults.

Before you decide whether to take part, please take your time to read the following information.

#### **What is the purpose of this survey?**

The survey aims to explore the acceptability and accessibility of HIV services, focusing on older adults, in two healthcare settings: GP practices and sexual health/HIV clinics.

The purpose of this survey is to explore, within the GP practice setting, healthcare professionals’:

- knowledge and awareness of HIV and HIV testing guidelines;
- perceptions and awareness of HIV in older compared to younger adults;
- attitudes towards discussing HIV risk with older compared to younger adults;
- attitudes towards offering a HIV test to older compared to younger adults;
- Provision of sexual health/HIV services for older compared to younger adults.

The survey has been distributed to GP practices across multiple CCG coverage areas in England

#### **Who is doing the survey?**

This survey is part of a wider PhD project by Sadie Bell (chief Investigator), funded by the University of York. The chief investigator for this project is working in collaboration with Professor Tim Doran (Professor of Health Policy, University of York), Dr Joy Adamson (Deputy Director of the York Trials Unit, University of York) and Dr Fabiola Martin (Senior Clinical

Lecturer in HIV Medicine at the Centre for Immunology and Infection (CII) and Hull York Medical School, University of York).

### **Who can take part?**

You can complete the survey if you are a:

- general practitioner;
- GP registrar
- advanced nurse practitioner;
- senior practice nurse/nurse practitioner;
- or practice nurse

### **Do I have to take part?**

No. Taking part in the survey is entirely voluntary.

### **What will be involved if I take part in this survey?**

You will be asked to fill in an online survey. The survey will take approximately 10 minutes to complete. You will only be required to complete one survey if you choose to participate.

In completing the online survey, consent to participate is implied.

Data collected from the surveys will be analysed and the findings used as part of a PhD project.

### **What are the advantages/disadvantages of taking part?**

There are no expected personal advantages or disadvantages to taking part in the survey. It is anticipated that there will be wider advantages to participating in the survey as it intended that data collected will contribute to a better understanding of how accessible and acceptable HIV services are, particularly to older adults. These findings may then be used to help optimise the effectiveness of HIV services in providing for older adults.

### **Can I withdraw from the survey at any time?**

When you have filled in each section of the survey, you will be asked to tick a box to confirm that you consent for the questionnaire to be submitted. Once this box has been clicked, and the questionnaire submitted, it will not be possible to withdraw the information that you

have provided. The data you provide will be completely anonymous and therefore cannot be traced to one individual and removed after submission.

If you decide to withdraw from the study, prior to clicking the questionnaire submit box, this can be done by closing the page.

### **Will the information I give be kept confidential?**

All of the information you provide will remain anonymous, with a number used to label data for analysis. No information will be provided by yourself that could lead to your identity being revealed, e.g. date of birth, name, address etc. Any direct quotations reported in the study findings, from open-questions within the survey, will remain anonymous.

Questionnaire data will be electronically stored in a secure storage drive at the University of York. Electronic data will be password protected.

The data will only be accessed by the chief investigator and the supervisors for the PhD project (Professor Tim Doran, Dr Joy Adamson and Dr Fabiola Martin - University of York).

### **What will happen to the results of the study?**

The results of the study will be reported for academic assessment as part of a PhD project. The results may also be presented at conferences and submitted for publication in research journals.

A collective report of findings will be distributed to general practices approached as sites to recruit participants and/or to clinical commissioning groups approached for the study.

### **Who has reviewed this study?**

The study has been granted ethical approval by the Health Sciences Research Governance Committee at the University of York and has received local Research and Development department approval for each CCG coverage area.

### **Who do I contact in the event of a complaint?**

Should you wish to raise a complaint, do not hesitate to contact:

Professor Tim Doran

**Email address:** tim.doran@york.ac.uk; **Telephone number:** 01904 321524

**Work address:** Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK

Dr Joy Adamson

**Email address:** joy.adamson@york.ac.uk; **Telephone number:** 01904 321378

**Work address:** Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK

**If you would like more information, or have any questions or comments, about the study please contact Sadie Bell (Chief investigator)**

**Email address:** slb521@york.ac.uk

**Work address:** Research Centre for the Social Sciences (RCSS), 6 Innovation Close, University of York, Heslington, York, YO10 5ZF

***Thank you for taking the time to read this information sheet***

## Appendix 15: Email invitation to participate in survey

THE UNIVERSITY *of York*

The Department of Health Sciences

### **Invitation to participate in a multi-centre cross-sectional survey exploring the provision of HIV prevention and testing services for older adults**

Dear Sir/Madam,

We are currently conducting a multi-centre cross-sectional survey at the University of York, as part of a PhD project, to explore the acceptability and accessibility of HIV services to older adults in two healthcare settings: GP practices and sexual health/HIV clinics.

Participants will be asked to complete an anonymous online survey, which will take approximately 10 minutes to finish. We have included a link to the participant information sheet and survey to this email:

Participant information sheet – [link]

Survey – [link]

We would be very grateful if you could forward this email to potential participants as an invitation to take part in the study. Eligible participants include: general practitioners; GP registrars; advanced nurse practitioners; senior practice nurses/nurse practitioners and practice nurses.

The aims of the survey are to explore healthcare professionals’:

- Knowledge and awareness of HIV and HIV testing guidelines;
- Viewpoints and knowledge surrounding HIV in older compared to younger adults;
- Attitudes towards discussing HIV risk with older compared to younger adults;
- Attitudes towards offering a HIV test to older compared to younger adults;
- Provision of sexual health/HIV services for older compared to younger adults.

The study has received approval from the Health Sciences Research Governance Committee at the University of York and has received local Research and Development department approval for each CCG coverage area.

Thank you for taking the time to read this email. Please do not hesitate to contact the chief investigator for the study (details provided below) if you have any questions, comments or concerns regarding the research study.

Kind regards,

Sadie Bell (Chief Investigator, Health Sciences PhD student at the University of York)

#### **Chief investigator contact details:**

- Sadie Bell

Email: slb521@york.ac.uk

Work address: Research Centre for the Social Sciences (RCSS), 6 Innovation Close, University of York, Heslington, York, YO10 5ZF

PhD supervisors:

- Professor Tim Doran (Professor of Health Policy, University of York)

Email address: tim.doran@york.ac.uk

Telephone number: 01904 321524

Work address: Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK

- Dr Joy Adamson (Deputy Director of York Trials Unit, University of York)

Email address: joy.adamson@york.ac.uk

Telephone number: 01904 321378

Work address: Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK

- Dr Fabiola Martin (Senior Clinical Lecturer in HIV Medicine at the Centre for Immunology and Infection (CII) and Hull York Medical School (HYMS), University of York)

Email address: fabiola.martin@hyms.ac.uk

Telephone number: 01904 328907

Work address: Centre for Immunology and Infection, University of York, Heslington, York, YO10 5DD, UK

