

Delayed HIV testing in HIV-positive sub-Saharan Africans.

Jessica Howells

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Abstract

There is evidence that some sub-Saharan African individuals suspect that they are HIV positive before diagnosis but delay being tested for HIV. This increases the likelihood of being diagnosed late (with a severely compromised immune system), a phenomenon that has been observed in sub-Saharan Africans diagnosed in the UK. Late diagnosis has negative personal and public health consequences. There is a lack of understanding of the psychological processes associated with delayed HIV-testing. This study used a Grounded Theory methodology. It aimed to produce a theoretical model to explain the psychological processes associated with delayed HIV testing in sub-Saharan Africans in the UK but also how these processes changed over time and contributed to the decision to test. Seven HIV-positive sub-Saharan African individuals from a London HIV clinic and one from a HIV charity were interviewed about their experiences. Analysis led to the development of a theoretical model of delayed HIV testing. This model consisted of three theoretical codes: moving in and out of uncertainty about HIV infection; preferring not to know HIV status; and making the decision to test for HIV. Participants' HIV risk perception fluctuated and was characterised by uncertainty. This, in combination with a preference to not know their HIV status due to a number of feared consequences of being HIV-positive, deterred them from testing. Participants' thoughts and feelings about knowing their HIV status changed over time. These changes were that they: wanted certainty, had hope of being HIV-negative and/or a hope for treatment and life and preparing for and accepting a potentially positive result. The findings can inform interventions to reduce delayed testing and suggest: a) intervening with ambivalence on an individual level and b) promoting awareness of HIV c) promoting the benefits of testing/costs of not testing at a population level. The findings are discussed in relation to existing research and theory. Strengths and limitations of the study are discussed, as are clinical implications and suggestions for future research.

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Chapter 1: Introduction

Overview of the study

Individuals of African origin account for around 1.8% of the population in England and Wales (Office for National Statistics, 2011) yet it is estimated that of the heterosexual adults living with Human Immunodeficiency Virus (HIV) in the UK, around 60% are black African¹ (Health Protection Agency [HPA], 2013).

The first step towards being treated for HIV is to be diagnosed with the condition. This study makes a distinction between 'late presentation' and 'delayed testing' in HIV. Late presentation is when an individual is diagnosed with HIV with a CD4 count of less than 350 cells per mm³, with an increased risk of morbidity and mortality for the individual. The CD4 cell count is typically used as a measure of immune function. A normal CD4 count is between 500 and 1200 cells per cubic millimetre of blood (National Aids Map [NAM], 2012). Delayed testing is when an individual perceives that they might be risk of being HIV positive but does not initiate a test immediately or soon afterwards.

A larger proportion of HIV-positive black Africans have been found to be present late, compared to white individuals in the UK (HPA, 2013). Late presentation in this population has been linked to a low risk perception of HIV (Anderson & Doyle, 2004; Burns et al., 2007; Burns et al., 2008; Hickson et al., 2009). However there is evidence to suggest that some individuals of sub-Saharan African origin do perceive risk of being HIV positive prior to testing and diagnosis but do not initiate a test immediately (Erwin et al., 2002; Hayward, 2013).

¹The terms 'sub-Saharan African' and 'black African' will be used to reflect their use in the literature but it is acknowledged that they are not interchangeable terms.

There is evidence of various psychological barriers to HIV testing for sub-Saharan Africans² in the UK, Europe and sub-Saharan Africa such as a fear of dying (Erwin et al., 2002; Meiberg et al., 2008), fear of the impact a diagnosis will have on relationships (Hickson et al., 2009), stigma and discrimination (Burns et al., 2008; Erwin et al., 2002; Jürgensen et al., 2012; Råssjö et al., 2007), a lack of knowledge about HIV testing and accessing testing (Manirankunda et al., 2009) and a lay construction of risk perception (e.g. whether one is physically unwell or not) (Mabunda, 2006; McPhail et al., 2008). However many of the participants in the studies listed above may have never tested for HIV or been diagnosed as HIV positive and thus actually delayed a HIV test (and then subsequently taken a test). Therefore, the extent to which these findings are relevant to HIV positive sub-Saharan Africans who delayed testing is unclear. No research has explicitly explored delayed HIV testing in HIV-positive sub-Saharan African individuals and so our understanding of the psychological processes that characterises this phenomenon is limited. This Grounded Theory study aimed to explore the psychological processes associated with delayed testing in this population.

Eight HIV-positive sub-Saharan African individuals who delayed HIV testing were interviewed about their experiences of perceiving risk of HIV but not taking a test immediately or soon after, up to their eventual diagnosis of HIV. This involved exploring their thoughts and feelings and how they changed over this period of time. The interview data was analysed using a Grounded Theory method (Charmaz, 2006), which produced three theoretical codes, each of which subsumed a number of focused codes. A theoretical model of delayed HIV testing in HIV-positive sub-Saharan African individuals was produced, which may inform interventions aimed at

²Sub-Saharan African is defined as anyone who identifies themselves as originating from a country deemed by the United Nations Statistics Division as sub-Saharan African (United Nations Statistics Division, 2013). A list of countries making up sub-Saharan Africa is provided in Appendix A.

reducing delayed diagnosis.

The Human Immunodeficiency Virus (HIV)

The Human Immunodeficiency Virus (HIV) destroys and impairs the function of immune cells. The result of this is immunodeficiency which means that the infected individual is more susceptible to infections and diseases and is in turn less able to fight these off (World Health Organisation [WHO], 2013). HIV can be transmitted via unprotected sexual intercourse, contaminated blood during infusion or sharing of needles or from mother to child during pregnancy, birth or through breastfeeding (WHO, 2013).

Stages and Symptoms of HIV. The symptoms an individual who is HIV positive experiences depends on the stage of the HIV infection (see Figure 1), which varies in progression between individuals. The HIV viral load, the number of viral particles found in each millilitre of blood, helps to measure the stage of the HIV infection. The higher the number of HIV viral particles, the faster the CD4 cells are destroyed which means a faster progression to AIDS.

Stage 1: Acute infection
-Two to four weeks after the initial infection
-The individual may experience flu like symptoms (acute retroviral syndrome [ARS])
-Viral particles are being replicated and CD4 cells are being destroyed
-CD4 count can fall rapidly
-Immune response brings virus level back down and becomes stable (Viral set point)
-CD4 count increases but may not return to pre-infection levels



Stage 2: Clinical Latency
-HIV virus reproduces at low levels
-The individual may not have a detectable level of virus in their blood and CD4 count may be normal
-The individual may show no symptoms or only mild ones
-Without HIV treatment, this stage lasts an average of 10 years but some people may progress faster
-At the end of the stage, the viral load begins to rise and CD4 count will drop
-As a result, the individual will experience constitutional symptoms



Stage 3: Acquired Immune Deficiency Syndrome (AIDS)
-An individual is considered to have progressed to AIDS when they have a CD4 cell count of less than 200 cells per cubic millimetre of blood
-The immune system is extremely compromised leaving the individual vulnerable to serious opportunistic infections (e.g. tuberculosis, cryptococcal meningitis and cancers such as lymphomas)
-Without treatment there is a life expectancy of around 3 years

Figure 1. The stages of Human Immunodeficiency Virus (information from US Department of Health and Human Services, 2013)

HIV in individuals in sub-Saharan Africa. Of the estimated 34 million people living with HIV worldwide, 69% are in sub-Saharan Africa (SSA) despite only 12% of the global population residing here (UNAIDS, 2012). The designation 'sub-Saharan Africa' is used to indicate all of Africa except northern Africa, but with Sudan included (United Nations Statistics Division, 2013).

Miahouakana-Matondo (2012) describes sub-Saharan Africa (SSA) as 'culturally complex' as it is linguistically, culturally and ethnically diverse, with there being variation both between and within countries. There is also considerable variation in the prevalence of HIV between the sub-Saharan African countries (UNAIDS, 2010). For example, in 2009 it was estimated that the adult prevalence of HIV in Swaziland in Southern Africa was 25.9% compared to 7% in Uganda in East Africa (UNAIDS, 2010).

HIV in individuals of sub-Saharan African origin in the UK. In 2012, it was estimated that 98,400 people were living with HIV in the UK (Health Protection Agency [HPA], 2013). It is estimated that 31.29% of these were black African (HPA 2013). Of the black African men and women living with HIV in the UK, it is estimated that 23% are undiagnosed (HPA, 2013).

Generally, it is estimated that over 50% of HIV transmissions are from people who are undiagnosed (Marks, Crepaz & Janssen, 2006). Those with a HIV diagnosis are more likely to reduce transmission risk behaviour after becoming aware of their serostatus (Fox et al., 2009) and can also start treatment that will reduce their viral load, meaning they are less infectious (Marks et al., 2006). To reduce the amount of undiagnosed HIV and thus onwards transmission, the uptake of testing needs to be increased.

The testing, diagnosis and treatment of HIV in the UK and sub-Saharan Africa

Guidelines on HIV testing in the UK. The current UK guidelines on HIV testing (The British HIV Association [BHIVA], 2008) recommends that HIV tests should be offered to everyone in particular healthcare settings such as Genitourinary Medicine (GUM) or sexual health clinics, antenatal services, termination of pregnancy services, drug dependency programmes and in services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma. The BHIVA (2008) guidelines made recommendations for routine testing in other settings to address undiagnosed HIV (HPA, 2011). For example, the guidelines recommend that an HIV test should be offered to all new registrations at general practices or to all general medical admissions in an area where the HIV prevalence in the local population exceeds 2 in 1000 people. Although individuals are required to 'opt-out' in certain settings, HIV testing should be voluntary and individuals have the right to decline a test offered to them (World Health Organisation, 2013). HIV testing may also be self-initiated however in settings such as GUM, sexual health clinics or general practices.

Access to HIV testing and treatment in the UK. HIV tests are available on the National Health Service (NHS) and are free of charge to anyone (NHS, 2012). Prior to October 2012, HIV treatment was not freely available to all on the NHS with there being charges for individuals who fell in to categories such as those who had entered the UK without proper permission or had overstayed a visa of any kind (NAM, 2013). One survey found that of the 708 black African heterosexual men and women who completed it at a North-East London NHS HIV clinic, approximately half of these had an 'insecure' residency status (Ibrahim, Anderson, Bukutu and Elford, 2008). It is unknown whether individuals, who previously may have not been entitled to HIV treatment, became aware of these changes in entitlement to HIV treatment. It is also unclear whether ineligible individuals were *actually* charged for HIV testing and

treatment before 2012.

Early versus late diagnosis of HIV in the UK. 'Late diagnosis' or 'late presentation' in HIV has generally been defined by a biological marker of immunologic status. That is, when an individual's CD4 cell count is <350 cells/mm³ (HPA, 2013). This is also when treatment should start. In the UK in 2012, 66% of black African heterosexual men and 61% of black African women, compared to 47% of white heterosexual men and 44% of white women were diagnosed late (HPA, 2013). Late diagnosis of HIV poses a risk of excess mortality (Nakagawa et al., 2012). A prompt HIV diagnosis after infection is important as antiretroviral therapy (ART) may need to be initiated, to maintain and improve physical and psychological wellbeing of the individual and to also prevent onward transmission (Williams et al., 2014). The National Institute for Health and Care Excellence (NICE) (2011) published clinical guidelines on ways to increase the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black African communities in the UK. This highlights the need to work within communities to promote the benefits of early diagnosis.

Antiretroviral therapy (ART) for HIV. The effectiveness and tolerability of ART has made significant advances over the past 15 years. The consequence of starting ART later than the BHIVA clinical practice guidelines (Williams et al., 2014) recommends is a reduction in life expectancy by up to a 15 years (Williams et al., 2014) and a tenfold increase in death rate within the first year of a late diagnosis compared to those with a CD4 cell count above 350 cells/mm³ (HPA, 2013). This is more likely to happen if there is a delay between infection and diagnosis. There is also evidence that early diagnosis and thus initiating ART early or when recommended can have an impact on onward transmission and incidence rates

(Cohen, Chen, McCauley et al., 2011). Late presentation also means that treatment will be more complex and it will take longer for the CD4 cell count to reach a satisfactory level (Coenen et al., 2011). Starting ART at the appropriate point is dependent on people testing for HIV as early after the initial infection as is possible.

Testing and treatment of HIV in sub-Saharan Africa. The introduction of ART led to changes in testing strategies in terms of funding, technology and access (Staveteig et al., 2013). Stand-alone voluntary counselling and testing clinics were the main testing modality in many sub-Saharan African countries until recently (UNAIDS, 2013a). WHO and UNAIDS published guidance on provider-initiated, 'opt-out' approach to testing in 2007, which was subsequently implemented across many sub-Saharan African countries. HIV-testing strategies in SSA currently include facility-based (e.g. in a clinic for sexually transmitted infections, maternal and child health or TB treatment) and community based approaches (e.g. offering testing at workplaces and educational establishments, mobile VCT services and in people's homes) (Staveteig et al., 2013). Despite increased access to HIV testing in SSA in the past decade (UNAIDS, 2013a), it is estimated that 36% men and women aged between 15 and 49 in SSA have never tested for HIV (Staveteig et al., 2013). Access to ART differs between regions and countries in sub-Saharan Africa. In 2012 to 2013, it is estimated that the percentage of individuals eligible for ART who were not receiving it was 59% in Eastern and Southern Africa but 79% Western and Central Africa (UNAIDS, 2013b).

Risk perception and HIV testing

Black African individuals in the UK are more likely to test late to services compared to individuals of other ethnicities (HPA, 2013). This is often linked to a low perception of HIV risk (the extent to which the person thinks they are HIV-positive)

observed in this population (Anderson & Doyle, 2004; Burns et al., 2007; Burns et al., 2008; Hickson et al., 2009).

Findings on the relationship between perceived risk of HIV and the uptake of HIV-testing across various populations are mixed. Some studies have found no significant association between perceived risk and testing (e.g. Ford et al., 2006; Huang et al., 2012; Johnston et al., 2010; Tun et al., 2012), whereas others have (e.g. Andrinopoulous et al., 2008; Thomas et al., 2008). Napper, Fisher & Reynolds (2012) note that health behaviour models such as the Health Belief Model (Rosenstock, 1974) and Protection Motivation Theory (Rogers, 1983) consider perceived risk as an important predictor of behaviour change. Within these models, risk perception is considered to be necessary but not sufficient alone for behaviour change.

Therefore an individual may present late to services for HIV testing due to a *conscious* delay when there is a perception of present HIV risk (Girardi et al., 2004). This is the concept of 'delayed testing' where one fails to take a test (immediately) when there is perceived risk of HIV (Siegel, Raveis & Gorey, 1998; Samet et al., 2001).

Delayed testing versus late testing

The concept of delayed testing can be considered a separate phenomenon to the medical phenomenon of 'late presentation'. Although there can be some overlap between late presentation and delayed testing, they have different meanings and can occur separately. For example, someone who delays testing after perceiving risk of infection increases their chances of being a late presenter but they are not considered so if they do not meet the specified biological parameters of this definition. This may be the case as the consequence of individuals' HIV infection on

(the decline of) immune functioning is highly variable (Samet et al., 2001). Similarly, late presentation does not imply the psychological process of ‘delaying’ testing if, for example, there is no risk perception of HIV. This is shown in Table 1.

Table 1.

Table showing different combinations of delayed testing and late presentation

CD4 count <350 at diagnosis	Perceived risk of/suspected HIV prior to diagnosis and delayed test		
		Yes	No
Yes		Delayed testing and late presentation	No delayed testing but late presentation
No		Delayed testing, but not late presentation	No delayed testing and not late presentation

The study of delay between HIV acquisition and HIV testing has been limited (Samet et al., 2001). The issue of delayed testing is important as the individual is consciously making the decision to delay testing and therefore suggests that there is an opportunity to intervene to facilitate earlier testing.

Delayed HIV testing across populations. There is evidence of delayed HIV testing in various populations. Wenger, Kusseling, Beck and Shapiro (1994) carried out a survey with 227 HIV-positive patients an outpatient HIV clinic in the United States, 81% of whom were men who have sex with men (MSM), to explore how and when individuals first suspected risk of HIV infection. 60% of the sample reported

that they did not suspect infection until they received a positive diagnosis. Of the 40% of patients who suspected HIV infection prior to testing and diagnosis, 48% reported delaying their testing by at least one year.

Samet et al. (2001) note that making the decision of whether to test or not is a difficult one for individuals who suspect HIV infection. They studied a sample of 200 patients attending an out-patient HIV clinic in the USA. 44% were black, 29% white and 25% Hispanic. 19% were men who have sex with men and 47% were injection drug users. Samet et al. (2001) found that 66% were aware of their HIV risk before testing and being diagnosed as HIV positive. The mean amount of time these participants felt at risk of HIV before testing was 2.5 years. Over 40% of these individuals reported getting tested to find out or to be honest with themselves. The authors did not explore what the concept of wanting to be honest with oneself meant however.

Lekas, Schrimshaw & Siegel (2005) interviewed a group of HIV-positive individuals who were either gay or bisexual men or heterosexual drug users who were diagnosed at age 50 or older. They used a qualitative analysis. All participants acknowledged engaging in behaviours which put them at risk for HIV but a number of the participants reported delaying testing due to psychological barriers. The gay and bisexual men reported denying their risk for HIV because of fears of not being psychologically ready to deal with the consequences of being HIV-positive. This was the reason why many of the heterosexual drug users who suspected HIV infection, also delayed testing. Some of the gay and bisexual men reported minimising the severity of their risk behaviours. Other gay and bisexual men reported attributing symptoms that they knew were HIV-related to other less-threatening explanations. It is possible that the age of the participants is linked to these psychological barriers as

they may have been more exposed to the changing information about HIV across the years. The two most common factors associated with testing in the sample were wanting to find out the cause of their physical symptoms and encouragement to test by health-care providers.

These findings highlight that despite having perceived risk of HIV, some individuals still do not go forward for an HIV test and in some cases, for a significant amount of time.

Delayed testing in the sub-Saharan African population in the UK. Delayed HIV testing has been observed in the sub-Saharan African population in the UK. One survey of HIV care-pathways in London which had 392 respondents found that 28% of HIV-positive black Africans perceived risk of HIV infection before testing and that 62% of these people delayed testing by at least 12 months (Erwin et al., 2002). The authors do not provide information on how they measured delayed testing in this sample. Delayed testing was also observed in a study by Hayward (2013) which looked at psychological correlates of delayed and late testing, using Theory of Planned Behaviour as a theoretical framework, in a sample of recently diagnosed individuals of sub-Saharan African origin in the UK. In a sample of 25 participants, 4 delayed testing and were late presenters, 1 delayed testing but was not a late presenter, 17 were late presenters but did not delay testing and 3 were not late presenters and did not delay testing.

The psychological impact of delayed testing

The combination of having delayed testing and being a 'late presenter', which has negative implications for prognosis, may be linked to poorer psychological wellbeing in the individual. Samuel et al. (2012) used a qualitative methodology to explore the

perceived psychological impact of HIV on a diverse sample of 24 individuals living in the UK, diagnosed at either an early or late stage of HIV. Those with a late diagnosis (CD4 count <200 cells) reported reduced quality of life, mood difficulties, a reduced capacity to work and an impaired ability to construct a positive identity with HIV. Those with an early diagnosis viewed themselves as healthy and felt HIV was manageable. Some of the individuals with a late diagnosis reported a delay of testing due to fear of knowing their status. Unfortunately the authors did not distinguish and compare the psychological impact of the late diagnosis in individuals who did or did not delay testing within the late diagnosis group. However it is possible that individuals who delay testing and are diagnosed late may experience psychological difficulties after diagnosis. This may be linked to feelings of regret about not having tested sooner if they are extremely unwell or guilt if they were to realise that they had transmitted HIV to a partner for example.

Understanding delayed testing

HIV research has focused on HIV-positive individuals who have presented late with there often being no reference as to whether these individuals delayed their HIV testing or not. No research has explicitly looked at psychological factors associated with delayed testing in SSA populations. However, research has identified a number of barriers to testing, for individuals of SSA origin in the UK, Europe and in sub-Saharan Africa.

Barriers to HIV testing for sub-Saharan Africans in the UK and Europe

Fears and concerns about the negative consequences of being HIV-positive are a commonly cited barrier.

Fear of HIV and death. A qualitative study by Manirankunda et al. (2009) used

focus group discussions to explore perceived barriers to HIV testing for 70 SSA individuals living in Belgium. It was not known how many were HIV-positive. It was found that fears of the consequences of HIV meant that most participants preferred not to know their HIV status. A significant fear was one of dying. Hickson et al. (2009) carried out a large-scale community research project to assess the HIV prevention needs of 2580 Africans in England. 39.5% (948 people) of the sample reported that they had never taken a HIV test. 23.5% (223) of these individuals were not sure of their HIV status and 2.3% (22) thought that they would test positive if tested. Hickson et al. (2009) found that 19.4% of those who were unsure of their HIV status had not tested because they were too afraid that they may have HIV. In the survey by Erwin et al. (2002), of the black African respondents, 66% reported fearing dying and 64% were concerned about not being able to make future plans. Participants in this study were recruited around 3 years after the initial introduction of combination ART (highly active antiretroviral therapy [HAART]) (Palmisano & Vella, 2011). Therefore knowledge about the availability of these drugs may have not been widespread and this may have been linked to people's decisions to seek or avoid seeking testing.

