

Increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black African communities living in England

Barriers to HIV testing

Final Full report

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Executive Summary

Background

Globally, the HIV epidemic continues to have an impact on the lives of millions of people. In 2008, there were an estimated 83,000 people living with HIV (both diagnosed and undiagnosed), equivalent to 1.3 per 1000 population in the UK. In that same year, 7,798 people were newly diagnosed with HIV. The global epidemic is reflected in the UK; around 38% (2,790) of these newly diagnosed infections were among black Africans who acquired their HIV through heterosexual contact. It is thought that most (87%) of these infections among black Africans in the UK were acquired abroad, mainly in sub-Saharan Africa (Health Protection Agency 2009).

Late diagnosis of HIV is defined as diagnosis taking place after anti-retroviral treatment would normally have begun, or when the person has an illness which defines them as having AIDS. It is the most important factor associated with HIV-related disease and death in the UK and is a particular problem among black Africans. In 2007, over 40% of new diagnoses among black Africans were classified as 'late'.

HIV testing can help reduce transmission of the virus. People who find out they have HIV may change their sexual behaviour as a result of the diagnosis. A negative HIV test provides an opportunity for preventive education and advice and may also lead to changes in behaviour. Increasing the frequency of testing may result in earlier detection of HIV following infection - when it is most virulent - providing greater opportunity to reduce transmission.

Objectives

The aim of this project was to systematically review qualitative literature that identifies the barriers and facilitators to the uptake of HIV testing among African communities in England. The review addresses one overarching question:

- What factors help or hinder the uptake of HIV testing by black African communities living in England and how can the barriers be overcome?

Primary question:

- What interventions have successfully reduced the social, personal and cultural barriers associated with testing among black African communities in the UK?

Secondary questions relating to the social and cultural factors associated with HIV testing:

1. What (if any) are the adverse or unintended consequences (positive or negative) of the interventions?
2. What environmental, social and cultural factors prevent or support the uptake of HIV testing?
3. How does HIV-related stigma affect the uptake of HIV testing?

Methods

A detailed search protocol based on the methodology in the NICE Methods Manual was developed. Nineteen electronic databases and nine websites were searched for qualitative studies that explored HIV testing among black Africans in England. Searches were restricted to studies published since 1996 (the introduction of highly active antiretroviral therapy) and written in English.

Two reviewers independently screened all titles and abstracts. Papers selected for full paper screening were then independently screened by two reviewers and selected for full review. Data extraction was performed by one reviewer and checked for accuracy by another. Papers were quality assessed by one reviewer and checked for accuracy by another. Each paper was graded according to a range of criteria that established whether potential sources of bias had been minimised and if study conclusions were open to any degree of doubt.

Thematic meta-analysis was used to synthesise the data. The review team attempted to understand and categorise the findings according to whether they represented barriers or facilitators to HIV testing. Evidence tables were used as a tool to extract the findings and deconstruct the themes identified in each study. One reviewer coded the themes and sub-themes and these were checked for accuracy by another. The results were presented in narrative summaries exploring each theme in detail.

Findings

Ten papers were identified from the literature review and underwent quality appraisal. All studies included black African participants living in England. Eleven themes and sub-themes were identified and categorised into two broad areas: “Factors that hinder the uptake of HIV testing” and “Factors that help the uptake of HIV testing”.

Factors that hinder the uptake of HIV testing

Evidence Statement 1: Stigma as a barrier to HIV testing

- ES 1.1. Four studies report that HIV is highly stigmatised within African communities living in England. These studies were conducted with men and women, some living with HIV and with experts working in the field of sexual health and HIV. (Burns et al, 2007[++]; Burns 2009 [++]; Prost et al, 2007 [++]; Elam et al, 2009 [-]) One of these studies, with key stakeholders working in sexual health and HIV finds this stigma is thought to be fuelled by perceptions that HIV is a deadly disease (Burns et al, 2007 [++]).
- ES 1.2. Two studies, one with people newly diagnosed with HIV and another with people from African communities in England report that low visibility of HIV and lack of positive imagery increase HIV related stigma within African communities (Prost et al, 2007 [++]; Burns, 2009 [++]).
- ES 1.3. Reluctance to undergo HIV testing due to fear of racism and prejudice from outside African communities is found in three studies with key stakeholders working in sexual health and HIV research. (Burns et al, 2007 [++]; Prost et al, 2007 [++]; Elam et al, 2009 [-])

Fear of Isolation

ES 1.4. Four studies report fear of isolation and social exclusion following HIV diagnosis as a barrier to HIV testing. (Burns 2009 [++]; Chinouya 2006 [+]; Chinouya & O'Keefe 2005 [+]; Chinouya & O'Keefe 2006[-]). Another study of patients attending a GP surgery finds lack of psychosocial support as a potential disadvantage to rapid testing in primary care. (Prost et al, 2009 [++])

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

Evidence Statement 2: Lack of perceived personal risk as a barrier to HIV testing

ES 2.1 Five studies report that there was low perception of personal risk among people from black African communities in England. (Burns et al, 2007 [++]; Burns 2009 [++]; Elam et al 2009 [-]; Chinouya & O'Keefe 2005 [+]; Paparini et al, 2008 [-]). Two of these studies conducted with key stakeholders working in sexual health and HIV and including people living with HIV find that this was due to HIV transmission being associated with stigmatised behaviours such as sexual promiscuity and unfaithfulness. (Burns et al, 2007 [++]; Elam et al, 2009 [-]).

ES 2.3. Participants in three studies with people living with HIV attending HIV clinics or HIV support groups (two with African men and women and one with African men who have sex with men) had only perceived themselves to be at risk of HIV after becoming seriously ill. (Burns 2009 [++]; Paparini et al, 2008 [-]; Chinouya & O'Keefe 2005 [+];)

ES 2.4 Increased risk perception is reported by participants who suspected infidelity in current or previous partners in two studies with HIV positive African men and women attending HIV clinics or support groups (Chinouya & O'Keefe 2005 [+]; Burns 2009 [++]) and one with HIV positive African men who have sex with men (Paparini et al, 2008 [-]).

ES 2.5 Two studies conducted with black African men and women living with HIV recruited in HIV clinics or HIV support groups report increased risk perception by participants who had been informed about the death/illness of a child or a concurrent or previous sexual partner of their spouse (Burns 2009 [++]; Chinouya & O'Keefe 2005 [+]).

ES 2.6 One study conducted with black African men and women newly diagnosed with HIV recruited in HIV clinics reported raised perception of risk by a participant who had multiple rape experiences (Burns 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England with black African people.

Evidence statement 3: Gender as a barrier to HIV testing

- ES 3.1 One study with black Africans attending HIV clinics and living with newly diagnosed HIV in London reports that denial of HIV risk had been more predominant in male participants. For example some men would not test for HIV despite their female spouses and/or children testing HIV positive. (Burns 2009 [++]).
- ES 3.2 Men were described as having fewer opportunities to test for HIV in one study with key stakeholders working in sexual health and HIV in African communities in England. (Burns et al, 2007 [++]). Another study of Zimbabwean men and women living with HIV and attending HIV clinics or support groups, finds that men were not being offered HIV testing in antenatal services alongside their partners (Chinouya & O'Keefe 2006 [-]).
- ES 3.3 One study with newly diagnosed African men and women recruited in HIV clinics in London finds that African women have less ability to control their risk of HIV exposure and less ability to access services (Burns 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England with black African people.

Evidence statement 4: Migration and cultural norms as a barrier to HIV testing

- ES 4.1 Three studies conducted with key stakeholders working in sexual health and newly diagnosed HIV positive African men and women attending HIV clinics report on difficulties faced by migrant Africans, such as economic hardship (including under- or unemployment); uncertain immigration status; childcare; housing and the pressure to send money home to Africa. These issues were said to take precedence over health and seeking an HIV test, even when experience ill-health. (Burns et al, 2007 [++]; Burns, 2009 [+]; Elam et al, 2009 [-])
- ES 4.2 Preventative health seeking behaviour, that is accessing HIV testing when well, was seen an unfamiliar concept to Africans in one study with key stakeholders working in sexual health and HIV among African communities in England (Burns et al, 2007 [++]).
- ES 4.3 One study with newly diagnosed African men and women recruited in an HIV clinic reported that the reliance on oral traditions in African societies made it difficult for migrant Africans in England to obtain appropriate information about HIV testing (Burns 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

Evidence Statement 5: Accessibility and Opportunity as a barrier

- ES 5.1 Six studies conducted with African men and women living with HIV or key stakeholders working with these communities report that complicated pathways to GUM clinics, for example multiple referrals from general practitioners, delayed HIV testing, resulting in late diagnosis (Burns et al, 2007[+]; Burns 2009 [+]; Chinouya & O’Keefe 2006 [-]; Chinouya & O’Keefe 2005 [+]; Elam et al, 2009 [-]; Prost et al, 2009 [+]).
- ES 5.2 Participants in two studies of African men and women living with HIV and attending HIV clinics or support groups report that GPs had failed to test them having dismissed their fears about HIV (Burns, 2009 [+]; Chinouya & O’Keefe 2005 [+]).
- ES 5.3 Four studies reported that HIV testing in sexual health clinics was seen as stigmatising, complicated and time consuming. These studies were conducted with African men and women living with newly diagnosed HIV and attending HIV clinics (Burns 2009 [+]), patients recruited as part of a study examining the feasibility and acceptability of HIV testing as part of a new GP health check (Prost et al 2009 [+]) and with key stakeholders working in sexual health and HIV with African communities (Prost et al 2007 [+]; Burns et al 2007 [+]).
- ES 5.4 Four studies conducted with African men and women living with HIV attending HIV support groups or HIV clinics and key stakeholders working in sexual health and HIV find that fears of breaches in confidentiality in clinical or community-based HIV testing services deterred individuals from accessing these services (Chinouya & O’Keefe, 2006 [-]; Burns et al, 2007 [+]; Burns 2009 [+]; Prost et al, 2007 [+]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

Factors that help the uptake of HIV testing

Evidence Statement 6: Improving accessibility and opportunity

- ES 6.1 Two of studies describe how participants (African men and women living with HIV attending HIV clinics or HIV support groups) had seen opportunistic offers of HIV testing in hospital as beneficial or routine (Burns 2009 [+]; Chinouya & O’Keefe 2005 [+]).
- ES 6.2 HIV testing outside of GUM clinics (for example in GP surgeries, community- or faith-based venues) is found to be acceptable in five studies conducted with people living with HIV recruited in HIV clinics and HIV support groups, (Burns 2009 [+]; Chinouya & O’Keefe 2005 [+]); key stakeholders working in sexual health and HIV (Elam et al, 2009 [-]; Prost et al, 2007 [+]) and patients recruited as part of a study examining the

feasibility and acceptability of HIV testing in GP surgery as part of new patient health check (Prost et al, 2009 [++]). Two studies with African men and women living with HIV attending HIV support groups (Chinouya & O'Keefe 2006 [-]) and with key stakeholders working with these communities (Elam et al, 2009 [-]) reported joint testing in ante-natal clinics as beneficial to women who may test positive but fear disclosing their HIV positive status to their male partners.

Speed of results

ES 6.3 Three studies with key stakeholders working in sexual health and HIV (Elam et al, 2009 [-]; Prost et al, 2007 [+];) and patients offered an HIV test as part of a new patient health check in a GP surgery (Prost et al, 2009 [++]) find that rapid testing and quick access to HIV test results is seen as advantageous and accessible

ES 6.4 One study with patients attending a GP surgery reports the belief that rapid testing as part of a new patient health check in GP surgeries might be problematic if patients were unprepared for an HIV test (Prost et al, 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

Evidence statement 7: Community involvement

ES 7.1 Mobilising community members to advocate about HIV testing through outreach and education programmes was identified as a potential factor in the success of HIV testing in three studies with key stakeholders working in sexual health and HIV (Burns et al, 2007; Prost et al 2007 [+]; Elam et al, 2009 [-]) and one study with African men and women newly diagnosed with HIV and recruited from an HIV clinic (Burns 2009 [++]).

ES 7.2 Four studies (three with key stakeholders working in sexual health and HIV and one African men and women living with HIV recruited in an HIV clinic) describe HIV prevention and testing messages that target African people only as problematic and stigmatising (Burns et al, 2007; Burns 2009 [++]; Prost et al 2007 [+]; Elam et al, 2009 [-]).

Perceived benefits of HIV testing

ES 7.3 Two studies (one with key stakeholders working in sexual health and HIV and one with African men and women living with HIV recruited in an HIV clinic) find that there are few highly visible HIV positive role models in England, which are needed to help breakdown the stigma associated with HIV (Burns 2009 [++]; Elam et al, 2009 [-]).

ES 7.4 Two studies (one with key stakeholders working in sexual health and HIV and one with African men and women living with HIV recruited in an HIV

clinic)report that increasing the awareness of the benefits of earlier diagnosis and access to HIV medication might increase HIV testing (Burns 2009 [++]; Elam et al, 2009 [-]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England with black African people.

Conclusions

The findings from this review highlight the central influence of HIV-related stigma in preventing individuals from seeking or accepting an HIV test. The evidence indicates that many of the structural barriers to testing can be overcome through interventions that aim to reduce stigma or increase awareness of and opportunities to access HIV testing services. However, there are substantial gaps in the evidence and more research is needed in the following areas:

- Feasibility and acceptability of HIV testing among staff and patients at GP surgeries.
- Identify appropriate services for opportunistic or routine testing in hospitals in high HIV prevalence areas
- Development or adaptation of interventions to reduce social, personal and cultural barriers, (especially HIV-related stigma) in African communities.
- Explore ways in which services could adapt in order to reduce the stigma associated with attending GUM clinics.

Glossary and Abbreviations

AIDS

Acquired Immune Deficiency Syndrome

Anonymous Testing

HIV testing where patients are given a code or number which is then linked to a blood (or other fluid) specimen. No names are recorded alongside the test or the result.

ART

Anti-retroviral therapy

BA

Before and After Study

BME

Black and Minority Ethnic Communities

CD4 + Cells

CD4+ or T Helper cells are a sub-group of T-lymphocytes that are used as a surrogate marker of the health of the immune system in HIV infection. A CD4+ count is a blood test that estimates how well a patient's immune system is working by counting CD4+ cells.

Confidential Testing

HIV testing linking an individual name to blood (or other fluid) specimen and recording the test result in a medical chart with a name. Confidentiality assured by clinical policy and practice.

CPHE

Centre for Public Health Excellence

CT

Cohort Study

GUM

Genitourinary Medicine - the clinics where sexually transmitted infections are diagnosed and treated

HAART

Highly Active Antiretroviral Therapy

HIV

Human Immunodeficiency Virus

HPA

Health Protection Agency

ITS

Interrupted Time Series

ITT

Intention To Treat Analysis

Late diagnosis

Diagnosis after anti-retroviral treatment would normally have begun, or when the person has an illness which defines them as having AIDS.