Appendix 16: Advert sent to BASHH for August newsletter inclusion

To: BASHH Office, Chester House, 68 Chestergate, Macclesfield, Cheshire SK11 6DY

## NEWSLETTER ITEM REQUEST



Email address of sender	slb521@york.ac.uk		
Date sent	25.06.2015	Date to be completed by	Please can this be included within the next newsletter – 22nd July 2015
TITLE OF ITEM	<u>Cross-sectional survey to explore the provision of HIV prevention and testing services for older adults at GP practices and sexual health/HIV clinics</u>		
<p><b>Text /links to be placed in the Newsletter</b></p> <p>(Please provide exact text as you would like it added)</p>	<p><u>Participants required for research study to explore the acceptability and accessibility of HIV prevention and testing services at sexual health/HIV clinics to older adults</u></p> <p>You are invited to take part in a research survey, funded by the University of York, to explore the acceptability and accessibility of HIV services to older adults.</p> <p>Participants will be asked to complete an anonymous online survey, which will take approximately 10 minutes to finish.</p> <p>Eligible participants include: sexual health/HIV consultants; sexual health/HIV registrars; SAS doctors in sexual health/HIV; sexual health/HIV nurse practitioners; sexual health/HIV specialist nurses. Participants must be working in England.</p> <p>If you are interested in participating, please open the following link for further study information and to access the online questionnaire:</p> <p><a href="https://www.surveymonkey.com/s/hcpsworkinginsexualhealth">https://www.surveymonkey.com/s/hcpsworkinginsexualhealth</a></p> <p>Further contact details: Sadie Bell (Chief Investigator – Health Sciences PhD student, University of York). Email: slb521@york.ac.uk</p>		
<p><b>Special Instructions</b></p>	<p>The advertisement contains one link – to the participant information sheet and online questionnaire. It is intended that the potential participant should be able to click on the link from the newsletter and access this attachment.</p>		



## Appendix 17: Advert as included by NAM

Advert included on Facebook (29<sup>th</sup> June 2015):



**NAM - the HIV/AIDS information charity**  
June 29 at 11:36am · 🌐


Can you help? A PhD student at the University of York is asking sexual health/HIV doctors and nurses in England to complete an online survey about services for older adults:  
<https://www.surveymonkey.com/s/hcpsworkinginsexualhealth>



**Questionnaire for healthcare professionals at sexual health/HIV clinics Survey**  
Web survey powered by SurveyMonkey.com. Create your own online survey now with SurveyMonkey's...  
SURVEYMONKEY.COM

Like · Comment · Share

Advert sent as tweets on 22<sup>nd</sup> April 2015 and 29<sup>th</sup> June 2015:




**NAM Publications @aidsmap** · Apr 22  
PhD student seeks sexual health/HIV doctors and nurses to complete an online survey about services for older adults:  
[surveymonkey.com/s/hcpsworkingi...](https://www.surveymonkey.com/s/hcpsworkingi...)

RETWEETS 5 FAVORITE 1

7:22 AM - 22 Apr 2015 · Details

Reply to @aidsmap



**Amanda O'D @amandaodonovan** · Apr 22  
"@aidsmap: PhD seeks GUM/HIV doctors & nurses to complete online survey about services for older adults: [surveymonkey.com/s/hcpsworkingi...](https://www.surveymonkey.com/s/hcpsworkingi...)"  
#BHIVA2015



**NAM Publications** @aidsmap · Jun 29

PhD student seeks sexual health/HIV doctors and nurses to complete an online survey about services for older adults:  
[surveymonkey.com/s/hcpsworkingi...](http://surveymonkey.com/s/hcpsworkingi...)

RETWEETS

3



3:33 AM - 29 Jun 2015 · Details



Reply to @aidsmap

Advert as included in the aidsmap news bulletins (20<sup>th</sup> April 2015; 5<sup>th</sup> May 2015; 29<sup>th</sup> June 2015)

and HIV update (29<sup>th</sup> April 2015):

### Survey: HIV services

PhD student, Sadie Bell, is inviting health professionals working in sexual health and HIV in England to take part in a research survey, funded by the University of York.

It aims to explore the acceptability and accessibility of HIV services to older adults.

Find out more on the survey website >>

## Appendix 18: Faculty of Sexual and Reproductive Healthcare (FSRH)

### Welcome to the FSRH

FSRH is a faculty of the Royal College of Obstetricians and Gynaecologists established on the 26th March 1993 as the Faculty of Family Planning and Reproductive Health Care. In 2007 the organisation changed its name to the Faculty of Sexual and Reproductive Healthcare as this was more relevant to the current functions of the speciality.

The Faculty grants diplomas, certificates, fellowships and equivalent recognition of specialist knowledge and skills in sexual and reproductive health care.

As a body it promotes conferences and lectures, provides a clinical advisory service and publishes the Journal of Family Planning and Reproductive Health Care.

[FSRH website survey – please tell us what you think](#) 

[FSRH and BASHH Rolling Survey](#) 

CEU Request for member feedback - [Survey of UK Medical Eligibility Criteria](#) 

Registrations for Current Choices 2015 is now open [Find out more](#) 

### Latest Updates


#### July 2015

- **All Party Parliamentary Group launch key report on accountability in SRH**

[APPG Report](#)  [FSRH Statement](#) 

- [FSRH Responds to Proposed Public Health Funding Cuts](#) 

- New CEU newsletter is now available to view in the members area of the website

- Participants required for research study to explore the acceptability and accessibility of HIV prevention and testing services at sexual health/HIV clinics to older adults. Further contact details: Sadie Bell (Chief Investigator – Health Sciences PhD student, University of York) Email: [slb521@york.ac.uk](mailto:slb521@york.ac.uk)  
Please open the following link for further study information and to access the online questionnaire: <https://www.surveymonkey.com/s/hcpsworkinginsexualhealth> 

#### June 2015

- New CEU Guidance - [Fertility Awareness Methods](#) 

- The 14th Congress and 2nd Global Conference of the European Society of Contraception and Reproductive Health will be held in Basel from 4th – 7th May 2016. *There is a significant reduction for members and for booking before 15th January 2016 - €520 compared to €850. The deadline for abstract submission is 15 November 2015.* Please [click here](#) for further information

- [Latest FSRH news](#) June 2015 

- [Minutes of AGM - 2015](#) 

- Public Health England are responsible for three national STI (excluding HIV) and contraception related datasets.

## Appendix 19: National HIV Nurses Association (NHIVNA)

### Participants Required for Research Study to Explore the Acceptability and Accessibility of HIV Prevention and Testing Services at Sexual Health/HIV Clinics to Older Adults

You are invited to take part in a research survey, funded by the University of York, to explore the acceptability and accessibility of HIV services to older adults.

Participants will be asked to complete an anonymous online survey, which will take approximately 10 minutes to finish.

Eligible participants include: sexual health/HIV consultants; sexual health/HIV registrars; SAS doctors in sexual health/HIV; sexual health/HIV nurse practitioners; sexual health/HIV specialist nurses. Participants must be working in England.

If you are interested in participating, please [open the link for further study information and to access the online questionnaire](#).

For further details please [email Sadie Bell](#) (Chief Investigator – Health Sciences PhD student, University of York).