Relationship concerns. Of the participants that delayed testing in the survey by Erwin et al. (2002), 74% were concerned about the impact of an HIV diagnosis on their family and 49% with their partner's reaction to a diagnosis. In the community research project by Hickson et al. (2009), 16% of those who thought they were definitely HIV positive had not tested due to fears about the problems the diagnosis would cause in their relationship.

Fear of stigma and discrimination. Earnshaw and Chaudoir (2009) note that the impact of stigma associated with HIV on efforts to prevent and treat HIV has been long documented. Earnshaw and Chaudoir (2009) created a theoretical framework of

how HIV stigma elicits a number of 'stigma mechanisms' which lead to negative outcomes for those both infected and uninfected by HIV. For those infected with HIV, the mechanisms are: enacted stigma (the actual experience of discrimination), anticipated stigma (the expectation that one will experience discrimination from others) and internalised stigma (the endorsement of negative beliefs and feelings about self). This leads to negative psychological, behavioural and health outcomes for individuals living with HIV. For uninfected individuals, stigma mechanisms of prejudice, discrimination and stereotypes impacts negatively on HIV testing and leads to social distancing in the form of avoidance.

Hickson et al. (2009) found that 12.6% and 11.2% of those in their sample who were unsure of their HIV status had never tested due to fears of being treated differently if they took a test or if they had HIV, respectively. Of the participants that delayed testing in the survey by Erwin et al. (2002), 68% reported that fears of discrimination following a HIV diagnosis was a pre-test concern. In the qualitative study by Manirankunda et al. (2009), social rejection and stigma was reported as a barrier to testing by many participants. Participants linked this stigma to culturally held beliefs about HIV such as it affecting those who were 'bad people' due to deviant sexual behaviours. Anticipated social exclusion meant that these participants preferred to not know their HIV status.

Lack of knowledge. Manirankunda et al. (2009) observed a lack of in-depth knowledge about HIV, its modes of transmission, how to obtain a HIV test and how to cope with HIV in daily life amongst SSA individuals in their sample and those generally in the community. This was reported as a barrier to testing by participants. The authors note how lack of knowledge about HIV transmission routes appeared to allow room for stigmatising and false beliefs about HIV to exist in the community.

Hickson et al. (2009) found that 25.3% of their sample reported not knowing where to get a HIV test if they wanted one. Thomas et al. (2010) carried out a qualitative study using focus groups with 70 individuals in England to explore the impact of perceived health-care charges on HIV testing and treatment in migrants from southern Africa. They found that there was a reported confusion amongst participants about health care entitlements, which was a contributing factor to avoidance of health-care services for testing (Thomas et al., 2010).

Limitations of the literature on barriers to testing. The literature suggests that low risk perception is a significant barrier to HIV testing for a number of SSA individuals in the UK and Europe. Other barriers to testing such as fear of various consequences of being HIV-positive and lack of knowledge around the infection and health care, exist. However, much of this research is carried out with community samples in which respondents may have not tested or may not have a HIV diagnosis. These participants are asked about the absence of testing (i.e. why they have never tested) and information about their perceived risk of HIV is not always provided. Therefore it is not clear whether they are intentionally delaying a HIV test or not or whether they never intend to test. It is only possible to explore delay in those who have actually tested for HIV but delayed their testing or prospectively in those who are actively delaying testing but go on to take a HIV test. It is possible that the identified barriers are associated with a complete lack of testing if the individuals in the sample never go on to test. Delayed testing may be associated with different psychological processes. Exploring delayed testing in sub-Saharan African individuals who are HIV positive is important as they are by definition, the group with the highest level of HIV risk, and are most important on individual and public health grounds.

A further limitation to these studies is that they did not explore factors that participants feel would have facilitated or did facilitate testing. This is important because individuals who delay testing eventually go on to have a HIV test. Therefore to fully understand delayed testing, it is important to know how factors that are linked to delay are overcome. Many participants in the cited studies had not tested which means that facilitators of testing could not be explored. However 60% of respondents in Hickson et al.'s (2009) project had tested for HIV. Also, the black African participants who had delayed testing in Erwin et al.'s (2002) study were diagnosed as HIV positive at the time of recruitment. However neither of these studies explored why participants had tested or how they overcame their pre-test concerns. Understanding the psychological processes that help overcome barriers and lead to uptake of testing is also important when considering strategies and interventions to reduce delay. Beardsell et al. (1996) describe a HIV test as a 'macro-process' consisting of sets of testing experiences which have a dynamic interdependence. In sub-Saharan African and other populations, there have been limited attempts to develop theoretical models of HIV testing which aim to capture and explain the process of deciding to take a test. Existing models in other populations have not explained the process of how individuals overcome barriers and go on to test such as the HIV testing decisions model by Spielberg et al. (2001).

Barriers and facilitators of HIV testing for sub-Saharan Africans in sub-Saharan Africa

A recent systematic review by Musheke et al. (2013) synthesised qualitative and mixed-methods findings on factors that deterred and enabled the uptake of HIV testing by individuals in sub-Saharan Africa. These forty-two studies were conducted in thirteen SSA countries. Musheke et al. (2013) grouped the factors that were found to deter or enable testing across the studies. The main groups were: a lay

construction of risk of infection, the mental burden of living with HIV, social support and exclusion, gender inequality and influence, reproductive health aspirations, organisation and delivery of HIV services, trust in the healthcare system and the financial costs of HIV testing. Some of the most commonly cited factors are now discussed.

Perception of risk of infection. A lack of physical symptoms or not being unwell deterred participants from testing. In a study using focus group discussions to explore views on voluntary counselling and testing (VCT) with adolescents and parents in two South African townships (McPhail, et al., 2008), participants reported a perception that VCT was only necessary for symptomatic people. In 17 of the studies, the presence of symptoms or deterioration of health increased perceived risk and the decision to test. In a study on VCT knowledge and practices in a rural South African village by Mabunda (2006), participants reported knowledge of VCT but only used this if they had signs and symptoms to suggest that they had HIV.

Fear of death and the psychological burden of HIV. Musheke et al. (2013) note that despite the increased availability of ART, it was reported in 17 of the studies that participants saw a HIV diagnosis as meaning a hastening death which they did not wish to know about. For example in a study using focus groups to explore psychosocial correlates of HIV VCT in 72 South African students (Meiberg et al., 2008), many participants expressed the belief that it was better to not know if they have HIV and were going to die young. Some of the participants expressed a belief that they may commit suicide if they tested positive. A study by Jürgensen et al. (2012) used in-depth interviews and focus groups with individuals in Zambia who both had and had not accessed VCT, to explore testing decisions. Participants expressed a great fear of knowing their status despite an awareness of treatment

and some reported the belief that the worry, associated with knowing they had HIV, would accelerate the progression of the disease.

Social exclusion and discrimination. 25 of the studies reviewed by Musheke et al. (2013) reported fear of stigma and discrimination as a deterrent to testing. Some of the participants in a study by Råssjö et al. (2007), which explored responses to VCT among young people in Uganda, described a fear of being rejected by friends and family or being mistreated which deterred them from testing. This was also reported by participants in the study by Meiberg et al. (2008), as well as a fear of being blamed by health care workers if HIV-positive. In the study by Jürgensen et al. (2012), participants felt that having a HIV diagnosis or being seen at a VCT site would mean a loss of moral standing, due to its strong link with promiscuity and prostitution, and result in discrimination from the community.

Limitations of research on deterring and enabling factors to testing in SSA. As with the research on barriers to testing for individuals of SSA origin in the UK and Europe, the majority of the participants in these studies were not diagnosed as HIV positive and many had not accessed VCT. It is not known if the participants perceived risk for HIV or were indeed 'at-risk'. Therefore these studies did not explicitly explore a sample of individuals who had delayed HIV testing.

Delayed diagnosis in other medical conditions

Patient delay in seeking a diagnosis has been observed and explored in other conditions such as cancer.

A model of patient delay in cancer. Andersen, Cacioppo and Roberts (1995, p.34) devised a model of patient delay in cancer which they describe as comprising

of 'a series of stages, each governed by a conceptually distinct set of decisional and appraisal processes'. The stages are: appraisal delay (the period between detecting unexplained signs or symptoms and inferring illness), illness delay (from illness being inferred to when the individual decides to seek medical help), behavioural delay (the point from deciding to seek medical help to the point where they act on this decision) and scheduling delay (the point from where the person makes an appointment and then first receives medical attention). Andersen et al. (1995) suggest that a move to the next stage is influenced by decisions made in the former. They found support for this staged conceptualisation of delayed diagnosis in their two studies which sampled 34 women in the US who had been diagnosed with gynaecological cancer in the previous two weeks and 63 women who were being investigated for breast cancer. They found that the appraisal delay stage accounted for the most amount of time in the delay period. Andersen et al. (1995) noted that understanding psychological processes underlying the stages of delay are important both theoretically and clinically.

Barriers and facilitating factors in patient delay in cancer. de Nooijer, Lechner & de Vries (2001) highlight the importance of understanding factors influencing decisions that move an individual from one stage to another if we are to try to reduce patient delay. De Nooijer et al. (2001) used qualitative interviews with 23 individuals diagnosed with a range of different cancers in the Netherlands, to explore factors that stimulated and impeded movement between the stages in Andersen et al.'s (1995) model of total patient delay. At appraisal delay, factors that stimulated transition to the next stage were knowledge, panic as a reaction to symptoms, interpreting symptoms as cancer and consulting others. Factors that impeded transition from this stage were not having a worried reaction to symptoms, feeling ashamed or embarrassed about symptoms and interpreting symptoms as a

common ailment. At illness delay, stimulators were fear, consulting a GP and consulting others. Fear which resulted in the denial of symptoms impeded transition to the next stage. The authors note how at this stage, participants dealt with their fear in different ways. They used the danger/fear control framework (Leventhal,1970) to make sense of this. This suggests that being aware of a danger (fear about symptoms) and having an effective solution (seeking medical attention) results in a danger control response. However others may engage in what is termed fear control where the individual focuses on the emotions experienced instead of the danger itself. Knowing others with cancer was both a stimulating and impeding factor for different people. At behavioural delay, factors impeding transition to the next stage was postponing visiting the GP due to emotional reactions or giving priority to other events. For scheduling delay, this was a fear of being told they had cancer. de Nooijer et al. (2001) note that in some individuals, these stages overlapped and were not necessarily independent.

Limitations in the applicability of research on delayed diagnosis in cancer to HIV. Research on patient delay in cancer suggests the presence of stages or intervals from symptom detection to treatment. The role of emotions such as fear and the impact they have on transitions through these stages is noted. Feelings of fear appear to be linked to the potentially fatal nature of cancer. This is similar to findings on barriers to HIV testing in sub-Saharan African individuals. Yet for both conditions, an earlier diagnosis can mean a better prognosis for the individual. The research also highlights the coping mechanism of avoidance that individuals may use to deal with the aversive experience of these emotions (de Nooijer et al., 2001) which contributes to patient delay in cancer.

This research highlights the importance of the individual perceiving their

symptoms to be cancer in order to seek medical help. Many symptoms in cancer are cancer specific (e.g. a lump in the breast) which increases cancer inference (de Nooijer et al., 2001). Around 70% of individuals experience seroconversion illness in the acute stage of HIV (Pilcher et al., 2004), the symptoms of which are 'flu-like' and are therefore not explicitly indicative of HIV. Therefore illness representations (Leventhal, Meyer & Nerenz, 1980) that are formed by individuals, based on these symptoms, may not lead them to conclude that they have HIV. This may be one of the reasons why they do not seek HIV-testing after experiencing them. Following this period, HIV may be asymptomatic for some time, unlike many cancers. Therefore the psychological processes involved in suspecting HIV and delaying testing may be quite different if illness is not inferred on the basis of physical symptoms but on other grounds (e.g. a partner being diagnosed with HIV).

Symptoms in HIV

Symptom presence in HIV. Willard et al. (2009) argue that the concept of 'asymptomatic HIV' during the clinical latency stage is not accurate as they found that in a sample of over 1900 HIV-positive individuals, symptoms were experienced regardless of their CD4 cell count or lack of opportunistic infections. The majority of black Africans in the UK are presenting to services with a CD4 cell count of <350 (HPA, 2013) and individuals are more likely to experience symptoms at this point as the immune system is more compromised. Frequently reported symptoms by those in the study by Willard et al. (2009) included fatigue, muscle aches, difficulty concentrating and dry mouth, all of which could be attributed to other illnesses.

Burns et al. (2008) carried out a survey based study with 263 newly diagnosed HIV-positive Africans in London found that 76.4% of respondents had seen their GP in the year prior to HIV diagnosis for symptoms including, flu or a chest

infection (45.9%) and dermatological symptoms (23%). Despite this population mainly coming from countries with a high prevalence of HIV, there was a low perception of HIV risk amongst respondents with 69.9% of them not considering the possibility of being HIV positive prior to diagnosis. Therefore it is likely that many individuals who sought medical attention for symptoms in the year prior to diagnosis did not consider that they could have been due to HIV. The way that individuals, who are unknowingly infected with HIV, interpret the symptoms that they have pre-diagnosis, may influence their perception of being HIV positive.

Siegel, Schrimshaw and Dean (1999) retrospectively explored the impact that the absence or presence of symptoms and the interpretation of them, had on the uptake of HIV testing in a group of HIV-positive middle-aged and older adults. An absence of symptoms meant that individuals believed that they could not be infected with HIV and were less willing to seek HIV testing. When symptoms were present, the causal interpretation that individuals made influenced whether testing was sought. Many individuals did not attribute their symptoms to HIV as it was not part of their 'common sense representation' of HIV which meant that testing was not initiated (Siegel, Schrimshaw & Dean 1999). Others attributed their symptoms to things other than HIV despite acknowledging they were at-risk for HIV. Siegel, Dean & Schrimshaw (1999) highlight the influence that stigma may have on the individual's propensity to interpret their symptoms as being related to HIV.

Symptom interpretation in HIV. Siegel, Dean & Schrimshaw (1999) note the importance of understanding how individuals with HIV interpret and evaluate physical symptoms as this will influence their response. This is also relevant for those who are not yet diagnosed with HIV but acknowledge their risk for HIV. Many models have tried to explain the process of how individuals make sense of their symptoms (e.g.

Common sense model of illness representations, Leventhal et al., 1980; Psychophysiological comparison theory, Cacioppo, Andersen, Turnquist & Tassinari, 1989). Siegel, Dean & Schrimshaw (1999) note that because symptoms can represent a threat to one's health and therefore evoke anxiety, psychological responses to symptoms may be to minimise, normalise or accommodate them. Croyle (1992) describes how symptoms can often be extremely ambiguous which is anxiety provoking for the individual. In the context of an ambiguous health threat, cognitive appraisals of symptoms can be understood as a process of motivated reasoning whereby individuals are motivated to conclude that the threat is not serious so that anxiety is reduced (Croyle, 1992).

While uncertainty can be seen as a source of psychological distress it may actually be preferable for some individuals to remain uncertain about their HIV status, rather to have negative certainty (Brashers et al., 1998). Mishel (1988), who proposed the theory of uncertainty in illness, noted that uncertainty about symptoms is not experienced as inherently negative or positive. Instead uncertainty and its implications can be appraised in both ways. Uncertainty can be seen as a source of distress or a source of hope for positive outcomes (Mishel, 1988). For those who perceive themselves as at-risk for HIV but are not diagnosed, uncertainty about status may be preferred as HIV testing could mean certainty about having an illness which can be highly stigmatised (Alonzo & Reynolds, 1995; Brashers et al., 1998). Flowers, Duncan & Knussen (2003) found that some participants from a sample of Scottish gay men preferred to live with uncertainty about their status if knowing about a positive status did not feel tolerable. Testing was used to relieve this uncertainty only when not knowing felt less tolerable than having a positive result.

Rationale for the current study

The literature reviewed highlights several key issues and findings which inform the present study and provide a rationale for further exploration. Individuals of sub-Saharan African origin living in the UK are presenting to health care services with a more advanced stage of HIV, which potentially has both negative personal and public health consequences. The advances in ART mean that with prompt testing, these consequences can be reduced and even potentially avoided.

Research on HIV has failed to distinguish between those who perceived risk of HIV and delayed testing prior to diagnosis and those who perceived no risk of HIV prior to diagnosis. Qualitative and quantitative methodologies have been employed to explore barriers to HIV testing faced by those of sub-Saharan African origin in both sub-Saharan Africa and in the UK. However many participants in these samples had not tested for HIV or were not HIV positive. It is also not clear whether these individuals were at risk of HIV or perceived any risk of HIV and were therefore actively delaying testing. Therefore the identified barriers may be associated with a lack of testing rather than delayed testing. This research has also failed to identify factors that facilitate testing, again due to many participants in the sample having not tested. Therefore by studying those who have delayed a HIV test but were subsequently diagnosed with HIV, it is possible to explore the psychological processes that characterise this testing process as a whole. This is particularly important in the SSA population as they represent the most cases and the highest rates of heterosexually acquired HIV in the UK and are more likely to present late to services than other ethnic groups (HPA, 2013).

Research on delayed diagnosis in other conditions such as cancer has received more attention and has produced frameworks for mapping out the dynamic

stages of the delay process. de Nooijer et al. (2001) state that transition through the stages is attended by different decisions (i.e. whether symptoms suggest cancer, whether to book an appointment with the GP) but the factors which influence these decisions are not fully clear. Research on delay in cancer diagnosis also highlights the role that symptom interpretation and emotional responses have in the delay process.

Many individuals with HIV in the clinical latency stage may not experience symptoms. However there is evidence to suggest that many individuals do experience symptoms (Willard et al., 2009), although they may not be 'HIV-specific'. Research on symptom interpretation has highlighted that appraisals of ambiguous, threat related symptoms may be motivated and biased to reduce anxiety. This has been observed in some populations of individuals at risk of and living with HIV (Siegel, Dean & Schrimshaw, 1999). Uncertainty about one's HIV status has also been found to be preferable for some and this may mean that testing is delayed until uncertainty becomes intolerable (Flowers et al., 2003). This may be because their appraisal of uncertainty changes over time.

There is no study that has explicitly explored the process of delayed testing in the HIV positive sub-Saharan African population. This includes the identification and mapping out of the psychological processes which facilitate or impede the process of HIV testing. An understanding of these processes is likely to be of clinical relevance when developing interventions to reduce delays in testing.

This study aims to address this gap in the literature by exploring the process of delayed testing, including facilitating and impeding psychological processes, from the perspective of those who have experienced delayed testing.

Research aims and questions

This study aims to build a theoretical model of delayed HIV testing in individuals of sub-Saharan origin that is grounded in the data collected via in-depth interviews. This will focus on the psychological processes that characterises the process of delayed testing. The model generated in this study will be discussed in the context of previous research findings.

Previous research exploring delay in cancer diagnosis has used qualitative methodology as it is recognised that such methods are able to provide insights in to the complexity of the issue of delay (de Nooijer et al., 2001). This includes for example, patients' experiences of symptom detection and interpretation, a detailed understanding of which may not be obtainable through other research methodologies (Green & Britten, 1998). Campbell et al. (2007) note the importance of using qualitative methodology to identify factors related to delayed presentation in health conditions that may be amenable to intervention.

As research on delayed testing in HIV-positive sub-Saharan Africans is limited, a qualitative, Grounded Theory methodology will be used. Such a methodology allows one to begin inquiry and gain an in-depth understanding of the phenomenon of delayed testing by exploring the experiences and perspectives of individuals who have participated in this process (Elliott, 1995). Grounded Theory methodology is suited to studying a phenomenon that is not well defined and where sensitivity to changing contexts and conditions is relevant to the study of it (Henwood & Pigeon, 2003). This is because a key aim of Grounded Theory is to analyse action and process (Glaser & Strauss, 1967) including the conditions under which these actions or processes arise, are maintained and vary (Birks & Mills, 2011). This matched the aims of the current research questions.

The main research questions that this study aims to address are:

1. *What are the psychological processes associated with delayed testing in a sample of SSA HIV positive people?*
2. *How do these processes change, from the point of initial risk perception to testing?*

Chapter 2: Method

Research Design

A cross sectional qualitative design was used. A Grounded Theory (Charmaz, 2006) methodology was used to collect, analyse and report data.

Ethical approval

The study gained ethical approval from an NHS Research Ethics Committee in August 2013, the Royal Holloway, University of London (RHUL) Departmental Ethics Committee (DEC) in September 2013 and a Research and Development (R&D) department at the NHS recruitment site in October 2013 (see Appendices B, C and D). The study was also granted approval by the peer review committee at the NHS recruitment site in July 2013 prior to gaining R&D approval.

