Late diagnosis of HIV in the United Kingdom:
An evidence review

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- Late diagnosis of HIV remains an important public health issue in the UK, with 40% of newly diagnosed individuals in 2014 diagnosed late (PHE, 2013)

- Reducing the number of people presenting to care at a late stage of HIV infection is a key public health priority in the United Kingdom. It is one of only three sexual health indicators included on the Public Health Outcomes Framework for England (DH, 2012) and a key ambition of the Framework for Sexual Health Improvement in England (DH, 2013)

- Late diagnosis of HIV is defined as having a CD4 count of less than 350 cells per mm^3 within 3 months of diagnosis (Antori et al, 2011) and is associated with significantly heightened levels of HIV related morbidity and mortality (Morcroft et al, 2014), increased risk of onward HIV transmission (Halve it, 2011) and higher healthcare costs (HPA, 2011)

- Evidence suggests that certain groups are disproportionally affected by late diagnosis, namely older adults, heterosexuals and non-national populations, in particular black Africans (PHE, 2013)

- Evidence suggest that the majority of individuals have lowered perceptions of their risk of acquiring HIV and for those who have recent high risk behaviour, fear of disease is an important barrier to testing. Amongst black African populations, there are additional barriers to testing including a heightened fear of disclosure due to stigma

- Amongst healthcare professionals, missed diagnostic opportunities are well documented and are linked to clinician's own perceptions of risk and a lack of knowledge of HIV and testing procedures

- Interventions to expand testing beyond routine settings have been shown as both acceptable and feasible to patients and staff and, cost effective (HPA, 2011). Pilots to expand testing in hospital and primary care settings have found varying levels of testing activity among clinicians suggesting that support and training for healthcare staff is necessary and effective in increasing testing (Rayment et al, 2011)

- Community outreach testing has been found particularly effective among MSM and black African populations. Research suggests that effective interventions must be: grounded in community mobilisation and outreach settings; normalise both testing and treatment for HIV and, address HIV related stigma (Burns et al, 2007; Fakoya et al, 2008). Emerging evidence also suggests that new home sampling and home testing methods will be particularly effective in accessing harder to reach groups particularly among MSM (HPA, 2011 and Brady et al, 2014)

CONTENTS

FIGURES

AKNOWLEDGEMENTS

INTRODUCTION

Reducing the number of people presenting to care with a late stage of HIV infection is a key public health priority in the United Kingdom. It is one of only three sexual health indicators included in the Public Health Outcomes Framework for England 2013 – 2016 (DH, 2012). Furthermore, one of the ambitions of the Framework for Sexual Health Improvement in England published by the Department of Health in 2013 is that *"Individuals and communities have information and support to access testing and earlier diagnosis and prevent the transmission of HIV and STIs"* (DH, 2013, p19).

AIM AND OBJECTIVES

Aim: Examine the causes of continuing late HIV diagnosis in the United Kingdom and review interventions to reduce the number of individuals presenting late.

Objectives:

- Describe current trends of late diagnosis in the United Kingdom
- Identify current national policy and targets specifically aimed at reducing late diagnosis of HIV
- Identify factors which contribute to a late diagnosis of HIV including clinical, behavioural and cultural factors and barriers to accessing testing and services
- Review interventions which have attempted to reduce late HIV diagnosis including increasing access to testing

METHODLOGY

A comprehensive literature review was completed using a subject specific search engine (PubMed) to identify relevant published literature. Key words were identified (key search terms included HIV, LATE DIAGNOS*, BARRIERS, INTERVENTIONS, TESTING) to inform the search and an exclusion and inclusion criteria established. The literature search was restricted to papers published in the United Kingdom and similar countries including Western Europe and the United States and published after 2000. An intital search produced 4,734 items which was narrowed using additional search terms. In total, 139 papers were saved for possible inclusion.

A grey literature search was also completed to review unpublished research, national guidance and policy and local policy initiatives. This included government websites such as the Department of Health, the National Institute of Clinical and Healthcare Excellence (NICE) and Public Health England, professional bodies including the World Health Organisation and the British HIV Association and non-governmental organisations such as the National AIDS Trust and Terrence Higgins Trust. Reference lists from relevant publications were cross referenced to identify other relevant literature. Secondary data published by Public Health England was used to identify current trends in relation to late HIV diagnosis in the United Kingdom.

WHAT IS LATE DIAGNOSIS?

The European Late Presenter Consensus Working Group worked together to define late diagnosis of HIV in 2009 (Anitori et al 2011). The UK accepted definition of a late diagnosis of HIV is having a CD4 count of less than 350 cells /mm^3 within 3 months of diagnosis. Individuals with a CD4 count of less than 200 cells/mm^3 within three months of diagnosis are described as "very late" or severely immunocompromised (Anitori et al 2011). A late diagnosis of HIV severely reduces the health outcomes of an individual; those diagnosed late are significantly more likely to experience increased morbidity and to progress on to AIDS (HPA, 2012, Mocroft et al, 2013). In addition, people diagnosed late have a ten-fold increased risk of death within 1 year of HIV diagnosis compared to those diagnosed promptly (3.8% vs. 0.35%) (HPA, 2012). Those diagnosed late will also have been unaware of their HIV diagnosis for a

significant length of time which increases the risk of onwards transmission to their sexual partners (Halve it, 2011). Those diagnosed late are also likely to incur greater healthcare costs (HPA, 2011).

THE SITUATION IN THE UK

In total 85,489 people were living with HIV in the UK and accessed treatment and care in 2014 of whom 6,151 were newly diagnosed (PHE, 2015). In 2013, Public Health England estimated that around one in four of those living with HIV are unaware of their HIV infection (an estimated 26,100 people; PHE, 2014) and in 2014, 40% of new cases were diagnosed late (PHE, 2015).

Between 2010 and 2012, 6,489 individuals in England were diagnosed with HIV at a late stage of infection representing 48% of new infections (PHOF, 2013). In 2014 alone, 1,975 individuals in the United Kingdom were diagnosed late (40% of new diagnoses; (PHE, 2015). In total 81% of the 2,000 AIDS-related deaths over the past ten years have been attributed to late diagnosis (PHE, 2013) and in 2014 there were 613 deaths among people living with HIV, most of whom were diagnosed late (PHE, 2015).