**Appendix 20: Characteristics of survey respondents not included in the analysis (only completed demographic questions)**

	<b>Number</b>	<b>% (1dp)</b>
<b>Sex</b>		
Male	3	25.0%
Female	9	75.0%
<b>Age group</b>		
25-34 years	0	0.0%
35-44 years	0	0.0%
45-54 years	7	58.3%
55-64 years	5	41.7%
65+ years	0	0.0%
<b>Professional role</b>		
Specialist sexual health	2	16.7%
Specialist HIV consultant	1	8.3%
Specialist sexual health	0	0.0%
Specialist HIV registrar	0	0.0%
Sexual health SAS doctor	2	16.7%
HIV SAS doctor	0	0.0%
Sexual health nurse practitioner	2	16.7%
HIV nurse practitioner	0	0.0%
Sexual health specialist nurse	1	8.3%
HIV specialist nurse	2	16.7%
Other	2 (Both Associate specialists)	16.7%
<b>HIV prevalence in workplace setting</b>		
< 2 per 1000	2	16.7%
2 - 4 per 1000	3	25.0%
> 4 per 1000	4	33.3%
Information not provided	3	25.0%

**Appendix 21: Number of attenders in each age group and risk group that left**

**GUM/sexual health services untested in England, 2014**

	<i>Sexual risk groups</i>			
<i>Age group</i>	<i>Heterosexual men</i>	<i>Men who have sex with men</i>	<i>Heterosexual women</i>	<i>All groups*</i>
<i>15-19</i>	4,238	410	20,078	31,042
<i>20-24</i>	9,720	1,458	29,176	48,290
<i>25-29</i>	8,341	1,589	22,312	37,536
<i>30-34</i>	6,140	1,424	14,314	25,706
<i>35-39</i>	4,036	1,059	9,193	16,968
<i>40-44</i>	3,272	965	6,772	13,107
<i>45-49</i>	2,669	841	4,902	10,034
<i>50-54</i>	2,031	591	2,842	6,394
<i>55-59</i>	1,304	341	1,590	3,729
<i>60-64</i>	834	221	953	2,267
<i>65-69</i>	655	138	575	1,511
<i>70+</i>	584	115	569	1,404
<i>All age groups</i>	44,056	9,166	114,783	200,750
<i>50+ age groups</i>	5678	1099	6529	15305

**Appendix 22: Likelihood of HIV test offer in sexual health/GUM settings by age and sexual risk group (2009-2014)**

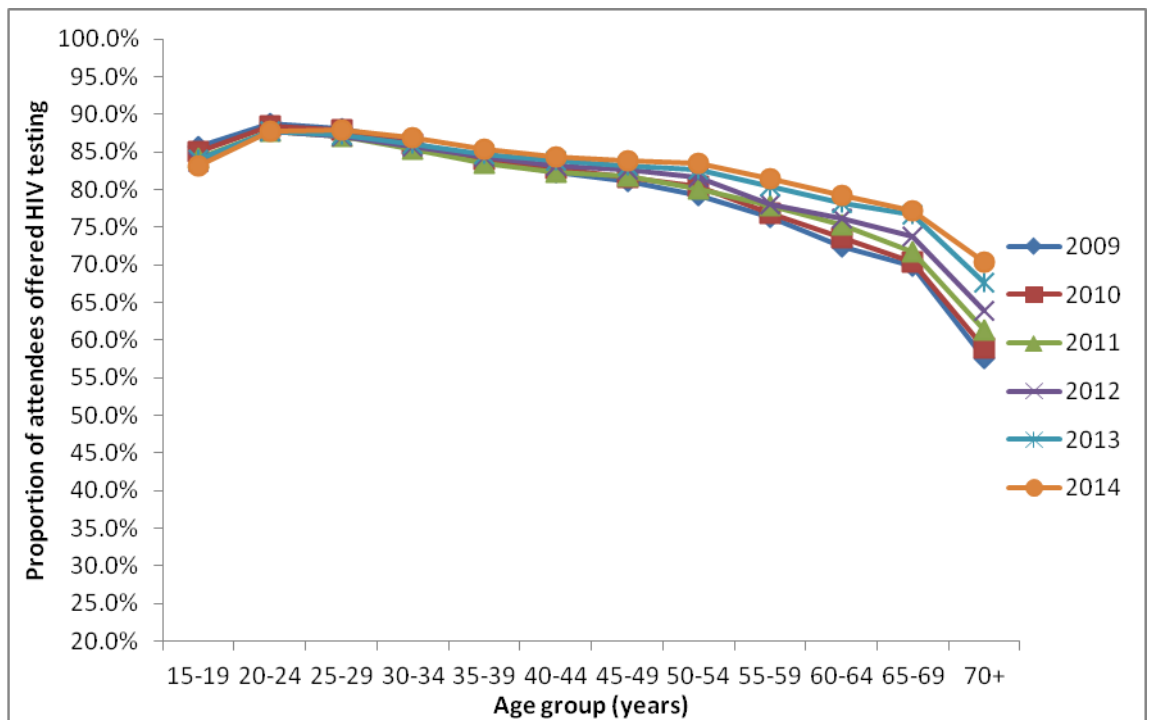


Figure 17: Proportion of attendees offered HIV testing (any sexual risk group) – England, 2009-2014

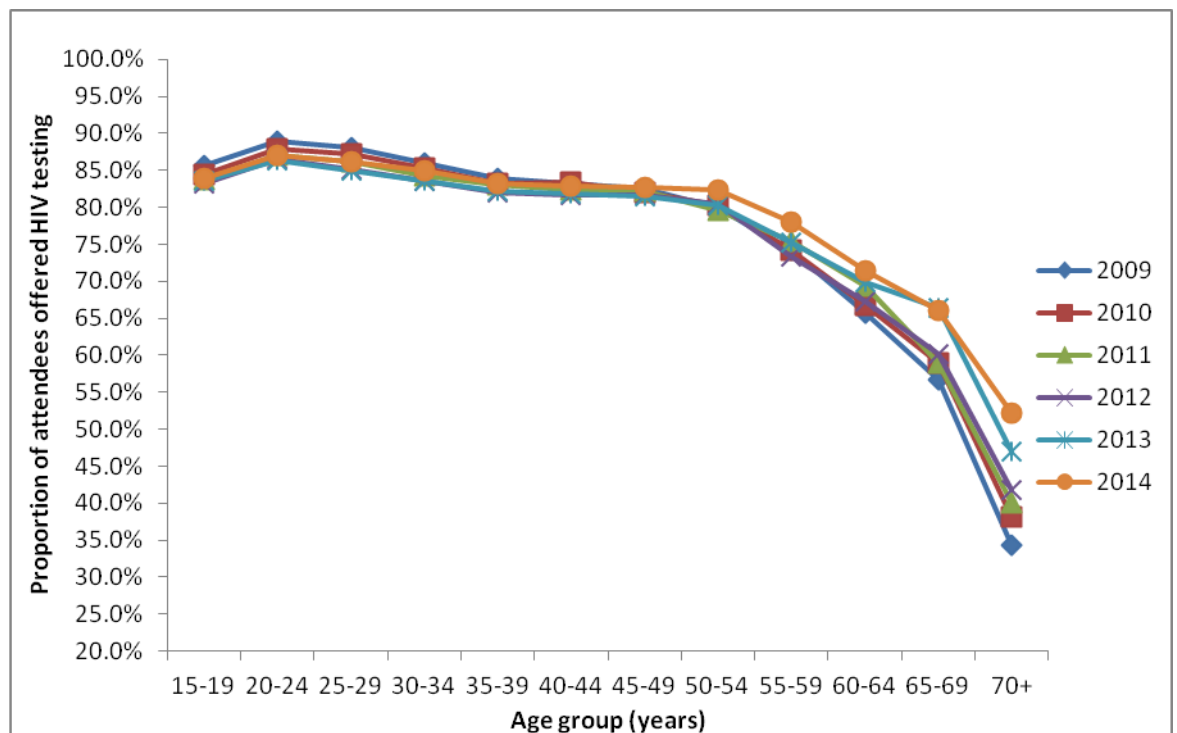


Figure 18: Proportion of attendees offered HIV testing (heterosexual females) - England, 2009-2014