Before the study commenced, there was some further communication with the peer review committee at the NHS recruitment site about the recruitment process. The research governance lead at the recruitment site suggested an amendment to the procedure, which would rely less on clinicians who were already pressured for time, to ensure that the study was introduced to patients. Therefore, following an initial favourable opinion from the REC, an amendment to change the procedure as recommended was submitted to the REC and approved in October 2013 (see Appendix E). The R&D office was informed. A second amendment was submitted to the NHS REC in January 2014 to broaden the inclusion criteria regarding the date of HIV diagnosis for participants (see appendix F). RHUL DEC approved both of these amendments also (see appendix G). The amendment to the RHUL DEC included the addition of a HIV charity as a recruitment site which was approved.

Ethical issues

Due to the potentially sensitive nature of the study there were a number of key ethical implications for participants that were considered. This included participation being completely voluntary, their identity in the research remaining anonymous, giving informed consent for participation and having the right to break or/and withdraw from the study at any time. Information on these ethical issues was outlined for participants on the participant information sheet (see appendix H).

Inclusion and exclusion criteria

Inclusion Criteria.

- a) Aged 18 years or above.

- b) Of sub-Saharan African origin: determined by self-reported country of origin as listed by United Nations Statistics Division (2013).

- c) HIV positive diagnosis.

- d) Aware of some level of risk of HIV infection prior to diagnosis.

- e) Delayed HIV test by at least 1 week from point of perceived risk.

Exclusion Criteria.

- a) Not able to comprehend or speak English: to avoid bias from interpretation.

- b) Deemed too distressed to participate by their clinician.

Recruitment

Recruitment Settings. Recruitment and data collection took place at a HIV clinic at an NHS hospital in an East London borough between November 2013 and March 2014. The NHS HIV clinic is a specialist service for people living with HIV. It provides free and confidential services including outpatient medical care, treatment support, sexual health advice and psychological support. 3.7% of the population in the East London borough where the NHS hospital is based is black African (Office for National Statistics, 2011). The prevalence rate of diagnosed HIV in individuals aged 15-59 is 6.2 per 1,000 people in this borough (Public Health England, 2012).

After data collection began at the NHS site, it became apparent that the minimum intended sample number was unlikely to be recruited from this one site. Therefore a HIV charity was added as a recruitment site. The HIV charity provides peer-led support, advocacy and information to people living with HIV in London. It runs a number of monthly peer-led support groups, one being for individuals from African communities. This is where participants were recruited from.

Recruitment process. The process of recruitment at the NHS HIV clinic consisted of six steps and is outlined in Figure 2 below.

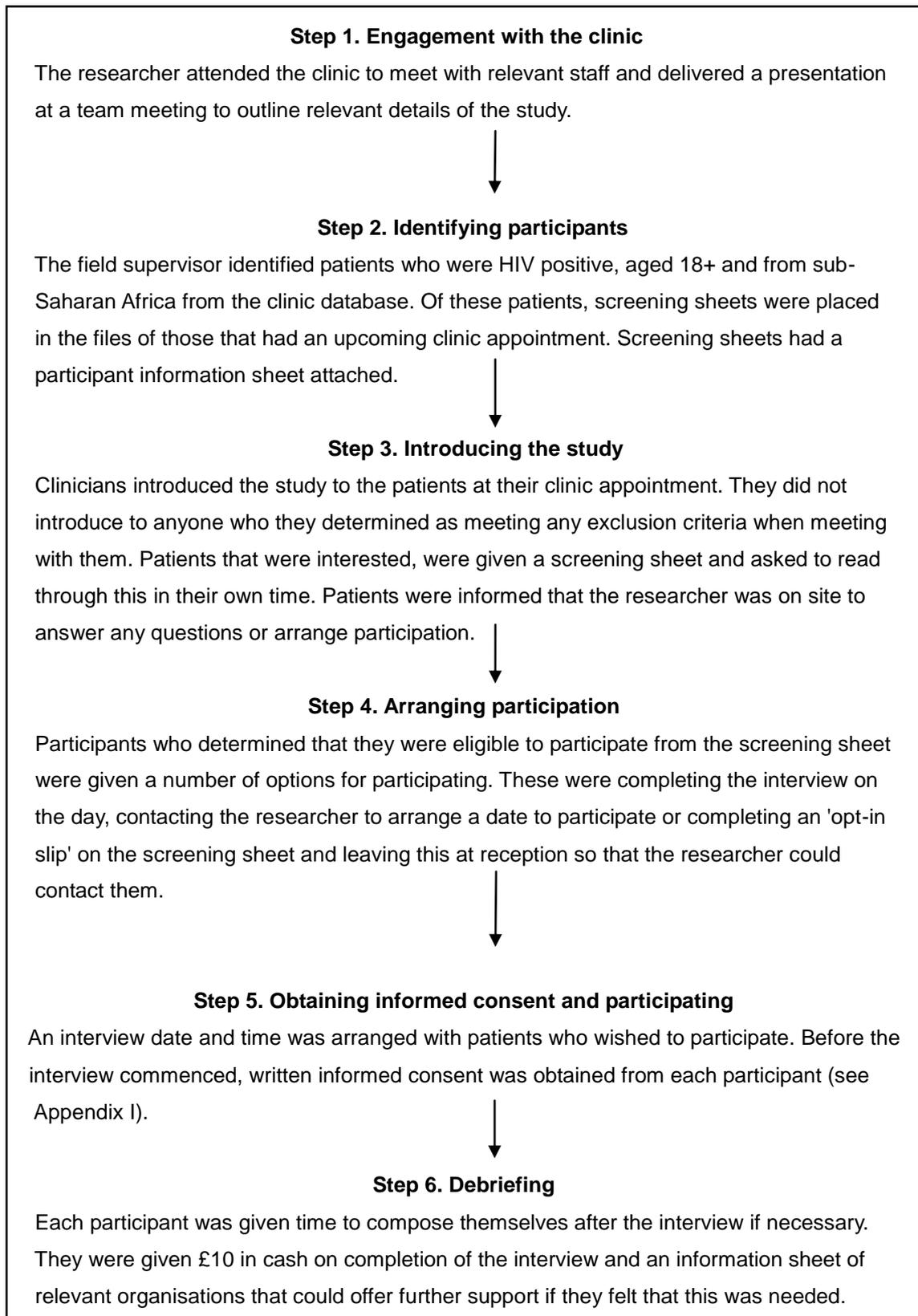


Figure 2: The six steps of the recruitment procedure

Screening sheet to determine delayed testing. Patients were given the screening sheet by clinicians to complete in their own time, to determine if they met inclusion criteria d (having an awareness of some level of risk of HIV infection prior to diagnosis) and e (delayed testing by at least 1 week from the point of perceived risk). The screening sheet consisted of 2 questions. The question which assessed the level of patients' perceived risk prior to testing was measured on a 5-point scale (see Appendix J). Any response at 25% and above on this scale was considered as perceiving risk of HIV. This method was used in a previous study (Hayward, 2013). It was hypothesised that rating the level of risk on a scale, as opposed to categorically stating if they did or did not perceive risk, was likely to give more accurate representations of the degree of HIV risk perception and normalise HIV risk perception prior to testing. Delay was operationalised as taking more than 1 week to seek medical help or test, from the point of initial perception. This was considered to give enough time for individuals to contact a health care professional or service to arrange or carry out testing.

Adapting the recruitment process for charities. To recruit from the charity site, the researcher was invited to attend one of the support groups for HIV-positive individuals from the African community. The researcher introduced and explained the study to the group of 20 individuals and left screening sheets so that anyone who was interested in the study could take one. The subsequent recruitment procedure was the same as steps 4, 5 and 6, outlined above. The researcher waited at the venue until the group had finished so that they could answer any questions that group attendees had or collect any opt-in slips that were completed.

Recruitment of participants. From the overall pool of patients in the NHS HIV clinic database, 645 were found to meet inclusion criteria a, b and c. Patients

who were 'lost to follow up', due to either not attending an appointment and rebooking a new one or from long-term disengagement from the service, were removed from this pool of patients (88). This left a pool of 557 potentially eligible patients (meeting criteria a, b and c). Of these patients, 177 had clinic appointments booked during the recruitment period. Screening sheets were placed in these patients' medical file.

Of the 177 patients who had a screening sheet in their file, 16 either met with the researcher or the clinician and were found to not meet inclusion criteria d and e. 3 met either of the exclusion criteria. 6 declined the screening sheet from their clinician. 5 completed the screening sheet and were eligible but the researcher was not able to make contact with them. It was known that 10 did not attend (DNA) their appointment. 8 patients completed the screening sheet, were eligible and discussed and arranged participation with the researcher. 1 of these patients did not attend their interview for unknown reasons. It was not possible for the researcher to be on site on for all clinics attended by potentially eligible patients and they did not have access to patient's personally identifiable information. Therefore the researcher could not follow up all patients who had a screening sheet put in their medical file. This meant that there was an unknown outcome for 129 patients, meaning they may have not attended their appointment, may have not been introduced to the study, declined a screening sheet or determined themselves to not meet inclusion criteria d and e. 7 patients consented to the study and completed an interview at the NHS site. 3 participants at the charity site expressed an interest in participating but only 1 was eligible and recruited. There was a final sample number of 8. The breakdown of this recruitment process can be seen in Figure 3.

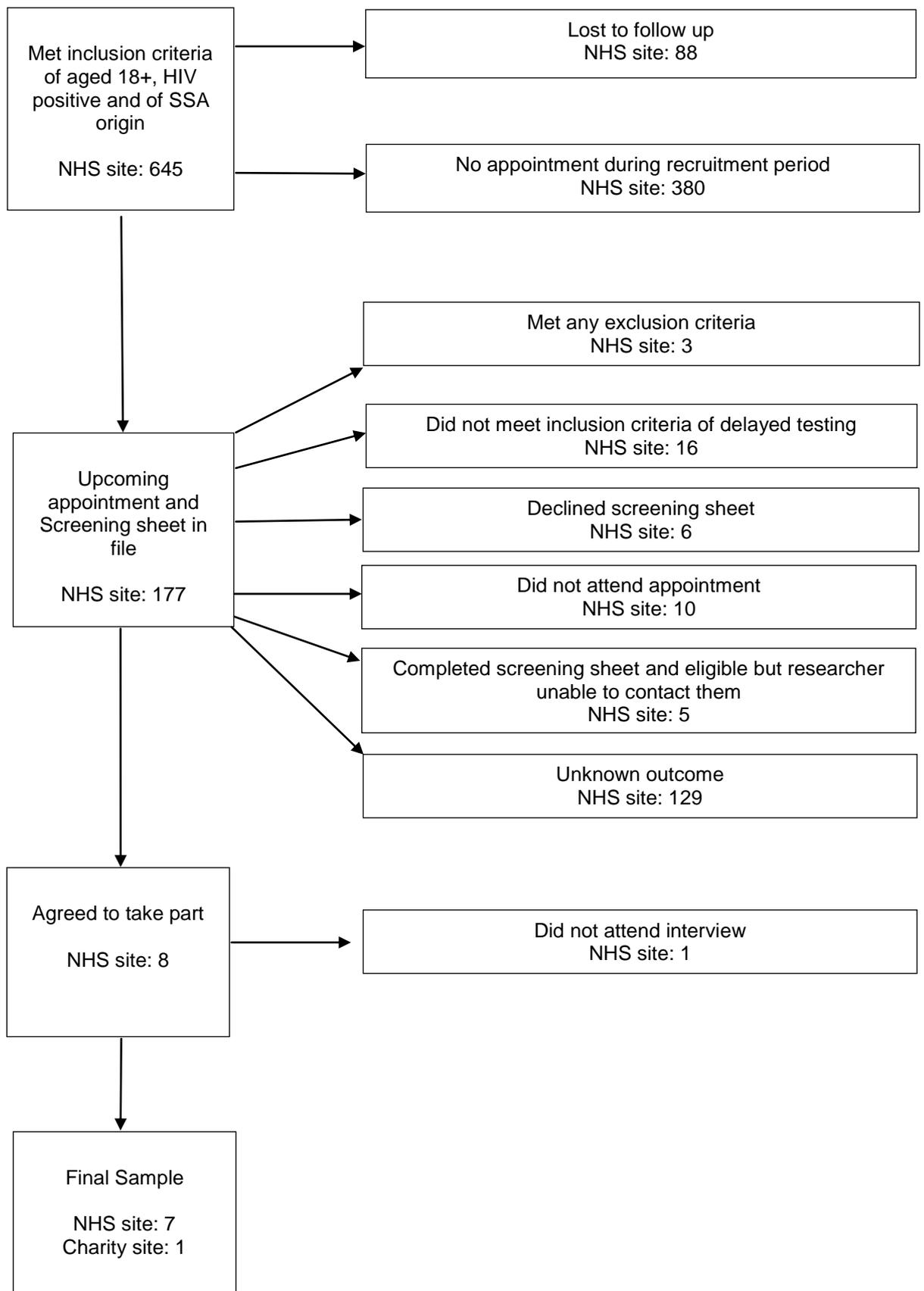


Figure 3: Recruitment flow diagram

Sample Characteristics

Table 2 provides demographic information for the participants in the sample, and also provides relevant HIV-related information. This information was collected from participants using a demographic information questionnaire at the beginning of the interview (see Appendix K). Any information that participants could not provide at the interview was obtained from the clinic medical files, with the participant's consent. The length of self-reported delay is from the point where participants perceived risk of HIV prior to the test in which they were diagnosed with HIV.

Table 2:

Participant demographic and HIV-relevant information

Participant Number	Gender	Age (at interview)	Country of birth	Length of self-reported delay	Year of diagnosis	CD4 count at diagnosis	Number of tests taken before diagnosis	Location of diagnosis	Setting of diagnosis
1	Female	34	Uganda	2 months	2011	74	3	UK	Sexual health clinic
2	Male	55	Uganda	2 years	1995	Not known	0	Africa	GP surgery
3	Male	46	Democratic Republic of the Congo	1 month	2005	220	0	UK	Sexual health clinic
4	Male	45	Zimbabwe	2 years	2001	5	0	UK	Sexual health clinic
5	Female	26	Malawi	6 years	2008	30	1	UK	Hospital ward
6	Female	49	Zimbabwe	14 years	2012	168	0	UK	Hospital ward
7	Female	49	Zimbabwe	3 years	2000	157	0	UK	Sexual health clinic
8	Female	42	Rwanda	3 years	1998	100	0	UK	Hospital ward

Choice of Methodology

Grounded Theory. Grounded Theory (Glaser & Strauss, 1967) is a qualitative method of analysis. It was developed as a way of discovering new contextualised theory which is 'grounded' in data that has been systematically obtained and analysed (Willig, 2001). This process starts with the study of individual experiences and cases and progresses towards the development of conceptual categories which explains the data (Charmaz, 2003). Through the study of how participants construct meanings, intentions and actions (Charmaz, 2003), the aim is to produce an explanatory framework which allows an understanding of a particular phenomenon (Willig, 2001).

Grounded Theory differs from other research methods in that data collection and analysis is done simultaneously to ensure that the analysis and theory is 'grounded' in the data (Willig, 2001). The fundamental process of coding of the data moves from a descriptive to analytical level where emerging theoretical categories are created. This is done by writing 'memos' which allows the researcher to define categories, to make comparisons between data and between codes and categories, to elaborate processes, assumptions and actions and also helps to identify gaps in the analysis that need to be addressed (Charmaz, 2006). Constant comparative analysis at each level of the analysis allows the researcher to link categories in a way that allows the emerging theory to capture all instances of variation (Charmaz, 2003).

Glaser and Strauss (1967) aimed to use Grounded Theory to develop abstract interpretations and theoretical explanations of social processes, with the study of action being central to this (Charmaz, 2006). Grounded Theory allows the researcher to explore how processes develop, are maintained or change (Charmaz, 2003).

While Grounded Theory's logical and systematic approach is linked to positivism, the interpretive element of Grounded Theory is linked to a symbolic interaction perspective (Charmaz, 2003). Concepts such as the 'self', society and reality are constructed through interaction with others. This interaction is dynamic and interpretative and therefore leads to meanings and actions being created, acted out and changed (Charmaz, 2006).

Theoretical saturation and theoretical sampling. According to Strauss and Corbin (1998) theoretical saturation is reached when: a) 'no new or relevant data seem to emerge regarding a category, b) the category is well developed in terms of its properties and dimensions demonstrating variation, and c) the relationships among categories are well established and validated' (p. 212). Theoretical sampling is used to help develop the theory and reach theoretical saturation. It involves collecting data that helps the researcher to refine and clarify theoretical categories and their properties in the emerging theory (Charmaz, 2006). Using theoretical sampling to reach theoretical saturation means that it is not possible to know how many participants or data sources you will use at the out-set (Birks & Mills, 2011). Due to the requirements of the clinical psychology doctorate, a proposed sample size was required at the out-set of the study and this was set at six (minimum) to ten (maximum) participants. However, given that the specificity of the phenomenon and sample under study, it was felt that there was a reasonable chance that theoretical saturation would be achieved with the majority of categories with this sample size.

Grounded Theory compared to other qualitative methods. As this study aimed to develop an understanding and model of the process of delayed HIV testing in HIV-positive sub-Saharan Africans in the UK, it was felt to be the most appropriate methodological approach. However other qualitative methods were considered

before making this decision.

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Osborn, 1997) was considered as a possible approach. This method aims to capture the quality and texture of individual experience including how the participant perceives and experiences the world (Willig, 2001). It aims to explore hidden meanings of experience and how individuals make sense of these (Grbich, 2009). While IPA is able to document individual feelings and experiences and changes in these, it does not aim to provide any explanatory account of the changes, which might limit our full understanding of a phenomenon (Willig, 2001). As the aim of the current study was to study a process and the changes within it, it was thought that a Grounded Theory approach would be better able to achieve this.

Discourse Analysis (DA) was also considered as a potential methodology for the study. Rather than focusing on psychological phenomena, DA examines language in terms of construction and function (Georgaca & Avdi, 2012). In DA, language is considered to mediate and construct reality (Starks & Trinidad, 2007) and is a form of social action (Georgaca & Avdi, 2012). Starks and Trinidad (2007) explain that using DA to analyse language can provide insight as to how social norms are created and maintained, how personal and group identities are constructed and how social and political and social interaction is negotiated. While constructed societal discourses and their impact are likely to be of importance in the study of delayed HIV-testing in sub-Saharan African individuals, a DA approach does not attend to individual experience. The research question aimed to explore changes in individual psychological processes albeit from a constructionist position.

Versions of Grounded Theory. Since the first introduction of Grounded

Theory by Glaser and Strauss (1967), the two authors have disagreed about the nature of the approach in terms of its epistemology and methodology (Charmaz, 2006). Glaser and Strauss have gone on to author divergent versions of Grounded Theory. Strauss moved the method of Grounded Theory towards one of verification and developed a more prescriptive version of Grounded Theory (Strauss and Corbin, 1990; Corbin & Strauss, 2008). Glaser described Strauss and Corbin's (1990) version of Grounded Theory as a different method altogether that produced a 'full scale conceptual forced description' (Glaser 1992: p61-2). Glaser (1992) saw Grounded Theory as a method of discovery and argued that categories emerge from the data through constant comparison (Grbich, 2009).

Willig (2001) notes that while Grounded Theory took an inductive rather than deductive approach, allowing categories and theories to 'emerge' from the data, it accordingly failed to acknowledge the role of the researcher and to take a reflexive stance. Charmaz (1990) proposed a social constructionist version of Grounded Theory that recognised the researchers' active role in constructing categories and theories through a process of interacting with the data. This interaction is influenced by the researcher's past and present experiences, assumptions, knowledge and disciplinary perspectives (Charmaz, 2006).

Rationale for using Charmaz's constructionist version of Grounded Theory. Charmaz's (2006) constructionist version of Grounded Theory states that 'we are the part of the world we study and the data we collect' (p. 10). Using Charmaz's (2006) constructionist version of Grounded Theory allowed the researcher to acknowledge and be aware of their active role in constructing the grounded theory, which previous versions neglected (Willig, 2001).

Charmaz (2006) is of the view that Grounded Theory offers researchers a set of practices and guidelines for collecting and analysing data that can be used flexibly. This is important given the requirements of the Clinical Psychology Doctorate such as providing a literature review and an interview schedule prior to the study commencing. Glaser and Strauss (1967) originally proposed that the literature review should be delayed until after the analysis due to concerns around the researcher imposing preconceived ideas on their work. However adopting a constructionist approach allowed the researcher to be aware of and reflect on this.

Theoretical sensitivity. Linked to reflexivity is the issue of theoretical sensitivity. Birks and Mills (2011) define theoretical sensitivity as the ability to recognise data that has relevance for the emerging theory and note that this increases as the research develops. Glaser and Strauss (1967) acknowledged that 'the researcher does not approach reality as a tabula rasa. He must have a perspective that will help him see relevant data and abstract significant categories from his scrutiny of the data (p.3)'. While a constructionist approach acknowledges the interactive role between the researcher and the research process, it is important that the researcher's assumptions and beliefs do not unduly influence the analysis (Birks & Mills, 2011).