Data from Public Health England (2014) indicates that late diagnosis is associated with certain demographic characteristics. Nationally, late diagnosis was lowest among men who have sex with men (MSM) where 31% of individuals were diagnosed late, and highest among heterosexual men (62% see figure 1 below). Older adults also have higher levels of late diagnosis, with 58% of those aged 50 years and over diagnosed late in 2013 compared with 39% of under 50s (PHE, 2014). Similarly, the levels of late diagnosis among those of black African ethnicity are also higher with 66% of black African men and 57% of black African women being diagnosed late (compared with 61% of white heterosexual men and 42% of white heterosexual women). Late HIV diagnosis also varies geographically, ranging from 52% of new diagnoses in the Midlands and the East of England to 35% of new diagnoses in London (PHE, 2013). However, rates of late HIV diagnosis in the UK are declining, with 58% of new HIV cases being diagnosed late in 2003 compared to the current rate of 40%. This decline was steepest among MSM, where the rate of late diagnosis has fallen from 42% in 2003 to 34% in 2012 (Figure 2, PHE, 2013).

FIGURE 1: LATE HIV DIAGNOSIS BY EXPOSURE GROUP, UNITED KINGDOM 2012
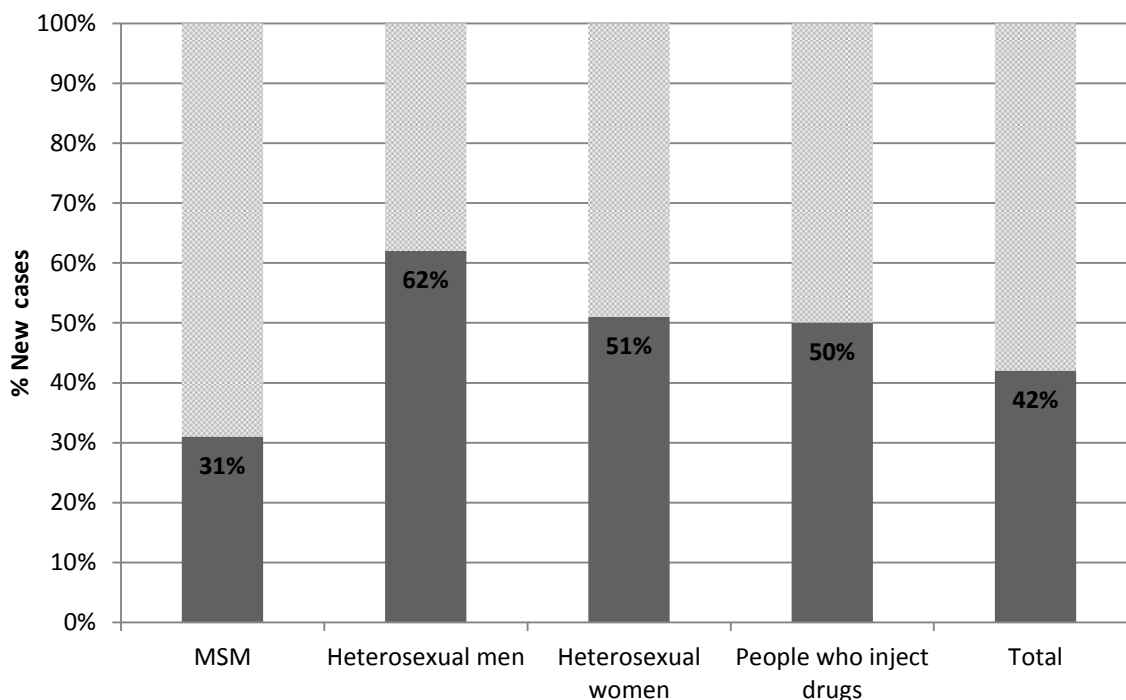
Data source: PHE, 2014

FIGURE 2: LATE DIAGNOSIS BY EXPOSURE GROUP, UNITED KINGDOM 2003-2012
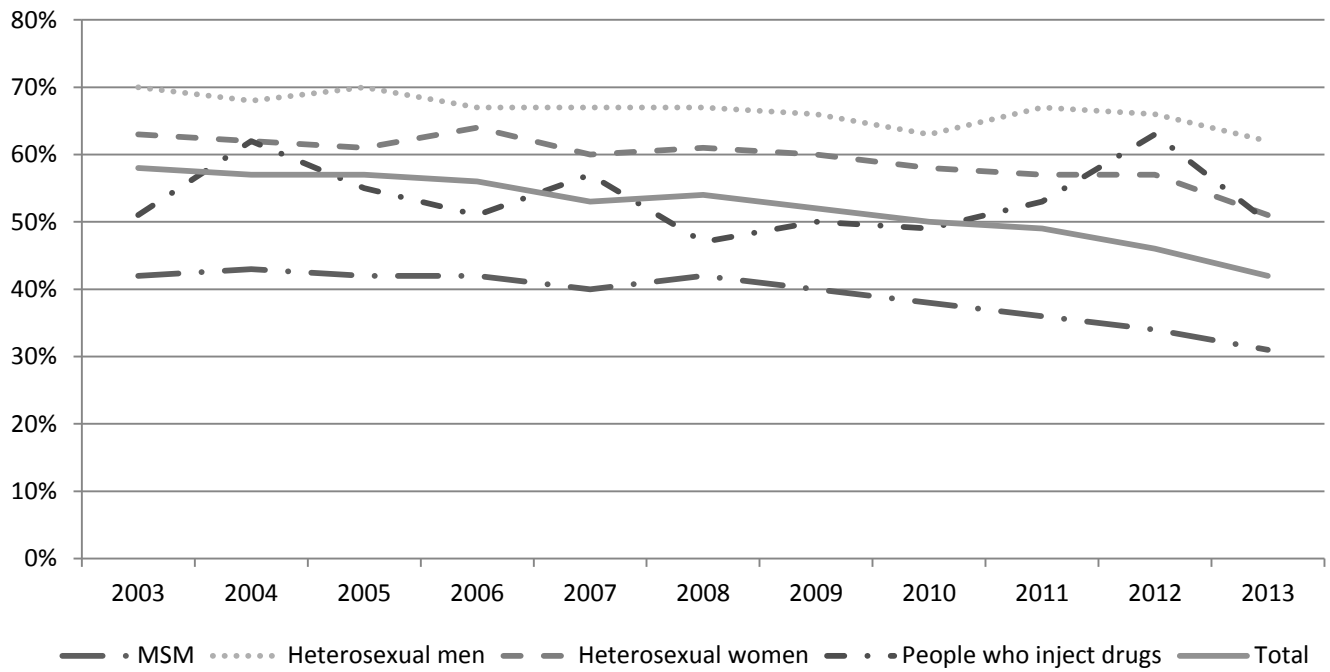
Data source: PHE, 2014