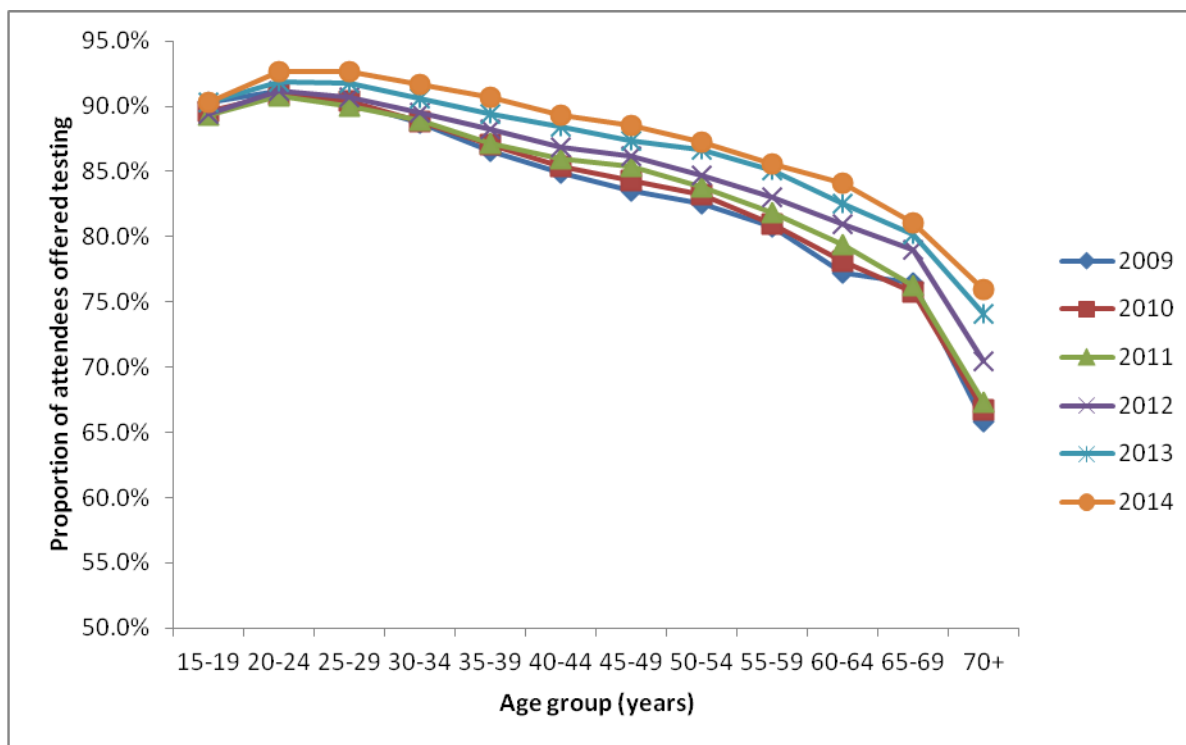


Figure 19: Proportion of attendees offered HIV testing (heterosexual males) - England, 2009-2014

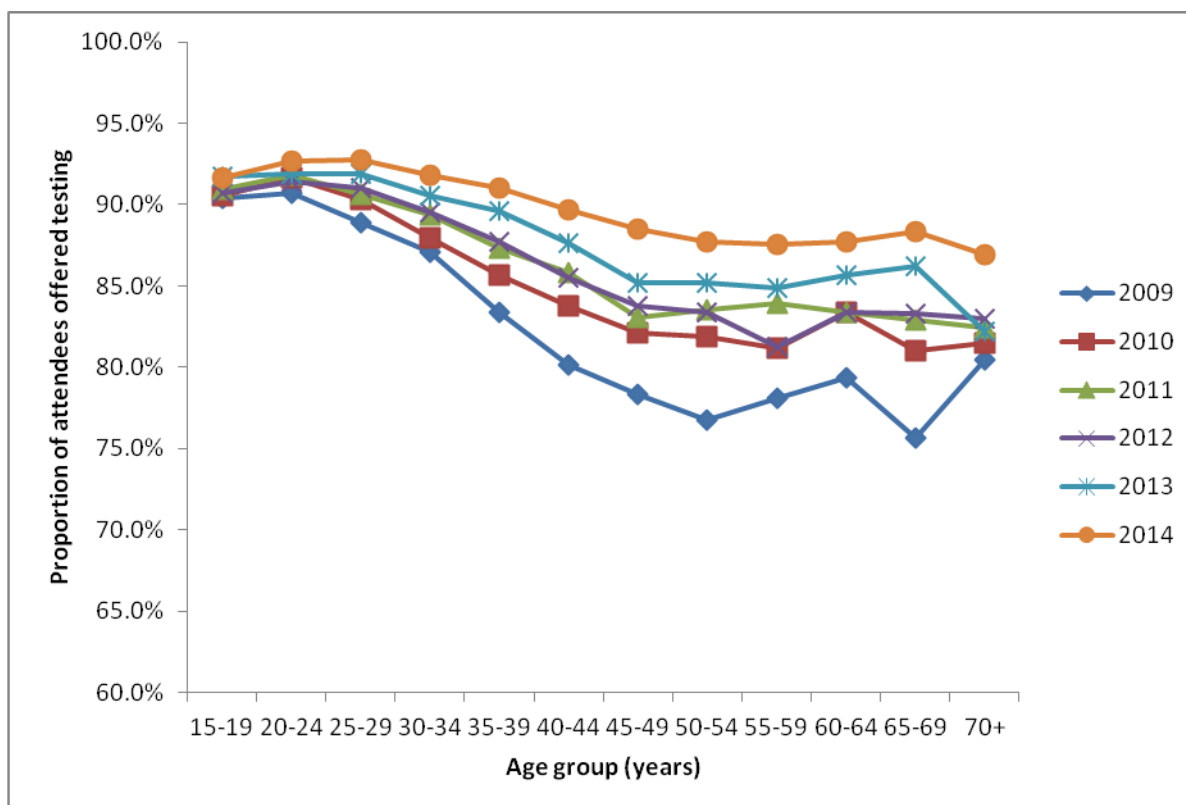


Figure 20: Proportion of attendees offered HIV testing (MSM) - England, 2009-2014