Taking a reflexive stance and thinking about the researcher's sensitivity to the data throughout the study was important given that the researcher of this study had a chronic health condition herself. This was an inflammatory bowel disease which can produce symptoms that can be difficult to talk about due to their potentially embarrassing nature (Mackner & Crandall, 2005). Prior to their diagnosis of this disease, the researcher had been through a process of experiencing symptoms of an unknown nature and had delayed seeking medical help. Although the condition was

not HIV, the researcher had her own understanding of why she had delayed seeking medical help for this medical condition.

The researcher is a white female and it was anticipated that the majority of the participants would also be female, as HIV is more prevalent in African women in the UK (HPA, 2013), but were likely to be black and have different cultural backgrounds. Therefore reflecting on the similarities and differences between the researcher and the participants and thinking about how these impacted on the analysis and interpretation of the data was important throughout the research process. At outset of the study, the researcher had limited knowledge about HIV and had not worked clinically with people living with HIV. However, after having to write a literature review as part of the doctorate research process, and with her own experiences of having a chronic medical condition, the researcher had her own ideas about factors that may have been relevant to individuals who had delayed HIV testing which were outlined in a reflective diary.

A reflective diary was used as a way to facilitate the researcher's reflexivity and keep their thoughts, feelings and opinions visible (Ortlipp, 2008). Excerpts from this are in Appendix L. It gave her space to think about her prior assumptions and reflect on her position in relation to the research.

Procedure

The interview schedule. A draft interview schedule was developed as part of the initial research proposal. A mock interview was carried out between the researcher and the academic supervisor. The schedule was further refined in collaboration with the academic and field supervisors. The interview schedule was organised chronologically from the point of perceived risk of HIV to the point of taking

the HIV test in which they were diagnosed. This is because the study aimed to gain an understanding of the process of delayed testing and a process is defined as consisting of 'unfolding temporal sequences' (Charmaz, 2006, p.10). Constructs from models of health-behaviours such as the Health Beliefs Model (Rosenstock, 1974) (e.g. outcome expectancies) and the Theory of Planned Behaviour (Fishebein & Azjen, 1975) (e.g. attitude toward behaviour) were also drawn on to guide questioning. A Grounded Theory approach recommends that questions should be open-ended and non-judgemental, to allow the participants' story to emerge (Charmaz, 2006).

Service User consultation for the interview schedule. Before data collection began, a process of service user consultation was carried out with a group of 8 HIV-positive African individuals from a voluntary sector organisation. This was to ensure that the questions were worded in an understandable and sensitive way and to identify anything related to HIV testing the questions failed to address. The feedback from the service users was generally positive and they did not feel that any of the questions were inappropriate. They provided some suggestions around making the questions clearer. The edited and final version of the interview schedule which incorporated these suggestions can be seen in Appendix M.

Data collection. 8 face-to-face semi-structured interviews were used to collect data for the study. Each interview was audio-recorded and relevant observations of the researchers' were recorded in a reflective diary at the end of each interview to maintain reflexivity. Interviews with participants recruited at the HIV clinic were carried out by the researcher at the clinic in a private consultation room. The participant recruited from the charity was interviewed in a private room at the charity base. The interviews lasted between 40.35 and 64 minutes and had a mean

length of 51.80 minutes. While the interview schedule was used, Charmaz (2006) notes that interviewing is a flexible and emergent technique. While the researcher aimed to cover particular topics or issues across interviews, they also followed leads as they appeared. The researcher provided summaries of what the participant said to ensure an accurate understanding where necessary.

Analysis of data

Transcribing. The audio-recorded interviews were transcribed verbatim, in to written form, so that the process of coding could take place (ten Have, 1999). Guidelines for doing so were followed (McLellan, MacQueen & Neiding, 2003). A denaturalized transcription style which represents speech in a verbatim fashion and aims to be accurate in representing meanings and perceptions shared in a conversation tends to be used by Grounded Theorists (Oliver, Serovich & Mason, 2005).

Coding. Charmaz (2006) explains that the process of coding is when the researcher begins to ask analytic questions of the data and relates to the differing levels of conceptual abstraction the researcher is developing (Birks & Mills, 2011). Charmaz (2006) proposes that coding consists of at least two phases of initial coding and focused coding. The research can then move to theoretical coding if the emerging analysis indicates that this is necessary.

Phase one: Initial coding. Initial line-by-line coding was carried out on each of the transcribed interviews. This involves naming each line of the written data (Glaser, 1978). Charmaz (2006) states that codes should stick closely to the data so that they are 'grounded' in it and this can be done by focusing on and preserving actions. This helps the researcher to refrain from imposing preconceived ideas on the

data and the researcher should remain open about the theoretical direction of the codes, following leads as they appear (Charmaz, 2006). In-vivo coding, where participants' language or special terms is used in codes to retain the meaning of their actions (Charmaz, 2006), was used where appropriate.

Phase two: Focused coding. Focused coding involves using the most significant or frequent codes from the initial coding phase to sort, synthesise and explain larger parts of the data (Charmaz, 2003). These codes are more conceptual than those in initial coding as the data is being analytically categorised. In this phase, the researcher identifies explanatory, conceptual patterns in the data (Birks & Mill, 2011). Charmaz (2003) notes that at all levels of coding, analytic distinctions are developed by using 'constant comparison methods' (Glaser & Strauss, 1967), which the researcher used. This involves comparing incident with incident to produce initial codes, the incidents in subsequent coded data are compared with these codes, then codes are compared with codes, codes are grouped in to categories, with which future codes are compared to and then categories are compared to categories (Birks & Mills, 2011). Charmaz (2003) explains that this is not a linear process and that ideas that are implicit in the data of some participants may become apparent after observing these explicitly in the data of other participants.

Phase three: Theoretical coding and diagramming. The phase of theoretical coding involves conceptualising how the tentative categories developed in focused coding relate to each other and therefore integrate in to a theory (Charmaz, 2006). The researcher used memos to establish theoretical links between the focused codes which formed these categories. Charmaz (2006) suggests using the memos to explain things such as the properties of the category including the processes it subsumes, specifying the conditions under which the category arises, is

maintained and changes, describing the consequences and showing how this category is related to other categories. A diagram was used to conceptually map out the grounded theory and to explain the properties of the categories and the relationships between them (Charmaz, 2006). The theory explains the process of delayed HIV-testing in the sample. The theory was compared with existing literature.

Memos. Memos were written throughout the coding process as a way of exploring analytical ideas and insights about the data and codes. They were important for documenting the constant comparison methods within and between data, codes and categories. The memos also helped the researcher to think about further questions to be explored and gaps in the analysis to be pursued (Charmaz, 2006). The memos are also a record of the theory development as they trace the movement from initial coding up to the theoretical codes, of which the theory is made up of (Charmaz, 2003). The memos encouraged the researcher to be reflexive by allowing a space to check that data and codes were grounded in the data and not forced due their prior personal or professional assumptions (Charmaz, 2006).

Research quality

Guidelines for good practice and quality in qualitative research were followed throughout the research (Elliot, Fischer & Rennie, 1999). This included:

Owning one's perspective. Owning one's perspective is essential due to the interactive nature between the researcher and the research. As explained, the researcher kept a reflective diary to make their own values and thoughts explicit and used supervision to reflect on how these related to the collection and understanding of the data that they came to (Mays & Pope, 2000).

Situating the sample. Elliot et al. (1999) recommend situating the sample by describing the participants so that the reader can consider the range of the studies' relevance to other people. This was done by providing participant demographic information in Table 2.

Providing credibility checks. The researcher also used validation methods to check the credibility of their categories and emerging theory. As Charmaz (2006) notes 'the quality and credibility of your study starts with the data' (p.18). Therefore after the first interview was carried out and transcribed, the researcher and the academic and field supervisors reflected on whether the interview schedule was collecting data that was rich and sufficient enough to explore the phenomenon of interest. Codes that were developed from the data in the first transcript were checked with the academic supervisor who is familiar with a Grounded Theory approach and also has extensive clinical and research experience in the area of HIV. This was also done with another trainee clinical psychologist using Grounded Theory. The academic supervisor also commented on whether the themes were exemplified by the quotes as the analysis progressed and verified the resulting categories, their properties and the emerging theory to provide a credibility check (Elliot et al.,1999).

Resonating with the reader. The theoretical codes were also verified by the field supervisor to confirm that such an understanding resonated with them, given their extensive experience of working with individuals with HIV and to ensure that the researcher did not miss any important themes (Elliot et al., 1999).

Coherence. The researcher aimed to provide a coherent understanding of the phenomenon by providing an integrated summary of their analysis by mapping out the grounded theory using a diagram, while providing a narrative account of the

model (Elliot et al., 1999).

Grounding in examples. Quotations from the data have been used throughout the results section when discussing the categories that make up the grounded theory to allow the reader to assess the fit between the data and the author's interpretation of it, while also considering the researcher's reflections on their role in the research (Elliot et al., 1999). A section of the transcript is provided in Appendix N to illustrate the interview process and examples of the initial codes that the researcher constructed for the raw data. Examples of memos are also provided in Appendix O to provide readers with further insight in to the analytical processes (Elliot et al., 1999).

Chapter Three: Results

Analysis of the data led to three theoretical codes that make up the proposed model. These are presented in Table 3. These theoretical codes consist of fifteen focused codes, each of which contains a number of specific properties that were produced during the initial coding stage. A table showing the presence of themes across participants can be found in Appendix P. An analysis of the theoretical codes, the focused codes they subsume and their properties is provided below. Quotes from participants have been used to illustrate the various codes and to show how they are grounded in the data. Any identifiable information has been removed from the quotes to maintain participant confidentiality. Furthermore, to ensure anonymity, participants are referred to using their designated participant number (P1 to P8). Finally, a diagrammatic account of the model is presented in Figure 4 at the end of the results section. This shows the proposed relationships between the three theoretical codes and the focused codes that they subsume.

Table 3:

Table showing theoretical codes, focused codes and initial codes

THEORETICAL CODES		SUB CODES (Focused coding)		PROPERTIES OF THE CODES (Initial coding)
1	Moving in and out of uncertainty about HIV infection	1.1	Considering HIV infection	Thinking that symptoms could be due to HIV
				Thinking about HIV due to experience/circumstances
				Not having an explanation for symptoms
				Doubts about HIV being challenged
		1.2	Doubting HIV infection	Having an alternative explanation for symptoms
				Doubting that HIV could develop after a long time
				Doubting HIV due to lack of symptoms
				Feeling reassured about symptoms not being HIV
				Symptoms going away
				Ex-partner being well
		1.3	Feeling uncertain about HIV infection	Feeling divided about HIV
				Not being able to be sure about HIV
		1.4	Not wanting to believe or think it is HIV	Denying thoughts about HIV
				Thinking positively about yourself

				Wanting things to be okay
				Reassuring self that they are okay
		1.5	Feeling more certain about HIV infection	Consoling self about having HIV
				Feeling sure about having HIV
		1.6	Not worrying about HIV infection	Not worrying about HIV when well again
				Forgetting worries about HIV
2	Preferring not to know about HIV status	2.1	Fear of facing death	Feeling afraid of dying from HIV
				Not wanting to know if you're going to die
		2.2	Fear of not being able to tolerate knowing	Knowing about HIV would be destructive/harmful
				Feeling unable to live with the knowledge of having HIV
				Fearing that knowing would mean deteriorating
		2.3	Fear of experiencing stigma and discrimination	Not wanting to be rejected
				Not wanting to be judged or labelled
				Not wanting family to be discriminated against
		2.4	Not wanting relationships and lifestyle to change	Fearing the impact of diagnosis on relationships
				Not wanting relationships and lifestyle to change
				Fearing the impact of discrimination on relationships

3	Making the decision to test for HIV	3.1	Having hope about being HIV negative	Having hope of being negative
		3.2	Wanting certainty about HIV-status	Wanting to find out what is going on
				Wanting to get rid of uncertainty
				Wanting to know status to make plans
		3.3	Having hope for medication and for life	Having hope for medication that will keep you alive
				Having hope that you will have some more life to live
				Wanting to be alive for their child/children
		3.4	Feeling ambivalent about testing	Considering testing and not testing
				Not being able to decide whether to test or not
		3.5	Preparing for and accepting a potentially positive result	Accepting that death is possible/likely
				Accepting that the outcome is already decided
				Preparing for the result going either way

1. Moving in and out of uncertainty about HIV infection

All of the participants perceived a risk of HIV following an initial trigger but following this, reported feeling uncertain about whether or not they were HIV positive. Feeling uncertain was the result of thinking there was a possibility that they were HIV-positive and also doubting that they were. However at times, some participants felt more certain that they either were or were not HIV-positive, due to particular experiences. These participants went back and forth between feeling uncertain and more certain about having and not having HIV. Feeling uncertain about their HIV status, contributed to the delay in participants' testing. This is because they initially felt that being uncertain about their status was preferable and more manageable than knowing their status. This is because they had a number of fears about knowing their status and potentially finding out that they were HIV-positive, which is described as a separate category. When participants felt more certain that they were HIV negative, this also contributed to the delay in testing as they were not motivated to test at all.

Considering HIV infection. Seven of the participants considered HIV infection as a possibility after an initial trigger experience. These triggers were: the onset of an illness or unexplained or unusual physical symptoms (n=3), after being raped (n=1), a partner being diagnosed with HIV (n=1), finding out their partner had been unfaithful (n=1) and the combination of having unusual symptoms after being raped (n=1). The thought of HIV being a possibility was associated with feelings of worry and fear for all participants.

"Umm...definitely I was worried. The first thought came...what if I am...or I am going to be diagnosed as positive, you understand?" (P3)

"And I went to read about it myself to say why would your protein be raised. And the point, it was either cancer or HIV. So that's when I started thinking, this could really be HIV". (P6)

"That's when I was starting to think about whether [she had HIV]³ because I had um, my sister in law who had almost the same symptoms and she had, I think she had died about...she died about 6 months before I got the shingles".
(P7)

All participants who initially considered HIV infection as a possibility also doubted HIV infection. The result of this for four participants was feeling uncertain about whether they had HIV. However three participants initially went on to believe that they were not HIV positive and stopped worrying about HIV. The participants who stopped worrying about HIV became uncertain about HIV infection when their experiences (e.g. symptoms) caused them to reconsider that they may be infected with HIV. These experiences were things such as having physical symptoms that participants did not have a non-HIV explanation for, based on their available knowledge.

Five of the participants were in Africa when they first considered that they may have HIV. They described their knowledge of HIV as being limited. However, having illnesses such as TB or shingles or symptoms such as a continuous flu, fever or unusual skin rashes that would not go away, led participants to consider HIV as a possibility:

"So the fact that they told me to go back [to the hospital] after three months [after an inconclusive HIV test] and the symptoms were there, like I might be. The 'I might not' was going down so the 'might have', was coming up every time I think about it. So because the 'might have' was coming up, it was scary". (P5)

³ Words placed within square brackets (i.e. *[she had HIV]*) have been added by the researcher so that the extract can be easily understood.

"But each time I had an illness or some fever or something, and then I would think again about, it could be this". (P6)

"So, my body couldn't cope, that's the other thing that made me y'know, think twice. Why am I being so tired? y'know". (P4)

For a number of participants, events or experiences that led them to reconsider having HIV as a possibility, would trigger previous thoughts and concerns which had been dismissed due to the doubt that they had about having HIV. These were experiences such as hearing people talking about HIV or talking about the prospect of having children for example. Participants described the intrusive nature of such thoughts, which appeared to uncontrollably come back in to their minds following these experiences:

"But it kept popping back every now and then. Because the lady, my fostered, y'know the foster lady that I used to live with, she was a Ugandan and she talked quite a lot about people dying of AIDS in this country". (P8)

"I didn't block it out because everything I saw this...this...every time I get the imagination of somebody having...y'know partner having unprotected sex with somebody else or having another partner". (P1)

"But then, you go somewhere, you hear about the HIV again and it creeps to your head- what if I have it and it's not showing". (P5)

"I was such a believer in that everything was okay, yet y'know there was a tiny bit of me that was telling me, that this could be, could be it, could be HIV". (P6)

When considering HIV infection as a possibility, two participants went on to feel more certain that they were HIV positive on occasions (described as a separate theme later on in the results section).

Doubting HIV infection. All of the participants had doubt about being infected with HIV at various times. Participants were motivated to have an accurate understanding of their situation (i.e. whether or not they had HIV) by drawing on their knowledge of HIV. A lack of knowledge about HIV along with stereotyped beliefs about how people with HIV look and how people contract HIV, influenced the understanding of whether or not they had HIV. After evaluating their situation (e.g. physical symptoms or experiences), they felt doubtful about having HIV. However, at times, some participants' reasoning about whether or not they had HIV appeared to be influenced by a motivation to not believe that they had HIV.

Participants' interpretation of their bodily symptoms, or lack of them, was a major source of doubt about having HIV. Five of the participants described how the lack of past or present symptoms or illnesses meant that they felt doubtful about having HIV. These participants thought that they would have symptoms if they were infected with HIV and some had in mind particular symptoms that they thought they would experience. For others, when their symptoms that had initially led them to consider HIV infection went away, they then became more doubtful about having HIV.

"No, I because I didn't think I might be because I never been sick. Um, and I wasn't feeling like sick". (P3)

"Because to me I was like okay, if I have it, I'll see the symptoms, anytime soon, y'know. So the fact that I wasn't having the actual symptoms that I thought I knew, was bringing my confidence back". (P5)

"It sort of, it sort of um...the proteins sort of like came down and I just was thinking that maybe if it was HIV, it wouldn't have gone down now that it's gone down". (P6)

Four of the participants had a non-HIV explanation for the symptoms that had

initially caused them to think they may have HIV. Therefore they felt more doubtful about having HIV. It seemed that participants were motivated to gain an understanding or explanation for their symptoms. As explained, this motivation appeared to be influenced, for some, by a desire to not believe that they had HIV. This is outlined in a separate theme later in the results section.

"Because being a nurse, you diagnose yourself in the morning, you can diagnose, by the end of the day you will have diagnosed yourself ten times so just thinking, I was just being maybe paranoid because of being a nurse.

"It was always like when you think about it, somebody comes around you with almost the same, maybe same complaints and uh, you think, I think it's just everybody's feeling the way I'm feeling and then you just forget about it, let me brush it aside". (P6)

"Yeah, the feeling was still there, I still had my flu like symptoms but then I had an excuse for the flu like symptoms when I came here because I was saying oh this country's cold anyway, what do you expect". (P7)

Feeling doubtful about having HIV was sometimes linked to direct and indirect reassurance from others. For example, being reassured by friends about the nature of their symptoms or there being a lack of concern from their doctor about their symptoms, led to participants doubting HIV infection.

"You know you just, also end up thinking, if the doctors are not even suspecting that I'm HIV positive, so it means I could be alright". (P6)

"Yeah um...like...as I say, when you ask people...and you're growing up, some people would tell you, no no, as you're growing, things like that will start". (P5)

Two of the participants had been raped in their country of origin. This was the initial experience that led them to consider HIV as a possibility. Part of their doubt

about having HIV was a belief that HIV could not develop after such a long time from when they thought they could have contracted the virus.

"Yeah. I definitely I thought I would not be catching AIDS after 3 years of being raped, no". (P8)

"But then over the years, I started thinking, okay, I was raped in 2003, this is 2005. Nothing has happening, what am I doing, I don't have it" (P5).

A source of doubt for two of the participants was that their previous partners were well and healthy and this reassured them that having HIV was unlikely. This is despite one of these participants initially thinking he may have HIV after his current wife who had been with for some time, was diagnosed with HIV.

"Oh yeah, I was doubting, because I mean um...sorry to say, but before I came to this country, I left two kids as well back home. So I had a relationship. And then my ex-partner and my kids, until today, they are fine. You understand, they are fine". (P3)

"Because the other thing which kept me strong was like but why would I have, the mother, my daughter's mum, she's still there, she's not positive, you understand". (P4)

When doubting HIV, four participants went on to stop worrying about HIV completely. Therefore their doubts about being infected with HIV had a significant role in keeping them away from testing. However for other participants, their doubt just meant that they were left feeling uncertain about whether or not they had HIV (described as a separate theme).

However, doubt also had a role in moving some participants towards testing. When doubting that they could be HIV-positive, three participants had hope that they

could be HIV-negative. This hope was a contributing factor to their decision to eventually test for HIV. This is explained as a separate theme in the results section.

"Yeah, because the way it came my mind is that, for the last two years, I was using condom and...eh because when they were teaching us at school, they said, you need to be a clean person after having sex. You got take a shower, with soap and eh, I, I had that thought, maybe". (P2)

Feeling uncertain about HIV infection. As all of the participants considered HIV infection as a possibility (or felt more certain about it) whilst simultaneously doubting it, all participants felt *uncertain* about HIV at times. When feeling uncertain, participants were divided in their belief about whether or not they were HIV-positive. Some participants described how it felt impossible to know or be sure whether or not they had HIV.