Reducing the number of late HIV diagnoses is recognised as a key national public health priority. The UK Government has made a national commitment to reducing the number of individuals diagnosed late with HIV, and this commitment forms part of the key policy documents summarised below:

BOX 1: LATE HIV DIAGNOSIS IN NATIONAL POLICY

> **Healthy Lives, Healthy People. Our Strategy for Public Health in England (2010)**
> *Department of Health (White Paper)*
- First Public Health White Paper published by the coalition government which outlined the government's commitment to "protecting the population from serious health threats, helping people to live longer, healthier and more fulfilling lives, and improving the health of the poorest, fastest" (p.4)
- In the paper's review of national Public Health priorities it recognised *"1 in 4 people with HIV are unaware that they are infected and around 1 in 2 new cases are diagnosed too late"* (p.20) as a key barrier to living well
- The White Paper also emphasised the importance of moving away from focusing solely on high risk groups and instead emphasised the importance of population level public health initiatives

> **Improving Outcomes and Supporting Transparency: A Public Health Outcomes Framework (PHOF) for England 2013-16 (2013)**
> *Department of Health*
- PHOF sets out the government's overarching vision for public health and identifies numerous opportunities to improve health across the life course.
- It identifies two high level outcomes: increasing healthy life expectancy and reducing the differences in life expectancy and healthy life expectancy between communities. This is addressed across four domains: improving the wider determinants of health; health protection; health improvement and, healthcare, public health and preventing premature mortality.
- People presenting with HIV at a late stage of infection is one of only three sexual health related indicators included on the PHOF. Specifically the indicator measures the percentage of adults (aged 15 years and over) who have a CD4 count of <350 cells per mm^3 within 91 days of diagnosis.

> **A Framework for Sexual Health Improvement in England (2013)**
> *Department of Health*
- The government's framework to improve the sexual health and wellbeing of the whole population by: reducing inequalities and improving sexual health outcomes; building an open and honest culture where everyone is able to make informed decisions about relationships and sex; and, recognise that sexual ill health can affect all parts of society – often when it is least expected.
- An ambition of The Framework is to reduce onward transmission and avoidable deaths due to HIV through: increasing understanding of HIV transmission risks; prevention and where to access testing and, ensure prompt referral into care.

In addition to this policy level commitment, several key guidance documents have been produced to address late HIV diagnosis through increasing testing and prevention work across the population and amongst high risk groups.

BOX 2: NATIONAL GUIDANCE ON REDUCING LATE HIV DIAGNOSIS

> **UK National Guidelines for HIV testing (2008)**
> *British HIV Association*
- BHIVA testing guidelines state that it should be within the clinical competence of any doctor, midwife, nurse or trained healthcare professional to obtain consent and conduct a HIV test.
- The guidelines recommend that universal HIV testing should be offered:
  A) In GUM, sexual health, antenatal, termination, drug dependency services and specialist services for Tuberculosis, Lymphoma and Hepatitis B and C.
  B) All men and women registering at General Practice and all general medical admissions in Local Authorities where diagnosed HIV prevalence exceeds 2 per 1,000 population
  C) All patients: with a HIV indicator condition, diagnosed with a sexually transmitted infection, whose partners are HIV positive, who disclose sexual contact with another man, who are female sexual contacts of MSM, who report a history of injecting drug use, who are from a high prevalence country or who have sexual contact with someone from a high prevalence country.

> **Increasing the uptake of HIV testing among black Africans in England (2011)**
> *National Institute for Clinical and Health Care Excellence*
- The aim of the guidance is to increase HIV testing, reduce the levels of undiagnosed HIV infection and reduce transmission among black African populations.
- The guidance is aimed at all commissioners, practitioners and managers in Local Authorities, public and private sector, community and voluntary organisations who have a responsibility for increasing HIV testing among black African populations.
- The guidance includes recommendations on: community engagement; planning services, assessing local need and developing strategies; promoting testing and reducing barriers to testing; recommending and offering a test and, HIV referral pathways.

> **Increasing the uptake of HIV testing among men who have sex with men (2011)**
> *National Institute for Clinical and Health Care Excellence*
- The aim of the guidance is to increase HIV testing among MSM, reduce levels of undiagnosed infection and reduce HIV transmission
- The guidance is aimed at all those with a responsibility for HIV testing among MSM including Local Authorities, the public sector and private, community and voluntary agencies.
- The guidelines include key recommendations on: planning services through an assessment of local need and strategy development; promoting HIV testing including outreach and rapid Point of Care Testing; recommending and offering testing in primary care, secondary care and sexual health; repeat testing and referral pathways for HIV.

WHY DO PEOPLE DIAGNOSE LATE FOR HIV?

Reasons for late HIV diagnosis have been linked to a number of demographic characteristics, and associated with a number of barriers to testing. Barriers to testing identified in the literature can be attributed to two overarching factors; individuals not considering themselves to be at risk of acquiring HIV and healthcare providers failing to offer a HIV test (Champenois et al, 2013).