MSM

Men who have Sex with Men

NAHIP

National African HIV Prevention Programme

NICE

National Institute of Health and Clinical Excellence

N-RCT

Non- randomised controlled Trial

NSMC

National Social Marketing Centre

PHIAC

Public Health Independent Advisory Committee

Rapid Testing

HIV test where patients are able to receive test results within 1-60 minutes.

RCT

Randomised Controlled Trial

Standard Testing

Most standard HIV tests use Enzyme-linked immunosorbent assay (ELISA). Blood is drawn from a vein and the ELISA is used to test for the presence of HIV antibodies. The results are generally available in 5-14 days.

STI(s)

Sexually transmitted infections

1. Introduction

This review was commissioned by NICE to provide qualitative evidence to support the development of guidance for interventions which aim to increase the uptake of HIV testing to reduce undiagnosed HIV infection among black African communities living in England. The guidance aims to provide recommendations for interventions that implement either client or provider initiated HIV testing and aim to:

- Increase awareness of HIV testing and its benefits. For example, mass-media and other media campaigns and one-to-one or group-based information provision (planned or opportunistic and offered by practitioners or peers).
- Increase the opportunity for, and uptake of, HIV testing. This could involve changes in service delivery (for example, changes to opening times or appointment systems), increasing the number or kinds of tests offered, and increasing the number and types of venue offering tests.
- Reduce the barriers to HIV testing, for example, peer education initiatives to reduce the stigma associated with HIV.

1.1. Background

Globally, the HIV epidemic continues to have an impact on the lives of millions of people. UNAIDS estimates that there were between 31.1 and 35.8 million people living with HIV in 2008, of whom 2.4-3.0 million were newly diagnosed that year (UNAIDS 2009). Sub-Saharan Africa remains the region most heavily affected by HIV, with 22.4 million adults and children living with HIV in 2008 (two thirds of global infections) and 1.4 million deaths due to AIDS. The prevalence of HIV among adults in sub Saharan Africa is on average 5.2%, although there is great variability between regions (UNAIDS 2009).

In contrast, the number of HIV infections in the UK is much smaller. HIV in the UK is concentrated among specific populations rather than the generalised epidemic seen in sub-Saharan Africa. In 2008, there were an estimated 83,000 people living with HIV (both diagnosed and undiagnosed), equivalent to 1.3 per 1000 population in the UK (Health Protection Agency 2009). In that same year, 7,798 people were newly diagnosed with HIV. The global epidemic is reflected in the UK; around 38% (2,790) of these newly diagnosed infections were among black Africans who acquired their HIV through heterosexual contact. It is thought that most (87%) of these infections among black Africans in the UK were acquired abroad, mainly in sub-Saharan Africa (Health Protection Agency 2009).

1.1.1. Late Diagnosis

Late diagnosis of HIV is the most important factor associated with HIV -related disease and death in the UK (British HIV Association 2008). Patients diagnosed late are more likely to become ill (Health Protection Agency 2007), have impaired response to medication (Stöhr et al. 2007) and increase costs to healthcare services (Krentz et al. 2004). Late diagnosis is defined as diagnosis taking place after anti-retroviral treatment (ART) would normally have begun, or when the person has an

illness which defines them as having AIDS. It is measured using a blood test known as a CD4+ count; this test estimates how well the patient's immune system is working by counting white blood cells that are targeted and destroyed by HIV (CD4+ cells).

Previous guidelines from the British HIV Association (BHIVA) recommended that patients begin ART when their CD4 + count measured fewer than 200 cells/mm³. Since 2008, BHIVA have recommended ART should be considered for patients with a CD4 count below 350 cells/mm³. Consequently the proportion of people who fit the definition of late diagnosis has increased.

Late HIV diagnosis is a particular problem among black Africans (Burns 2008; Health Protection Agency 2008). In 2007, over 40% of new diagnoses among black Africans were classified as 'late' (Health Protection Agency 2008).¹ More recent estimates, which look at diagnoses among heterosexual men and women (95% of whom are black African), suggests that 61% of women and 66% of men are diagnosed with a CD4+ count of fewer than 350 cells/mm³ (Health Protection Agency 2009).

Estimates from anonymised data suggest that approximately 25% of HIV-positive, African born heterosexuals leave sexual health clinics undiagnosed (Health Protection Agency 2009). This could be because they refused or were not offered an HIV test. Lack of a diagnosis – or late diagnosis – can deprive people (including the partners of those infected) of treatment and support. It can also increase the potential for onward transmission of HIV.

1.1.2. History of HIV Testing

HIV testing was introduced in genitourinary medicine (GUM) clinics in the UK in 1985. At that time HIV infection was often accompanied by stigma and discrimination, with very little to offer in the way of effective medication. Civil libertarians and gay rights advocates feared that HIV may become defined as a "dangerous disease" with registries of infected persons, and the possibility of behavioural restrictions, and even quarantine, imposed on those infected (Bayer 1991). There was broad consensus that people should only be tested with informed, voluntary and specific consent; this differs from the procedure used for other blood tests, which are usually obtained with the "presumed consent" of the patient. As a result pre- and post-test counselling has usually accompanied HIV testing. This process of managing HIV differently to other chronic and infectious health conditions became known as HIV exceptionalism (Bayer 1991).

In 2008, while acknowledging that stigma is still associated with HIV infection, BHIVA published HIV testing guidelines that encourage the 'normalisation' of HIV testing. The guidelines seek to place HIV testing within the competence of any doctor, midwife, nurse or trained healthcare worker by formally addressing misconceptions about pre-and post-test discussions. Specifically, they state that lengthy pre-test HIV counselling is not a requirement and that the primary purpose of the pre-test discussion was to establish informed consent for HIV testing (British HIV Association 2008).

¹ Defined as being diagnosed with CD4 count < 200cells/mm³

1.1.3. Benefits of HIV testing

HIV testing can help reduce transmission of the virus. People who find out they have HIV may change their sexual behaviour as a result of the diagnosis. For example, they may start using condoms with partners who are not HIV-positive or whose HIV status is unknown (Weinhardt et al. 1999; Coates et al. 2000; Marks et al. 2005). In addition, people diagnosed with HIV may choose to receive anti-retroviral therapy, which suppresses the virus and can reduce further transmission. A negative HIV test provides an opportunity for preventive education and advice, and may also lead to changes in behaviour. For example, people who find out they do not have HIV might use condoms or have non-penetrative sex with partners who have HIV (or whose HIV status is unknown). Increasing the frequency of testing may result in earlier detection of HIV following infection - when it is most virulent - providing greater opportunity to reduce transmission.

1.2. Aims and Objectives

The aim of this project was to systematically review qualitative literature that identifies the barriers and facilitators to the uptake of HIV testing among African communities in England.

1.3. Research Questions

The review addresses one overarching question from the NICE scope:

- What factors help or hinder the uptake of HIV testing by black African communities living in England and how can the barriers be overcome?

A primary question was developed in order to explore the overarching question:

- What interventions have successfully reduced the social, personal and cultural barriers associated with testing among black African communities in the UK?

In addition to exploring the barriers and facilitators to accessing interventions, the review also explored secondary questions relating to the social and cultural factors associated with HIV testing:

1. What (if any) are the adverse or unintended consequences (positive or negative) of the interventions?
2. What environmental, social and cultural factors prevent or support the uptake of HIV testing?
3. How does HIV-related stigma affect the uptake of HIV testing?

1.4. Operational definitions

Black African: Black African communities encompass diverse population groups from a range of countries. The term also encompasses people who identify themselves as being black African – whether they are migrants from Africa, African descendants or African nationals. Throughout this review, ‘black African’ is used to describe all of these groups.

1.5. Review Team (Alphabetical order)

| Team member / expertise | Project role |
|--|--|
| Dr Fiona Burns, NIHR Clinical Lecturer, Centre for Sexual Health and HIV Research. Programme Lead: Migration Ethnicity and Sexual Health (MESH) Programme | Overall management responsibility for the project, third reviewer in study selection. Commented on various drafts of the report and contributed to writing of report. |
| Ms Ibidun Fakoya, Research Associate, Centre for Sexual Health and HIV Research. Programme co-ordinator: African Communities HIV Research Programme. | Developed and executed search strategies, study selection, data extraction, and quality assessment of qualitative studies. Wrote the initial draft of the report and responsible for overall content of the final draft. |
| Professor Graham Hart, Head of the Department of Infection and Population Health and Director of the Centre for Sexual Health and HIV Research, University College London. | Overall management responsibility for the project. Commented on various drafts of the report and contributed to writing of report. |
| Dr Audrey Prost, Lecturer in International Health, Centre for International Health and Development, University College London. | Study selection, data extraction, and quality assessment of qualitative studies. Commented on various drafts of the report and contributed to writing of report |

Declaration of interests

Review team members were authors of four of the ten papers selected for inclusion in this review, and both IF and AP were joint authors of one paper. While we acknowledge the conflict of interest that this may present, we have consistently and systematically applied the reviewing criteria set by NICE in order to counter our own biases in the selection and presentation of studies.

2. Methodology

2.1. Search Strategy

Nineteen electronic databases were searched using detailed search strategies developed by the review team in collaboration with information specialists at NICE (see Appendix A). Searches were restricted to studies published since 1996 (the introduction of highly active antiretroviral therapy - HAART) and written in English. The results were downloaded into a de-duplicated database in Reference Manager 11 (Thomson ResearchSoft). Items which were not able to be downloaded were saved into separate Microsoft Word or Excel documents.

The following databases were searched:

- Allied and Complementary Medicine
- Cumulative Index to Nursing & Allied Health Literature
- IBSS
- EMBASE
- Cochrane Library databases
- Current Contents
- Database of Abstracts of Reviews of Effects
- Health Management Information Consortium
- Health Technology Assessment
- ISI Web of Science (Social Science Citation Index)
- Medline (Ovid) Includes Medline In-Process & Other Non-Indexed Citations
- PsychINFO
- Social Policy and Practice
- UK Clinical Research Network Portfolio Database
- AEGIS (AIDSLine and International AIDS Society abstract archives)
- Eric (Education Resources Information Centre)
- EPPI Centre
- NHS Evidence (National Library for Public Health and National Library for Ethnicity and Health)
- Popline

In addition, the websites of African-led community based organisations and other key websites were searched. The majority of the grey literature was retrieved from these searches.

Websites searched:

- African HIV Policy Network www.ahpn.org

- African HIV Research Forum www.ahrf.org.uk
- Avert www.avert.org
- Black Health Agency www.blackhealthagency.org.uk
- Centers for Disease Control (Diffusion of Effective Behavioural Interventions) www.effectiveinterventions.org
- Global Network of People Living with HIV (GNP+) www.gnpplus.net
- National Africa HIV Prevention Programme (NAHIP) www.nahip.org.uk
- Naz Project London www.naz.org.uk
- NICE website and former Health Development Agency www.nice.org.uk

The search process was documented by compiling the search strategies used to explore each resource (see sample search strategy in Appendix A). Audit information detailing numbers of records retrieved and retained from each resource, were also recorded.

2.2. Inclusion and exclusion criteria

2.2.1. Population

The review team had anticipated that there would be few studies about the barriers and facilitators to accessing HIV testing that focused exclusively on or included black Africans living in England. Our previous experience suggested that while some evidence on HIV testing among this specific population does exist, studies were conducted using research methods of low quality.

Although there is more evidence available about the barriers and facilitators to accessing HIV testing from studies conducted in Africa, we concluded that the generalisability of these studies to African communities in England is questionable for several reasons. First, HIV testing, health service provision and care referral pathways in resource poor settings are very different from those in England. Second, the process of migration can change individual behaviour and present barriers to HIV testing not found in the country of origin. Third, many people living in the UK who identify as black African are part of long established minority ethnic communities. HIV-related stigma within these communities and race-related prejudice from the wider community present challenges to HIV testing interventions not encountered in the African context. Finally, black African communities in the UK are far more heterogeneous than those in Africa. Country specific, tribal, cultural and linguistic differences are magnified in the UK context.

For these reasons we hypothesised that studies that examined HIV testing among other migrant or black and minority ethnic communities in England were more likely to reflect the experience of black African communities in England than those of black Africans living in Africa.

Black African men who have sex with men are not included in this review, but will be included in the guidance. Evidence about this population is included in a NICE

commissioned systematic review about increasing HIV testing among men who have sex with men.

Studies were eligible for inclusion if the study population included:

- Black African men and women living in England
- Other Black, Asian and Minority Ethnic groups living in England
- Sexual Health and HIV prevention, treatment and care providers working with Black, Asian and Minority Ethnic groups in England

2.2.2. *Outcomes*

Eligible studies:

- Studies that examine or describe awareness of how Black African communities in the UK view HIV testing and how they think the barriers to testing can be overcome.
- Studies that examine or describe attitudes towards HIV testing among Black Africans and service providers in the UK.
- Studies that describe or examine the environmental, social, cultural and personal barriers to HIV testing for both Black Africans and service providers.

2.2.3. *Study designs*

Types of studies considered for inclusion:

- document analysis studies;
- qualitative studies featuring observation and participant observation;
- qualitative studies featuring focus group discussion and
- qualitative studies featuring in-depth interviews.

2.3. ***Selection of Studies***

Studies were selected using a two stage screening approach. IF and AP used CPHE approved checklists to independently screen titles and abstracts.. Full paper copies of the selected studies were then screened and assessed independently by IF and AP using a full paper screening tool developed by the review team (Appendix B). Where agreement could not be reached about study inclusion FB acted as third reviewer for both screening phases.

In total 4370 references were retrieved from database and website searches. Reviewers identified 21 references eligible for full paper screening. Three additional references were provided by authors contacted to supply papers identified for full paper screening.

Figure 1 summarises the search results and the outcome of the screening process. Ten papers met the inclusion criteria for quality appraisal (Appendix C). Studies excluded at the full-paper screening stage, with reasons for their exclusion are presented in Appendix D.