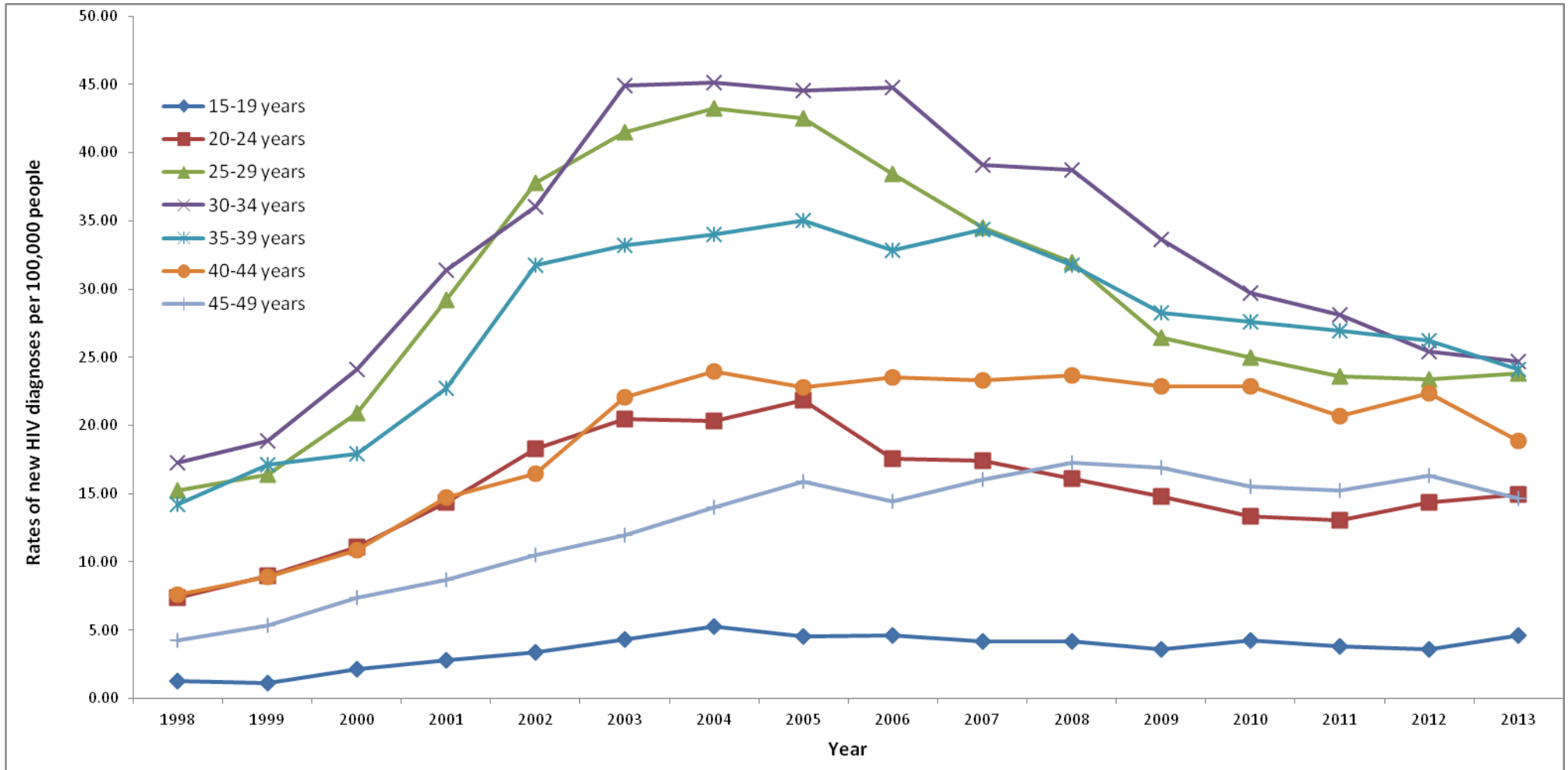


**Appendix 23: Association between age and test offer, acceptance and performance in GUM/sexual health clinics in England –by sexual risk group, 2009 to 2014 (Spearman’s Rho calculations)**

Year	Sexual risk group											
	Heterosexual males			MSM			Heterosexual females			All groups (including WSW)		
	Offered	Accepted	Performed	Offered	Accepted	Performed	Offered	Accepted	Performed	Offered	Accepted	Performed
2009	R <sub>s</sub> - 0.988 ***	R <sub>s</sub> - 0.545	R <sub>s</sub> - 0.951 ***	R <sub>s</sub> - 0.797 ***	R <sub>s</sub> - 0.600 *	R <sub>s</sub> - 0.734 **	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.611 *	R <sub>s</sub> - 0.825 ***	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.364	R <sub>s</sub> - 0.846 ***
2010	R <sub>s</sub> - 0.979 ***	R <sub>s</sub> - 0.434	R <sub>s</sub> - 0.923 ***	R <sub>s</sub> - 0.923 ***	R <sub>s</sub> - 0.601 *	R <sub>s</sub> - 0.762 **	R <sub>s</sub> - 0.951 ***	R <sub>s</sub> - 0.483	R <sub>s</sub> - 0.792 **	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.070	R <sub>s</sub> - 0.792 **
2011	R <sub>s</sub> - 0.979 ***	R <sub>s</sub> - 0.441	R <sub>s</sub> - 0.930 ***	R <sub>s</sub> - 0.944 ***	R <sub>s</sub> - 0.692 *	R <sub>s</sub> - 0.795 **	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.483	R <sub>s</sub> - 0.790 **	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.385	R <sub>s</sub> - 0.741 **
2012	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.505	R <sub>s</sub> - 0.888 **	R <sub>s</sub> - 0.932 ***	R <sub>s</sub> - 0.954 ***	R <sub>s</sub> - 0.902 ***	R <sub>s</sub> - 0.956 ***	R <sub>s</sub> - 0.536	R <sub>s</sub> - 0.797 **	R <sub>s</sub> - 0.930 ***	R <sub>s</sub> - 0.088	R <sub>s</sub> - 0.736 **
2013	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.483	R <sub>s</sub> - 0.797 **	R <sub>s</sub> - 0.863 ***	R <sub>s</sub> - 0.716 **	R <sub>s</sub> - 0.858 ***	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.406	R <sub>s</sub> - 0.734 **	R <sub>s</sub> - 0.930 ***	R <sub>s</sub> - 0.141	R <sub>s</sub> - 0.591 *
2014	R <sub>s</sub> - 0.923 ***	R <sub>s</sub> - 0.438	R <sub>s</sub> - 0.783 **	R <sub>s</sub> - 0.897 ***	R <sub>s</sub> - 0.697 *	R <sub>s</sub> - 0.881 ***	R <sub>s</sub> - 0.958 ***	R <sub>s</sub> - 0.238	R <sub>s</sub> - 0.699	R <sub>s</sub> - 0.797 **	R <sub>s</sub> - 0.547	R <sub>s</sub> - 0.559

\* p <0.05; \*\* p <0.01; \*\*\* p <0.001

**Appendix 24: Rates of new HIV diagnoses in younger age groups (15-49 years), from 1998 to 2013 - England**



*Figure 21: Rates of new HIV diagnoses in younger age groups (15-49 years), from 1998 to 2013 - England*