DEMOGRAPHIC CHARACTERISTICS OF THOSE WHO ARE DIAGNOSED LATE

Numerous social and demographic factors have been associated with being diagnosed late. The majority of studies acknowledge the link between late diagnosis and age, particularly being aged 50 years or older (Smith et al, 2010; Camoni et al, 2013, Iwuji et al, 2013). Research from the UK suggests evidence of low contraception use and high risk behaviour amongst older adults and this age group are often reluctant to discuss sexual problems with their doctor and neglected in terms of the information made available in sexual health clinics (Smith et al, 2010). Being heterosexual (Manavi et al,2004; Hoyos et al 2013; Camoni et al, 2013; Moorcroft et al, 2013; Iwuji et al, 2013), being non-national (Alder et al, 2011 cites Boyd et al, 2005, Sabin et al, 2004, Sullivan et al, 2005) and being an injecting drug user (Camoni et al, 2013; Shorsbee et al, 2014) are also frequently associated with late diagnosis. Evidence on the relationship between late diagnosis and gender is mixed with several studies reporting higher levels of late diagnosis in males (Alder et al, 2011 cites Gupta et al, 2000 and Saul et al, 2000) which is thought to reflect the universal antenatal testing available to women in many countries in Europe, whilst other studies report lower levels of testing and higher numbers of indicator conditions amongst females (Hoyos et al 2013; Shrosbee et al 2014). In the UK, living in a low prevalence area and living outside of London are also associated with late diagnosis (Chadborn, 2005). Other factors associated with being diagnosed late include having a HIV test in the past and having children (Alder et al, 2011).

It is important to acknowledge the distinction between those that are diagnosed late and other late presenters. Late presenters include not only those who are diagnosed at a late stage of HIV but also those who re-present post-HIV diagnosis; that is individuals who have previously been diagnosed with HIV but have then been lost to clinical follow up post-diagnosis and subsequently access clinical care at a later stage of HIV. Lee et al (2012) found that the mean time between diagnosis and re-presenting for care in a post-diagnosis cohort was 7.3 years. This group also have distinct characteristics which differ from those who are diagnosed late; the post diagnosis group are more likely to be non-nationals or visitors from abroad and more likely to have a history of injecting drug use. The health of this group is different, with this post diagnosis group more likely to have clinical indicator conditions for HIV, psychiatric co-morbidities, social care issues and a history of alcohol and substance use. The main reasons reported for being lost to follow up were travelling abroad, transferring care to another centre, religious views and treatment avoidance (Lee, 2012).

INDIVIDUAL BARRIERS

European cohort studies of newly diagnosed patients suggest that between 32-55% of individuals will have never tested for HIV prior to their diagnosis (Champenois et al 2013, Deblonde et al, 2014). Similarly, a Spanish study of 5,920 individuals at a mobile testing unit found that 40% of individuals had never previously tested for HIV (Hoyos et al, 2013). The most commonly cited reasons for testing was experiencing symptoms, suggesting that individuals frequently do not access testing until a more advanced stage of HIV (Champenois et al, 2013; Hoyos et al, 2013). Other reasons for testing included risk exposure, voluntary testing or "checking one's status", and routine testing such as antenatal testing (Champenois et al, 2013; Hoyos et al, 2014).

The most common reason for not accessing testing was a low perception of risk either based on the belief that their behaviours were not putting them at risk or feeling healthy (Dowson et al, 2011; Kall et al, 2012; Araya et al, 2013; Hoyos et al, 2014; Deblonde et al, 2014). However, research suggests that individuals often underestimate their own

level of risk; for example Hoyos et al (2013) found that nearly half (46.5%) of individuals classified as high risk considered themselves low risk. Similarly, a semi-structured interview study with MSM found that more than half of men who were diagnosed positive were surprised by their diagnosis and believed themselves to have only practiced safe sex (Dowson et al, 2011). Furthermore, a study by Deblonde et al (2014), reports that 73% of newly diagnosed individuals had not previously tested for HIV due to a low perception of risk.

Fear of disease or the health consequences of a positive diagnosis was another frequently cited barrier (Dowson et al, 2011; Flowers, 2012; Hoyos et al, 2013; Deblonde et al; 2014; Morcroft et al, 2014). A qualitative interview study with MSM found that fear of becoming ill and dying was an important reason for not testing amongst this group and this was largely influenced by personal experiences such as the death of friends and partners and the prevention campaigns of the 1980s and 1990s. The study reported that the participants knew very little about advances in HIV treatment and many still considered HIV to be a death sentence (Dowson et al, 2011).

Other factors including anonymity, lack of information about the test, fear of discrimination and financial and legal reasons were reported but less commonly cited (Araya et al, 2013, Hoyos et al, 2013; Deblonde et al, 2014); however this varied across risk groups and countries. Dowson et al (2011) report that stigma and discrimination associated with a positive diagnosis was an important barrier amongst MSM and respondents expressed anxiety over the test itself and the implications of a positive diagnosis being disclosed (Dowson et al, 2011). Issues of anonymity and confidentiality varied across countries, and were reported to be of greater concern amongst Estonian (Deblonde et al; 2014) and Spanish (Hoyos et al, 2013) respondents. These cultural differences have important implications when considering late diagnosis in non-national populations in the UK.

Several studies have identified non-nationals as more likely to present late (Boyd et al 2005, Sabin et al 2004, Sullivan et al, 2005, Sarcino et al, 2013). Some studies suggest that perception of risk is lower among black African communities with Boyd et al (2005) reporting that 41% of black Africans in the UK tested due to perceived risk compared with 72% of non-Africans. Secondly, black Africans who do not perceive themselves to be at risk are more likely to postpone testing for twelve months compared with non-Africans (Erwin et al, 2002). Research also identifies a number of linguistic, cultural and socio-economic barriers which are unique to non-national communities (Kall et al, 2012). These include uncertain residency status, not understanding their rights to care under the NHS system, a lack of ethnic minority representation in decision making, and negative media publicity related to "health tourism" (Burns et al, 2007; Fakoya et al, 2008; Alder et al, 2011). Fear is also a more considerable concern amongst non-national communities with fear of dying due to low awareness of treatment advances (Erwin et al, 2002; Fakoya et al, 2008) and fear of stigma or discrimination both important concerns (Alder et al, 2011). For example, studies suggest that black Africans in the UK are less likely to disclose their status to friends and family compared with non-Africans (Erwin et al, 2002). Non-national communities also report higher levels of scepticism towards ART and this is influenced by a multitude of factors including religious views and belief in alternative therapies (Dodds et al 2004, Alder et al 2011, Lee, 2012, Fakoya et al, 2012).