"Yeah, that's when I started thinking that maybe or maybe not. It's something you can never be sure of because it's a lottery you understand". (P4)

"My...half of me was saying, I might not have it. Because like, that time they told me it's inactive [having an inactive HIV result], was like eh...giving my confidence back. But then part of me was saying, I might have it. So, you see like, something that you never had, it's coming after something has happened to you. So it was like a divided thought. I might have it, I might not". (P5)

"I thought, oh...I don't know if I'm positive or not". (P3)

"So when I came [to test], it was 50/50 I think". (P7)

"You heard about it and your just thinking well, maybe I didn't catch it, maybe I did". (P8)

Three participants who initially felt uncertain about whether they were HIV-positive became increasingly doubtful and believed more that they were not infected with HIV. This meant that they stopped worrying about HIV infection completely.

However particular experiences (e.g. symptoms, hearing people talk about HIV) made them reconsider HIV infection as a possibility and they felt uncertain about whether or not they had HIV once again.

Participants stated that feeling uncertain about HIV infection was a factor that held them back from testing. Participants preferred to remain uncertain about their HIV status. This is because they all had various reasons for not wanting to gain certainty about their status, which was established as a separate theoretical category (outlined later in the results section). It seemed that participants felt able to tolerate being uncertain about their status, at least initially, because they were so fearful of knowing if they were HIV-positive.

"It was because of um, uncertainty. Because I wasn't sure...I was in-between, whether I'm gonna be negative or positive... I was 50/50 so was that uncertainty...holding on to that uncertainty." (P1)

"Yeah, so I told myself, if I don't know, sometimes, I'll be happy, sometimes I'll think about it but there's no proof". (P5)

However some participants also described the experience of being in this uncertain state, where they are not sure either way, as psychologically difficult.

"But then if I became a bit unwell, it would, in, at the back of my mind, it would think, could it be, could it not? And that's the worst thing that you go through." (P6)

"You are like someone who is in the middle. So you are not stable". (P2)

Not wanting to believe it is HIV. After the trigger experience, it seemed that all participants wanted to come to an understanding about whether or not they had HIV. This resulted in them doubting HIV infection at various points and in turn, some

participants went on to stop worrying about HIV. However, on reflection of their experiences at the interview, four of the participants acknowledged and described a desire to not believe or think that they could have HIV. Therefore, the doubt experienced by these participants was influenced and driven by this desire. Two participants described how they would try and block out or berate the thoughts that they had about having HIV.

"I just kept blocking it out, like something you don't know doesn't hurt. That's how it works. I just didn't think...because I just didn't want to think about...if I am positive". (P1)

"Yeah I just kept rebuking them [the thoughts about having HIV]. But I said well I'm fine, why do I really want to have HIV, AIDS, why do I want to make myself a victim". (P8)

Other participants described how they would reassure themselves that they were okay which influenced their reasoning about whether they had HIV. They did not want to believe that anything was wrong and it seemed that this was linked to wanting things to be 'okay' and for life to be able to just carry on as 'normal'.

"So you know at times you want to assure yourself that there's nothing wrong and you want very much for things to be right, that's how I was feeling. I was just wanted everything to be so, so well that I didn't even want anything to disturb that part of my thinking.

Uh, just the belief that it can't happen to me [laughs]. Yeah, it can't happen, I doubt if it can happen to me, it can't happen to me and my husband, we are so much in love and he can't betray me". (P6)

"And you definitely be thinking positively towards yourself because... I was the last person to think... but where would I get it because there so many things which go through your head. Why would I have HIV? Why me, y'know? All sorts of things. So y'know, it's to y'know, carry on my life". (P4)

The feared consequences of knowing that they were HIV-positive seemed to

drive this desire to believe that they did not have HIV. Therefore this desire appeared to be an attempt to control the anxiety evoked by the feared consequences.

"But then I didn't want to think about it in that way because I was hearing stories about insurance, that maybe if the insurance people knew that I was HIV, they would um, not give me like insurances". (P6)

"No, I didn't want to think about it. I didn't. Because of course when you start thinking about it, you just, you just thinking of dying". (P8)

Feeling more certain about HIV infection. Three of the participants felt more certain about having HIV at different points in time. One initially felt certain about being HIV-positive after the initial trigger experience but went on to feel uncertain. The other two participants went on to feel more certain about being HIV-positive after initially feeling uncertain about HIV infection. The participant who initially felt certain after the trigger experience was not showing any symptoms at this point and so his certainty about having HIV was based on his belief that his partner had HIV. This was in Africa in the early 1990's, before anti-retroviral medications were available.

"Because I knew, I knew, I am already HIV, so what is the point of going there? There's no medication". (P2)

The fact that he felt certain about having HIV and had fears about being diagnosed with HIV, meant that testing was not something that he considered. Given his situation, his response was one of acceptance of HIV and death. The other two participants had initially felt uncertain about HIV but due to their on-going evaluation of the symptoms they were experiencing, they went on to feel more certain that they had HIV. This was in the context of being hospitalised for one patient. Furthermore, one of these participants moved back and forth between feeling certain she was infected with HIV and uncertain if she was infected with HIV.

"Until, later in...March, April, that's when I started thinking no, this kind of losing weight is not...is not what I'm thinking. At the end yes, I was like ah now this is it. This is it and I can't deny it. So I kind of accepted it". (P5)

"So then, that's when I, before even the doctor came to tell me we're going to do a HIV test because you know they do talk to you before they go ahead, I knew that um...I worried a lot that uh, why is my temperature not coming down. And now, all the realities were now coming to me that, this is uh what I've always thought about, all those years, could now be coming to pass". (P6)

The participant who was in hospital when she felt more certain about being HIV-positive was aware of HIV medication but as she was so unwell, she believed she was going to die. The other participant was not aware of HIV treatment (in the UK in 2008). This led her to want to kill herself so that she did not have to suffer from HIV. Therefore, there was a sense of hopelessness that came with feeling more certain about HIV infection as participants associated being HIV-positive with dying.

"Sometimes I'll be like, the whole week, thinking about it [having HIV]. Yes, because I spent maybe the whole week in my room writing letters, explaining, yeah.. I'm sorry I had to do this [commit suicide] but this is what, this is what is happening to me.

I think like, y'know like when you have something on your skin and then you keep looking at it...it's coming". (P5)

Feeling certain about HIV was closely linked to an acceptance of having HIV, which is a separate theme.

Not worrying about HIV infection. Four of the participants felt certain that they were not infected with HIV at times and no longer worried or thought about having HIV. This was because of the doubt that they had about being infected with

HIV. It is likely that this was a position that these participants readily accepted and embraced due to the feared consequences of being HIV positive and for some, a desire to not believe they had HIV. By not worrying, these participants were able to carry on with their lives - something that they feared would not be possible if they knew that they were HIV-positive. Two of the participants described how focusing on their work helped them to continue not to worry about HIV. One participant described how having TB caused him to think that he may be infected with HIV but the successful treatment of it led him to believe that it could not have HIV. As a result, he was no longer concerned about HIV.

"But y'know then I bounced back and I thought probably...y'know it was one of those things. So then I just uh...I just uh...didn't bother y'know so and just carried on, that was it". (P4)

He describes how his belief that he did not have HIV was maintained by the fact that he was still being accepted in society:

"And even if you approach a woman and she accepts a date with you, you think, I'm fine, you understand. It's like physical, your physical appearance was the, y'know, main thing. I believed it because as long as you're in the mainstream society, they're accepting you, you're okay". (P4)

Other participants described how their doubts about having HIV (due to being reassured about symptoms, having a lack of symptoms or symptoms going away) led them to conclude that they did not have HIV. As a result, their concerns subsided and they felt more certain about not having HIV.

"Yeah maybe for like a month or two I'd be okay, not even thinking about it. If a rash comes on my hand and then at the hospital they tell me, ah it's nothing, that's it, I'll forget about it.

So because of the person that I've seen um...maybe being ill with HIV or AIDS, those symptoms, that's what I had in my mind. I have to have those symptoms for me to know that I'm positive. So if I didn't have them, to me I didn't have it." (P5)

"And then there comes a time when you are well and you just forget about it, you think oh, maybe it was just my mind. I ended up just telling myself, no, I have nothing to worry about". (P6)

"So not having a lot of information about it just sort of relaxes your mind and you just, you just don't worry about it but there's nothing really for you to concentrate on worrying about it." (P8)

However all of these participants stopped believing that they did *not* have HIV and felt uncertain about being HIV-negative when their experiences caused them to consider the possibility of being HIV-positive.

2. Preferring to not know about HIV status

When feeling uncertain about their HIV status, participants equally believed that they could be HIV-positive or negative. All participants expressed a preference to not know their status as they believed there was a possibility that they were HIV-positive. Initially, there was no desire to find out if they were HIV-negative. Instead the preference to not know about their HIV status was overpowering. The preference to not know their HIV status maintained their uncertainty as testing was not initiated. A number of participants explicitly expressed this preference:

"You're much more certain of being ignorant about it than getting to know about it." (P1)

"So, I just thought y'know, as long as I...uhh I don't know, avoid it y'know, doesn't hurt me". (P4)

"I would rather live without knowing than live knowing that I have it. (P5)

"I would rather just not know what is going on with me". (P6)

Participants reported that their preference to not know their HIV status was due to a variety of related fears. These are subsequently explained as themes. Some participants had multiple reasons for not wanting to know. On reflection of this during the interview, some participants felt that it was naive or foolish of them to have preferred not to know about their HIV status. This preference to not know their HIV status contributed to the ambivalence felt by three participants. Their desire to not know their status competed with a desire to gain certainty about their status, which resulted in ambivalence about testing. These are outlined as separate themes.

Fear of facing death. Five of the participants described a fear of knowing that they would die and a fear of actually dying if they knew they had HIV. They reported that this stopped them from considering or initially taking a test. Participants linked HIV to death with many of them having known someone who died of HIV or AIDS.

"...there was a lot of death in Africa within the family y'know and everyone would be talking about it. That was the taboo in Africa, once you are HIV positive...you are a dead man walking and y'know you've got no survival chances, it's like zero". (P4)

"Umm, just the fear. Yeah. Just the fear. The fear of dying". (P3)

Participants linked HIV to death because they perceived there to be no access to or availability of treatment. This was while in Africa in the early to mid-2000's for some of them.

"I didn't want to go back [to the hospital to get tested], I was really afraid. Having a disease that doesn't have any medication. That's how it feels

because...when you think about it, okay, I might have HIV, I might be HIV positive...the only thing that comes to you is dying. That's how I was feeling".
(P5)

Other participants described how they saw knowing that you have HIV as an act of confirming your imminent death. Therefore they preferred to not burden themselves with this knowledge.

"Personally, it was one of those things that...y'know automatically in your head you're a dead man walking. So, I didn't want to have that negative thought in my life. So...it's like...really to even think about going for testing, it's like you're going to sentence yourself". (P4)

"I think it's the thought of knowing and then knowing how much, looking at how much it was, well, many people were dying with those kinds of symptoms. And I was saying if I know that I am positive, it means I'm going to die very soon and my son is 4 years old. I might as well not know and do what I have to do and look after him. Yeah, it makes no difference, if I'm going to die, I'm going to die anyway". (P7)

It appeared that participants felt that waiting for death, while tolerating the uncertainty associated with this, was preferable to knowing their status for certain.

Fear of not being able to tolerate knowing. Three of the participants explicitly described fears about not being able to tolerate the knowledge that they were HIV-positive. This was very much linked to their fear of dying from HIV. Knowing that they would die was seen as a psychological burden that they felt they would not be able to tolerate. One also feared that knowing that they were HIV-positive would potentially be physically damaging. The fears about the psychological and physical impact of knowing that one is HIV positive appeared to be linked to seeing other

people who were diagnosed with HIV either kill themselves or physically deteriorate extremely quickly.

"Would I even be able to hold it y'know, within myself? Because knowing it...especially knowing that you're positive, you'd actually...damage yourself internally. So you'd rather just stay focused on what you're doing and avoid it because there was no cure, you understand, there was no cure. So you know, it's better if you don't know, because what are you going to try and prove to yourself?"

Yeah, then y'know, I've seen people who are like that and y'know who would commit suicide, that time, they would commit suicide because they'd found out they were positive". (P4)

"That means I will still be thinking about it and I will end up killing myself. But then, at the end of the day, I want life. So if I know I'm HIV positive, definitely I will try to commit suicide. But not knowing, I will carry on with my life. But if I know, I will be thinking about it every day, it will drive me to committing suicide". (P5)

"And because I'd nursed so many people in Zimbabwe who had died and the knowledge of being HIV, once they didn't know that they were HIV, they were okay but the moment that they were given the diagnosis, they would just go so down y'know...deteriorate so quickly and the next minute you hear that they are dead. I was afraid of that happening to me, that uh, maybe the knowledge of um, me being HIV, maybe it would just strike me so hard that it would affect me, I would deteriorate". (P6)

One of these participants described a belief and a fear that knowing about HIV when she was fit and well would have affected her differently compared to if she was to find out when she very unwell. She felt that she would not have been

prepared for the result unlike when she was extremely ill and had prepared for a positive result.

"But if I had just been told when I walking like maybe being well and somehow I got a blood test and it came, it would maybe have affected me in a different way than it affected me now". (P6)

Fear of experiencing stigma and discrimination. All eight of the participants anticipated and feared being subjected to discrimination if they were to be HIV positive. This was from various sources and in various contexts. One participant described how she anticipated being judged by health care professionals at the sexual health clinic in the UK and this deterred her from testing. She believed that they would assume that she had HIV because she was black African and she did not want to be subjected to this judgment. She believed this was likely to happen as she perceived there to be a lack of black professionals in sexual health clinics.

"So it changes your mind in to doing the test... because you're like scared of the stereotype that all black people have HIV. So now, when you go in to a place and you want to do a HIV screening and you find only white people there, it sort of clouds your judgment." (P1)

Participants described living in quite tight-knit communities in Africa where people would know the 'business' of other people. Therefore some participants described being worried that people would find out about them being HIV-positive. As a result they feared stigma and discrimination from the community in general due to the negative ideas that people held about those with HIV. There was a sense of shame attached to HIV because of its link to sex. It seemed that participants did not want to be blamed or labelled in a negative way for having HIV and subsequently be subjected to discriminatory behaviour such as being mocked or rejected. Gender was

a factor that appeared to be tied up in the labelling and judgement that participants feared.

"Because the whole village would know ahh, that man, was a womaniser, died of HIV. Yeah, the reason why I didn't take test by that time...I didn't want...to be pressurised more. Because, as I told you, my first marriage, I was just trying to avoid more embarrassment, to know exactly". (P2)

"And neighbours would be laughing at us. People would be talking at us. So family, they would be embarrassed. To even think that they have me as their daughter or have me as their family, that kind of thinking was the one that was putting me off.

But if I know it, every day I'll be thinking, okay who knows. Okay, uh they are looking at me, they are laughing, they are laughing at me". (P5)

"I think it was going to be worse blame really because I'd been blamed already for his walking out so I didn't want anymore. And you, the problem with, in Africa, it's not the problem is not the woman sometimes, no the man, blame is always given to the woman". (P7)

One participant had sought asylum in the UK after having experienced a series of traumatic events during the Rwandan genocide. She went to live with a foster parent on her arrival in the UK whom she heard talking negatively about people with HIV and AIDS. This included stereotypes and misconceptions about how HIV is transmitted. She feared rejection by her foster parent if she was to be diagnosed with HIV, which would have left her in an even more vulnerable position:

"She would definitely just send you out of her house and then you're thinking, where am I going to live, where am I, you're new in the country and you just don't know that much". (P8)

This anticipated stigma also appeared to impact on participants' decision to

talk to others about their HIV concerns with only three of the participants doing so. It seemed that some participants would have wanted to talk with others more openly but did not due to fear of stigma. For example one participant described how when asking questions and for advice about her symptoms, she would not say that it was her that had the symptoms.

"You'll don't really tell them that it's you that's having it, you tell like, what can you do if you have this". (P5)

Not wanting relationships and lifestyle to change. Three of the participants spoke about a fear of the impact that having HIV would have on their relationships, both romantic and familial. One participant felt that a HIV diagnosis would impact on her intimate relationships. This is because she would have to be very cautious so not to transmit HIV to others.

"Whereas when you know about it, you have to take all sorts of precautions, you have to change your lifestyle, you have to be very cautious of what you're doing.

You have to, have all the time, protected sex if you are to go down that route".
(P1)

Another participant was in a relationship at the time, which was clearly very important to him. He describes how a HIV positive diagnosis would be damaging, in that it would ruin his relationship.

"I had a girlfriend at that time as well and it's one of those things whereby...I just thought, if I get it, it's just going to destroy my world". (P4)

For another participant, the concerns were about her relationship with her family being impacted by a HIV diagnosis. She worried that her family would be

angry with her because she thought they would also be affected by the discrimination associated with HIV. Therefore she was afraid that her family would also isolate her.

"They'll be angry at you for being isolated from the society. So it was a no-no, it's like, no, I don't want to put them through that and I don't want to put myself through that. Because if they are being isolated, they will isolate me".

(P5)

3. Making the decision to test for HIV

Participants' thoughts and feelings changed over time which meant they went from preferring to not know their HIV status to making the decision to test for HIV. The changes that occurred were that: feeling uncertain became a psychologically negative experience meaning that certainty was wanted, certainty about their status was perceived to have benefits, some felt more doubtful about being HIV-positive and thus hopeful that they were HIV-negative and some became hopeful about getting treatment that would prolong their life. The hope of being HIV-negative and hope of getting treatment if HIV-positive were linked to their want for certainty. Implicit in the desire for certainty and the hope for treatment was the psychological process of preparing for and accepting that one may be HIV positive prior to testing. Four participants first felt ambivalent about testing before deciding to test. This was because of the competing motivations for certainty and uncertainty about their status. As the changes in participants thinking were linked, it was a combination of changes that made up each participants decision to take a test.

Having hope about being HIV-negative. Three of the participants described developing a hope that they could be HIV-negative. This was linked to the doubt that these participants had about being infected with HIV. In two cases, participants' thought processes appeared to increasingly focus on their doubts about having HIV,

which then evolved in to hope of being HIV-negative. This hope was powerful in that it was an important factor that motivated participants to consider testing and was one of the factors that drove their want for certainty.

"Maybe, is it, is it like, is... I thought that...it might be a miracle that I am negative. That uh...maybe, you never know. Miracle can happen. So, maybe I can have a chance. That what made me to go and have test. My partner, she the one who sick, maybe I am, I maybe have a chance of being negative. That's what I thought". (P2)

"That part, 50% as well did help me to say okay, let go find out myself...if I was a negative and things would have been different, you understand. That's another part of um....the thing who pushed me to go and do that. Because I had a bit of hope as well. Seeing my past, I didn't go through much a lot. So I knew, I was a bit confident that, I might, apart from my wife, I might be...negative, you understand". (P3)

For these two participants, it appeared that the hope about being negative triggered their testing decision making process. For another participant, there was a desire to gain certainty and part of this was driven by a hope that she could be HIV-negative. She described how this hope about being HIV-negative was rooted in her doubt about her symptoms being due to HIV.

"Well I was hoping it was going to be negative and that it was just being shingles and just the shock. And I was thinking that oh Hepatitis B is just Hepatitis B. They said it's just Hepatitis B". (P7)

Wanting certainty about HIV status. Seven of the eight participants described wanting to resolve their uncertainty about their HIV status and gain certainty. There was a change in participants' thoughts and feelings over time, which

for some appeared to be linked to a consideration of or influenced by external factors. Changes in participants' thinking meant that uncertainty was perceived to be negative and certainty was seen to have internal (i.e. psychological) and external (i.e. physical) benefits.

Two of the participants spoke about the psychologically aversive experience of feeling uncertain about their HIV status. For some participants, the negative experience of being uncertain appeared to be linked to not being able to tolerate the thoughts that they had about possibly being HIV-positive. Therefore having certainty about whether this was the case was seen to be favourable. For others, including those who had hope about being HIV-negative, there was the desire to have confirmation of whether they were HIV positive or negative. It seemed that these participants felt psychologically out of control while feeling uncertain and testing was a way of taking control by gaining certainty.

"The time I thought about the break up and put those images in to my head, definitely pushed me to say, no, I need to get this off my head and get to know". (P1)

"Because I wanted confirmation. Hmm...because that way of thinking you are negative, you are positive, I wanted to get rid of it. I wanted to get one thing. Positive. Negative. Just one. I need to be at one step, am I positive, am I negative.

I wanted it to release pressure because the pressure was too much. So I wanted to cope with this situation". (P2)

For other participants, their appraisal of certainty became positive as it provided external benefits such as being able to access medication or make plans in anticipation of their death. These plans included being able to arrange care for their

children, being able to kill themselves to avoid anticipated suffering, being able to make a will and to ask for forgiveness from God if they were positive.