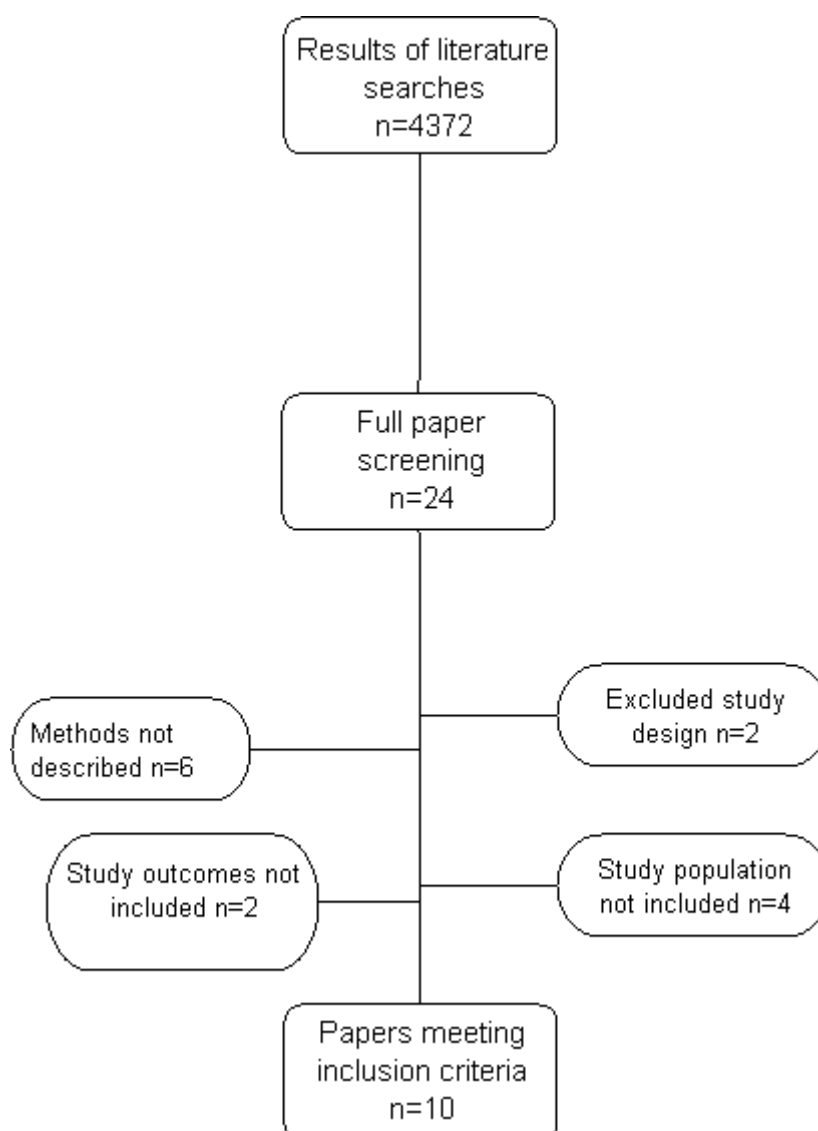


Figure 1. Summary of number of papers included and excluded at each stage in the study selection process

2.4. Data Extraction

For all included studies, data about the study population, setting, methodology, analysis and results was extracted from using evidence tables created in Microsoft Word (see Appendix K of the NICE Methods Manual). Data extraction was performed by one reviewer and checked for accuracy by another. Full evidence tables are presented in Appendix E.

2.5. Quality Appraisal

Nine papers were quality assessed by one reviewer (IF) and checked for accuracy by another (AP) using a Microsoft Excel Quality Appraisal checklist supplied by the NICE CPHE team (See Appendix H of NICE Methods Manual 2009). Review team members were authors of four of the ten papers and both IF and AP were joint authors of one paper. This paper was quality assessed by a PhD student (Sonali Wayal) at the Centre for Sexual Health and HIV Research and checked for accuracy

by IF. Disagreements about quality appraisal scores were resolved through consensus.

Each study received a quality rating for internal validity; this was rated according to a range of criteria which establish whether potential sources of bias have been minimised and if study conclusions are open to any degree of doubt.

Each study was rated ('++', '+' or '-') to indicate its quality:

- | | |
|----|---|
| ++ | All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter |
| + | Some of the checklist criteria have been fulfilled, where they have not been fulfilled or not adequately described, the conclusions are unlikely to alter |
| - | Few or no checklist criteria have been fulfilled and the conclusion are likely or very likely to alter |

Inter-rater reliability of the quality appraisal process was calculated using Kappa scores (SPSS 14.0):

- Internal validity Kappa score: 0.85

This score indicates there was a very good level of agreement between the two reviewers.

2.6. Data Synthesis

Nearly all the identified studies used Framework or Grounded Theory as the methodological approach to analysis. As a result, the review team decided that thematic meta-analysis would be the most appropriate method for synthesising the data. Contemporary health services research is mainly grounded in theoretical models which focus on targeting interventions at barriers and facilitators to behaviour change. Additionally the overarching and primary questions for this review explicitly addressed factors that help or hinder individual access to HIV testing. With these factors in mind, the review team attempted to understand and categorise the findings according to whether they represented barriers or facilitators to HIV testing.

Evidence tables were used as a tool to extract the findings and deconstruct the themes identified in each study. One reviewer coded the themes and sub-themes and these were checked for accuracy by another. Within each theme the findings were compared and contrasted, where appropriate with particular emphasis on the experiences of the different sub-populations in each study. The results are presented below in narrative summaries exploring each theme in detail.

2.7. Applicability Assessment and Formulation of Studies

Evidence statements for each theme were derived by examining the quality and consistency of the findings and assessing the applicability to the English context. The review team examined study groupings as a whole, assessing how similar (and applicable) the populations, settings, interventions and outcomes of the studies were

to black African communities in England. Following assessment, we categorised each evidence statement as:

- directly applicable
- partially applicable
- not applicable

3. Findings

3.1. *Overview of selected studies*

Ten papers met the inclusion criteria for this topic and underwent quality appraisal (Table 3.1). All studies were conducted in England using either semi-structured/in-depth interviews or focus groups to collect data. Three studies gathered opinions from key informants / stakeholders (for example, clinicians, public health commissioners and people living with HIV) working in the field of sexual health (Burns et al 2007, [++]; Prost et al 2007, [+]; Elam et al 2009 [-]). Four studies examined attitudes or barriers to HIV testing as part of a wider study exploring the experiences of black African people living with HIV (Paparini et al 2008 [-]; Chinouya & O’Keefe 2005 [+]; Chinouya 2006 [+]; Chinouya & O’Keefe 2006 [-]). Black Africans living with HIV were also participants in a further study (Burns (2009, [++]) which explored the reasons behind late diagnosis. Two studies collected data from patients attending non-GUM or HIV clinics: Nnoaham et al (2006, [++]) interviewed African-born patients attending a London TB clinic and Prost et al (2009, [++]) interviewed patients offered HIV testing as part of an intervention at a GP surgery. Table 3.1 summarises the studies and the quality scores (see Appendix E for full evidence tables).

The themes that emerged from the studies were categorised into two groups: “Factors that hinder the uptake of HIV testing” and “Factors that help the uptake of HIV testing”. Table 3.2 summarises the identified themes and sub themes.

3.2. *Quality Assessment*

Table 3.1 shows the quality ratings for each paper. Four studies were rated high [++], three medium [+] and three low [-]. Most of these qualitative papers were printed in medical or disease specific journals that mainly publish studies using quantitative methods. These journals often have word limits that generally restrict the amount of data authors can include. While assessing the included studies, reviewers were aware of the constrictions placed on qualitative researchers who publish in such journals. As a result we were not inclined to award low ratings [-] to papers that did not meet all the checklist criteria. In particular, studies that did not report the role of the researcher, data storage, triangulation or describe the context in detail, were still able to achieve high [++] or medium [+] scores.

Table 3.1 Summary of included studies

| Study & Rating | Aim | Population and Method | Overview of (review) themes |
|---------------------------------|---|--|--|
| [++] rated studies (n=4) | | | |
| Burns et al, 2007 [++] | To identify key issues influencing service uptake by HIV positive Africans. | Semi-structured interviews with key informants working in the field of sexual health | Stigma; perceived personal risk; (lack of) confidentiality; accessibility & opportunity; migration and cultural norms; gender; community involvement |
| Burns 2009 [++] | To develop a contextual understanding of the factors contributing to late presentation to HIV services for Africans in Britain. To elicit suggestions on means of improving access to HIV services | In-depth interviews with newly diagnosed HIV positive Africans | Stigma; perceived personal risk; perceived benefits; (lack of) confidentiality; accessibility & opportunity; migration and cultural norms; gender; community |
| Nnoaham et al, 2006 [++] | To explore the experiences and perceptions of African-born people in London living with TB, focussing on issues influencing voluntary presentation and treatment adherence and experiences of stigmatisation. | In depth interviews with patients attending non-GUM/HIV clinics | Stigma |
| Prost A et al, 2009 [++] | To explore the acceptability of rapid HIV testing among patients attending new health check. | In depth interviews with patients attending non-GUM/HIV clinics | Accessibility & opportunity; speed of results; isolation |
| [+] rated studies (n=3) | | | |
| Chinouya 2006 [+] | To explore how Africans parents in UK make sense of the language of children's rights. To explore reasons for telling or not telling children that HIV affects them. | Semi structured interviews with HIV positive Africans | Stigma; isolation |

| Study & Rating | Aim | Population and Method | Overview of (review) themes |
|--------------------------------|---|--|---|
| Chinouya & O'Keefe 2005 [+] | To explore how religion plays a part in the lives of Africans living with HIV in Milton Keynes. | Semi structured interviews with HIV positive Africans | Stigma; isolation; perceived personal risk; accessibility and opportunity |
| Prost et al, 2007 [+] | To determine whether service model of VCT from Kenya would be acceptable to African communities in London and feasible in the context of NHS clinical governance. | Focus group discussions with HIV positive Africans. Focus group discussions with key informants working in the field of sexual health. | Speed of results; accessibility and opportunity; stigma; confidentiality; community involvement |
| [-] rated studies (n=3) | | | |
| Chinouya & O'Keefe 2006 [-] | To explore the meaning of <i>Ubuntu-Hunhu</i> and the applicability of this concept in human rights discourses. To investigate how the concept of <i>Ubuntu-Hunhu</i> might help to offer a human rights approach for those living with HIV and its transferability to non-health settings. | Semi structured interviews with HIV positive Africans | Accessibility and opportunity; isolation; confidentiality |
| Elam et al, 2009 [-] | Explore which approaches to HIV testing are effective in raising the numbers of people who are aware of their HIV status and detecting undiagnosed HIV. | Roundtable discussions with key informants working in the field of HIV and sexual health | Stigma; perceived personal risk; perceived benefits; accessibility & opportunity; migration and cultural norms; community involvement |
| Paparini S et al, 2008 [-] | To explore the experiences of a group of black African men who define themselves as gay and are living with HIV in the UK | Semi structured interviews with HIV positive Africans | Accessibility & opportunity; perceived personal risk |

The three studies rated low [-] had substantial omissions in their reporting. Papparini et al, (2008 [-]) based their findings on eight subjects who were not purposively or theoretically sampled. The paper did not include any data extracts to support the findings. The methods used by Elam et al, (2009 [-]) were not reliable: it was unclear how participants were selected; the data were not fully transcribed; there were few data extracts and the method of analysis was unclear. Chinouya & O'Keefe (2006 [-]) did not describe their sampling strategy well. Many of the conclusions are unclear and the authors do not discuss the limitations of the study or explore any alternative explanations for the findings. Where possible data extracts from the studies were used to illustrate themes. Several of the quotes used are from papers authored by FB or AP as these papers included more raw qualitative data than the others.

Table 3.2 Themes emerging from included studies

| Theme | Subtheme | Number of studies discussing theme |
|--|-------------------------------|---|
| <i>Factors that hinder the uptake of HIV testing</i> | | |
| Stigma | | 6 |
| | Isolation | 5 |
| Perceived personal risk | | 5 |
| Gender | | 3 |
| Migration and cultural norms | | 3 |
| Accessibility and opportunity | | 8 |
| | Confidentiality | 4 |
| <i>Factors that help the uptake of HIV testing</i> | | |
| Accessibility and opportunity | | 7 |
| | Speed of results | 3 |
| Community Involvement | | 4 |
| | Perceived benefits of testing | 2 |

Factors that hinder the uptake of HIV testing

3.3. Stigma

The negative impact of HIV-related stigma on HIV testing was explored in seven studies (Burns et al, 2007 [++]; Burns 2009 [++]; Nnoaham et al, 2006 [++]; Chinouya 2006 [+]; Chinouya & O'Keefe 2005 [+]; Prost et al, 2007 [+]; Elam et al, 2009 [-]).

In all seven studies, HIV-related stigma was discussed in general terms, describing how participants feared the reactions, feelings and expectations of others in relation to either being diagnosed with HIV or going for an HIV test.

“Even if you go [for a test] and you're negative they can't believe it. They say, ah, she's been there, she's happy, that means that she's lying. As long as you come here they want to know.” (33 year-old Zimbabwean woman. Burns 2009, [++])

“I happened to mention to this friend of mine ‘oh, I'm going for an HIV test’... and she said ‘well why do you want to know?’. You know, as if I was stupid to talk about having an HIV test. Well you know, it's not about you, but actually I'm stigmatised with HIV.” (Female participant (South Africa), women's group. Prost et al, 2007 [+])

“These days, if you have TB they say it's AIDS. If you have pneumonia, they say it's AIDS. If you have common fever, make sure you stay inside your house! Once you lose one kilogram, you're finished. Some won't even shake your hands or eat with you, The stigma is too much. So people prefer to die” (37 year old man, Nigeria. Nnoaham et al, 2006 [++])

Four studies (Burns et al, 2007[++]; Burns 2009 [++]; Prost et al, 2007 [++]; Elam et al, 2009 [-]) explored how fear of high levels of HIV-related stigma - specifically within African communities in England- acted as a barrier to HIV testing. Burns (2009 [++]) conducted a study with newly diagnosed Africans living in London. It described how participants felt the disease was strongly associated with promiscuity and inappropriate sexual behaviour. They discussed feeling viewed by others within African communities as a threat of infection.

“And people, they find like it's a laughing thing if you've got HIV, they feel like maybe you're the most dirtiest person, you know. It's not like it's just proper sex, they think maybe you've been sleeping with so many man [sic], that's the way they put it.” (34 year-old Malawian woman. Burns 2009 [++])

Participants in a study with 11 key informants working in sexual health with Africans in the UK, Burns et al (2007 [++]) concluded that fear of stigma within African communities in England was predominantly due to the perception of HIV as a deadly disease, directly resulting from home country experience.

“There is a set of assumptions that an HIV diagnosis is an immediate death sentence because that's the experience they've come from... So there is a vision of what HIV means which I think colours a lot of stuff.” (Clinical informant. Burns et al, 2007[++])

Other studies (Prost et al, 2007 [++]; Burns 2009 [++]) suggested that HIV was virtually invisible in England in comparison to some parts of Africa where media and educational campaigns increased awareness of HIV. This low visibility and

general lack of positive imagery about HIV meant that Africans in England may face stronger HIV-related stigma than in Africa.