PROFESSIONAL BARRIERS

Missed diagnostic opportunities in Europe and in the UK specifically, are well documented and individuals have often been seen by health professionals with an indicator condition in the twelve months prior to diagnosis (Winscleslaus, 2008; Ellis et al, 2012; Nardone et al, 2013; Scognamilglio et al, 2013; Champenois et al, 2013; Brawley et al, 2013). A 2010 BHIVA audit found that a quarter of those newly diagnosed had been seen in a clinical setting 12 months earlier where an opportunity for diagnosis had been missed and of these, 71% of individuals were subsequently diagnosed late (Ellis et al, 2012). Similarly, an audit of 22 GP practices (Whittle et al, 2013) found that 54% of patients presented at their GP with one or more indicator conditions of which 51% were offered a HIV test. However, a study of non-specialist clinicians in three South Coast hospitals compared testing practices in 2002-3 with practices in 2010-11 and found a rise in median time to diagnosis for those with an indicator condition; from 4 days in 2003 to 1 day in 2011

and, similarly; the number diagnosed within seven days rose from 70% to 81% (Clarke et al, 2013). This study suggests not only that there is improvement in testing in non-specialist settings but also suggests that increasing clinician awareness through audit can also lead to changes in testing behaviour.

Importantly, evidence suggests that low levels of testing are likely to be due to low numbers of tests being offered by clinicians rather than a lack of patient acceptance. A UK systematic review reports 9.3% of those with an indicator condition are offered a test compared with 29.5% in screening settings (pooled estimates), however uptake of testing for those with indicator conditions was much higher at 87.4% (compared with 69% in screening settings; Elmhadi et al, 2013). Respondents in a qualitative study of MSM felt that a more proactive approach from general practitioners would encourage testing and those that had refused a test from their GP felt there was a lack of explanation from the professional offering the test. However, the majority of participants stated a preference for GP testing over GUM as it was more convenient, more frequently visited and less embarrassing (Dowson et al, 2011). Similarly, a qualitative study of black Africans in the UK reported a lack of cultural awareness, a lack of integration with support services and, GPs inability to address HIV effectively as institutional barriers to testing (Burns et al, 2007).

Evidence from the UK, Europe and US suggests that HIV testing is linked to clinicians own perceptions of patient risk; with health care providers being more inclined to offer a test to those in high risk groups where they feel the testing offer is more likely to be accepted (Elmhadi et al, 2013). Clinicians report numerous barriers to HIV testing including the belief that a lengthy counselling procedure is required, worry about informing people of a positive result, lack of training on offering a test and conducting it, lack of knowledge of HIV and potential risk behaviours and language barriers (Kall et al, 2012; Elmhadi et al, 2013; Morcroft et al, 2014). Interestingly, a London hospital study of new employees own willingness to test for HIV found that 26% of respondents would not test for HIV because they would rather not know if they were positive (Hamill et al, 2010); this highlights that some knowledge barriers may contribute to health providers perception of risk. In addition, practical barriers including lack of time and difficulty ordering a test have also been identified (Elmhadi et al, 2013).

INTERVENTIONS TO REDUCE LATE DIAGNOSIS

The 2008 BHIVA HIV testing guidelines aimed to increase HIV testing across the United Kingdom and reduce the burden of late diagnosis, however evidence suggests that uptake of the guidelines has been low and that both financial and practical barriers have limited uptake (Nardone et al, 2013; Champenois et al, 2013). Nardone et al (2013) suggest that commissioners have a vital role to play in expanding HIV testing by including HIV testing in service specifications. A recent national audit of the testing guidelines found that 80% of high prevalence areas had commissioned some sort of expanded testing but this was mainly targeted testing for high risk groups. Just over half of areas had commissioned testing in the community (51%) followed by 49% in general practice and 36% in hospital departments. Testing in general practice tended to be commissioned in only a minority of practices. Full Compliance with the BHIVA guidelines was low, with only 31% of high prevalence areas commissioning routine testing of new general practice registrants and 14% had introduced routine testing of all general medical admissions. Most areas (77%) reported that they expected testing to increase over the next year; however 94% cited lack of resources as a barrier to testing in their area (Hartney et al, 2014).

Following the introduction of the 2008 BHIVA guidelines, a series of eight "Time to Test" pilots were funded by the Department of Health to examine the feasibility of expanding routine HIV testing into general medical, primary care and community settings. In total 11,503 tests were completed across the eight pilots resulting in 51 HIV diagnoses, a positivity rate of 4 per 1,000 tests completed. The cost of testing varied across the pilots with the lowest cost in hospital settings (£3-£12 per test) and the highest cost in community outreach settings (£21-47). Importantly, the pilots found that offering HIV testing in all of these settings was both acceptable and feasible to patients and staff. In

addition, many of the pilots produced a positivity rating of 1 per 1,000 tests; the threshold at which testing is deemed to be cost-effective (HPA, 2011).

The highest level of testing uptake in the "Time to Test" pilots was in primary care (59-75%) and hospital settings (62-91%). However, the rates of testing in both these settings varied considerably depending on the clinician offering the test (HPA, 2011). Clinicians attitudes to HIV testing in these settings was explored in the HIV Testing in Non-Traditional Settings (HINTS) study which aimed to examine the feasibility and acceptability of introducing HIV testing in four non-specialist settings across London (including primary care; Rayment et al, 2010). The majority of staff (<90%) felt HIV testing was appropriate in these settings, however only between 42-54% of staff felt they would be comfortable offering a test. Pre-test surveys identified several barriers with the majority feeling they would require training to undertake testing, a lack of time and predicting low levels of patient acceptability. However, focus groups conducted after the study found that most of these staff fears were allayed particularly in relation to time and patient acceptability (Rayment et al 2010 and Thornton et al, 2012). This emphasises the importance of engagement and support for staff in departments conducting testing. An extensive education programme for primary care health professionals in South-West London found a 184% increase in diagnoses in primary care over a five year period indicating the success of interventions involving sustained support and education for clinicians in increasing HIV diagnoses (Wilkin-Crowe, 2013).

A systematic review of expanded testing found the highest level of testing (83%) was a study in an acute medical admissions unit in Croydon; which had repeated a previous study conducted several years earlier which found coverage of less than 1% in the same setting (Chan et al, 2011). This indicates that a prospective study design can be an effective intervention in itself which can lead to improving and high testing coverage amongst non-specialist clinicians as awareness of testing increases (Chan et al 2011; Elmhadi et al, 2013).