Appendix 25: Proportion of new HIV diagnoses in heterosexual women by age group, 1998 to 2013 (England)

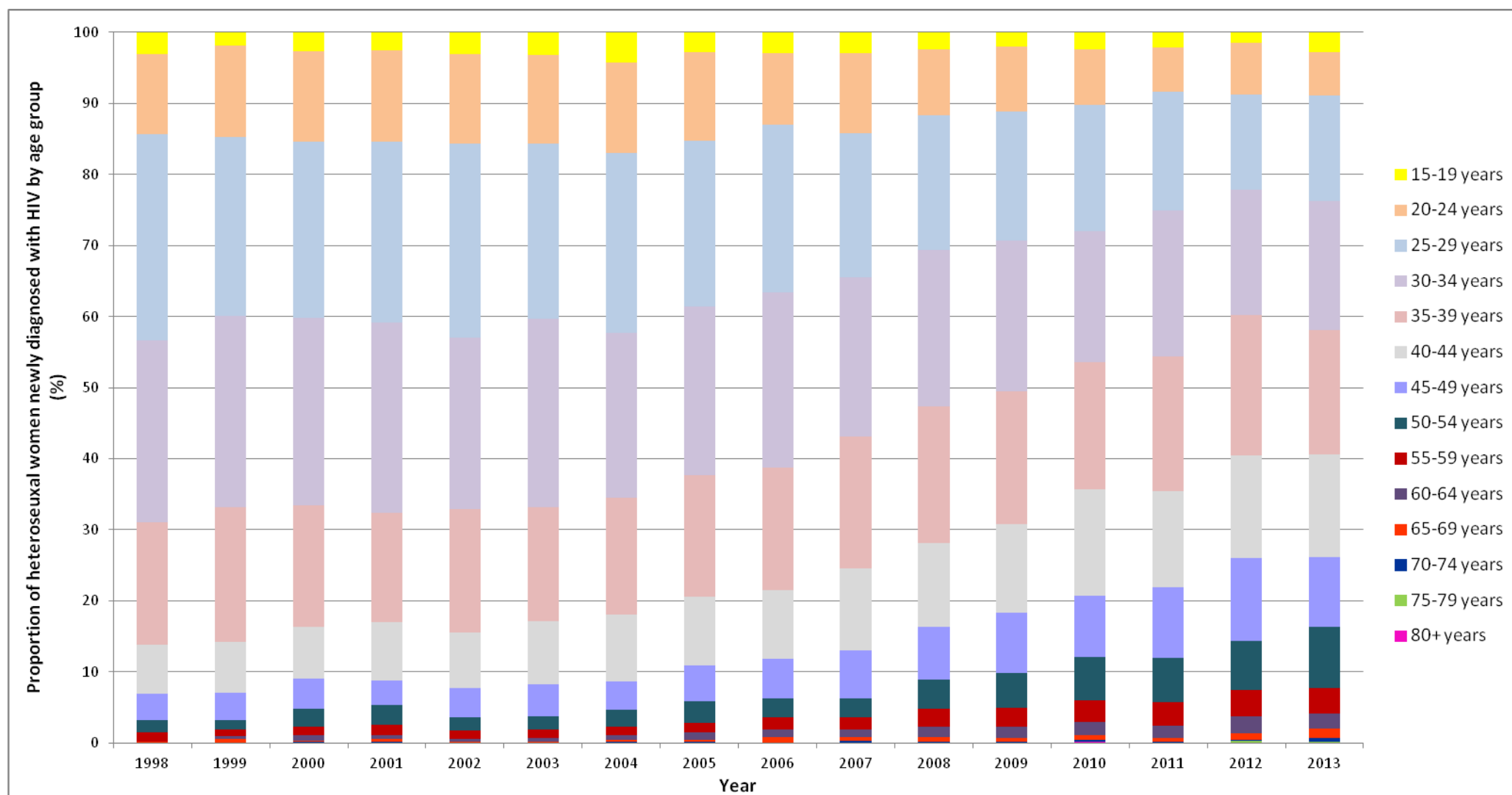


Figure 22: Proportion of new HIV diagnoses in heterosexual women by age group, from 1998 to 2013- England

Appendix 26: Proportion of new HIV diagnoses in heterosexual men by age group, 1998 to 2013 (England)