"My finding out wasn't to get treatment, but I was like if I find out that I'm positive, I'll just kill myself because I just didn't want to go through that". (P5)

"And when I thought of that, I was saying to myself, maybe it would be better to know, then you could kind of make arrangements, if there are any arrangements to be made. And talk to people and say, if I die today, could you look after my children or whatever else". (P7)

"So I wanted to confirm that I have sinned and beg God, so that he can forgive me". (P2)

For two participants, the changes in their thoughts and feelings about wanting certainty was linked to their physical health deteriorating, which was impacting on their day to day life.

"And I need to know right now because...I couldn't cope physically with work. But because of my physical inability, I just say to myself, you know what, I cannot keep beating around the bush". (P4)

One of these two participants, who was in hospital due to becoming very unwell with meningitis, described how she started to feel more certain about having HIV at this point. She reflected how she was probably thinking that she was going to die. Being extremely unwell in hospital, it seems that death was becoming more of a reality to her and so she decided that she would prefer to know if she was going to die.

"Maybe there was a time when I was thinking, this is the end of me, I'm dying anyway so that's what I thought, I thought I was dying. So, I'd rather know and die." (P6)

When the doctors in the hospital suggested to her that they did a HIV test to find out why she was so unwell, she describes it being relief that she was finally going to find out if the thing she had been fearing for such a long time - HIV, was a reality.

"It was a relief sort of (laughs). I just said, whatever I have been fearing for the past few years, like past 10 years, now is going to come to know exactly what I am". (P6)

Having hope for treatment and life. Three of the participants described how having hope about being able to access treatment, which would mean that they could continue to live, helped them to make the decision to take a HIV test. Therefore this was also a factor driving their desire for certainty. This hope developed after being told about the availability of medication in the UK, thinking that treatment was more likely to be available in the UK or thinking about those that they knew who were HIV positive and living a normal life while on medication.

"But if I'm positive anyway, they said, there's treatment. It's not cured but there's treatment". (P7)

"Being here, you've got...so many opportunities even you are sick, you might get help or treatment, you understand. And then all those came to my mind, I said okay. Because ...before that, I knew a family friend, my wife's family- just their friend- a lady who was long time diagnosed with HIV positive. But she was just living normal life because she was taking treatment. And I thought okay...maybe if tomorrow they said I'm positive, I might um, have the chance to have the treatment and live a bit longer". (P3)

"My friend told me that y'know there's uh, now medication for it here. So, he had information whereby people can be supported. Also, there is medication which is ready available which is y'know, you don't have to pay for. So, that to

me...y'know changed a lot of things within my thinking". (P4)

For two of the participants, getting diagnosed and therefore getting medication, which would allow them to continue to live, was important for the sake of their children. They wanted to be able to see their children grow up but there was also a sense of paternal responsibility in that they needed to support their children financially and did not want their children to have to live without a father.

"So yeah, I was thinking y'know...if I can have another 10 years of my life or another 20 years, then they will be big. That's when I decided no, for the sake of my kids, let me just go and know my status". (P3)

"So that was my other worry...y'know that...if I can be treated then fine, then at least I can see my daughter grow.

But then, for me now, because I had so many demands, I had to...my daughter starting school so I had to go to work". (P4)

Feeling ambivalent about testing. Four participants described feeling ambivalent after first considering testing. This is because they had competing desires- to gain certainty versus avoiding their fears associated with being HIV-positive. On one hand they thought that testing would be beneficial (e.g. they could find out that they are negative, could be certain and make plans) and wanted to test. However there were also worries about potentially being positive, which meant they also did not want to test. They described switching between the two options of testing and not testing in their mind but then feeling undecided for some time about what to do.

"Your head is full, full of thinking, you think too much. It is if you have...you are writing like an essay. You consider having test, you consider not having it. You consider your death, you consider your future. Yes, yes and sometimes

like, during the day, you can, you have...you you, you wake up having no plan, you don't know what to do". (P2)

"You start thinking, shall I go...or...shall I stay, y'know. Yes. Should I go...sometime you think, no I don't wanna go. And the other time you think...oh...I think it might be beneficial, you understand, if I go". (P3)

"I think it was difficult because it's...one time you would say to yourself, let me just go and have this or let me go to another town and have this tested so that I see and see what I can do. But then you say to yourself, no why should I do that, let me just leave it. And it was in and out of thought that yes let me go, yes let me not go". (P7)

"But at the same time, when I came back, I thought about it to say, maybe let me go have a HIV test to know." (P6)

It appeared that the first two participants saw testing to have benefits other than the one that initially caused them to consider testing and these overruled their desire not to know their status. It also seemed that they first considered testing because they were hopeful of being HIV-negative but they stopped feeling ambivalent about testing when they started to accept that they could be HIV-positive. However for the other two participants, their desire to not know their status prevailed at first until they later decided to test.

Preparing for and accepting a potentially positive result. Seven of the eight participants described coming to a point where they started to prepare for and accept that they could be HIV positive. This acceptance was implicit in some of the other changes in their thinking such as wanting certainty or having hope for treatment. Therefore participants acknowledged that they may be positive and prepared for this being the outcome of the test. This preparation appeared to

'balance out' the hope of being HIV-negative for those that had that hope. Therefore if their hope of being negative was not realised, then they had also prepared for the consequences of being HIV-positive, and for some participants, this still meant death. This preparation and acceptance appeared to be an important factor in helping participants to make the decision to test. There was a sense that participants realised that testing would only reveal what the already decided outcome was, which could not be changed.

"When I made the decision to do it, I was like, so be it, whatever comes, may be. We shall deal with it then, whatever happens. That was my solution now". (P1)

"Sometimes, you c... I came to a point. If I am negative, let come what may. If I am positive, let come what may. Hmm, because after all, you cannot live forever, you have to die. You have no choice. It is decided. It is written...eh, because you cannot take away. If you have a chance, you are negative, if you don't, you are positive- that's it". (P2)

"I mean I had no relationship that time, and I just said to myself, if I'm going to die, y'know let it be. Let me, let me go for it and...y'know, and I had no one to really report to because I was single. Yeah it more like accepting and also like, giving up life, if I'm gonna die anyway, I'm gonna die". (P4)

As mentioned, it seemed that some participants had an expectation that they were likely to die if they were HIV-positive. This helped them to prepare for and accept a potentially positive result as they felt that this was unchangeable and therefore they now had nothing to lose by knowing.

"Because I was already, very unwell and I was prepared for anything because anything could have happened... I just felt like there was no going back. You know at times, that was the time when I just resigned, it was like, I was

thinking that I was dying anyway so I didn't have anything to lose". (P6)

"Courage...um...in that situation, knowing you are like a dead man walking, you understand. Eh...but let me just go and find myself, who I am". (P3)

4. Model of delayed HIV testing in HIV-positive sub-Saharan Africans

The aim of this study was to develop a model of delayed HIV testing in HIV-positive sub-Saharan Africans who did not test for HIV soon after thinking that they might be HIV-positive. Figure 4 shows the proposed model. The theoretical categories and their sub-codes constructed in the grounded theory analysis represent the psychological processes involved in the process of delaying a HIV test. This process follows an initial trigger point, which caused participants to either consider that they might have or definitely had HIV, up to the point of actual testing. The model shows categories, their sub-codes and the relationships between them (as shown by the arrows), which together explain the process of why participants delayed their HIV test but also why participants decided to eventually take a HIV test.

Seven participants had a trigger experience that meant that they considered being infected with HIV. The other participant initially felt more certain about being HIV-positive. However they also had doubt about being infected with HIV. This doubt was for some participants, influenced by a desire to not believe that they were HIV-positive. The processes of considering and doubting the possibility of HIV infection involved participants evaluating and interpreting their experiences using knowledge and reasoning. The result of both considering and doubting the possibility of being infected with HIV was for all participants, at some point, experienced as a state of uncertainty about whether or not they had HIV. At various points in time, when some participants doubted HIV, they went on to feel more certain that did not have HIV and no longer worried about it. However when they experienced something that made

them consider the possibility of having HIV once again, they felt uncertain. Similarly, when some participants considered HIV infection as a possibility, they went on to feel more certain that they did have HIV at times. Therefore most participants oscillated between feeling more certain about being HIV-positive, more certain about being HIV-negative and feeling uncertain. Other participants remained feeling uncertain for the period of their delay. Feeling uncertain or certain that they were HIV-negative meant that participants delayed testing.

Participants described a number of feared consequences of knowing that they had HIV. They wished to avoid these consequences and thus preferred not to know about their HIV status. As participants felt uncertain, they were able to tolerate (initially) this preference to not know their status and so they remained uncertain. These fears also drove a desire to not believe that they could be infected with HIV for some participants. Participants' feared consequences of a HIV diagnosis were of dying or knowing they would die, which was linked to a fear of not being able to tolerate knowing. They also feared stigma and discrimination and changes in their relationships.

Participants went from preferring not to know their status to engaging in the process of making the decision to test. This was due to changes in their thoughts and feelings. Seven participants made the decision to test with one delaying testing but becoming too unwell to eventually consent to testing when she was admitted to hospital. One of the changes in seven of the participants' thoughts and feelings was that they wanted certainty about their HIV status. Uncertainty about their status was experienced as negative or intolerable and certainty was perceived to have both psychological and physical benefits. Other changes in their thoughts, linked to their want for certainty, were that some participants developed a hope of being negative

and/or a hope of having treatment and continued life. Having hope for treatment and wanting certainty were linked to the psychological process of preparing for and accepting a potentially positive result which all participants who decided to test described doing. At least one of these factors, alongside preparing to accept a positive result was part of all participants' decisions to test. Four participants felt ambivalent after initially considering testing due to the competing motivations of wanting to test (i.e. because there was hope of being negative, wanting certainty) and not wanting to test (i.e. because of fears associated with being HIV-positive). Two of these participants overcame their ambivalence by preparing for a positive result, which helped them to test. Two of the participants decided not to test when feeling ambivalent because of their fears associated with being HIV positive but then later made the decision to test.

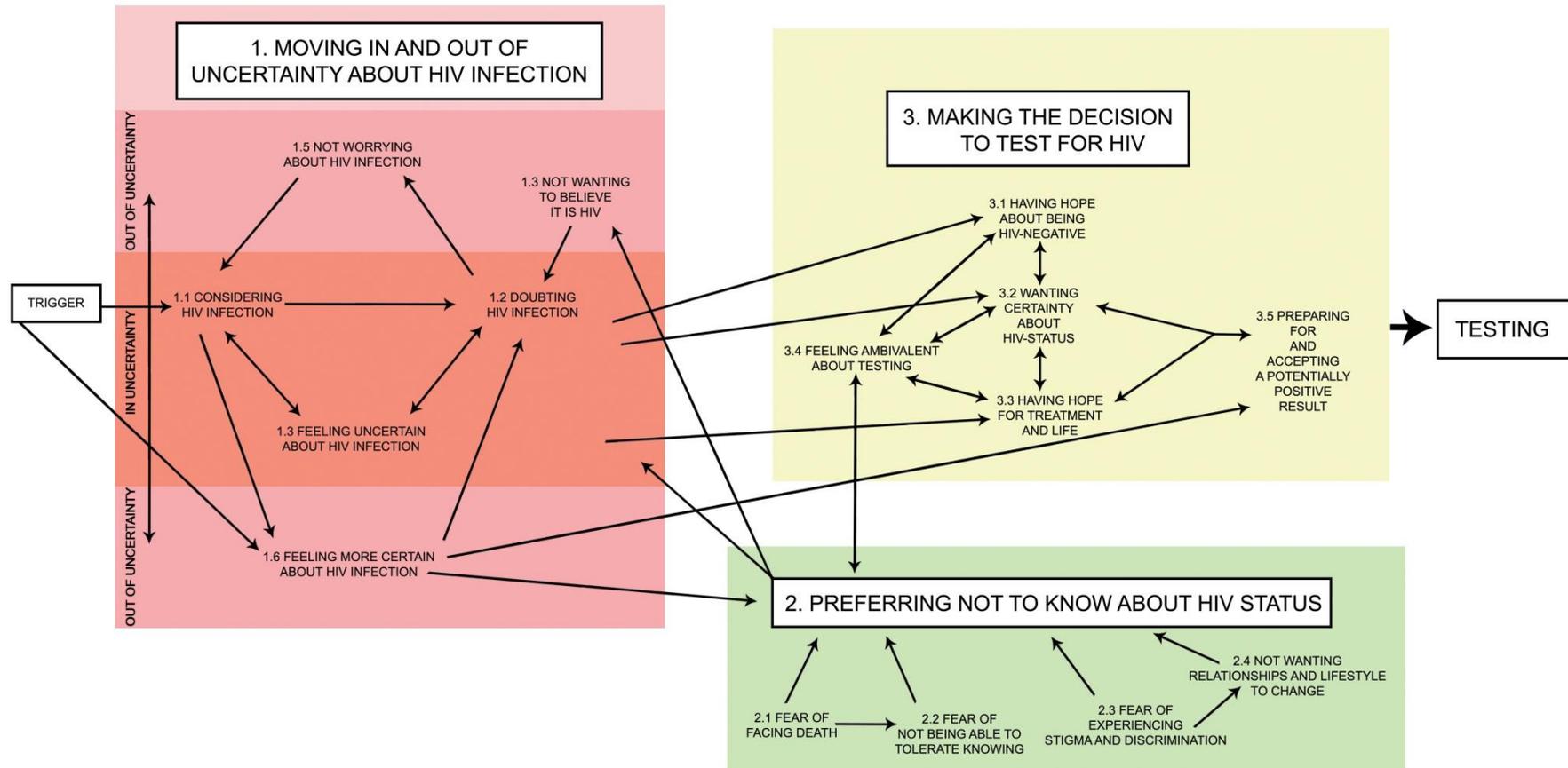


Figure 4: A model of delayed HIV testing in HIV-positive sub-Saharan African

Chapter four: Discussion

This study explored the process of delayed HIV testing in a group of HIV-positive sub-Saharan Africans. Eight participants were interviewed about their experiences. A Grounded Theory methodology (Charmaz, 2006) was used to collect and analyse data with the aim of answering the following research questions:

- a) What are the psychological processes associated with delayed testing in a sample of SSA HIV positive people?*
- b) How do these processes change, from the point of initial risk perception to testing?*

Three theoretical codes were elicited from the data to describe the psychological processes associated with the process of delayed testing, from the point of initial risk perception to the point of testing and being diagnosed with HIV. These were:

- 1) Moving in and out of uncertainty about HIV infection
- 2) Preferring not to know about HIV status
- 3) Making the decision to test for HIV

Overview of findings

The findings of the study show the various psychological processes that were associated with delayed HIV testing in the sample and were influenced by relational, cultural and systemic factors. It also shows the changes in these processes which make up the process of delaying HIV testing as a whole. The categories 'Moving in and out of uncertainty about HIV infection' and 'Preferring not to know about HIV

status' were the two main psychological processes which appeared to contribute to the period of delay. Prior to testing, all participants felt uncertain about their HIV status which meant that they equally believed the possibility that they were and were not infected with HIV. All participants reported fears associated with being HIV-positive. Therefore, as they believed that they *could* be infected with HIV, all participants described initially preferring to not know their status. It seemed that because participants were uncertain rather than convinced about being HIV-positive, they were able to initially tolerate not knowing their status. This meant that they avoided testing and thus this contributed to the delay. There were also times however where some participants felt more certain that they were HIV-negative and they stopped worrying about HIV. This also contributed to the delay as participants did not consider testing during these times. All participants went from not wanting to know their status to wanting certainty about it. This was because of changes in their thoughts and feelings. This included changes in their thoughts and feelings about being uncertain about their status and linked to this, having hope about being negative (linked to their doubt about being HIV-positive) and a hope for treatment and life (linked to their belief that could be HIV-positive). It seemed that all participants needed to psychologically prepare themselves for a positive test result when making the decision to test.

Discussion of categories

Moving in and out of uncertainty about HIV infection. All of the participants perceived that they were at risk of HIV following an initial 'trigger' experience. For seven of the participants this perceived risk was characterised by uncertainty. Many of the participants remained feeling uncertain about their HIV status for long periods of time whereas some became more certain about being HIV-positive or negative at times. Previous studies with sub-Saharan African individuals

who have delayed testing (Erwin et al., 2002) or are uncertain about their HIV-status but have not tested (Hickson et al., 2009) have not looked at *changes* in risk perception and how this relates to the decision to test. The findings of the current study show that individuals' risk perception is fluid. This is important given that participants reported that the uncertainty they felt about having HIV was a factor that deterred them from testing. Due to their doubt, they were able to avoid testing as they feared the consequences of being positive. These are individuals who are by definition 'high-risk' as they went on to be diagnosed with HIV but some dismissed the possibility of HIV for long periods of time. It is possible that if they felt more certain about having HIV, they may have not felt able to avoid testing or at least for an extended period of time.

Participants considered HIV as a possibility due to their evaluation and interpretation of symptoms they experienced. Studies on factors enabling and deterring HIV testing in various populations across sub-Saharan African countries such as South Africa, Uganda and Burkina Faso have found that having symptoms perceived to be due to HIV gave participants a reason to test (Mabunda, 2006; Obermeyer et al., 2009; Råssjö et al., 2007). For some participants it was their circumstances (e.g. suspecting or knowing a partner was unfaithful or their partner being diagnosed with HIV) that caused them to consider HIV. This is also consistent with research on factors enabling HIV-testing in SSA (Musheke et al., 2014).

However in the current study, participants also had doubts about having HIV. Participants doubted HIV infection because they a) expected to have symptoms or be ill which they were not b) expected particular symptoms which they did not have or c) had a non-HIV explanation for symptoms they experienced. This is consistent with studies in sub-Saharan Africa which have found a reluctance to test amongst

participants unless they have any symptoms or symptoms they associate with HIV, despite there being an acknowledgment of personal risk for HIV (Day et al., 2003; Jürgensen et al., 2012). Siegel, Schrimshaw & Dean (1999) note that historically, HIV and AIDS have been socially constructed as an aggressive illness and this may inform individuals' illness representation of HIV. Therefore a lack of symptoms is interpreted as HIV not being possible. This is inconsistent with the reality of HIV being potentially asymptomatic for some time. Indeed some of the participants reflected on the fact that they did not know HIV could be asymptomatic and therefore a lack of or improvement in symptoms led to doubt about HIV. Others had symptoms but due to a lack of knowledge about HIV, some participants did not attribute their symptoms to be due to underlying HIV or reasoned that they could be due to other factors. This appears to be consistent with the findings of the retrospective survey with 256 HIV positive African individuals in London by Burns et al. (2008). Despite having physical symptoms and seeking medical attention in the year prior to the diagnosis, the majority of the participants had not considered the possibility of having HIV.

This part of the delay process can be likened to the stage of 'appraisal delay' in Andersen et al.'s (1995) model of patient delay in cancer. They found this stage, where the individual is interpreting their symptoms (and must infer illness in order to move to the next stage) accounted for most of the delay in seeking a cancer diagnosis in two groups of women diagnosed with cancer (Andersen et al., 1995). The finding that participants felt uncertain about their symptoms can be understood by using Mishel's (1988) model of uncertainty in illness (UIT). Mishel (1988) describes uncertainty as a cognitive state which results from not being able to categorise or assign a definite value to an object or event. UIT proposes that individuals process stimuli (using a 'stimuli frame') and construct a cognitive schema

for an illness event which creates less uncertainty. These components are symptom pattern (number, intensity, frequency, duration and location), event familiarity (novelty and complexity) and event congruence (consistency between what is expected and experienced in illness-related events) (Mishel, 1988). These components are influenced by a) 'cognitive capacity' - the information processing abilities of the person and b) 'structure providers'- the resources available to the individual which assists their interpretation of the stimuli frame such as education, social support and trust and confidence in health care providers. If a cognitive schema cannot be formed then the result is a state of uncertainty (Mishel, 1988). This is comparable to the state of feeling divided experienced by participants where they had equally weighted, conflicting interpretations of their experiences (e.g. having ambiguous and unfamiliar symptoms which led them to consider HIV infection but also doubt it or not having symptoms or symptoms they expect to have if they had HIV). However participants' non-symptom experiences (e.g. partner being diagnosed with HIV, being raped) which for some, triggered their initial risk perception, also contributed to their uncertainty. Also as UIT proposes, their interpretation also seemed to be influenced by their knowledge of HIV symptomatology or moreover, a lack of it. Many participants described there being a lack of knowledge generally in their communities. It seems that this allowed stereotypes about how someone with HIV would look to exist as participants described expectations of looking very unwell if they were to have HIV. Therefore as they did not look like these stereotypes, they did not perceive risk (Earnshaw et al. 2012). Also due to stigma, many did not seek support social support. Mishel (1988) proposes that such support can reduce uncertainty. Mishel (1988) noted that uncertainty can be appraised as being a danger or an opportunity. An 'opportunity' appraisal can occur when the alternative to uncertainty is certainty that is negative. As a result, uncertainty is preferred. Being uncertain means that hope about a positive outcome can develop (Mishel, 1988). As

a result people may use strategies such as avoidance or selecting ignoring. This is consistent with the present study where participants initially preferred not to know their status as gaining certainty through testing and learning about a potentially positive status had feared consequences. For some, the uncertainty they had about having HIV led to hope about having a negative result. However, being uncertain about their status was eventually responded to differently. Mishel (1988) described this as a 'danger' appraisal of uncertainty and has much to do with the individual's belief about their ability to cope with the uncertainty. The participants perceived uncertainty as intolerable or to have disadvantages.