Community and GUM based Point of Care Testing pilots report that testing is feasible and acceptable to patients and service providers in both high and low prevalence settings and successfully reached target groups including those who would not have otherwise tested (MacPherson et al, 2012). In the "Time to Test" pilots, positivity rates were highest in community settings. Three community based projects were included in the programme, aimed specifically at testing for MSM and black African communities. The pilots found that among MSM there was high acceptability for community testing including in social venues. This contradicts findings from an earlier qualitative study with MSM and gay venue owners which suggested negative views towards the expansion of testing in gay social venues; with privacy, hygiene and discussion of results particularly under the influence alcohol, all viewed as barriers to testing (Prost et al, 2007). Among black African communities, there was a preference for testing within the community rather than more formalised settings such as the offices of providers. However, the pilots did identify some barriers to testing in these community settings particularly finding a suitable venue for testing and difficulties in recruiting and retaining staff (HPA, 2011). This suggests that whilst testing in community settings is both cost effective and acceptable, the viability of these interventions is dependent on both a long term financial and political commitment.

Interventions aimed at expanding HIV testing have been shown to be both cost effective and acceptable (HPA, 2011); however, expanding testing requires HIV related training for healthcare staff (Nardone et al, 2012) and can be limited by a number of operational barriers particularly in community settings (HPA, 2011). New methods of HIV testing, including home sampling and home testing may be a way in which to bypass some of these barriers particularly when expanding testing to harder to reach populations (Nardone et al, 2012). The "Time to Test" programme included one home sampling pilot which allowed MSM to access oral swab tests via the internet and in outreach settings. The samples were then posted to a virology laboratory for testing. The project did not result in any new HIV diagnoses; however the project did demonstrate the feasibility of a postal testing scheme. The pilot also found that over a third of participants had never tested for HIV and only 15% had attended a GUM clinic in the past twelve months (HPA, 2011). Similarly, a home testing scheme run by HIV charity Terrence Higgins Trust found that 52% of those requesting a test did not want to attend a STI clinic (Brady et al, 2014). This suggests home

sampling services are effective in accessing harder to reach populations who would not otherwise consider HIV testing (HPA, 2011). Home testing for HIV was made legal in the UK in April 2014 (PHE, 2014), with the first kit approved for sale in April 2015; therefore evidence on the effectiveness of home testing as an intervention is not yet available.

CONCLUSION

Late diagnosis of HIV remains an important public health issue in the UK, with 40% of newly diagnosed individuals classified as late in 2014 (PHE, 2012). In addition, evidence suggests certain groups are disproportionally affected by late diagnosis, namely older adults, heterosexuals and non-national populations, in particular black Africans. The literature review identified that reasons for not testing promptly are mainly linked to individual perceptions of risk and missed opportunities to test by healthcare professionals (Champenois et al, 2013). Evidence suggests that the majority of individuals have lowered perceptions of their risk of acquiring HIV and for those who have recent high risk behaviour; fear of disease is an important barrier to testing. Amongst black African populations, there are additional barriers to testing including cultural factors and a heightened fear of disclosure. Amongst healthcare professionals, missed diagnostic opportunities are well documented and are linked to clinician's own perceptions of risk and a lack of knowledge of HIV and testing procedures.

Interventions to expand testing beyond routine settings have been show as both acceptable and feasible to patients and staff and cost effective. However, studies in hospital and primary care settings have found varying levels of testing among clinicians suggesting that support and training for healthcare staff is necessary and effective in increasing testing. Community outreach testing has been found particularly effective among black African populations and evidence suggests that effective interventions must be grounded in community mobilisation and outreach settings; normalise both testing and treatment for HIV and, address HIV related stigma (Burns et al, 2007; Fakoya et al, 2008). Community testing is also an effective testing strategy for MSM and emerging evidence suggests that new home sampling and home testing methods will be particularly effective in accessing harder to reach groups (HPA, 2011 and Brady et al, 2014).

This literature review has found that there is substantial evidence documenting the factors associated with late HIV diagnosis and successful interventions to increase prompt access to testing. However, whilst these interventions demonstrate high levels of patient acceptability and uptake; national implementation of testing guidelines has been slow (Hartney et al, 2014). Evidence from pilots suggests that professional and organisational factors are the main barriers to achieving expanded HIV testing. In conclusion, this evidence review suggests it is possible through appropriate interventions to reduce the number of late diagnoses of HIV within the United Kingdom; however, this can only be achieved through a political, professional and financial commitment from commissioners and healthcare providers.

- **HIV prevention and testing messages should include an honest indication of what is considered high risk behaviour:** the most common reason for not accessing HIV testing was a low perception of risk and research suggests that individuals often underestimate the level of risk in their own behaviours. To address this, campaigns should clearly communicate what constitutes high risk behaviour and advise on how to reduce sexual risk.

- **Ensure that all sexual health promotion and advice is accessible to the over 50s:** being aged over 50 years is associated with late diagnosis of HIV; risky sexual behaviour is high in this group and contraception use low. However, evidence suggests that this group often feel reluctant or neglected when it comes to accessing sexual health care. Sexual Health prevention messages and campaigns should be made relevant to the over 50s including clear and concise messages about the importance of HIV testing.

- **HIV testing messages for MSM should address fear of dying and stigma and discrimination:** evidence suggests that MSM may put off testing due to fear of dying or illness; messages should therefore focus on the improved prognosis for an individual who is tested and begins treatment early. Messages should also focus on normalising HIV testing for the MSM community to alleviate anxiety both about the test process and associated stigma.

- **HIV testing messages for black African communities should address cultural barriers, fear of dying and stigma and ART scepticism:** evidence suggests that non-national communities experience a number of cultural and socio-economic barriers including residency status, limited understanding of UK health systems and fear of stigma and discrimination and HIV testing messages should be sensitive in addressing these barriers. Evidence also suggests fear of dying is an important barrier due to lack of knowledge of treatment advances as well as high levels of ART scepticism among some communities. HIV testing messages should therefore highlight the availability of ART and the impact of treatment and prompt testing on the prognosis for someone diagnosed with HIV.

- **Ensure that HIV testing is included in service specifications:** BHIVA recommend HIV testing for all GP registrants and general medical admissions in high prevalence local authorities, as well as testing for at risk populations and indicator conditions in all local authority areas. However, evidence suggests that current commissioning of HIV testing is low and not universally implemented in high prevalence areas. Including HIV testing in service specifications is therefore vital to expanding HIV testing and thus reducing late diagnosis.