“I wouldn’t think that there is HIV in this country. It’s totally different. You wouldn’t think, and I’ve never come across a person who I’d say I suspect, no. I don’t want to lie, I don’t think. Maybe because people have the thing because of the medication, the food, everything, their lives, whatever, you won’t think.” (38 year-old Malawian woman, Burns 2009 [++])

Fear of HIV-related stigma within African communities was compounded by fear of prejudice and racism from the wider community (Burns et al, 2007 [++]; Prost et al, 2007 [++]; Elam et al, 2009 [-]).

“In Kenya it’s [Voluntary Counselling and Testing for HIV] for the general population where... 30%, 25% of the population are HIV positive, and even if there is still a lot of stigma, almost everyone knows somebody who is HIV positive [...] and when you just transfer that here, African communities, ... there is something that says we’re being targeted, ‘we’re the one’s that have the virus’ Why not make it community, but community to everyone”. (Female participant (Zambia), mixed focus group discussion. Prost et al, 2009 [++])

“Africans are seen as vectors of infection. Testing in this environment just reinforces prejudices.” (Voluntary sector. Burns et al, 2007 [++])

3.3.1. Fear of Isolation

In the studies that focussed on the experiences of African people living with HIV in England (Burns 2009 [++]; Chinouya 2006 [+]; Chinouya & O’Keefe 2005 [+]), the fear of isolation and social exclusion following disclosure was mentioned as a specific disincentive to test. In their study exploring how African parents in England talk about living with HIV with their children, Chinouya (2006[+]) described how fear of stigma led some parents to test their children for HIV without their knowledge or consent.

“No. I would not trust an under 10...they would just talk that there is HIV or whatever at home, but then it’s what comes after that. ‘Cause if their class mates they will take the information to their parents and the other children will be told not to associate with those people. That is why I say that it’s too early for them. They may share the information with their friends and their friends will go and tell their parents, and the parents will say you must not play with them and the kids will suffer” (father. Chinouya 2006 [+])

In another study, Prost et al (2009 [++]) explored the advantages and disadvantages of rapid testing as part of the new patient health check at a GP surgery. The potential lack of support for newly diagnosed people living HIV was mentioned as a disadvantage for rapid testing in primary care.

“I would also be concerned about the psychological support, if someone came up positive, about how the GPs would be able to cope with that. Maybe they’d have special training, maybe they already know how to cope with that. But in a sexual health clinic, I’m sure they already have special training.” (Male participant, UK. 24 Prost, 2009 [++])

Evidence Statement 1: Stigma as a barrier to HIV testing

ES 1.5. Four studies report that HIV is highly stigmatised within African communities living in England. These studies were conducted with men and women, some living with HIV and with experts working in the field of sexual health and HIV. (Burns et al, 2007[++]; Burns 2009 [++]; Prost et al, 2007 [++]; Elam et al, 2009 [-]) One of these studies, with key stakeholders working in sexual health and HIV finds this stigma is thought to be fuelled by perceptions that HIV is a deadly disease (Burns et al, 2007 [++]).

ES 1.6. Two studies, one with people newly diagnosed with HIV and another with people from African communities in England report that low visibility of HIV and lack of positive imagery increase HIV related stigma within African communities (Prost et al, 2007 [++]; Burns, 2009 [++]).

ES 1.7. Reluctance to undergo HIV testing due to fear of racism and prejudice from outside African communities is found in three studies with key stakeholders working in sexual health and HIV research. (Burns et al, 2007 [++]; Prost et al, 2007 [++]; Elam et al, 2009 [-])

Fear of Isolation

ES 1.8. Four studies report fear of isolation and social exclusion following HIV diagnosis as a barrier to HIV testing. (Burns 2009 [++]; Chinouya 2006 [+]; Chinouya & O'Keefe 2005 [+]; Chinouya & O'Keefe 2006[-]). Another study of patients attending a GP surgery finds lack of psychosocial support as a potential disadvantage to rapid testing in primary care. (Prost et al, 2009 [++])

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

3.4. Perceived personal risk

Low perception of personal risk as a barrier to HIV testing was identified and explored in five studies (Burns et al, 2007 [++]; Burns 2009 [++]; Elam et al 2009 [-]; Chinouya & O'Keefe 2005 [+]; Paparini et al, 2008 [-]). Two studies with key informants working in African communities affected by HIV suggested that low perception of personal risk was an extension of the stigma associated with HIV transmission (Burns et al, 2007 [++]; Elam et al, 2009 [-]). Individuals associate HIV acquisition with unfaithfulness, promiscuity and other risk behaviours with which they themselves do not identify.

In three studies with people living with HIV few participants perceived themselves to be at risk of HIV infection prior to diagnosis (Burns 2009 [++]; Chinouya & O'Keefe 2005 [+]; Paparini et al, 2008 [-]). Supporting the views of the key informants, participants in these studies believed that their behaviours did not put them at risk of HIV infection.

“In Ghana we are not very promiscuous. South Africa, Botswana, they are promiscuous because I have been there, I know how the places, how they are.” (39 year old Ghanaian man, Burns 2009 [++])

Some participants in these studies only perceived themselves to be at risk of HIV after becoming seriously ill or enduring persistent illness that disrupted their every day lives.

“I had difficulties in breathing...I could not go to work” (male, Chinouya & O’Keefe 2005 [+])

Additionally, risk perception was raised if participants: suspected infidelity in current or previous partners (Paparini et al, 2008 [-] Chinouya & O’Keefe 2005 [+]Burns 2009 [++]); had been informed about the death/illness of a child or a concurrent or previous sexual partner of their spouse (Burns 2009 [++]; Chinouya & O’Keefe 2005 [+]); or had multiple rape experiences (Burns 2009 [++]).

“I was worried about HIV as you can’t have sex with more than 100 men and not think about HIV” (31 year old Ugandan woman. Burns 2009 [++])

Evidence Statement 2: Lack of perceived personal risk as a barrier to HIV testing

- ES 2.1 Five studies report that there was low perception of personal risk among people from black African communities in England. (Burns et al, 2007 [++]; Burns 2009 [++]; Elam et al 2009 [-]; Chinouya & O’Keefe 2005 [+]; Paparini et al, 2008 [-]). Two of these studies conducted with key stakeholders working in sexual health and HIV and including people living with HIV find that this was due to HIV transmission being associated with stigmatised behaviours such as sexual promiscuity and unfaithfulness. (Burns et al, 2007 [++]; Elam et al, 2009 [-]).
- ES 2.3. Participants in three studies with people living with HIV attending HIV clinics or HIV support groups (two with African men and women and one with African men who have sex with men) had only perceived themselves to be at risk of HIV after becoming seriously ill. (Burns 2009 [++]; Paparini et al, 2008 [-];Chinouya & O’Keefe 2005 [+];)
- ES 2.4 Increased risk perception is reported by participants who suspected infidelity in current or previous partners in two studies with HIV positive African men and women attending HIV clinics or support groups (Chinouya & O’Keefe 2005 [+]Burns 2009 [++]) and one with HIV positive African men who have sex with men (Paparini et al, 2008 [-]).
- ES 2.5 Two studies conducted with black African men and women living with HIV recruited in HIV clinics or HIV support groups report increased risk perception by participants who had been informed about the death/illness of a child or a concurrent or previous sexual partner of their spouse (Burns 2009 [++]; Chinouya & O’Keefe 2005 [+]).

ES 2.6 One study conducted with black African men and women newly diagnosed with HIV recruited in HIV clinics reported raised perception of risk by a participant who had multiple rape experiences (Burns 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England with black African people.

3.5. Gender

Burns (2009 [++]) explored the differences in risk perception between men and women and found that denial of HIV risk was particularly evident in the accounts given by men. The study cites the examples of men who did not accept they were at risk of HIV despite their wives or their children testing HIV positive.

“Occasionally you’d think about it but then you want to be, you want to brush it off your mind and you say, oh no, not me, it’s someone else have it, not you. No, you are careful but you are not because sometimes you have unprotected sex as well.” (39 year-old Ghanaian man. Burns, 2009 [++])

Similarly, another study found that women diagnosed in antenatal clinics were left with the burden of referring their partners to HIV testing (Chinouya & O’Keefe 2006 [-]). In some cases their partners had not believed them.

“He just said ‘don’t worry you know sometimes these machines make mistakes [laughs]’ (A mother, Chinouya & O’Keefe 2006 [-])

Burns et al (2007 [++]) also mentioned the influence of gender on HIV testing. Informants in this study suggested that African men lack a “front door” to services (compared to women who access services for pregnancy and childcare issues). Men were seen as greater risk takers and less willing to seek help unless absolutely necessary.

Burns (2009 [++]) found that gender inequalities, and the subjugated position of African women in society, influenced women’s ability to control the risk of HIV exposure; it also impacted on some women’s ability to access HIV services.

“And could a woman ask a man to have an HIV test?”

It’s difficult to in our culture, for really approaching, say, your husband and telling him that we should go for an HIV test is really difficult. I don’t lie to you, it’s difficult. Because most of the time we see men as the head of the house and then the women are still like subordinates, yes. You can be educated, you have a nice house, have money but still the men will always be on top, that’s how it is in our culture” (29 year-old South African woman. Burns 2009 [++])

Evidence statement 3: Gender as a barrier to HIV testing

ES 3.1 One study with black Africans attending HIV clinics and living with newly diagnosed HIV in London reports that denial of HIV risk had been more predominant in male participants. For example some men would not test for

HIV despite their female spouses and/or children testing HIV positive. (Burns 2009 [++]).

- ES 3.2 Men were described as having fewer opportunities to test for HIV in one study with key stakeholders working in sexual health and HIV in African communities in England. (Burns et al, 2007 [++]). Another study of Zimbabwean men and women living with HIV and attending HIV clinics or support groups, finds that men were not being offered HIV testing in ante-natal services alongside their partners (Chinouya & O’Keefe 2006 [-]).
- ES 3.3 One study with newly diagnosed African men and women recruited in HIV clinics in London finds that African women have less ability to control their risk of HIV exposure and less ability to access services (Burns 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England with black African people.

3.6. Migration and cultural norms

The difficulties encountered by migrants were identified as a key factor impacting on HIV testing uptake by key informants in three studies (Burns et al, 2007 [++]; Burns, 2009 [+]; Elam et al, 2009 [-]). Economic hardship due to under- or unemployment, pressure to work in order to send funds back home; disempowerment due to uncertain immigration status; childcare and housing were mentioned in all three studies as issues that take precedence over health and seeking an HIV test, even when unwell.

“You want an HIV test, you are not sure whether you are HIV or not but you have got to go there, queue for, I don’t know, 4 hours sometimes and wait. A lot of people are just going to say, well - and most people are being paid per hour in this country and they aren’t going to, you know, wait for 4 hours because that’s about half-a-day’s wage they’re going to lose in there.” (30 year-old Zimbabwean man, Burns, 2009 [++])

One study (Burns et al, 2007 [++]) mentioned cultural norms, that is, experiences and ideals people bring with them when they migrate. Key informants in this study suggested that most Africans would be unfamiliar with the concept of an open access sexual health clinic where a person would routinely test for HIV, even if feeling well. The importance of the oral tradition within African societies and the reliance of word-of-mouth were seen as the basis for perpetuating fear and stigma around HIV transmission. Individuals would therefore find it difficult to access appropriate information about HIV testing and health services.

Evidence statement 4: Migration and cultural norms as a barrier to HIV testing

- ES 4.1 Three studies conducted with key stakeholders working in sexual health and newly diagnosed HIV positive African men and women attending HIV clinics report on difficulties faced by migrant Africans, such as

economic hardship (including under- or unemployment); uncertain immigration status; childcare; housing and the pressure to send money home to Africa. These issues were said to take precedence over health and seeking an HIV test, even when experience ill-health. (Burns et al, 2007 [++]; Burns, 2009 [+]; Elam et al, 2009 [-])

ES 4.2 Preventative health seeking behaviour, that is accessing HIV testing when well, was seen an unfamiliar concept to Africans in one study with key stakeholders working in sexual health and HIV among African communities in England (Burns et al, 2007 [++]).

ES 4.3 One study with newly diagnosed African men and women recruited in an HIV clinic reported that the reliance on oral traditions in African societies made it difficult for migrant Africans in England to obtain appropriate information about HIV testing (Burns 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

3.7. Accessibility and opportunity

Poor access to services and missed opportunities to undergo HIV testing in primary care or antenatal clinics were mentioned in seven studies (Burns et al, 2007[++]; Burns 2009 [++]; Chinouya & O'Keefe 2005 [+];Chinouya & O'Keefe 2006, [-] Elam et al, 2009 [-]; Prost et al, 2007 [+]; Prost et al, 2009 [++]). Three of these studies report that the pathways to HIV testing are sometimes not straightforward. Patients are often referred from their initial point of contact (for example, a GP surgery) to a sexual health clinic. This often means multiple visits to health services before an HIV test is undertaken.(Burns et al, 2007[++]; Burns 2009 [++];Elam et al, 2009 [-];)

“One of the biggest barriers to HIV testing is how poorly accessible health services are in the UK. It's only when you're very, very sick that you're persistent. So people who access [HIV services] normally will have been to four or five different health facilities before they end up [here] - time and time again that's what you see.”(Clinical practitioner, Burns et al 2007 [++])

Female participants in one study (Chinouya & O'Keefe 2006, [-]) recounted how they had expected joint testing with their husbands while attending ante-natal care but had been tested individually for HIV. Participants in two other studies (Burns, 2009 [++]; Chinouya & O'Keefe 2005 [+]) described occasions where they themselves had identified HIV as the underlying cause for their illness but the GP had dismissed their fears without testing.

“Like the very first day when I went to see [the GP], I told her I've got some rashes that I don't know where they're coming from and I heard some people with HIV they do develop some symptoms, then she goes, ah, I don't think it's that. So that's what made me think I was ok ... that.” (27 year-old Zimbabwean woman. Burns 2009 [++])

*“My GP told me that having continuous diarrhoea does not mean you are HIV”
(Female, Chinouya & O’Keefe 2005 [+])*

Participants associated sexual health clinics with complex appointment systems, long waiting times, a perceived lack of confidentiality and stigma attached to sexually transmitted diseases. (Prost et al 2007 [+]; Burns et al 2007 [++]; Burns 2009 [++]; Prost et al 2009 [++]).

I thought [that] if you wanted to get and HIV test it would be really hard normally. [...]I just didn’t know GPs would offer it at all. I though you had to go to a GUM clinic or go and queue in a long hospital queue or something. (Female participant, UK, 22. Prost et al 2009 [++])

3.7.1. Confidentiality

Four studies (Chinouya & O’Keefe, 2006 [-]; Burns et al, 2007 [++]; Burns 2009 [++]; Prost et al, 2007 [+]) discussed how individuals are deterred from testing by a lack of trust in service providers to keep either the act of an HIV test or an HIV positive diagnosis confidential. In one study examining the feasibility and acceptability of HIV testing in non-healthcare related, community based settings, participants raised concerns about potential breaches of confidentiality (Prost et al, 2007 [+]).