Some participants described a desire to not believe that they had HIV which appeared to be a part of the doubt they felt about having HIV. Croyle (1992) notes that the appraisal of ambiguous health threats is when motivated reasoning biases are most likely to occur. Kunda (1990) notes that motivated reasoning, which can affect one's beliefs, evaluations and decisions, occurs when an individual has the goal of a) arriving at an accurate conclusion or b) a particular directional conclusion (if there is evidence to support this conclusion). Croyle (1992) proposes that under conditions of an appraised threat (Lazarus & Folkman, 1984) (e.g. thinking you may have HIV), the individual has a goal of a directional conclusion. This is the conclusion that they are healthy and thus their appraisal of their symptoms is self-enhancing. This is achieved through a memory search for supporting beliefs or using knowledge to create new, supporting beliefs (Kunda, 1990). This appeared to be the case for a number of the participants. They had plausible, non-HIV explanations or found evidence through reasoning which allowed them to arrive at the desired conclusion- that they did not have HIV. Siegel, Schrimshaw & Dean (1999) note that the threat of having a life-threatening illness and one which is highly stigmatised, means an individual may be disinclined to consider their symptoms to be HIV-related. By

avoiding this, they maintain their 'preferred identity' (Charmaz, 1987) which was the case for some participants who went on to no longer worry about HIV at times and carried on with their life.

Preferring not to know about HIV status. All of the participants spoke about a preference to not know their status when feeling uncertain about HIV. As a result, their uncertainty was tolerated and this meant that some delayed testing for many years. The preference not to know one's status and the motivations for this are consistent with findings on barriers to testing for sub-Saharan Africans in the UK and sub-Saharan Africa.

The fear of dying if HIV positive reported by a number of participants in the current study is consistent with the finding in the survey by Erwin et al. (2002) in which fear of dying was cited by patients who delayed testing as a pre-test concern. Numerous studies in sub-Saharan Africa have found a fear of death to be a barrier to testing as people prefer not to know if they are going to die, which is believed to be the inevitable outcome of a positive result (Meiberg et al., 2008; Obermeyer et al., 2009). Many of the participants in the study first considered the possibility of HIV when they were in Africa in the 1990's and 2000's. Despite the reduction in AIDS-related deaths since the introduction of ART, 1.2 million people still died of AIDS in sub-Saharan Africa in 2012 (UNAIDS, 2013). In 2003, ART coverage was estimated to be at less than 10% for all countries in sub-Saharan Africa except Botswana (10-25%) and Senegal (25-50%) (WHO/UNAIDS/UNICEF, 2008). Participants who first perceived risk of HIV in Africa did so in the years 1993 to 2002. Even by 2007, ART coverage in the participants' countries of origin were estimated to only be between 10-25% (Democratic Republic of the Congo, Zimbabwe), 25-50% (Uganda, Malwai) and 50-75% (Rwanda) (WHO/UNAIDS/UNICEF, 2008). Participants who first

perceived risk of HIV in Africa spoke about medication not being accessible, especially for those who were not wealthy. This appeared to be linked to the fear of dying experienced by a number of participants, which deterred them from testing.

Another fear associated with knowing one's status reported by participants was of not being able to tolerate knowing if they were HIV-positive. Participants believed that knowing this may cause them to deteriorate and die or that the burden of knowing would be intolerable and feared that they may want to kill themselves. This finding is consistent with studies of barriers to VCT in Zambia and South Africa in which participants reported fears that the worry that would come with knowing would accelerate the progression of the disease (Jürgensen et al., 2012) or that the stress of knowing would affect one more than AIDS itself, which caused many participants to consider suicide (McPhail et al., 2008).

A third reason cited by participants in the current study for preferring not to know their status was fearing stigma and discrimination if they tested or were HIV positive. Many of them were very aware of the stigma in their communities. The current findings reflect existing findings on stigma being a barrier to testing in the UK (e.g. Erwin et al., 2002) and sub-Saharan Africa. In a review of qualitative studies on factors that enabled and deterred HIV testing in sub-Saharan Africa (Musheke et al., 2013), 25 of the 42 included studies reported fear of stigma and discrimination as a barrier for participants. This included feared rejection from friends and family (Råssjö et al., 2007), discrimination from the general community (Jürgensen et al., 2012) and judgement by health-care workers (Meiberg et al., 2008). Participants in the current study also reported fearing stigma and discrimination from these various sources. Alonzo and Reynolds (1998) note that individuals who perceive risk of HIV will be aware of the potential consequences of having a HIV diagnosis including stigma and

describe this as a 'pre-stigmatic fear'. Therefore, they may prefer an ambiguous HIV status rather than to realise a stigmatised identity. This appeared to be the case for the participants in the current study who preferred to be uncertain about their status. Mbonu et al. (2009) note that across the world, HIV has been accompanied by stigma and discrimination but there is a particularly strong association between HIV and stigma in sub-Saharan Africa. There appears to be a number of reasons why this is the case. These include the cultural constructions of HIV and AIDS in SSA, which are based on beliefs about contamination, sexuality and religion (Mbonu et al., 2009). In sub-Saharan Africa, there are high levels of religiosity. A common religious belief held in SSA is that sexual transgression and HIV are linked to sin and immorality (Mbonu et al., 2009). Also, there is a generally a communal way of living in SSA where the whole community will often know about each individual's life (Mbonu et al., 2009). Therefore, this type of environment makes it more likely that stigma and discrimination will occur. A consequence of stigma and discrimination related to HIV is that individuals are reluctant to take up HIV testing which enables them to get treatment (Chadourir and Earnshaw, 2009; Mbonu et al., 2009). This was observed in the current study.

A final reason for participants not wanting to know their HIV status was having fears about the impact of a HIV-positive diagnosis on their romantic and familial relationships including rejection and emotional reactions such as anger. This seemed to be linked to the stigma they anticipated. This finding is consistent with the findings of Erwin et al. (2002). This has also been found to be a barrier to testing in SSA based studies. For example a fear of being abandoned by their partners if diagnosed with HIV was reported in the survey by Obermeyer et al. (2009) and a fear of abandonment by family in a study of young males in Malawi and Uganda (Izugbara et al., 2009).

The Protection Motivation Theory (Rogers, 1983) can be used to understand the link between the participants' perceived risk of HIV and the feared consequences of a potentially positive result and their contribution to delayed testing. The model describes adaptive and maladaptive coping responses to a health threat. In the context of this study, the adaptive responses would be testing and maladaptive would be not testing. This is the result of two cognitive appraisal processes: threat appraisal and coping appraisal. Floyd, Prentice-Dunn & Rogers (2000) describe how the threat appraisal process evaluates the maladaptive behaviour. This includes the intrinsic and extrinsic rewards of the maladaptive response (e.g., avoiding the burden of knowing they are positive) and perception of threat including the severity of and vulnerability to the disease. Increased rewards of not testing will increase the probability of the maladaptive response and increased threat will decrease it. The coping appraisal process evaluates the ability to cope with the threat. This includes self-efficacy and response efficacy (e.g. confidence in ability to cope with being HIV-positive and the belief that this will protect them) and response costs (e.g. a potentially positive result meaning possible death or stigma). Higher response efficacy and self-efficacy increase the probability of the adaptive response whereas response costs decrease this. The result of strong threat and coping appraisals is protection motivation and thus behavioural intentions to perform the health behaviour (Umeh, 2005). In the case of the present study, not testing meant avoiding feared consequences of potentially being HIV-positive and the perception of threat was characterised by high severity but uncertain vulnerability thus increasing the likelihood of maladaptive coping. This response (not testing) aims to reduce anxiety rather than danger itself (Umeh, 2005). Participants reported low-self efficacy in that they felt that they would be unable to cope with knowing they were HIV-positive. As many participants initially feared that they would die from HIV, the response efficacy of testing in terms of protecting them would have been low as knowing their status

would not change this. The response costs of testing would have been high in terms of increasing the likelihood of the feared consequences of testing positive occurring, thus reducing the likelihood of adaptive coping responses. Janis & Mann (1977) note how maladaptive coping responses vary and may include rationalisation and denial (avoidance) (Umeh, 2005) which were observed in this study.

Making the decision to test for HIV. A key finding was that 7 of the 8 participants described eventually having a desire for certainty about their HIV status, which testing was able to provide them. For all of these participants, it seemed that feeling uncertain about whether they were HIV-positive became psychologically aversive over time and certainty was seen to have more psychological and physical benefits.

In some studies in SSA, participants have reported perceived advantages of HIV testing such as allowing one to be free from the fear of HIV (Day et al., 2003) or knowing one's status means that they will be free from worries (Mabunda, 2006). These advantages suggest that individuals are gaining certainty through testing but this may have been in the context of anticipating a negative result which was not the case for all participants in this study. The desire to reduce the distress associated with not knowing one's HIV status by testing has been found in other populations. For example it was cited as a reason to test by participants in a study of 120 men who have sex with men (Siegel et al., 1989). The current findings are consistent with the findings of a study by Flowers et al. (2003) which explored the perceived advantages and disadvantages of testing in a group of Scottish men who have sex with men (MSM). Some men who were unsure of their status saw testing as a way to reduce uncertainty and anxiety but this was in the context of expecting a negative result. For other men who had reason to suspect they were positive, their decision to test was

not related to hope for a negative result but instead was due to no longer being able to tolerate an unknown HIV status. Flowers et al. (2003) explain that this was only when not knowing was seen as worse than knowing they were positive. Having hope about getting treatment was a change in participants thinking that contributed to their want for certainty and thus decision to test. In 7 of the 42 studies included in the review by Musheke et al. (2014), the wider availability of medication in SSA which could prolong life was a factor cited as encouraging participants to test.

The Transtheoretical Model of Change (TTM) (Prochaska & DiClemente, 1983) describes five motivational stages which individuals go through before finally making a behaviour change. These are pre-contemplation, contemplation, preparation, action and maintenance. When participants preferred not to know their status, they would be classified as being in the pre-contemplation stage. However as changes in their cognitions and emotions occurred (e.g. wanting certainty, having hope) they moved in to contemplation/preparation as they were making the decision to test. However for three participants, changes in their emotions and cognitions that moved them out of pre-contemplation left them feeling ambivalent. This is because they also had fears about the consequences of being HIV positive. Rollnick, Kinnersley and Scott (1993) describe ambivalence as a state of psychological conflict about choosing between two possible actions, both of which have benefits and costs. Rollnick et al. (1993) note that it is when individuals are moving from 'contemplation' to 'preparation' stage, where they are making the decision to change a behaviour, that the feeling of ambivalence will be most heightened. However because the factor that motivated them to consider testing (e.g. having hope for a negative result) was linked to other factors (e.g. wanting certainty), this additional factor moved these participants in to preparation and towards the stage of action (testing) (Prochaska & Velicer, 1997). The TTM proposes that there are ten processes of change which are

covert and overt activities that individuals use to progress through the stages. The first five are experiential and used for transition in the earlier stages whereas the other five are behavioural and used for later stages. Some of these processes can be used to understand the changes in participants' thinking as they moved towards testing. For example, 'dramatic relief' which involves experiencing and releasing emotions can be applied to when participants eventually experienced uncertainty as psychologically aversive and testing was able to provide a relief of these negative emotions. However the findings are not consistent with most of the processes of change in the TTM such as consciousness raising where the individual recalls information they were given on how to stop the problem behaviour or reinforcement management of the healthy behaviour for example. This may be because TTM focuses on 'problem' behaviours such as smoking and drug use and these are likely to be viewed by the individual differently to the behaviour of not testing. They also suggest that the relative weighing of the pros and cons of changing are important in that as individuals move from pre-contemplation (where there are more cons to change) to contemplation, the pros of changing increase. As they move from contemplation to action, the cons of changing decrease (Prochaska & Velicer, 1997). Indeed individuals tolerated uncertainty because they perceived there to be many cons of testing and knowing their status. However participants' appraisal of the uncertainty became negative because of the internal and external (for some) negative consequences of not knowing. Therefore their appraisal of testing and certainty became more positive despite believing they could be HIV-positive.

For a number of participants their eventual desire for certainty about their HIV status which meant they went for a test was, in part, linked to a hope about receiving treatment that would allow them to continue to live. For other participants, potential access to treatment was not described as a facilitator of testing. This appeared to be

because it was not actually available at that point, they were not aware of its availability in the UK and because they had become so unwell immediately prior to testing that they anticipated dying despite being aware that treatment was available. As previously noted, access to ART was low across most of the participants' countries of origin at the time when they first perceived risk of HIV there. Therefore their beliefs about the availability of treatment in the UK may have been informed by their experiences in Africa, particularly if they did not have information to contradict this. It is also possible that reducing the aversive experience of uncertainty was a more motivating factor to test for these participants than the benefits of treatment, regardless of whether they knew that treatment was available and helpful. For the participants who did not describe HIV treatment as a facilitator of testing, their desire for certainty about their HIV status was linked to other benefits such as relieving the psychologically and physically aversive experience of uncertainty itself. For some, this was linked to the belief that there was a chance they were HIV negative and therefore wanted to find out if this was the case.

Beck's (1976) model of anxiety can be used to understand both the delay in testing and why the desire for certainty was a key facilitator of testing in this sample. This model proposes that anxiety is the result of the perception that danger is likely and would be serious and that the individual would not be able to cope and that rescue factors would not be present. This results in safety seeking behaviours such as avoidance. All participants at some point considered being HIV positive as a possibility and that the consequences would be serious (i.e. discrimination, death). Also, the perceived ability of being able to cope with these consequences was low and that rescue factors (i.e. availability of medication) would not be present. This led to a state of anxiety and thus the coping behaviour of avoidance (i.e. avoiding knowing their HIV status). However, the level of anxiety about knowing one's HIV

status reduced when there were changes in these four constructs which meant that uncertainty about their HIV status became aversive for participants and they went on to test. For example, for some participants, there was a hope about being HIV-negative and therefore the likelihood of threat (i.e. being HIV-positive) was reduced. For most participants, uncertainty about their status became intolerable (both psychologically and physically) and therefore the perceived threat of knowing their HIV-status became lower as knowing was able to provide relief through certainty. All participants who made the decision to test started to prepare for and accept the fact that they could be HIV-positive, prior to testing, which appeared to be a way of coping with the possibility of being HIV-positive and thus appeared to help them to test. For some participants, the perceived availability of medication and thus hope for life meant that a rescue factor was present also.

All of the participants described a psychological process of preparing for and accepting a potentially positive result. This seemed somewhat necessary given that they either thought HIV was a possibility or more of a certainty and eventually wanted to find out their status. The literature on coping can help to make sense of this process. Schwarzer & Knoll (2004) describe a type of coping called 'anticipatory coping' which may be used when there is an imminent threat, which is certain or fairly certain to occur and is likely to mean harm or loss. Schwarzer and Knoll (2004) explain how this approach may lead to the individual trying to solve the actual problem or by redefining the situation as less threatening. Consistent with this type of coping, some participants redefined the possibility of being HIV positive as less threatening by thinking about the treatment that may be available to them which helped them to prepare for a positive result. Folkman and Chesney (2013) note how there must be a fit between the appraisal of the changeability of the outcome of the threat and the coping response in order to minimise distress (i.e. not trying to change

outcomes that are not controllable). Some of the participants acknowledged that the outcome had already been decided (whether they were positive or negative) and therefore they were not able to do anything to change it. This appeared to help them to prepare for and accept it a potentially positive result as testing was recognised as a way of finding out something that was already there.

Strengths and limitations

Strengths. A strength of this study was that it addressed a specific gap in the existing literature by recruiting a group of individuals who had delayed testing. Most research has focused on the clinical outcome of late presentation. A Grounded Theory methodology allowed exploration in to the psychological processes associated with delayed testing. As participants had tested at the time of recruitment, it also allowed an understanding of how the participants went on to test, hence trying to understand delayed testing as a process. This is something that has been neglected in the limited number of previous studies which have detected individuals who have delayed testing.

A systematic sampling method was used which meant that all potentially eligible patients with an appointment in the recruitment period had a screening sheet put in their file. The recruited sample were all from sub-Saharan Africa, were HIV positive, had delayed HIV testing and were also late presenters which increases internal validity. Of the seven participants who made the decision to test, five of these sought out testing and two accepted provider-initiated testing. There was a mix of male and female participants and they originated from five different countries in SSA which increases the external validity given the characteristics of the wider HIV positive population. Despite the length of time that participants delayed testing ranging from one month to fourteen years, common psychological processes

associated with delayed testing were found across participants.

Another strength of this study was the importance placed on and efforts made to ensure and maintain the quality and credibility of the findings. For example, writing memos so that the researcher could trace their analytical decisions and using a reflective diary to reflect on their relationship and interaction with the data maintained internal validity (Meyrick, 2006). The internal supervisor provided external validation of initial coding by providing feedback on fit with the data and also checking that themes were not overlooked. Both the academic and field supervisors verified the resulting themes, their properties and the emerging theory to provide a credibility check and confirm that it resonated with their clinical experiences (Elliot et al., 1999). Both the external and internal supervisors are clinical psychologists who previously or currently worked clinically in the field of HIV.

Gaining service user feedback on the interview schedule was a helpful process in that it allowed the researcher to refine questions to ensure clarity and sensitivity. As was doing a mock-interview with the internal supervisor. The interview further evolved as the researcher's theoretical sensitivity developed and they followed up new themes emerging from the data in later interviews. Although none of the participants became distressed during the interview, Kvale and Brinkman (2009) suggest debriefing participants after interviews as this can strengthen validity of the study. When doing so, many of the participants explained how they had either not thought about the experiences discussed in the interview for a long time or had not even discussed them with anyone and therefore they valued the experience of being able to do so.

Limitations. Due to the relatively small sample size, it is likely that not all categories reached saturation. However common themes consistently came up across participants which made the Grounded Theory. This is likely to be due to the specificity of the research aims. Charmaz (2006, p.114) notes that studies with 'modest claims' may reach saturation quicker. The concept of theoretical saturation has been interpreted and viewed differently by various researchers with some noting that the point of saturation could be 'potentially limitless' (Green & Thorogood, 2009, p.120), which is particularly problematic in research limited by time and resources. The use of theoretical sampling would have allowed a greater confidence in having reached theoretical saturation. This may have involved recruiting individuals who tested more recently and those from different regions of sub-Saharan Africa. However this was not possible due to the time-constraints of the research process. It may have been beneficial to sample more participants who both perceived their risk of HIV and tested for HIV more recently in the UK as this would give insight in to barriers and facilitators to testing in the current context of HIV testing and treatment. This was the original aim of the study but due to difficulties with recruitment, the inclusion criterion regarding date of diagnosis was relaxed. As a result, more participants who first perceived risk in Africa at a time when ART was less available were recruited.

Data collection and analysis may have been influenced by the literature review that the researcher was required to complete prior to the study commencing. To counter this, the researcher reflected on their own assumptions and made these explicit in her reflective diary before beginning data collection to ensure that these did not have undue influence on the analysis. They also used questions that were open to the participants' experiences rather imposing preconceived ideas and ensured to elicit the participants' definition and meaning of situations and terms that they used

(Charmaz, 2006). It would have been useful for a participant from the study to provide a credibility check on the emergent themes and categories as the analysis progressed to enhance quality (Elliot, Fisher & Rennie, 1999). However one participant who agreed to do so was contacted but did not respond.

As all participants were late presenters also, the findings may not be generalisable to those who delayed but were not late presenters although this is likely to be a small population. The longer that individuals delay, the more likely they are to also be late presenters and to experience symptoms and illness as their immune system weakens. For those who delay and test early, the psychological processes in delayed testing may be different as they are less likely to have physical symptoms. Although the heterogeneity of the sample is a strength in terms of external validity, this is a limitation for internal validity.

Four of the participants who came to the UK and were diagnosed here, after first perceiving risk of HIV in Africa, described not being aware of or having limited knowledge about access to treatment in the UK. For two of these participants, obtaining knowledge that treatment was available contributed to their decision to test. Their beliefs about treatment availability in the UK may have been linked to their experiences and perceptions of treatment availability in Africa and thus contributed to their delay in testing. While medication was more likely to be available in the UK at that time, compared to Africa, some participants were delaying testing at a time when treatment such as HAART had not been available for a substantial period of time. However the availability and awareness of treatment has since changed in both SSA and the UK. Therefore their experiences need to be placed in context of this. It had been the original aim to study those diagnosed within the last 3 years but this was changed due to recruitment difficulties. However of the two participants who first perceived

risk of HIV in the UK and tested more recently, only one of these described treatment availability as a facilitator of testing. It is not known whether this was not mentioned by the other participant because they were unaware of treatment availability and tested for other reasons or whether they were aware of treatment but were more motivated to test by other factors.