- **Develop both specific training and a sustained programme of education and support for staff in settings offering HIV testing:** training should include clear communication of who is at risk of acquiring HIV, rates of patient acceptability and uptake and a clear description of the site specific testing procedure.

- **Increase GP awareness of HIV indicator conditions as listed in the British HIV Association Testing Guidelines (2008):** evidence indicates that missed diagnostic opportunities are well documented with a substantial number of individuals presenting in clinical settings with indicator conditions in the twelve months prior to diagnosis.

- **Introduce regular HIV testing audits to improve health professional awareness of the practices recommended by the BHIVA testing guidelines (2008):** evidence suggests that auditing health professionals HIV testing practices in non-specialist settings can lead to increased awareness and positive changes in testing behaviour.

- **Ensure any outreach testing programmes for harder to reach groups have sustained political and financial support:** evidence suggests high acceptability for community based HIV testing among MSM and particularly among black African communities. Research also suggests that such testing is cost-effective with pilots finding high positivity rates. However, evidence suggests that the viability of these programmes is dependent on economic and political factors including suitable venues for testing and recruiting and retaining staff.

- **Keep up to date with the effectiveness of new HIV testing developments, particularly in relation to home testing:** new methods of testing including home sampling and home testing may present an opportunity to reduce some of the barriers to testing particularly for harder to reach groups. Evidence on home testing is limited but following the legalisation of home testing in the UK in April 2014 it is likely that the evidence base around these methods will increase in coming years.

REFERENCES

Alder et al (2009). Late diagnosis of HIV in Europe: definitional and public health challenges. *AIDS Care.* 21(3):284-93

Anitori, A. et al (2011). Late presentation of HIV: a consensus definition. Short Communication. HIV Medicine Vol 12 (1): 61-4

BHIVA, BASHH and BIS (2008). *UK National Guidelines for HIV Testing*. London: BHIVA.

Boyd AE et al (2005) Ethnic differences in stage of presentation of adults of newly diagnosed with HIV-1 infection in south London. *HIV Medicine:* 6:59-65

Brady M et al (2014). *Home HIV sampling linked to national HIV testing campaigns: a novel approach to improve HIV diagnosis.* Third Joint Conference of BHIVA with BASHH. Liverpool, 1-4 April 2014.

Brawley D et al (2013). Missed opportunities for HIV diagnosis: a three-year audit in the West of Scotland. *Scott Med J* 58(3):173-7

Bryce G et al (2011). A study to assess the acceptability, feasibility and cost-effectiveness of universal HIV testing with newly registering patients (aged 16-59) in primary care. *HIV med (Suppl 1)* 17:3

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. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* 19(1):102-108

Camoni L et al (2013). Late presenters among persons with a new HIV diagnosis in Italy, 2010-2011. *BMC Public Health* 13:281.

Champenois K et al (2013). Missed opportunities for HIV testing in newly diagnosed patients, a cross sectional study. *BMC Infectious Diseases* 13:200

Chan SY et al (2011). Acceptance of HIV testing in medical inpatients: a local acceptability study. *Int J STD AIDS* 22(4):187-9

Clarke E et al (2013). A glimmer of hope? Evaluation of time for non-genitourinary medicine physicians to diagnose HIV in patients presenting with HIV-related illness. *Int J STD AIDS* 24(8):639-41

De Blonde J et al (2014). HIV testing practices as reported by HIV-infected patients in four European countries. *AIDS Care* 26(4): 487-496

De Blonde J et al (2010). Barriers to HIV testing in Europe: a systematic review. *European Journal of Public Health* 20(4): 422-432.

Delpeche V et al (2013). Quality of HIV care in the United Kingdom: key indicators for the first 12 months from HIV diagnosis. *HIV Medicine* 14(3): 19-24

Department of Health (2010). *Healthy Lives, Healthy People. Public Health White Paper*. London:TSO

Department of Health (2012). *Public Health Outcomes Improvement Framework for England*. London:TSO

Department of Health (2013) *A Framework for Sexual Health Improvement in England.* London:TSO.

Dowson et al (2012). Why some MSM present late for HIV testing: a qualitative analysis. *AIDS Care: Psychological and Socio-medical aspects of HIV* 24(2): 204-209.

Duncan S. and Saitha L (2012) Up to the test? Routine HIV testing in everyday clinical practice. *Int J Clin Pract* 66(5): 425-30

Ellis, S et al (2012). HIV diagnoses and missed opportunities. Results of the British HIV Association (BHIVA) Audit 2010. *Clin Med* 12(5):430-4.

Elmahdi R et al (2014). Low levels of HIV test coverage in clinical settings in the UK: a systematic review of adherence to 2008 guidelines. *Sex Tranms Infect* 90:119-124.

Erwin et al (2002). Pathways to HIV testing and care by black African and white patients in London. *Sex Transm Inf* 78:37-39

Fakoya I et al (2012). Religion and HIV diagnosis among Africans living in London. *HIV Med* 13(10):627-622

Fakoya I et al (2008). Barriers to HIV testing for migrant black Africans in Western Europe. *HIV Medicine*: 9(2):23-25.

Flowers P 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. *HIV Medicine* 14:92-98

Gilbart VL et al (2006). Late diagnosis of HIV infection among individuals with low, unrecognised or unacknowledged risks in England, Wales and Northern Ireland. *AIDS Care: Psychological and socio-medical aspects of AIDS/HIV* 18(2): 133-139.

Goodall L and Leen C (2011). Late diagnosis of HIV: could this be avoided? *Scott Med J* 56(2):84-6

Hamill et al (2006). Incentives for voluntary HIV testing in NHS staff. *Occupational Medicine* 56:426-429

Hall HI et al (2013). Late diagnosis and entry in care after diagnosis of human immunodeficiency virus infection: a country comparison. *PlosONE* 18(11):e77763

Halve it Coalition (2013). *Halve it – Position Paper.* London: Halve it.