“People’s biggest fear is their result being known in their particular community, (...) the fear of ‘do they know my auntie, do they know my...’ Even if they are supposed to be confidential, that for me would be the biggest concern” (Prost et al, 2007[+])

Chinouya & O’Keefe (2006 [-]) also explore the possibility that policies designed to preserve individual confidentiality in ante-natal clinics may prevent joint HIV testing of couples. This then places the burden of disclosure on HIV positive women, who may fear telling their husbands to go for an HIV test.

“So I could not believe that was the issue, so I began to cry and then I said ‘You must phone my husband and ask him to come to the hospital and tell him. Because for me to go home and tell him this story I don’t think he is going to understand. So you must tell me when he is there. It will be better for me...’ they told him and gave baba [husband] a letter to go and be tested... I would not do that!” (A mother Chinouya & O’Keefe 2006 [-])

“Confidentiality at times... when you tell [the] person alone...is killing us” (A widowed mother Chinouya & O’Keefe 2006 [-])

Evidence Statement 5: Accessibility and Opportunity as a barrier

ES 5.1 Six studies conducted with African men and women living with HIV or key stakeholders working with these communities report that complicated pathways to GUM clinics, for example multiple referrals from general practitioners, delayed HIV testing, resulting in late diagnosis (Burns et al, 2007[++]; Burns 2009 [++];Chinouya & O’Keefe 2006 [-]; Chinouya & O’Keefe 2005 [+]; Elam et al, 2009 [-]; Prost et al, 2009 [++]).

- ES 5.2 Participants in two studies of African men and women living with HIV and attending HIV clinics or support groups report that GPs had failed to test them having dismissed their fears about HIV (Burns, 2009 [++]; Chinouya & O’Keefe 2005 [+]).
- ES 5.3 Four studies reported that HIV testing in sexual health clinics was seen as stigmatising, complicated and time consuming. These studies were conducted with African men and women living with newly diagnosed HIV and attending HIV clinics (Burns 2009 [++]), patients recruited as part of a study examining the feasibility and acceptability of HIV testing as part of a new GP health check (Prost et al 2009 [++]) and with key stakeholders working in sexual health and HIV with African communities (Prost et al 2007 [+]; Burns et al 2007 [++]).
- ES 5.4 Four studies conducted with African men and women living with HIV attending HIV support groups or HIV clinics and key stakeholders working in sexual health and HIV find that fears of breaches in confidentiality in clinical or community-based HIV testing services deterred individuals from accessing these services (Chinouya & O’Keefe, 2006 [-]; Burns et al, 2007 [++]; Burns 2009 [++]; Prost et al, 2007 [+]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

Factors that help the uptake of HIV testing

3.8. Improving accessibility and opportunity

Seven studies (Burns et al, 2007 [++]; Burns 2009 [++]; Chinouya & O’Keefe 2005 [+]; Chinouya & O’Keefe 2006 [-]; Elam et al, 2009 [-]; Prost et al, 2007 [+]; Prost et al, 2009 [++]) explored how increased opportunities for testing and more accessible services could increase HIV testing in black African communities in England.

Two studies (Chinouya & O’Keefe 2006 [-]; Elam et al, 2009 [-]) reported joint testing in ante-natal clinics as beneficial to women who may test positive but fear disclosing their HIV positive status to their male partners.

Participants in one study (Elam et al, 2009 [-]) suggested the ability of GUM clinics to provide better services by expanding opening times and quicker appointments was limited. The same study also reported big differences in the capacity of GUM services within and outside London, but did not identify the reasons for these differences.

Two studies with people living with HIV (Burns 2009 [++]; Chinouya & O’Keefe 2005 [+]) described how participants had seen the opportunistic offer of an HIV test in hospital settings as beneficial or routine.

Offering HIV testing in GP surgeries, community based organisations or faith based organisations was generally seen to be acceptable by participants in five studies (Burns 2009 [++]; Chinouya & O’Keefe 2005 [+]; Elam et al, 2009 [-]; Prost et al, 2007 [+]; Prost et al, 2009 [++]). Participants felt that the stigma, delay and complex nature of accessing testing in GUM was avoided by testing in these settings. Testing in GP surgeries increase the perception of HIV testing as routine.

“Interviewer: Do you think GPs should have these tests?”

Interviewee: Oh, yes. They should have them because this will enable a lot of people to find out in time. You know, sometimes to go to some AIDS clinic, once you go there, once you go in, people just know what you’re there for. They know you most probably have some sexual disease going down there. [...] With the AIDS clinic, you don’t go there until when you know you have a problem, so I think the GP having it is good.”
(Male participant, Nigeria, 28. Prost et al 2009 [++])

“How do you think we could improve health services?”

I think GPs are the key. Everyone goes to the GP. You only go the hospital if you are really sick. People are scared to come to this place [Sexual Health Clinic].” (31 year-old Ugandan woman .Burns 2009 [++])

“No one actually has the guts to take it from the hospitals and take it into the community, so it has become a taboo. So you have to find ways of breaking that taboo”
(Female participant – Zimbabwe, young people’s focus group discussion. Prost et al, 2007 [+])

3.8.1. Speed of results

Rapid testing allows patients to receive their results almost immediately, whereas standard testing results are received after two weeks. Participants in three studies

(Elam et al, 2009 [-]; Prost et al, 2007 [+]; Prost et al, 2009 [++]) suggested that reducing the waiting time for results was an advantage that makes testing more accessible.

“My friends have told me that the main reason that they haven’t gone for a test is because the results takes too long. I think the advantage with this service is that in 15 minutes you know your results. I do not think it matters where the service is, people will use it.” (Female participant (UK/Ghana), young people’s focus group discussion. Prost et al, 2007 [+])

In one study, a participant suggested that rapid testing as part of new patient health checks in GP surgeries could be a problem if patients were unprepared for the test (Prost et al, 2009 [++]).

Because it is so quick, you know, 20 minutes [...] especially if people hadn’t maybe even, you know, gone in for that test, and then kind of thought, “oh well I might as well try it”, and then, and I’m sure it’s a very sort of, small minority that actually would have a positive test, but you know, if they did, then it could be a real shock. (Female participant, UK, 27. Prost et al, 2009 [++])

Evidence Statement 6: Improving accessibility and opportunity

ES 6.1 Two of studies describe how participants (African men and women living with HIV attending HIV clinics or HIV support groups) had seen opportunistic offers of HIV testing in hospital as beneficial or routine (Burns 2009 [++]; Chinouya & O’Keefe 2005 [+]).

ES 6.2 HIV testing outside of GUM clinics (for example in GP surgeries, community- or faith-based venues) is found to be acceptable in five studies conducted with people living with HIV recruited in HIV clinics and HIV support groups, (Burns 2009 [++]; Chinouya & O’Keefe 2005 [+]); key stakeholders working in sexual health and HIV (Elam et al, 2009 [-]; Prost et al, 2007 [+]) and patients recruited as part of a study examining the feasibility and acceptability of HIV testing in GP surgery as part of new patient health check (Prost et al, 2009 [++]). Two studies with African men and women living with HIV attending HIV support groups (Chinouya & O’Keefe 2006 [-]) and with key stakeholders working with these communities (Elam et al, 2009 [-]) reported joint testing in ante-natal clinics as beneficial to women who may test positive but fear disclosing their HIV positive status to their male partners.

Speed of results

ES 6.3 Three studies with key stakeholders working in sexual health and HIV (Elam et al, 2009 [-]; Prost et al, 2007 [+]) and patients offered an HIV test as part of a new patient health check in a GP surgery (Prost et al, 2009 [++]) find that rapid testing and quick access to HIV test results is seen as advantageous and accessible

ES 6.4 One study with patients attending a GP surgery reports the belief that rapid testing as part of a new patient health check in GP surgeries might be

problematic if patients were unprepared for an for an HIV test (Prost et al, 2009 [++]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England and included black African people.

3.9. Community involvement

Four studies (Burns et al, 2007; Burns 2009 [++]; Prost et al 2007 [+]; Elam et al, 2009 [-]) explored how involving African communities in the development, delivery and dissemination of information about testing interventions could increase the uptake of HIV testing among African communities. Participants in these studies said that information about how to access HIV testing services or how the testing process worked was not freely available in African communities. They suggested that the success of innovative behavioural or structural interventions was dependent on widespread community advocacy, outreach and education programmes that raised awareness of available services.

“It is not out there in my college, you know, that you could see signs, that there is counselling over there or that kind of stuff. They do not know anything about it. If you can get the counsellors out of their offices to go around and talk about the work, it would help. (...)” (Female participant (Zimbabwe), young people’s group. Prost et al, 2007 [+])

Although increasing the visibility of HIV testing services was identified as important, participants felt strongly that HIV prevention and testing messages should be universal and not directly targeted at African communities. Directly targeting only African people found to be problematic and was thought to fuel stigma and discrimination.

“HIV is HIV. Don’t look at it as ‘African’ or ‘European’. HIV is just there. HIV has no age, colour...so I think the message has to be general.” (37 year-old Zambian man. Burns 2009 [++])

“If you target Africans only, they just feel targeted. Maybe they say, they think I am carrying it. But if it is targeting everyone, then that is better. And also we say we will be targeting African communities, but many Africans don’t have that feeling of belonging to a ‘community’. Which community are you talking about? They never felt part of a community so it’s not their problem.” (Female participant - Burundi, mixed focus group discussion. Prost et al, 2007 [+])

Participants in two studies mentioned that people living with HIV should be directly involved in the development and delivery of community-based HIV testing interventions (Prost et al, 2007[+]; Elam et al, 2009 [-]).

“In a way I would say you [as a person living with HIV] could become counsellors, because you have the experience, you are now the living example. You have more experience than anybody who comes in!”

“Most of the HIV positive people who are living here are struggling. They are struggling to work. And this is work that we can do!” (Male & female participants -

Uganda & Zambia, focus group discussion with people living with HIV. Prost et al, 2007 [+]

3.9.1. Perceived benefits of testing

Community mobilisation was seen as necessary to raise awareness of the benefits of HIV testing in two studies (Burns 2009 [++]; Elam et al, 2009 [-]). For example, respondents in both studies said there were few highly visible HIV positive role models in England. Participants in one study (Burns 2009 [++]) said the public disclosure of his HIV positive status by high profile individuals such as former Cabinet Minister Chris Smith was important for breaking down the stigma associated with HIV. Without such efforts the perceived benefits of HIV testing were outweighed by the perceived risks.

Participants in these two studies (Burns 2009 [++]; Elam et al, 2009 [-]) also suggested there was a lack of awareness of the availability and benefits of testing early and therefore accessing highly active anti-retroviral treatment (HAART). The need for more information on entitlement and access to health services, confidentiality, and that healthcare is free was frequently mentioned by participants in one study (Burns 2009 [++])

'I did see some leaflets in his surgery, which told me about HIV testing and the fact treatments were available and that they were free. That was what made me ask him for the test. I didn't know there were treatments or that it was free until then.' (31 year-old Ugandan woman. Burns 2009 [++])

Evidence statement 7: Community involvement

ES 7.1 Mobilising community members to advocate about HIV testing through outreach and education programmes was identified as a potential factor in the success of HIV testing in three studies with key stakeholders working in sexual health and HIV (Burns et al, 2007; Prost et al 2007 [+]; Elam et al, 2009 [-]) and one study with African men and women newly diagnosed with HIV and recruited from an HIV clinic (Burns 2009 [++]).

ES 7.2 Four studies (three with key stakeholders working in sexual health and HIV and one African men and women living with HIV recruited in an HIV clinic) describe HIV prevention and testing messages that target African people only as problematic and stigmatising (Burns et al, 2007; Burns 2009 [++]; Prost et al 2007 [+]; Elam et al, 2009 [-]).

Perceived benefits of HIV testing

ES 7.3 Two studies (one with key stakeholders working in sexual health and HIV and one with African men and women living with HIV recruited in an HIV clinic) find that there are few highly visible HIV positive role models in England, which are needed to help breakdown the stigma associated with HIV (Burns 2009 [++]; Elam et al, 2009 [-]).

ES 7.4 Two studies (one with key stakeholders working in sexual health and HIV and one with African men and women living with HIV recruited in an HIV

clinic)report that increasing the awareness of the benefits of earlier diagnosis and access to HIV medication might increase HIV testing (Burns 2009 [++]; Elam et al, 2009 [-]).

Applicability

This evidence is directly applicable to black African communities in England. All studies were conducted in England with black African people.

4. Discussion

4.1. *Findings into context*

This review aimed to provide evidence to support those developing guidance for interventions which aim to increase the uptake of HIV testing to reduce undiagnosed HIV infection among black African communities living in England.

Ten studies were found and included in this review. All of the studies included the views of black Africans in the England, many of whom were living with HIV. The data from the retrieved studies were synthesised and the eight emergent themes categorised into two groups:

- Factors that hinder the uptake of HIV testing
 - Stigma
 - Perceived personal risk
 - Gender
 - Migration and cultural norms
 - Accessibility and opportunity
- Factors that help the uptake of HIV testing
 - Improving opportunity and accessibility
 - Community Involvement

4.2. *Implications of findings*

The extracted themes allowed the review team to address the overarching review question:

- What factors help or hinder the uptake of HIV testing by black African communities living in England and how can the barriers be overcome?

Two of the secondary questions were also addressed:

- What environmental, social and cultural factors prevent or support the uptake of HIV testing?
- How does HIV-related stigma affect the uptake of HIV testing?

It is apparent from the evidence that fear of HIV-related stigma is a commonly cited barrier to seeking or accepting an HIV test. There is little exploration of the cause of such high levels of HIV-related stigma in African communities in England or whether similar levels exist in the wider community. But it is clear that there is a culture of secrecy and silence around HIV, possibly because HIV transmission is associated with negative and stigmatised behaviours such as promiscuity and unfaithfulness. The stigma of HIV transmission is then transferred to HIV testing itself.

The evidence also highlights that low perception of personal risk acts as a barrier to HIV testing, perhaps as an extension of the stigma attached to HIV transmission.

Other barriers include structural factors (for example, complicated pathways to GUM clinic testing), differences in cultural norms and the impact of the migration process. These structural barriers were often connected with late diagnosis, with two studies in particular noting the missed opportunities for earlier HIV testing in primary care.

There is some information about how factors that hinder the uptake of testing can be overcome. In the case of stigma, the retrieved evidence suggests that raising the awareness of the benefits of testing and providing high profile HIV positive role models could reduce stigma. Community involvement, particularly of people living with HIV, also reduces stigma. Community involvement could also overcome barriers associated with cultural norms (for example oral traditions in African communities) by increasing community-wide knowledge of HIV testing services.