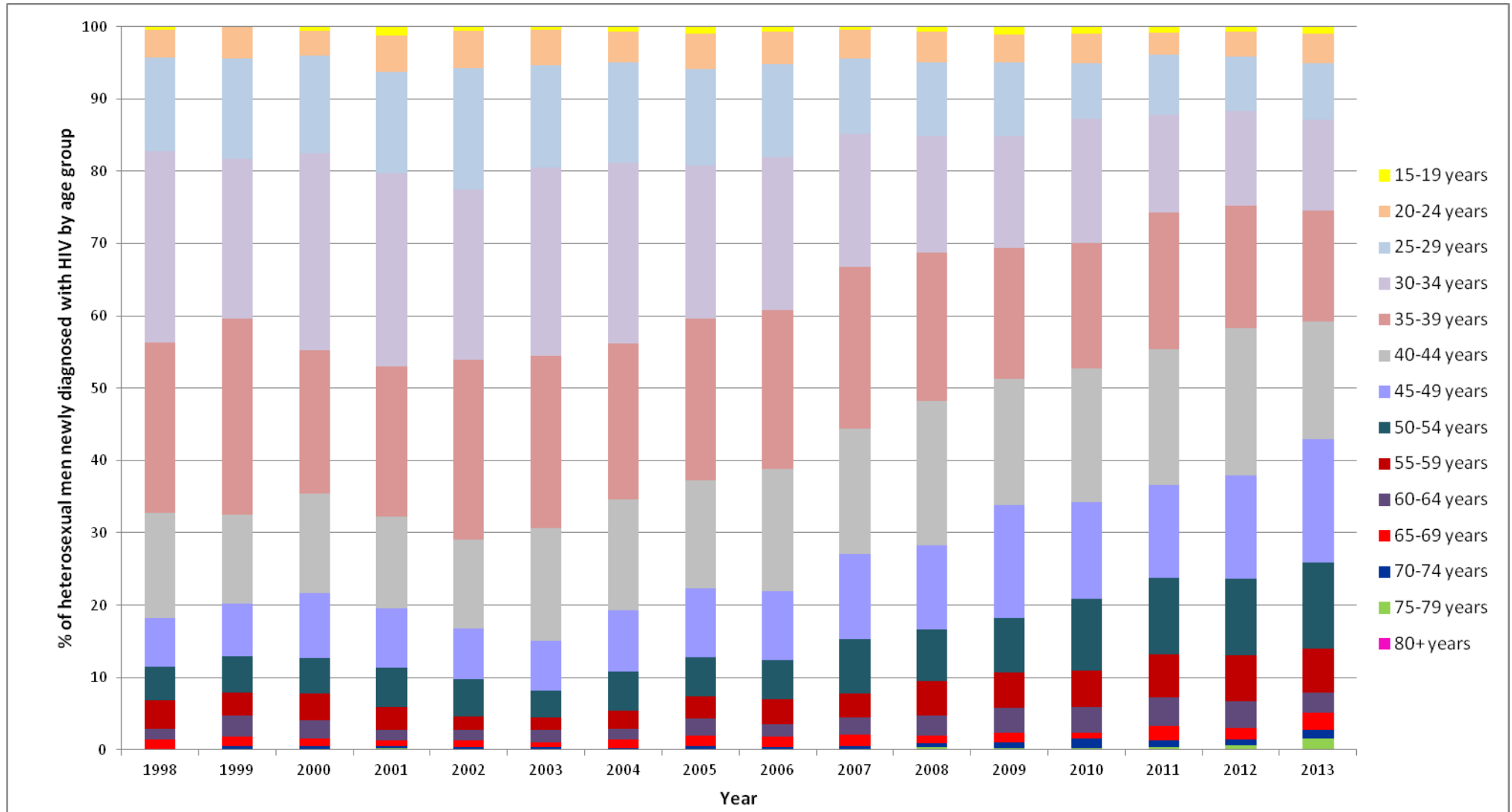


Figure 23: Proportion of new HIV diagnoses in heterosexual men by age group, from 1998 to 2013- England

**Appendix 27: Proportion of new HIV diagnoses in MSM by age group, 1998 to 2013 (England)**

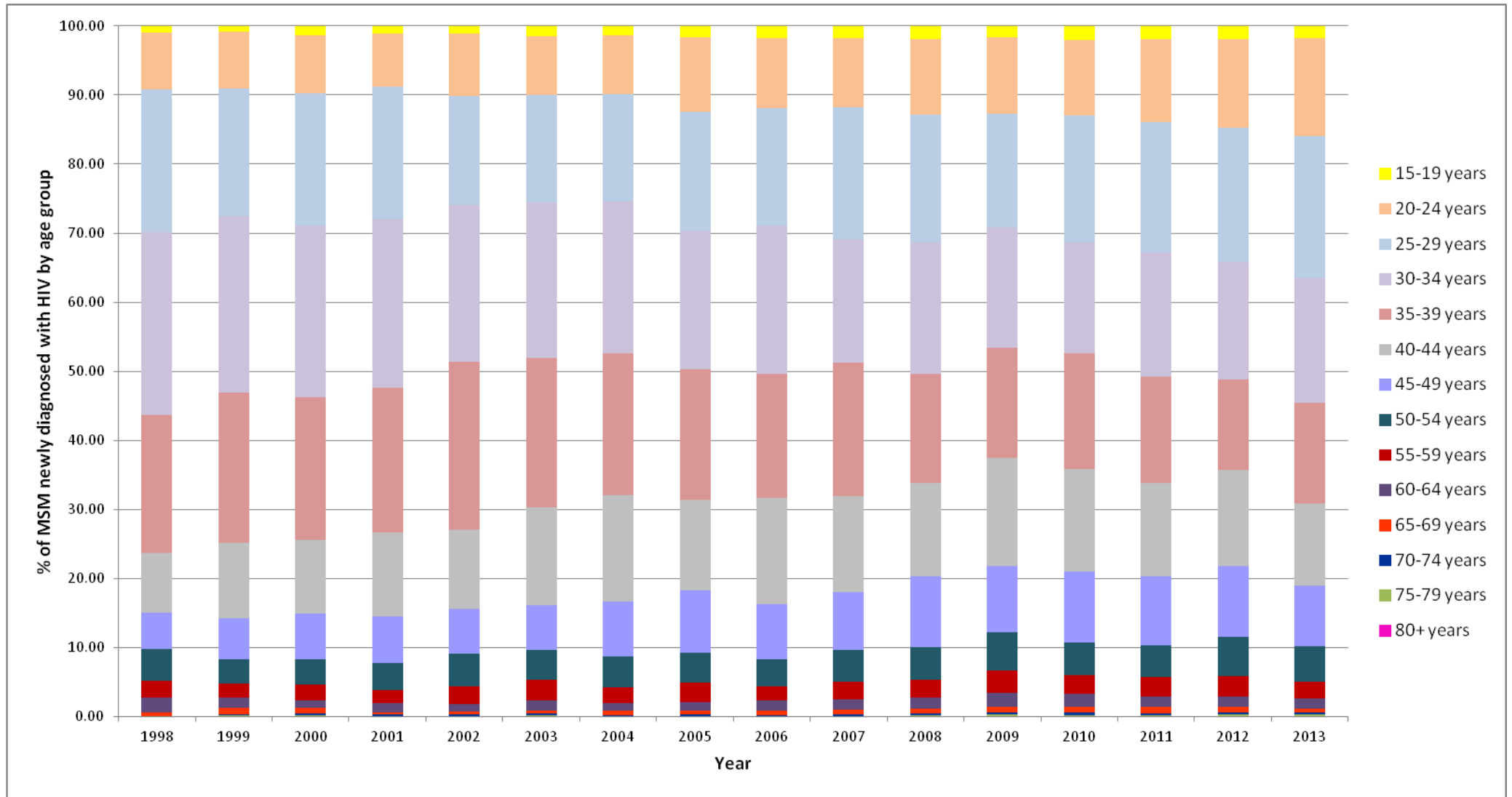


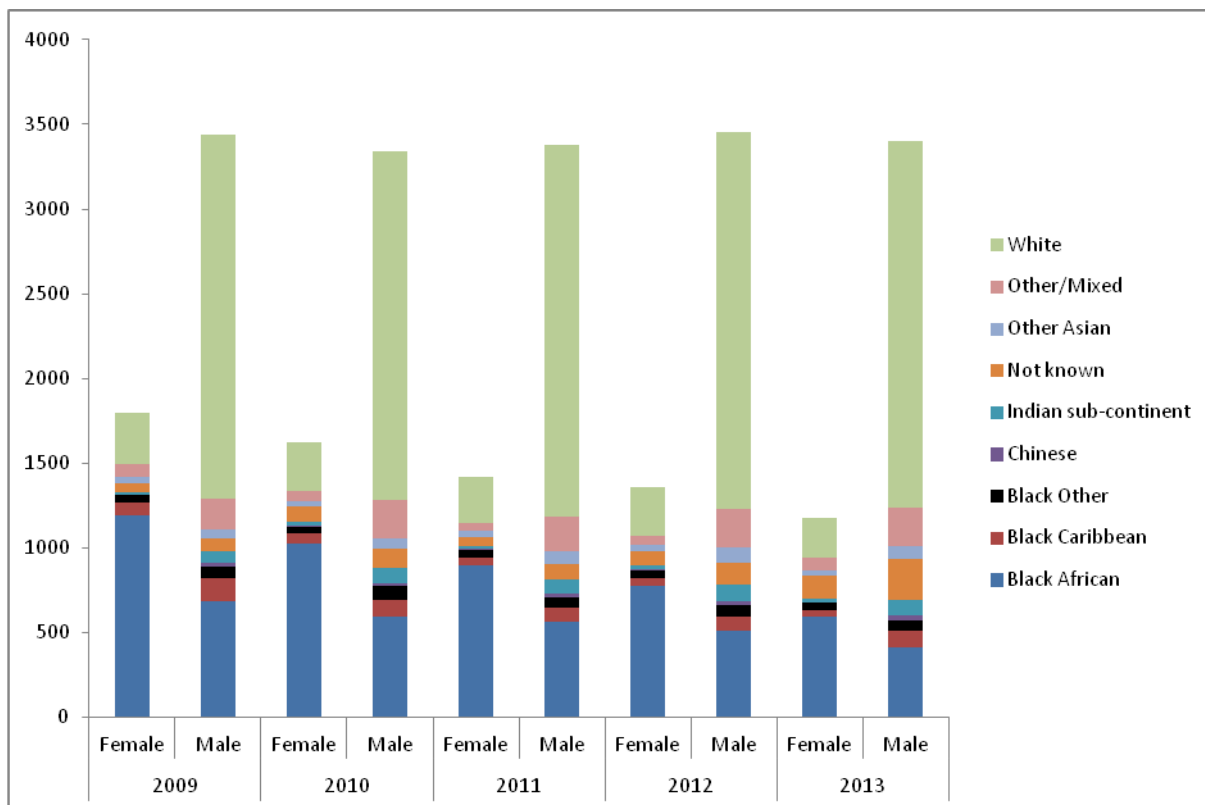
Figure 24: Proportion of new HIV diagnoses in MSM by age group, from 1998 to 2013 - England