Hartney T et al (2014). Expanded HIV testing in high prevalence areas in England: results of a 2012 audit of sexual health commissioners. *HIV Medicine* 15:251-254

Health Protection Agency (2012a) *HIV in the United Kingdom 2012*. Colindale: HPA

Health Protection Agency (2012b). *Evidence and resources to commission expanded HIV testing in priority medical services in high prevalence areas.* Colindale: HPA

Health Protection Agency (2011) *Time to test for HIV: expanding HIV testing in healthcare and community services in England.* Colindale: HPA

Hemminki E et al (2012). Is HIV testing normal or special? Opinions of health professionals in four European countries in 2008. *AIDS care: Psychological and socio-medical aspects of AIDS/HIV*. 24(1):91-99

Hoyos et al (2013) Never tested for HIV in Latin American migrants and Spaniards: prevalence and perceived barriers. *Journal of the International AIDS Society* 16:18560

Hunter E et al (2012). HIV testing: getting the message across – a survey of knowledge, attitudes and practice among non-HIV specialists. *Postgrad Med J* 88:59-65.

Iwuji CC et al (2013). Older HIV-infected individuals present late and have higher mortality: Brighton, UK cohort study. *BMC Public Health* 13:397

Kall M et al (2012). Late HIV diagnosis in Europe: A call for increased testing and awareness among general practitioners. *European Journal of General Practice* 18:181-186

Lazarus JV et al (2011). Overcoming obstacles to late presentation for HIV infection in Europe. *HIV Medicine* 12:246-249

Lee MJ et al (2013). Comparison of two cohorts of patients presenting with AIDS: patients with previously known HIV diagnosis and true late presenters. *Sex Transm Infect* 89: 553-556

MaCarthey S et al (2014). Late presentation to HIV/AIDS testing, treatment or continued care: clarifying the use of CD4 evaluation in a consensus definition. *HIV Med*15:130-134.

Manavi K et al (2004). Heterosexual men and women with HIV test positive at a later stage of infection than homo- or bisexual men. *Int J STD AIDS* 15(12):811-4

Mocroft, A et al (2013). Risk Factors and Outcomes for Late Presentation for HIV-Positive Persons in Europe: Results from the Collaboration of Observational HIV Epidemiological Research Europe Study (COHERE). *PLoS Med* 10(9): e1001510

National Institute for Clinical and Healthcare Excellence (NICE) (2011) *Increasing the uptake of HIV testing to reduce undiagnosed and prevent transmission among black African communities living in the UK. Public Health Guidance PH33.* London: NICE

National Institute for Clinical and Healthcare Excellence (NICE) (2011) *Increasing the uptake of HIV testing to reduce undiagnosed and prevent transmission among men who have sex with men. Public Health Guidance PH43.* London: NICE

Nardone, A et al (2013). HIV in the UK: test, test and test again. *The Lancet* 382: 1687-8

Newman CE et al (2013). Engaging nonHIV specialist general practitioners with new priorities in HIV prevention and treatment: qualitative insights from those working in the field. *Sexual Health* 10(3) 193-198

Pollard A et al (2013).Opt-out testing for HIV: perspectives from a high prevalence community in south-east England, UK. *Int J STD AIDS* 24(4)307-12

Prost et al (2007). "There is such a thing as asking for trouble": taking rapid HIV testing to gay venues is fraught with challenges. *Sex Transm Infect* 83:185-188

Prost et al (2007b). HIV voluntary counselling and testing for African communities in London: learning from experiences in Kenya. *Sex Transm Infect* 83:547-551

Public Health England (2015). HIV New Diagnoses, Treatment and Care in the UK*. Colindale: PHE.

Public Health England (2014). *HIV in the United Kingdom 2014.* Colindale: PHE.

Public Health England (2013). *HIV in the United Kingdom 2013.* Colindale: PHE.

Public Health England (2014). HIV testing and self-testing. Answers to frequently asked questions. Colindale:PHE

Public Health Outcomes Framework (PHOF) (2013) Public Health Outcomes Framework Data Tool. London:DH

Rayment M et al (2012). Testing in non-traditional settings – The HINTS study: A multi-centre observational study of feasibility and acceptability. *PLoS ONE* 7(6): e39530

Sabin CA et al (2013) Do people with HIV infection have a normal life expectancy in the era of combination antiretroviral therapy? *BMC Medicine* 11:251

Samji H et al (2014). Closing the gap: increases in life expectancy among treated HIV-positive individuals in the United States and Canada. *Plos One*. 8(12): e81355.

Scognamiglio P et al (2013) The potential impact of routine testing of individuals with HIV indicator conditions in order to prevent late HIV diagnosis. *BMC Infectious Diseases* 13:473

Shrosbree J et al (2013). Late HIV diagnosis is a major risk factor for intensive care unit admissions in HIV-positive patients: a single centre observational cohort study. *BMC Infectious Diseases* 13:23

Simmons EM et al (2011). Barriers and facilitators to HIV testing in primary care among healthcare providers. J Natl Med Assoc 103:432-38

Smith RD et al (2010) HIV transmission and high rates of late diagnoses among adults aged 50 years and over. *AIDS* 24(13):2109-15

Thornton et al (2012). Exploring staff attitudes to routine HIV testing in non-traditional settings: a qualitative study in four healthcare facilities. *Sex Transm Infect* 88:601-606

Van Bergen, JE (2012). Normalizing HIV testing in Primary Care. European Journal of Primary Care. 18:133-135

Wada N et al (2014). Cause-specific mortality among HIV-infected individuals, by CD4$^+$ cell count at HAART initiation, compared with HIV-uninfected individuals*. AIDS* 28:257-265.

Waters and Sabin (2011). Late presentation: epidemiology, clinical implications and management. *Expert Rev Anti Infect Ther.* 9(10):877-89

Waters L et al (2011). Responses to highly active antiretroviral therapy and clinical events in patients with low CD4 cell count: late presenters vs late starters. *HIV Med* 12(5): 289-98

Wilkin-Crowe H et al (2013). Changing trends in HIV testing in an inner city London teaching hospital 2007-2011. *Int J STD AIDS* 24(4):269-72

Winceslaus SJ et al (2008). HIV diagnosis: why and how do we miss important clues? *Int J STD AIDS* 84:101–102

Whittle A et al (2013). Increasing opportunities for HIV diagnosis in primary care: a borough wide evaluation of HIV testing and pre-diagnosis care in general practice. Oral Abstract O2. *HIV Medicine:* 14(2):1

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