Improving access to testing by routinely offering it in services outside of sexual health services could mitigate some of the barriers associated with attending GUM clinics. Additionally, offering HIV testing in a range of venues, from GP surgeries to community- or faith based organisations, could increase the opportunity for testing. Here too, community involvement could be used to raise awareness of the benefits of testing early. In particular, it can be used to provide community-wide information about the availability of, and entitlement to, HIV medication.

Improving the opportunities for HIV testing could also overcome some of the gender related factors that hinder the uptake of testing. Joint couples testing in ante-natal services could provide a “front door” to services for African men.

4.2.1. . Limitations of the evidence and gaps

While there was a relatively large amount of data available to address some of the review questions, only a small number of studies were retrieved in this review. As a result there are substantial limitations and gaps in the evidence making it difficult to answer the remaining research questions.

Primary question:

- What interventions have successfully reduced the social, personal and cultural barriers associated with testing among black African communities in the UK?

Secondary question:

- What (if any) were the adverse or unintended consequences (positive or negative) of the interventions?

While the findings from most of these studies have implications for the development and delivery of future interventions, only two studies examined specific interventions to increase testing. One study discussed the acceptability to Africans in London of a proposed community-based testing model from Kenya (Prost et al, 2007 [+]). The other study examined the acceptability and feasibility of rapid HIV testing as part of new patient health check in a GP surgery (Prost et al, 2009 [++]). It was the only study which described an intervention that had been implemented. It was also a pilot study that included non-African participants. As a result there is no detailed

evidence about what different types of interventions work well or how they are viewed by different sub-populations within African communities.

All the studies in this review adopted a similar methodological and analytical approach. As a result, there was some breadth but little depth to the data. Much of the evidence skims the surface of each identified theme, but does not delve deeper to explore some of the complex mechanisms beneath the observations. For example, it is not clear how community involvement in interventions would be implemented nor is there any in-depth exploration of the reasoning behind why this would work. Similarly, it remains unclear exactly why it is problematic and stigmatising to directly target African communities with HIV prevention and testing messages. Additionally, the interaction between these two themes - that is whether community involvement could alleviate fears about targeting African communities – is not explored.

Although many themes were identified, there was little exploration of differences by population within the studies. Evidence about how to increase HIV testing in different black African populations such as young people, people living with disabilities or men who have sex with men is lacking in this review.

The views and opinions of healthcare professionals not working in HIV or GUM services, especially general practitioners, are missing from this review. As a result, there is a gap in the evidence about how this group view offering HIV testing in their services.

4.3. *Limitations of the review*

There are only a small number of studies included in this review limiting some of the evidence statements. Many of the studies excluded at the full paper screening stage were undertaken with black Africans living in England. These studies discussed themes that emerged in this review (for example stigma, cultural norms and migration) but not in relation to HIV testing. It is possible that by focussing solely on HIV testing, other evidence that may have been applicable to the research questions could have been missed. However, expanding the inclusion criteria to include all aspects of HIV prevention, treatment and care would have reduced the precision and applicability of the findings and resulting evidence statements.

5. Conclusion and Recommendations

There are many environmental, social and structural factors that hinder the uptake of HIV testing among black Africans living in England. The findings from this review highlight the central influence of HIV-related stigma in preventing individuals from seeking or accepting an HIV test. The evidence indicates that many of the structural barriers to testing can be overcome through interventions that aim to reduce stigma or increase awareness of and opportunities to access HIV testing services. However, there are substantial gaps in the evidence and more research is needed in the following areas:

- Feasibility and acceptability of HIV testing among staff and patients at GP surgeries.
- Identify appropriate services for opportunistic or routine testing in hospitals in high HIV prevalence areas
- Development or adaptation of interventions to reduce social, personal and cultural barriers, (especially HIV-related stigma) in African communities.
- Explore ways in which services could adapt in order to reduce the stigma associated with attending GUM clinics.

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Appendix A

Sample Search Strategy

Strategy used to search Medline (Ovid). This strategy was adapted for other databases and websites.

| | |
|---|---|
| Database name | MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) |
| Database host | Ovid |
| Database coverage dates | 1950 to Present |
| Searcher | Ibidun Fakoya |
| Search date | 28/01/10 |
| Search strategy checked by | Paul Levay, Fiona Burns, Audrey Prost |
| Number of records retrieved | 1676 |
| Name of RefMan library | Qualitative280110 |
| Number of records loaded into RefMan | 1664 |
| Reference numbers of records in RefMan library | 1-1664 |
| Number of records after deduplication in RefMan library | 1661 |

Search Strategy

| # | Searches | Results |
|----|--|---------|
| 1 | exp attitude to health/ | 214115 |
| 2 | patient satisfaction/ | 41721 |
| 3 | health services accessibility/ | 35667 |
| 4 | Access to Information/ | 2032 |
| 5 | health education/ or consumer health information/ or patient education as topic/ or sex education/ | 107475 |
| 6 | Health Promotion/ | 37129 |
| 7 | Preventive Health Services/ or Community Health Services/ | 31426 |
| 8 | exp Sexual Behavior/ | 61960 |
| 9 | "patient acceptance of health care"/ or patient compliance/ or treatment refusal/ | 67187 |
| 10 | risk reduction behavior/ or risk-taking/ | 16040 |
| 11 | (health* adj3 (educat* or aware* or opportunit* or attitude* or access* or inform* or promot* or prevent* or behavio?r*)).ti,ab. | 97895 |
| 12 | (sex* adj2 (behavio?r* or educat*)).ti,ab. | 22006 |
| 13 | (risk* adj3 (taking or factor* or behavio?r* or educat* or reduc*)).ti,ab. | 290043 |

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| | | |
|----|--|---------|
| 14 | (patient* adj3 (satisfaction or educat* or behavio?r* or compliance or comply or complie*)).ti,ab. | 51998 |
| 15 | exp Culture/ | 85992 |
| 16 | Language/ or linguistics/ or communication barriers/ | 26365 |
| 17 | ((language* or linguistic* or communicat*) adj3 barrier*).ti,ab. | 1387 |
| 18 | (culture* or social* or societ* or communit*).ti,ab. | 1139675 |
| 19 | Politics/ or Public Policy/ or Health Policy/ | 89986 |
| 20 | exp Social Behavior/ | 118909 |
| 21 | prejudice/ or psychosocial deprivation/ or social values/ | 34767 |
| 22 | (prejudice or discriminat* or "social value*" or poverty or depriv* or "low socioeconomic status").ti,ab. | 167707 |
| 23 | (social adj (inclusion or exclusion)).ti,ab. | 547 |
| 24 | ((low or lowest or lower) adj3 (socioeconomic or status or education or social class*)).ti,ab. | 16517 |
| 25 | ((poor or poorest or poorer) adj3 (socioeconomic or status or education or social class*)).ti,ab. | 5538 |
| 26 | social class/ | 24899 |
| 27 | exp poverty/ | 22570 |
| 28 | "Discrimination (Psychology)"/ | 12584 |
| 29 | Stigma*.ti,ab. | 11189 |
| 30 | (barrier* or facilitat* or hinder* or block* or obstacle* restrict* or restrain* or obstruct* or inhibit* or impede* or delay* or constrain* or hindrance).ti,ab. | 2264676 |
| 31 | (attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or incentive* or reason*).ti,ab. | 589968 |
| 32 | Motivation/ | 38310 |
| 33 | or/1-32 | 4404894 |
| 34 | AIDS serodiagnosis/ | 5236 |
| 35 | hiv-ct*.ti,ab. | 80 |
| 36 | (hiv adj3 (test* or counsel* or vct or voluntary counsel*)).ti,ab. | 11862 |
| 37 | or/34-36 | 14559 |
| 38 | 33 and 37 | 8208 |
| 39 | exp Africa/ | 139940 |
| 40 | africa*.ti,ab. | 98672 |
| 41 | minorit*.ti,ab. | 30023 |
| 42 | black*.ti,ab. | 69527 |
| 43 | Minority Groups/ | 8038 |
| 44 | (Afro Caribbean* or Caribbean* or afrocaribbean*).ti,ab. | 5910 |
| 45 | (Angolan* or Beninese or Motswana or Batswana or Burkinabe or Burundian* or Cameroonian* or Cape Verdian* or Cape Verdean* or Central African* or Chadian* or Congolese or Ivorian* or Djibouti or Equatorial Guinean* or Equatoguinean* or Eritrean* or Ethiopian* or Gabonese or Gambian* or Ghanaian* or Guinean* or Guinea-Bissauan* or Jamaican* or Kenyan* or Mosotho or Basotho or Liberian* or Libyan* or Malagasy or Malawian* or Malian* or Marshallese or Mauritanian* or Mauritian* or Mozambican* or Namibian* or Nigerien* or Nigerian* or Rwandan* or Senegalese or Seychellois or Sierra Leonean* or Somali* or South African* or Sudanese or Swazi or Tanzanian* or Togolese or Ugandan* or Zambian* or Zimbabwean*).ti,ab. | 31323 |
| 46 | african continental ancestry group/ | 26332 |
| 47 | ethnic*.ti,ab. | 54912 |
| 48 | (race or racial*).ti,ab. | 55293 |
| 49 | refugee/ | 5429 |

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| | |
|--|----------|
| 50 (asylum seeker* or refugee*).ti,ab. | 4882 |
| 51 or/39-50 | 371570 |
| 52 38 and 51 | 2178 |
| 53 limit 52 to yr="1996 -Current" | 1733 |
| 54 limit 53 to english language | 1676 |
| 55 animals/ | 4470591 |
| 56 humans/ | 10960736 |
| 57 55 not 56 | 3335453 |
| 58 54 not 57 | 1676 |

Appendix B

Methodology Checklists

HIV Testing in Black Africans

Title/Abstract Screening Checklist

| | | | |
|----|---|------------------------|--------------|
| 1. | <p>Does the study population include:</p> <p>Black African men and women living in England</p> <p>OR</p> <p>Other Black, Asian and Minority Ethnic groups living in England</p> <p>OR</p> <p>Sexual Health and HIV prevention, treatment and care providers working with Black, Asian and Minority Ethnic groups in England</p> | YES/UNCLEAR – go to Q2 | NO – exclude |
| 2. | <p>Does the paper/study:</p> <ul style="list-style-type: none"> • examine or describe awareness of how Black African communities in the UK view HIV testing and how they think the barriers to testing can be overcome <p>OR</p> <ul style="list-style-type: none"> • examine or describe attitudes towards HIV testing among Black Africans and service providers (that is, whether or not there is any stigma associated with HIV tests) in the UK <p>OR</p> <ul style="list-style-type: none"> • describe or examine the environmental, social, cultural and personal barriers to HIV testing for both Black Africans and service providers. | YES/UNCLEAR – go to Q3 | NO – exclude |
| 3. | <p>Are any of the following outcomes measured/described in the study?</p> <ul style="list-style-type: none"> • awareness of how black African communities view HIV testing and how they think the barriers to testing can be overcome • attitude towards HIV testing among black Africans and service providers (that is, whether or not there is any stigma | YES/UNCLEAR – go to Q4 | NO – exclude |

| | | | |
|----|---|------------------------|--|
| | <p>associated with HIV tests)</p> <ul style="list-style-type: none"> the barriers to HIV testing for both black Africans and service providers. For example, a change in the cultural and language barriers faced by some groups and a change in any additional barriers that may face asylum seekers and new migrants awareness of the benefits of early HIV diagnosis awareness of HIV services, including HIV testing | | |
| 4. | Was the study published in 1996 or later? | YES/UNCLEAR – go to Q5 | NO – exclude |
| 5. | <p>Are the methods used:</p> <ul style="list-style-type: none"> Document analysis; <p>OR</p> <ul style="list-style-type: none"> observation and participant observation; <p>OR</p> <ul style="list-style-type: none"> focus group discussion <p>OR</p> <ul style="list-style-type: none"> in-depth interviews | YES/UNCLEAR – go to Q6 | NO – Exclude |
| 6. | Are Black African men and/or women or Sexual Health and HIV prevention, treatment and care providers working with Black, Asian and Minority Ethnic groups in England among the study population | NO /Unclear - Exclude | YES – <u>Include for Full paper review</u> |

HIV Testing in Black Africans

Full paper screening Checklist

| | | | |
|----|--|------------------------|--------------|
| 7. | <p>Does the study population include:</p> <p>Black African men and women living in England</p> <p>OR</p> <p>Other Black, Asian and Minority Ethnic groups living in England</p> <p>OR</p> <p>Sexual Health and HIV prevention, treatment and care providers working with Black, Asian and Minority Ethnic groups in England</p> | YES/UNCLEAR – go to Q2 | NO – exclude |
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| 8. | <p>Does the paper/study:</p> <ul style="list-style-type: none"> examine or describe awareness of how Black African communities in the UK view HIV testing and how they think the barriers to testing can be overcome <p>OR</p> <ul style="list-style-type: none"> examine or describe attitudes towards HIV testing among Black Africans and service providers (that is, whether or not there is any stigma associated with HIV tests) in the UK <p>OR</p> <ul style="list-style-type: none"> describe or examine the environmental, social, cultural and personal barriers to HIV testing for both Black Africans and service providers. | YES/UNCLEAR – go to Q3 | NO – exclude |
| 9. | <p>Are any of the following outcomes measured/described in the study?</p> <ul style="list-style-type: none"> awareness of how black African communities view HIV testing and how they think the barriers to testing can be overcome attitude towards HIV testing among black Africans and service providers (that is, whether or not there is any stigma associated with HIV tests) the barriers to HIV testing for both black Africans and service providers. For example, a change in the cultural and language barriers faced by some groups and a change in any additional barriers that may face asylum seekers and new migrants awareness of the benefits of early HIV diagnosis awareness of HIV services, including HIV testing | YES/UNCLEAR – go to Q4 | NO – exclude |
| 10. | Was the study published in 1996 or later? | YES/UNCLEAR – go to Q5 | NO – exclude |
| 11. | <p>Are the methods used:</p> <ul style="list-style-type: none"> Document analysis; <p>OR</p> <ul style="list-style-type: none"> observation and participant observation; | YES/UNCLEAR – go to Q6 | NO – Exclude |

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| | <p>OR</p> <ul style="list-style-type: none"> • focus group discussion <p>OR</p> <ul style="list-style-type: none"> • in-depth interviews | | |
| 12. | Has the methodological approach has been clearly described. | YES <u>go to Q7</u> | NO - Exclude |
| 13. | Are Black African men and/or women or Sexual Health and HIV prevention, treatment and care providers working with Black, Asian and Minority Ethnic groups in England among the study population | NO /Unclear - Exclude | YES – <u>Include for quality appraisal</u> |