## Appendix 28: Overview of changes to new HIV diagnoses by age group and sexual risk group from 1998 to 2013

Heterosexual males					Heterosexual females					MSM				
Age group (years)	Proportion of new HIV diagnoses in this age group in 1998	Proportion of new HIV diagnoses attributed in this age group in 2013	% change – between 1998 proportion and 2013 proportion for this age group	Year in which this age group had its highest proportion of HIV diagnoses	Age group (years)	Proportion of new HIV diagnoses in this age group in 1998	Proportion of new HIV diagnoses in this age group in 2013	% change – between 1998 proportion and 2013 proportion for this age group	Year of peak proportion of HIV diagnoses attributed to this age group	Age group (years)	Proportion of new HIV diagnoses in this age group in 1998	Proportion of new HIV diagnoses in this age group in 2013	% change – between 1998 proportion and 2013 proportion for this age group	Year of peak proportion of HIV diagnoses attributed to this age group
80+	0.00%	0.11%	+0.11	2010 and 2011 (0.18%)	80+	0.00%	0.00%	0.00	2010 (0.10%)	80+	0.00%	0.07%	+0.07	2008 (0.08%)
75-79	0.00%	1.49%	+1.49	2013 (1.49%)	75-79	0.00%	0.18%	+0.18	2012 (0.28%)	75-79	0.00%	0.19%	+0.19	2012 (0.25%)
70-74	0.00%	1.14%	+1.14	2010 (1.25%)	70-74	0.00%	0.54%	+0.54	2013 (0.54%)	70-74	0.08%	0.26%	+0.18	2010 (0.40%)
65-69	1.42%	2.40%	+0.98	2013 (2.40%)	65-69	0.16%	1.27%	+1.11	2013 (1.27%)	65-69	0.46%	0.56%	+0.10	1999 and 2011 (0.90%)
60-64	1.42%	2.75%	+1.33	2011 (3.97%)	60-64	0.00%	2.08%	+2.08	2012 (2.33%)	60-64	2.15%	1.57%	-0.58	1998 (2.15%)
55-59	4.05%	6.06%	+2.01	2012 (6.39%)	55-59	1.29%	3.62%	+2.33	2012 (3.67%)	55-59	2.46%	2.35%	-0.11	2009 (3.30%)
50-54	4.66%	11.90%	+7.24	2013 (11.90%)	50-54	1.77%	8.69%	+6.92	2013 (8.69%)	50-54	4.61%	5.51%	+0.9	2012 (5.69%)
45-49	6.68%	17.05%	+10.37	2013 (17.05%)	45-49	3.70%	9.77%	+6.07	2012 (11.65%)	45-49	5.30%	8.81%	+3.51	2010 (10.20%)
40-44	14.57%	16.36%	+1.79	2012 (20.42%)	40-44	6.92%	14.39%	+7.47	2010 (14.97%)	40-44	8.61%	11.83%	+3.22	2009 (15.68%)
35-39	23.48%	15.33%	-8.15	2009 (27.12%)	35-39	17.23%	17.56%	+0.33	2012 (19.70%)	35-39	19.98%	14.59%	-5.39	2002 (24.39%)
30-34	26.52%	12.59%	-13.93	2000 (27.26%)	30-34	25.60%	18.10%	-7.50	1999 (26.90%)	30-34	26.44%	18.07%	-8.37	1998 (26.44%)
25-29	12.96%	7.78%	-5.18	2002 (16.83%)	25-29	28.99%	14.94%	-14.05	1998 (28.99%)	25-29	20.68%	20.53%	-0.15%	1998 (20.68%)
20-24	3.85%	4.12%	+0.27	2001 (5.00%)	20-24	11.27%	6.15%	-5.12	2001 (12.91%)	20-24	8.22%	14.30%	+6.08	2013 (14.30%)
15-19	0.40%	0.92%	+0.52	2011 (1.23%)	15-19	3.06%	2.81%	-0.25	2004 (4.21%)	15-19	1.00%	1.72%	+0.72	2010 (2.06%)

Figure 25: Proportion of new HIV diagnoses by age group in heterosexual males, heterosexual females, and MSM - a comparison between 1998 and 2013 values for England

**Appendix 29: New HIV diagnoses in adults aged 15-49 years by gender and ethnicity, England (2009 to 2013)**



*Figure 26: New HIV diagnoses in adults aged 15-49 years by gender and ethnicity, England (2009 to 2013)*





## Abbreviations

AIDS	Acquired immune deficiency syndrome
AHPN	African HIV Policy Network
APPG	All-Party Parliamentary Group on HIV/AIDS
ART	Antiretroviral therapy
BASHH	British Association for Sexual Health & HIV
BHIVA	British HIV Association
BIS	British Infection Society
CDC	Centers for Disease Control and Prevention
DfE	Department for Education
DH	Department of Health
FPA	Family Planning Association
GMC	General Medical Council
GMFA	Gay Men Fighting AIDS
GU	Genitourinary
GUM	Genitourinary medicine
HAART	Highly active antiretroviral therapy
HCP	Healthcare professional
HPA	Health Protection Agency
HPE	HIV Prevention England
HIV	Human immunodeficiency virus
IDU(s)	Injection drug use(rs)
LGBT	Lesbian, Gay, Bisexual, Transgender
MSM	Men who have sex with men
NAO	National Audit Office
NAT	National AIDS Trust
NATSAL	National Survey of Sexual Attitudes and Lifestyles
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIH	National Institute of Allergy and Infectious Diseases
ONS	Office for National Statistics
PIS	Participant information sheet
PHE	Public Health England
PLWHA	People living with HIV/AIDS
PrEP	Pre-exposure prophylaxis
PEP	Post-exposure prophylaxis
RCGP	Royal College of General Practitioners
STI	Sexually transmitted infection
TasP	Treatment as prevention
THT	Terrence Higgins Trust
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation
WSW	Women who have sex with women



## References

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