Appendix C

Included Papers

1. Burns, F. M., Imrie, J. Y., Nazroo, J., Johnson, A. M., & Fenton, K. A. 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*, vol. 19, no. 1, pp. 102-108.
2. Burns, F. M. 2009, An investigation into newly diagnosed HIV infection among Africans in London, PhD, University College London.
3. Chinouya, M. & O'Keefe, E. 2005, "God will look after us: Africans, HIV and religion in Milton Keynes", *Diversity in Health & Social Care*, vol. 2, no. 3, pp. 177-186.
4. Chinouya, M. 2006, "Telling children about HIV in transnational African families: tensions about rights", *Diversity in Health & Social Care*, vol. 3, no. 1, pp. 7-17.
5. Chinouya, M. & O'Keefe, E. 2006, Zimbabwean cultural traditions in England: *Ubuntu-Hunhu* as a human rights tool *Diversity in Health & Social Care*, vol. 2, no. 1, pp. 89-98.
6. Elam, G., Caswell, G., Reynolds, R., Alfred, S., Nwokolo N., Nelson, M., Head. Approaches to Voluntary Counselling and Testing: exploring policy and practice in the UK, US, Ghana, Malawi, South Africa and Ethiopia. African HIV Policy Network. London. 2009
7. Nnoaham, K. E., Pool, R., Bothamley, G., & Grant, A. D. 2006, "Perceptions and experiences of tuberculosis among African patients attending a tuberculosis clinic in London", *International Journal of Tuberculosis & Lung Disease*, vol. 10, no. 9, pp. 1013-1017.
8. Paparini, S., Doyal, L., & Anderson, J. 2008, "'I count myself as being in a different world': African gay and bisexual men living with HIV in London. An exploratory study", *AIDS Care*, vol. 20, no. 5, pp. 601-605.
9. Prost, A., Sseruma, W. S., Fakoya, I., Arthur, G., Taegtmeier, M., Njeri, A., Fakoya, A., & Imrie, J. 2007, "HIV voluntary counselling and testing for African communities in London: learning from experiences in Kenya", *Sexually Transmitted Infections*, vol. 83, no. 7, pp. 547-551.
10. Prost, A., Griffiths, C. J., Anderson, J., Wight, D., & Hart, G. J. 2009, "Feasibility and acceptability of offering rapid HIV tests to patients registering with primary care in London (UK): a pilot study", *Sexually Transmitted Infections*, vol. 85, no. 5, pp. 326-329.

Appendix D

Excluded Studies

Reason for excluding papers at full paper screening

| Study | Reason for exclusion |
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| Baxter, J. & Bennett, R. 2000, "What do pregnant women think about antenatal HIV testing?", <i>RCM Midwives Journal</i> , vol. 3, no. 10, pp. 308-311. | Study population not included |
| Bell, E., Mthembu, P., O'Sullivan, S., & Moody, K. 2007, "Sexual and reproductive health services and HIV testing: Perspectives and experiences of women and men living with HIV and AIDS", <i>Reproductive Health Matters</i> , vol. 15, no. 29, pp. 113-135. | Methodological approach not clearly described. |
| de, Z. P. & Boulton, M. 2007, "Routine antenatal HIV testing: the responses and perceptions of pregnant women and the viability of informed consent. A qualitative study", <i>Journal of Medical Ethics</i> , vol. 33, no. 6, pp. 329-336. | Study population not included |
| Edmunds, L., Rink, E., & Zukoski, A. 2004, "Male Involvement: Implications for Reproductive and Sexual Health Programs", <i>Prevention Researcher</i> , vol. 11, no. 5, pp. 10-14. | Study population not included |
| Erwin, J., Morgan, M., Britten, N., Gray, K., & Peters, B. 2002, "Pathways to HIV testing and care by black African and white patients in London", <i>Sexually Transmitted Infections</i> , vol. 78, no. 1, pp. 37-39. | Study design not qualitative |
| Fakoya, I., Reynolds, R., Caswell, G., & Shiripinda, I. 2008, "Barriers to HIV testing for migrant black Africans in Western Europe.", <i>HIV Medicine</i> , vol. 9, p. Suppl-5. | Methodological approach not clearly described. |
| Fakoya, I. HIV Testing Campaign Revamp: Formative Evaluation Report. UCL. London 2009 | Methodological approach not clearly described. |
| Khotenashvili, L. M. 2008, "HIV testing and counselling policies and practices in Europe: Lessons learned, ways forward", <i>HIV Medicine</i> , vol. 9, no. SUPPL. 2, p. Jul. | Methodological approach not clearly described. |
| Minnie, K., Klopper, H., & C 2008, "Factors contributing to the decision by pregnant women to be tested for HIV", <i>Health SA Gesondheid</i> , vol. 13, no. 4, pp. 50-65. | Study population not included |
| National AIDS Trust 2007, <i>Updating Our Strategies: Report of an expert seminar on HIV testing and Prevention 22 March 2007</i> , National AIDS Trust, London | Methodological approach not clearly described. |
| Prost, A., Elford, J., Imrie, J., Petticrew, M., & Hart, G. J. 2008, "Social, behavioural, and intervention research among people of Sub-Saharan African origin living with HIV in the UK and Europe: literature review and recommendations for | Review that does not meet review level data criteria |

Study

intervention.", *AIDS & Behavior*, vol. 12, no. 2, pp. 170-194.

Roberts, C. "Sexual health needs of specific target groups".

Sadler, K. E., McGarrigle, C. A., Elam, G., Ssanyu-Sseruma, W., Othieno, G., Davidson, O., Mercey, D., Parry, J. V., & Fenton, K. A. 2006, "Mayisha II: pilot of a community-based survey of sexual attitudes and lifestyles and anonymous HIV testing within African communities in London", *AIDS Care*, vol. 18, no. 4, pp. 398-403.

Sinha, S., Curtis, K., Jayakody, A., Viner, R., & Roberts, H. 2007, "'People make assumptions about our communities': sexual health amongst teenagers from black and minority ethnic backgrounds in East London", *Ethnicity & Health*, vol. 12, no. 5, pp. 423-441.

Reason for exclusion

Methodological approach not clearly described.

Outcomes not included

Outcomes not included

Appendix E

Evidence Table

| Study Details | Research parameters | Population and sample selection | Outcomes and methods of analysis Results | Notes |
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| <p>Authors: Burns FM, Imrie JY, Nazroo J, Johnson AM, Fenton KA.</p> <p>Year: 2007</p> <p>Citation: 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. <i>AIDS Care</i>; 19(1):102-108.</p> <p>Quality score: ++</p> | <p>Research questions: Aim to identify key issues influencing service uptake by HIV positive Africans.</p> <p>Theoretical approach: NR</p> <p>Data collection: Semi-structured, face-to-face, interactive and exploratory interviews based on a topic guide. Conducted by FB July – Sept 2003. 7 interviews tape recorded & transcribed verbatim, 4 interviews recorded using extensive field notes</p> | <p>Source: Key constituencies in the field of HIV and African communities in the UK and organisations within these.</p> <p>Recruitment: Purposive sampling identified key informants from clinical; public health; health services access researchers; voluntary sector; health promotion and health policy constituencies.</p> <p>Sample size: 11</p> <p>Exclusion criteria: NR</p> <p>Inclusion criteria: NR</p> | <p>Analysis: Framework analysis: ordering and synthesising verbatim data within a thematic matrix. Themes developed from research question & participants accounts.</p> <p>Key themes:</p> <p>Lack of awareness if personal risk of HIV infection.</p> <p>HIV-related stigma within African communities and perception HIV is a deadly disease:</p> <p><i>“There is a set of assumptions than an HIV diagnosis is an immediate death sentence because that’s the experience they’ve come from... So there is a vision of what HIV means which I think colours a lot of stuff” (Clinical informant)</i></p> <p>Confidentiality (perceived lack of) and fear that an HIV diagnosis may be disclosed to immigration authorities.</p> <p>Cultural norms – preventative medicine, open access to health care, free POCT, not well established in African communities</p> <p>Migration – lack of linguistically appropriate prevention messaging. Disempowerment of asylum seeker. Cultural diversity of African communities not addressed in services.</p> | <p>Limitations</p> <p>Author: No service users in the sample.</p> <p>Reviewer: No details on the role of the researcher and not all interviews recorded and transcribed. Limited information of date analysis. Many themes explores but insufficient level of detail and limited use of original data. Only one researcher coded and analysed data.</p> <p>Future research: Exploration of the experience of service users.</p> <p>Funding: NR</p> |

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| | | | <p>Gender – failure of health services to engage with African men directly</p> <p>Structural and cultural institutional barriers including institutional inertia, cultural bias, lack of advocacy, GP failure to address HIV, poor appointment systems, lack of childcare and negative media portrayals.</p> <p><i>“Africans are seen as vectors of infection. Testing in the environment just reinforced prejudices. (voluntary sector)”</i></p> <p><i>“one of the biggest barriers to HIV testing is how poorly accessible health services are in the UK ” (clinical)</i></p> | |
| <p>Authors: Burns FM</p> <p>Year: 2009</p> <p>Citation: An investigation into newly diagnosed HIV infection among Africans in London, PhD, University College London.</p> <p>Quality score: ++</p> | <p>Research questions: Develop a contextual understanding of the factors contributing to late presentation to HIV services for Africans in Britain. Elicit suggestions on means of improving access to HIV services.</p> <p>Theoretical approach: NR</p> <p>Data collection: In-depth interviews, based on a topic guide. Conducted by FB February – December 2005. All 26 interviews were taped and</p> | <p>Source: Newly diagnosed HIV positive Africans receiving hospital based care in London</p> <p>Recruitment: Purposive sampling of individuals recruited as part of a larger quantitative study. Participants were recruited at 15 HIV treatment centres across London, within one year of diagnosis. After completing the main study questionnaire, participants were invited to participate in in-depth interviews.</p> | <p>Analysis: Framework analysis: ordering and synthesising verbatim data within a thematic matrix. Themes developed from research question & participants accounts.</p> <p>Key themes:</p> <p>Stigma: there is fear of testing due to HIV-related stigma in African communities.</p> <p><i>‘Well, it’s a disease which people look upon you as somebody - it’s an inferiority disease, do you know what I mean, it’s a disease which community does not accept.’ - 37 year-old Zambian woman.</i></p> <p>African experience of HIV is negative and no imagery in the UK to replace African experience. The testing process itself is stigmatised:</p> <p><i>‘Even if you go [for a test] and you’re negative they can’t believe it. They say, ah, she’s been there, she’s happy, that means that she’s lying. As long as you come here they want to know.’ -33 year-old</i></p> | <p>Limitations</p> <p>Author: Only involves newly diagnosed Africans. Recall bias. Group analyses of migrant Africans may falsely construct homogeneity and the reduction of complexity</p> <p>Reviewer: No sub group analysis or in-depth exploration of gender differences.</p> <p>Funding: NR</p> |

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| | <p>transcribed.</p> | <p>Sample size: 26</p> <p>Exclusion criteria: Non-English speakers; patients receiving care from FB</p> <p>Inclusion criteria: NR</p> | <p><i>Zimbabwean woman.</i></p> <p>Perception of personal risk: few participants perceived themselves to be at risk and considered it to be a disease that affected others.</p> <p><i>'I thought I was too young to have HIV' 19 year-old Cameroonian woman.</i></p> <p>HIV testing was not considered until the onset of ill health.</p> <p>Lack of perceived benefit of HIV testing: the benefits of early diagnosis and access to treatment are not widely known in Africa. This is compounded by the perceived risks of testing.</p> <p><i>'I feel, people feel to have a test to find out the results costs you more stress, damage and things. ... you don't check because people say when they check it puts up their stress and makes them get worried and fall sick, you know.'</i> - 39 year-old Ghanaian man.</p> <p>Migratory and institutional factors: economic hardship, under employment had an impact on delayed diagnosis.</p> <p><i>'you want an HIV test, you are not sure whether you are HIV or not but you have got to go there, queue for, I don't know, 4 hours sometimes and wait. A lot of people are just going to say, well - and most people are being paid per hour in this country and they aren't going to, you know, wait for 4 hours because that's about half-a-day's wage they're going to lose in there.'</i> - 30 year-old Zimbabwean man.</p> <p>Missed opportunities for earlier diagnosis including</p> | |
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| | | | <p>participants who had been diagnosed with shingles and a GP who had dismissed HIV testing when it was suggested by the patient.</p> <p><i>'Like the very first day when I went to see [the GP], I told her I've got some rashes that I don't know where they're coming from and I heard some people with HIV they do develop some symptoms, then she goes, ah, I don't think it's that. So that's what made me think I was ok ... that.'</i> 27 year-old Zimbabwean woman.</p> | |
| <p>Authors: Chinouya, M Year: 2006 Citation: Telling children about HIV in transnational African families: tensions about rights. Diversity in Health & Social Care; 3(1):7-17 Quality score: +</p> | <p>Research questions: Explore how Africans parents in UK make sense of the language of children's rights. Explored reasons for telling or not telling children that HIV affects them. Theoretical approach: NR Data collection: Semi-structured interviews with HIV positive African parents at</p> | <p>Source: HIV positive African parents living in the UK Recruitment: Participants recruited at outpatient's clinics, through support groups and through snowballing. Selection strategy not reported. Sample size: 60 Exclusion criteria: NR Inclusion criteria: NR</p> | <p>Analysis: Thematic Analysis Key themes: Parents of younger children felt unable to disclose their HIV positive diagnosis due to fear of stigma. They also reported testing their children (under 16) for HIV without their knowledge of consent. Many parents did not report the HIV negative test result for fear it would raise questions why the test was performed. <i>"No. I would not trust an under 10...they would just talk that there is HIV or whatever at home, but then it's what comes after that. 'Cause if their class mates they will take the information to their parents and the other children will be told not to associate with those people. That is why I say that it's too early for them. They may share the information with their friends and their friends will go and tell their parents, and the parents will say you must not play with them and the kids will suffer" (father)</i></p> | <p>Limitations Author: None Reviewer: Sampling strategy not clear. Analysis and coding may have been done by one researcher. Conclusions do not appear to flow directly from the data. Future research: Funding: Economic and Social Research Council</p> |
| <p>Authors: Chinouya M,</p> | <p>Research questions:</p> | <p>Source: HIV positive</p> | <p>Analysis: Thematic Framework analysis.</p> | <p>Limitations</p> |

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| <p>O'Keefe, E Year: 2005 Citation: God will look after us: Africans, HIV and religion in Milton Keynes Diversity in Health & Social Care; 2(3):177-86 Quality score: +</p> | <p>Explore how religion plays a part in the lives of Africans living with HIV in Milton Keynes. Theoretical approach: NR Data collection: Gender matched semi-structured interviews in 2003 undertaken by one male and one female interviewer. Interviews took place in clinic consultation rooms. FGD used to gather data from faith leaders. All discussions taped and transcribed verbatim.</p> | <p>patients accessing care and living in Milton Keynes Recruitment: Interview participants recruited at outpatient's clinics, by doctors, nurses or researchers. FGD participants recruited through multifaith group in Milton Keynes. Sample size: Interviews: 22 FGD: 20 Exclusion criteria: NR Inclusion criteria: NR</p> | <p>Key themes: Respondents reported being concerned about their health after persistent illness that disrupted their lives. Most were diagnosed in hospital; half after being hospitalised. Once in hospital the offer of an HIV test was perceived to be routine. Some participants reported that GPs were slow to respond to suspected HIV infections: <i>"My GP told me that having continuous diarrhoea does not mean you are HIV" (female)</i> Some participants had tested after becoming suspicious about the fidelity of previous or current partners. Participants considered HIV to be isolating and stigmatising and they did not feel they could discuss their feelings apart from with hospital staff.</p> | <p>Author: Interview participants recruited over a short period or time. Study does not explore different experiences by denomination, nationality or tribal diversity. Discussion confined to Christians. Reviewer: Sampling strategy not clear. Analysis and coding may have been done by one researcher. Conclusions do not appear to flow directly from the data. Future research: Funding: NR</p> |
| <p>Authors: Chinouya,M O'Keefe,E. Year: 2006 Citation: Zimbabwean cultural traditions in England: <i>Ubuntu-Hunhu</i> as a human rights tool Diversity in Health & Social Care; 2(1):89-98 Quality score: -</p> | <p>Research questions: Explored the meaning of <i>Ubuntu-Hunhu</i> and the applicability of this concept in human rights discourses. Investigated how the concept of <i>Ubuntu-Hunhu</i> might help to offer a human rights approach for those living with HIV and its; transferability to non-</p> | <p>Source: Zimbabwean men and women living with HIV in London and its suburban hinterland. Recruitment: Interviews: research advertised through posters and flyers displayed in support groups. No details how participants were selected once they had</p> | <p>Analysis: NR Key themes: Female participants reported that they had expected to undergo joint HIV testing while in ante-natal care. Instead they were diagnosed alone, leading to fear and isolation. Participants felt that joint HIV testing for sexual partners should be encouraged since fear might prevent partner notification and disclosure. <i>"So I could not believe that was the issue, so I began to cry and then I said 'You must phone my husband and ask him to come to the hospital and</i></p> | <p>Limitations Author: NR. Reviewer: Sampling strategy not clear. Analysis and coding may have been done by one researcher. Conclusions nor clear or coherent Future research: Funding: NR</p> |

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| | <p>health settings.</p> <p>Theoretical approach: NR</p> <p>Data collection: Interviews audiotaped interviews that took place at author's place of business (university) or support group settings. 3 FGD held: one at university 2 in support group settings. All discussions taped and transcribed verbatim.</p> | <p>contacted researchers.</p> <p>Sample size: Interviews: 30 FGD: NR</p> <p>Exclusion criteria: Non Zimbabwean support group members</p> <p>Inclusion criteria: Zimbabwean and HIV positive</p> | <p><i>tell him. Because for me to go home and tell him this story I don't think he is going to understand. So you must tell me when he is there. It will be better for me...' they told him and gave baba [husband] a letter to go and be tested... I would not do that!" (A mother)</i></p> | |
| <p>Authors: Elam, G., Caswell, G., Reynolds, R., Alfred, S., Nwokolo N., Nelson, M., Head.</p> <p>Year: 2009</p> <p>Citation: Approaches to Voluntary Counselling and Testing: exploring policy and practice in the UK, US, Ghana, Malawi, South Africa and Ethiopia</p> <p>Quality score: -</p> | <p>Research questions: What approaches to HIV testing in settings within and outside the UK working with Africans are effective in raising the numbers of people who are aware of their HIV status and detecting undiagnosed HIV? How do these approaches achieve this whilst limiting the stigmatising impact of an HIV diagnosis? How can they encourage disclosure and testing among partners and children who may have</p> | <p>Source: Roundtable discussions - key constituencies in the field of HIV and African communities in the UK and organisations within these (including people living with HIV). In depth interviews – staff and volunteers at VCT sites.</p> <p>Recruitment: Locations selected due to convenience.</p> <p>Sample size: Roundtable – 60 In depth interviews - 72</p> <p>Exclusion criteria: NR</p> | <p>Analysis: Thematic Analysis</p> <p>Key themes:</p> <p>Individual Barriers: low risk perceptions among married or faithful; health seeking behaviour; experiences in country of birth</p> <p>Structural barriers include overwhelming problems related to migration. Lack of opportunities for testing in primary care and other settings (for example, outpatients, emergency, acute care) need to be optimised and investment provided to develop and rigorously evaluate these and community based innovations.</p> <p>Social barriers: fear of stigma, immigration status; social exclusion; faith beliefs.</p> <p>Community preparedness programmes delivered over time to the community and community based</p> | <p>Limitations</p> <p>Author: No observation of GP services, community outreach or mobile testing. Evidence based on provider accounts, experiences of users of services mainly absent from data.</p> <p>Reviewer: Data not fully transcribed and recorded. Analysis poorly described. No details about researchers or who carried out analysis.</p> |

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| | <p>also acquired HIV infection?</p> <p>Theoretical approach: NR</p> <p>Data collection: Two round –table discussions (approximately 30 participants in each) in London in April and August 2007. Notes made of facilitated discussions.</p> <p>Non participant observation and in-depth interviews at VCT sites USA, South Africa, Ghana, Malawi and Ethiopia between November 2007 and February 2008. Interviews recorded and notes taken from recordings.</p> | <p>Inclusion criteria: NR</p> | <p>testing sites facilitates dialogue about barriers to HIV testing and creates a supportive environment for people living with HIV.</p> | <p>Future research: Review literature documenting evaluations of different approaches to VCT and community mobilisations.</p> <p>Funding: Elton John AIDS Foundation, Peter Moores Foundation, Gilead Sciences Ltd and St Stephen’s AIDS Trust</p> |
| <p>Authors: Nnoaham KE, Pool R, Bothamley G, Grant AD.</p> <p>Year: 2006</p> <p>Citation: Perceptions and experiences of tuberculosis among African patients</p> | <p>Research questions: Explore the experiences and perceptions of African-born people in London living with TB, focussing on issues influencing voluntary presentation and</p> | <p>Source: Outpatients in London Hospital TB clinic.</p> <p>Recruitment: Consecutive enrolment after routine consultation in TB clinic.</p> <p>Sample size: 16</p> | <p>Analysis: Grounded Theory. Coding themes, topics and categories emerging from transcripts using NVivo software. Comparison of themes within and between interviews leading to higher order generalisations. Iterative interviewing process.</p> <p>Key themes:</p> <p>Stigma. HIV tests initially declined because worried about the outcome and possibility of stigmatisation.</p> | <p>Limitations</p> <p>Author: Sample size, not representative either of TB patients or Africans with TB in the UK.</p> <p>Reviewer: No details on the role of the</p> |

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| <p>attending a tuberculosis clinic in London. International Journal of Tuberculosis & Lung Disease 2006; 10(9):1013-1017.</p> <p>Quality score: ++</p> | <p>treatment adherence and experiences of stigmatisation.</p> <p>Theoretical approach: Grounded Theory</p> <p>Data collection: In-depth, semi-structured interviews in private room in hospital. Interviews tape recorded and transcribed including paralinguistic features (pauses, emphasis & body language).</p> | <p>Exclusion criteria: Individuals attending clinic for preventative therapy and those receiving a diagnosis for first time.</p> <p>Inclusion criteria: Adults aged 18 years +, at East London Hospital, born in Africa, self-identified as African & willing to be interviewed in English</p> | <p><i>"I requested not to do it [HIV test]. I wasn't sure. I thought to myself, if I get that news, I would die". – 46 year old woman, South Africa</i></p> <p><i>"These days, if you have TB they say it's AIDS. If you have pneumonia, they say it's AIDS. If you have common fever, make sure you stay inside your house! Once you lose one kilogram, you're finished. OSme won't even shake your hands or eat with you, The stigma is too much. So people prefer to die" – 37 year old man, Nigeria</i></p> | <p>researcher or number of interviews not tape recorded. Convenience sampling rather than purposive or theoretical sampling. Analysis not cross checked. No data triangulation.</p> <p>Future research:</p> <p>Funding: NR</p> |
| <p>Authors: Paparini S, Doyal L, Anderson J.</p> <p>Year: 2008</p> <p>Citation: 'I count myself as being in a different world': African gay and bisexual men living with HIV in London. An exploratory study. <i>AIDS Care</i>; 20(5):601-605</p> <p>Quality score: –</p> | <p>Research questions: Exploratory study of the experiences of a group of black African men who define themselves as gay and are living with HIV in the UK</p> <p>Theoretical approach: Modified Grounded Theory approach</p> <p>Data collection: Individual semi-structured interviews conducted on hospital premises but non-clinical spaces. All interviews tape-recorded and</p> | <p>Source: African MSM living with HIV in London</p> <p>Recruitment: Convenience sample. Study advertised through voluntary organisations for people living with HIV, e-networks of black gay/bisexual men and specialist HIV clinics in a number of London hospitals.</p> <p>Sample size: 8</p> <p>Exclusion criteria: NR</p> <p>Inclusion criteria: NR</p> | <p>Analysis: Verbatim transcripts subjected to thematic analysis using modified Grounded Theory approach</p> <p>Key themes:</p> <p>Undertaking HIV testing due to ill health, doubts about partner's behaviour or routine check. Anxiety and prejudices about HIV when asked to test. Shock of HIV test result and expectation of immediate death due to experiences in home country.</p> | <p>Limitations</p> <p>Author: Small sample size not representative</p> <p>Reviewer: No data extracts in the paper to support the conclusions drawn. Alternate sampling strategy likely to have altered results. Little generalisability.</p> <p>Future research: Additional research needed for this group examining influences on testing.</p> <p>Funding: The Derek</p> |

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| | transcribed verbatim. Feb 2006 – Feb 2007 | | | Butler Charitable Trust |
| <p>Authors: Prost A, Griffiths CJ, Anderson J, Wight D, Hart GJ.</p> <p>Year: 2009</p> <p>Citation: Feasibility and acceptability of offering rapid HIV tests to patients registering with primary care in London (UK): a pilot study. <i>Sexually Transmitted Infections</i>; 85(5):326-329.</p> <p>Quality score: ++</p> | <p>Research questions: Exploring the acceptability of rapid HIV testing among patients attending new health check.</p> <p>Theoretical approach: NR</p> <p>Data collection: Semi structured interviews with patients attending new health check at London GP carried out by AP in a private room located in the clinic. Dec 2007 – March 2008.</p> | <p>Source: Patients attending primary care in London</p> <p>Recruitment: Purposive sampling of participants from a range of ethnic backgrounds attending new health care check at a GP centre offered an HIV test. Patients accepting the test (17) were interviewed after the test was carried out but before results delivered.</p> <p>Sample size: 20</p> <p>Exclusion criteria: NR</p> <p>Inclusion criteria: NR</p> | <p>Analysis: Framework analysis used to analyse data and identify emerging themes.</p> <p>Key themes:</p> <p>Advantages: rapid tests reduced the time spent waiting for results and made testing process seems “Routine”. Patients reluctant to go to sexual health clinics would be encouraged to know their HIV status if rapid tests were available in primary care.</p> <p><i>IV: Do you think GPs should have these tests?</i></p> <p><i>IE: Oh, yes. They should have them because this will enable a lot of people to find out in time. You know, sometimes to go to some AIDS clinic, once you go there, once you go in, people just know what you’re there for. They know you most probably have some sexual disease going down there. [...] With the AIDS clinic, you don’t go there until when you know you have a problem, so I think the GP having it is good. (Male participant, Nigeria, 28)</i></p> <p>Disadvantages</p> <p>Potential lack of support for newly diagnosed and lack of preparation for test result that could be positive.</p> | <p>Limitations</p> <p>Author: None</p> <p>Reviewer: Lack of information about data analysis and limited results from the qualitative data</p> <p>Future research: Evaluating the effectiveness and cost effectiveness of rapid testing in primary care.</p> <p>Funding: UK MRC</p> |
| <p>Authors: Prost A, Sseruma WS, Fakoya I, Arthur G, Taegtmeyer M, Njeri A et al.</p> <p>Year: 2007</p> | <p>Research questions: Determine whether service model of VCT from Kenya would be acceptable to African communities in London and feasible in the</p> | <p>Source: African people living in London. Key constituencies in the field of HIV and African communities and organisations within these (clinical, community and</p> | <p>Analysis: 3 researchers coded and analysed data for recurrent themes using Framework approach.</p> <p>Key themes: Perceived benefits include fast results and accessibility and community ownership.</p> <p><i>“I wasn’t sure when we started [the discussion], but now I think this would be a great, especially if it is</i></p> | <p>Limitations</p> <p>Author: Small number of participants from London may comprise generalisability of findings. African men’s views may be under</p> |

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| <p>Citation: HIV voluntary counselling and testing for African communities in London: learning from experiences in Kenya. Sexually Transmitted Infections; 83(7):547-551.</p> <p>Quality score: +</p> | <p>context of NHS clinical governance.</p> <p>Theoretical approach: NR</p> <p>Data collection: Focus group discussion (FGD) and participatory methods (key informant workshop, Nov 2006). Discussions tape recorded and transcribed verbatim. Francophone group notes only.</p> | <p>academic).</p> <p>Recruitment: FGD advertised through African CBOs and community venues Purposive sampling of young people aged 18-29, people living with HIV and women. Workshop attendees identified through community, academic and clinical networks.</p> <p>Sample size: FGD=42; Workshop=28</p> <p>Exclusion criteria: NR</p> <p>Inclusion criteria: NR</p> | <p><i>owned by Africans and positive people can be employed through it and share their knowledge.” - Female participant (South Africa), women’s group</i></p> <p>Perceived barriers include: fear of HIV-related stigma in African communities compounded by racism in wider community; anxiety about breaches of confidentiality; concerns about potential lack of professionalism.</p> <p><i>“If you target Africans only, they just feel targeted. Maybe they say, they think I am carrying it. But if it is targeting everyone, then that is better. And also we say we will be targeting African communities, but many Africans don’t have that feeling of belonging to a ‘community’. Which community are you talking about? They never felt part of a community so it’s not their problem.” -Female participant (Burundi), mixed group</i></p> | <p>represented.</p> <p>Reviewer: A large proportion of participants were involved with HIV organisations in London and this may have influenced results about feasibility and acceptability. A sample including more men, triangulation using in-depth interviews may have yielded different results.</p> <p>Future research: Verify results with in-depth interviews. Pilot testing of VCT</p> <p>Funding: Clinical Research and Development Committee at UCH, London.</p> |
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NR=Not reported.