The participants in this study were recruited from one inner-city London hospital and one from a London-based charity, which potentially limits the generalisability of the findings to other individuals of sub-Saharan African origin accessing other services in the UK.

This study employed a retrospective design. While none of the participants indicated that they were not able to recall their experiences with accuracy, it is likely that the passing of time since when they first perceived risk of HIV and tested allowed for recall biases which impacts on the reliability and validity of the data (Hassan, 2006). The study relied on participants being able to accurately recall what had first led them to consider that they may have been infected with HIV. This was related to identifying when they first perceived risk of HIV and thus the start point of delaying testing. Half of the participants in the sample reported first perceiving risk of HIV following an external event such as being raped, a partner being diagnosed with HIV or finding out their partner had been unfaithful. The other half of the participants in the sample reported first perceiving risk of HIV after experiencing unexplained or unusual symptoms. The experience of physical symptoms was also an important part of many participants' fluctuating HIV risk perception. Polkinghorne (2005) notes that participants' accounts of their experiences obtained through an interview are not true reflections of their experiences, as they occurred in the past. Instead the accounts are reconstructions of the past. As all of the participants were HIV positive at the time

of the interview, they were recalling their experiences with the knowledge that they now had HIV and had contracted it at some point in the past. Therefore, the knowledge that they are HIV positive may have impacted on their recall and reconstruction of their experiences. With hindsight, participants may have been attributing their HIV risk perception to experiences which they did not at the time of the actual experience. Polkinghorne (2005) proposes that reflection on an experience, changes the experience itself. A number of participants described being 'foolish' or 'naive' because they did not realise that their symptoms suggested HIV or because they did not want to believe that they could be due to HIV. Again, as participants were reflecting on their experiences from their current position, feelings such as shame or regret about not having sought help sooner, may have impacted on the participants reconstruction of their experiences. However many of the experiences that led participants to perceive risk of HIV were highly emotionally salient. Therefore this may have made it easier for participants to accurately recall these experiences. It seemed that having distance from their experiences allowed some participants to reflect on things that may have not been more apparent to them at the time of them such as not wanting to believe they had HIV. The study also aimed to understand how participants' thoughts and feelings changed over time. However it was sometimes difficult for participants to explain how exactly their thoughts changed. This could be due to a number of reasons including not actually knowing how they changed, not being able to remember or not wanting to say.

In this study, delayed testing was defined as when an individual took seven days or more to take a HIV test from the point of first perceiving some level of risk of HIV. Although this was considered enough time for an individual to test, it is possible that an individual may not have tested within seven days and not 'delayed' testing (e.g. due to the availability of an appointment with a health care professional).

Within this sample, the shortest length of time an individual delayed taking a test, from the initial point of risk perception was one month.

It was not possible to follow up the outcome of all patients who had a screening sheet put in their file. Therefore it is not possible to calculate the response rate amongst those eligible. Eighty-eight of the potentially eligible HIV-positive sub-Saharan African patients at the NHS clinic were lost to follow up and so not considered for participation and an unknown percentage of the potentially eligible patients who had appointments during the recruitment period did not attend them. Therefore the present sample may have only included those who are engaged in services. It was not possible to capture participants who may have, in addition to delaying testing, also delayed or disengaged with treatment (Girardi, 2004). Therefore these findings may not be generalisable to these patients.

Suggestions for future research

Given the many changes in the policy and promotion (e.g. campaigns) of HIV testing and treatment and continuous efforts to raise knowledge of HIV, in both the UK and sub-Saharan Africa, it would be of benefit to explore the psychological processes associated with delayed testing in individuals who tested since 2013 for example. It is possible that the psychological processes will be similar to those found in the present study. However such findings could be more useful when developing health promotion interventions as they will be more contextualised and will highlight which barriers exist despite on-going efforts to increase the uptake of testing.

Something that did not come up in the interviews in the present study was the issue of sexuality. The HPA (2013) data on late presentation in black Africans is from heterosexual men and women. 34% of men who have sex with men (MSM)

presented late in the UK in 2012 (HPA, 2013), but no data is available on their ethnicity. Research shows MSM across Africa with high rates of HIV. There is also political, cultural and religious hostility towards MSM in some parts of Africa (Smith et al., 2009). Research could explore whether and how the issues of ethnicity, sexuality and HIV are linked to testing experiences for African MSM in the UK. It is possible that anticipated or experienced discrimination linked to these three issues could impact on risk perception and testing decisions.

Future studies with individuals at risk of HIV (e.g. those presenting to GUM clinics) could use a longitudinal design and combine quantitative and qualitative methods to explore what changes occur in cognitive and emotional processes in individuals who both do and do not delay testing but also the mechanisms of these changes. This is more likely to provide an accurate reflection of how these changes occur and therefore more helpful for informing interventions. Many of the findings in the current study can be likened to a number of concepts in models of health behaviours such as perceived benefits of testing (Health Belief Model [HBM], Rosenstock 1974) and outcome expectancies (Social Cognitive Theory, Bandura, 1986) as well as stages and processes in models of change (TTM). Therefore these may be useful constructs to monitor in such a piece of research.

Clinical implications

The findings of this study highlight a number of relevant issues when developing interventions for delayed HIV diagnosis in sub-Saharan African individuals. An important factor that contributed to the delay of testing in the current study was the uncertainty felt by participants about whether or not they had HIV. This allowed some participants to completely stop worrying about HIV at times despite them being in a 'high risk' group. An important part of the on-going and fluctuating

risk evaluation made by participants was the lack or presence of symptoms and their interpretation of them when present. This suggests that clear, accurate information about a) the potential lack of symptoms and b) the potential symptoms that someone infected with HIV may experience needs to be disseminated to the sub-Saharan African population. This would normalise HIV and tackle stereotypes. If individuals who are infected with HIV are better able to accurately assess their risk, they may be more likely to seek testing. While doing so, it would be important to not incite unnecessary fear about having HIV however as this may give rise to further stigma and discrimination (Bastien, 2011). Therefore it should be stressed that it is important for individuals who have been in any situations that may suggest risk of HIV (e.g. finding out a partner has been unfaithful) and either have symptoms or no symptoms, should seek out HIV-testing. It is important to highlight that these may be situations that individuals have not necessarily put themselves in as this is less blaming. Melkote, Moore and Velu (2014) suggest that information about HIV risk and symptoms needs to be provided in a repetitive and pervasive manner and may be done so using mass media and targeted education campaigns. Peer education approaches may be a useful way of providing such information. Norr, Tlou and Matsidiso (2004) note how peer groups can provide a variety of benefits such as social support, detailed information, allow the development of new norms and values that support HIV prevention and increased self-efficacy through role modelling which can in turn encourage behavioural change.

The NICE (2011) guidelines on increasing HIV testing in black African communities in the UK note that community engagement and involvement is key in order to plan and deliver methods to increase the uptake of testing. The implementation of peer educational approaches would likely require working with existing community groups and projects as individuals may avoid new groups

specifically linked to HIV due to fear of discrimination. This would involve the challenge of identifying and working collaboratively with important stakeholders within the community (Melkote et al., 2014).

While increasing individual's understanding of HIV risk could be important in terms of encouraging the consideration of testing, the preference not to know one's HIV status and ambivalence felt about testing is equally important to tackle. Stigma and discrimination is still very much a reality for those living with HIV. It is important that efforts to tackle it are continued, especially in populations such as sub-Saharan Africans. Community mobilisation is a process whereby local individuals, groups or organisations work to identify needs, make plans to meet them and carry them out. It has been recognised as a potentially useful way to tackle HIV-related stigma and has been implemented in various countries (e.g. Apinundecha et al., 2007). Community mobilisation can be a way for individuals, groups or communities who are affected by HIV-related stigma and discrimination to be empowered to make decisions about what interventions are needed to tackle it and by doing so are using their power to resist and respond to stigma and discrimination (Parker & Aggleton, 2003). Parker and Aggleton (2003) argue that creating a social climate of equality where stigma and discrimination will not be tolerated, through community mobilisation, is key to tackling the existence of stigma. Again, engaging and working with African communities and in particular, community leaders would be essential to implement such approaches.

If SSA individuals perceive risk of HIV but fear the consequences of being positive or are ambivalent about testing, they may be avoiding HIV-testing. This poses a challenge for intervening at an individual level. However these individuals are likely to be accessing health-care services such as their general practitioner or hospital departments such as antenatal, outpatients or accident and emergency.

While it is important that health-professionals ensure that they offer HIV-testing to individuals according to the BHIVA (2008) guidelines, there may be the need and opportunity to offer short, structured psychological interventions to encourage the uptake of testing. These could provide psychoeducation on HIV risk and symptomatology and would need to address psychological barriers such as those highlighted in the current study (e.g. fears about being able to cope with knowing one is HIV-positive). An intervention that may be of use is motivational interviewing (MI) (Miller, 1983) which helps individuals resolve ambivalence and move ahead with change (Miller & Rollnick, 2004). This is a non-judgemental and non-confrontational approach which supports patients to think about and express the negative and positives of their behaviour which in this case would be not testing (Resnicow et al., 2002). The therapist helps the individual to think about how their behaviour may conflict with their values or life and health goals. As part of this they would address discrepancies in the individuals' knowledge, beliefs or behaviours but without giving advice or eliciting defensive responses. Information is presented neutrally so that individual can interpret it and evaluate their own pros and cons of changing (Resnicow et al., 2002). Indeed some of the participants wanted certainty because of life values and goals such as wanting to have care in place for their children or being able to make a will. The hope for treatment and continued life that some participants had was important as it meant that they would be alive for their children. This helped them to test. Some of the fears that participants had such as being discriminated or relationships changing may indeed be a reality for some. Therefore using interventions such as cognitive-behavioural therapy (CBT), which aim to restructure dysfunctional beliefs, may not be appropriate in moving people towards change. However CBT may be able to provide individuals with coping skills post-diagnosis if these fears do become a reality and have a negative impact on their psychological wellbeing.

It is not known whether MI could be facilitated when promoting HIV-testing in large groups of people as this is usually provided as a 'real-time', face-to-face intervention (Resnicow et al., 2002). Therefore larger-scale interventions for increasing prompt uptake of testing in those who perceive risk may need to focus on promoting the factors that helped participants to decide to test (e.g., the psychological and medical benefit of knowing one's status). These are likely to address some of the factors that were linked to participants not wanting to know their status (e.g., fear of dying and being able to tolerate knowing). The question is how best to do this. There has been extensive research on message framing (Rothman & Salovey, 1997) - that is whether advocating the benefits of a behaviour (gain-framed) or the costs of a behaviour (loss-framed) maximises the persuasive impact of a health message. This research has grown out of Prospect Theory (Tversky & Kahneman, 1981) which proposed that people are fundamentally risk averse. Moreover, when risks are certain, gain-framed messages are likely to be more effective and for uncertain risks, loss-framed messages are more effective. Rothman and Salovey (1997) made a distinction between detection and prevention health-behaviours proposing that the former is more likely to involve the risk of an unpleasant outcome (e.g. finding a health problem) and therefore loss-framed messages will be more effective. The latter is more likely to be perceived as a safe behaviour and therefore gain-framed messages are more likely to be effective. In the context of perceiving HIV testing as a risk as participants were uncertain of the outcome, findings do not support this proposition with loss framed messages being found to be equally as effective as gain framed messages (Apanovitch et al., 2003). Rothman et al. (2006) suggest that risk should be conceptualised as the extent to which the behaviour will have an unpleasant outcome. For example some individuals may engage in detection behaviours such as testing as a health-affirming act (Rothman et al. 2006). Indeed some participants in the current sample had hope of

being negative which helped them to test. Others who were uncertain eventually wanted to know their status despite anticipating that it could be positive. Clearly more research is needed to unravel the complexities of whether loss or gain framed messages are more effective in promoting HIV testing in the sub-Saharan African population, taking in to consideration the issues of perceived risk for HIV and beliefs about the consequences of testing. However it is important that large-scale interventions to increase testing must stress either the gains of testing or the losses of not testing. These may take the form of mass media campaigns or peer education. This may focus on the achievement of (if they test) or missing out on (if they do not test) the psychological benefit of knowing one's status (whether it is positive or negative) rather being stuck in a state of uncertainty. Alongside this, there needs to be the reassurance that even if one is positive, they will be able to receive free medication which is a) more effective when individuals are diagnosed as early as possible and b) allows individuals to live a normal healthy life. It should also highlight that they will be able to access psychological support for help around adjustment to and management of their illness.

Personal reflections

Engaging in this research process brought with it the challenge of adding the new role of researcher, on top of trainee clinical psychologist, while acknowledging that the latter would influence the former, along with my own social and cultural background. During the interview process, I had to manage my inclination to engage in a therapeutic style which can be somewhat interpretative when trying to understand relevant unconscious psychological processes in someone's experiences. At times I felt sadness and empathy because of their difficult experiences but also admiration because of their resilience. It was difficult at times to be a researcher with the agenda of exploring a particular experience in a time-limited

meeting where some emotions were still raw. Some of these participants spoke a lot about their experiences post-diagnosis. Clearly these were experiences that were important to them but given that many of them had limited time for the interview, there was a pressure to ask participants questions about the period of delayed testing as this was the research aim.

Throughout this process I reflected on similarities and differences between the participants and myself and the impact these had on the data collection and analysis process. I reflected on the fact that I am a white, middle-class female who had grown up in the UK interviewing a group of black, sub-Saharan African men and women, some of whom had experienced traumatic experiences, aside from having been diagnosed with a chronic, highly stigmatised condition. I was wondering how participants felt about sharing their experiences with me. The first participant had spoken about her fears about being judged by white health-care professionals as a black-African and I initially wondered if ethnicity may be a barrier to participants sharing experiences in the context of having a highly stigmatised disease. I also wondered whether the participants thought about my HIV status and my ability to understand their experiences. Dwyer and Buckle (2009) explain that a benefit of being a member of the group you are studying is acceptance and a level of trust that you might not otherwise experience. Despite the participants not knowing my HIV status, I found them to be very open and indeed enthusiastic to take part in the research. There are also arguments against being an 'insider' (being a member of the group you are studying) with objectivity being questioned (Kanuha, 2000). I had my own assumptions at the beginning of the research and I reflected on their potential impact on it using my research diary. However being an 'outsider' and not having a great knowledge of HIV and its related issues prior to the research process meant that I was very open to any possibilities when collecting and analysing data.

When participants spoke about their preference not to know, I connected with this experience in terms of my experiences of having a chronic inflammatory bowel disease for which I had delayed seeking medical help and treatment. I made sure to reflect on this using my reflective diary and supervision, to reflect on the impact this could have on my interpretation of the data, to minimise this. However I reflected on the fact that my medical condition was not highly stigmatised and despite it causing potentially embarrassing symptoms, I felt able to talk to friends and family about my worries during the pre and post diagnosis phases whereas for most of these participants, it was a very private process.

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Appendix A: List of sub-Saharan African countries (United Nations Statistics Division, 2013)

Eastern Africa

Burundi	Mozambique
Comoros	Réunion
Djibouti	Rwanda
Eritrea	Seychelles
Ethiopia	Somalia
Kenya	South Sudan
Madagascar	Uganda
Malawi	United Republic of Tanzania
Mauritius	Zambia
Mayotte	Zimbabwe

Middle Africa

Angola
Cameroon
Central African Republic
Chad
Congo
Democratic Republic of the Congo
Equatorial Guinea
Gabon
Sao Tome and Principe

Northern Africa

Sudan

Southern Africa

Botswana
Lesotho
Namibia
South Africa
Swaziland

Western Africa

Benin	Mali
Burkina Faso	Mauritania
Cabo Verde	Niger
Cote d'Ivoire	Nigeria
Gambia	Saint Helena
Ghana	Senegal
Guinea	Sierra Leone
Guinea-Bissau	Togo
Liberia	

Appendix B: Letter from ethical approval from NHS Research Ethics Committee (REC)



NRES Committee London - Central
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 797 22560

29 August 2013

Miss Jessica Howells
University of London, Royal Holloway
Egham
Surrey
TW200EX

Dear Miss Howells

Study title: Delayed HIV testing in HIV-positive sub-Saharan Africans.
REC reference: 13/LO/1092
IRAS project ID: 129814

Thank you for your letter of 19 August 29, 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Julie Kidd nrescommittee.london-central@nhs.net

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of insurance or indemnity		01 August 2012
Investigator CV		27 June 2013
Other: Dr Stuart Gibson		03 July 2013
Other: Dr Michael Evangeli		03 July 2013
Other: Interview schedule	2	16 May 2013
Other: Screening Sheet	1	22 June 2013
Other: Participant further information sheet	1	24 June 2013
Other: Opt-In Slip		
Other: Demographic Information Questionnaire	3	08 August 2013
Participant Consent Form	3	08 August 2013
Participant Information Sheet	3	08 August 2013
Protocol	5	08 August 2013

REC application		26 June 2013
Referees or other scientific critique report		13 May 2013
Response to Request for Further Information		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at [National Research Ethics Service website > After Review](#)

13/LO/1092	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



pp

Dr Andrew Hilson
Chair

Email: nrescommittee.london-central@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Appendix C: Email of ethical approval from Royal Holloway University of London (RHUL) Departmental Ethics Committee (DEC)

Ref: 2013/077R1 Ethics Form Approved

 DELETE  REPLY  REPLY ALL  FORWARD 
mark as unread



Psychology-Webmaster@rhul.ac.uk
Fri 15/11/2013 10:48

To: nwjt084@rhul.ac.uk; Evangelii, Michael;
Cc: PSY-EthicsAdmin@rhul.ac.uk; Leman, Patrick; Lock, Annette;

Application Details: View the form click [here](#) Revise the form click [here](#)

Applicant Name: **Jess Howells**

Application title: **Delayed HIV testing in HIV-positive sub-Saharan Africans.**

Appendix D: Letter of approval from Research and Development (R&D)

FINAL R&D APPROVAL

18 October 2013

Dr Stuart Gibson

Dear Dr. Gibson,

Protocol: Delayed HIV testing in HIV-positive Sub-Saharan Africans

ReDA Ref: 009223

REC Ref: 13/LO/1092

I am pleased to inform you that the Joint Research Management Office for Barts Health NHS Trust and Queen Mary University of London has approved the above referenced study and in so doing has ensured that there is appropriate indemnity cover against any negligence that may occur during the course of your project. Approved study documents are as follows:

Type	Version	Date
REC approval		29.08.2013
REC approval	Amendment 1 (cond. met)	18.10.2013
Protocol	v.6	14.08.2013
Participant Information Sheet	v.4	14.08.2013
Participant Screening Sheet	v.2	14.08.2013
Interview Schedule	v.2	16.05.2013
Demographic Information Questionnaire	v.3	08.08.2013
Participant Consent Form	v.3	08.08.2013
Participant Information Sheet	v.1	24.06.2013

Please note that all research within the NHS is subject to the Research Governance Framework for Health and Social Care, 2005. If you are unfamiliar with the standards contained in this document, or policies that reinforce them, you can obtain details from the Joint Research Management Office or go to:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

You must stay in touch with the Joint Research Management Office during the course of the research project, in particular:

- If there is a change of Principal Investigator
- When the project finishes
- If amendments are made, whether substantial or non-substantial

This is necessary to ensure that your R&D Approval and indemnity cover remain valid. Should any

Serious Adverse Events (SAEs) or untoward events occur it is **essential** that you inform the Sponsor within 24 hours. If patients or staff are involved in an incident, you should also follow the Trust Adverse Incident reporting procedure or contact the Risk Management Unit on

We wish you all the best with your research, and if you need any help or assistance during its course, please do not hesitate to contact the Office.

Yours sincerely

search Resources

Copy to: Sponsor – Royal Holloway, University of London
CI – J. Howells

Appendix E: Letter of approval of ethics amendment from NHS REC



NRES Committee London - Central

Skipton House
80 London Road
London
SE1 6LH

Tel:

Fax:

08 October 2013

Miss Jessica Howells
University of London, Royal Holloway
Egham
Surrey
TW200EX

Dear Miss Howells

Study title: Delayed HIV testing in HIV-positive sub-Saharan Africans.
REC reference: 13/LO/1092
Amendment number: Substantial Amendment 1- Participant Screening Sheet
Amendment date: 04 September 2013
IRAS project ID: 129814

The above amendment was reviewed at the meeting of the Sub-Committee held on 08 October 2013.

Ethical opinion

No ethical issues.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Screening Sheet	2	14 August 2013
Screening Sheet	2	14 August 2013
Participant Information Sheet	4	14 August 2013
Protocol	6	14 August 2013
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1- Participant Screening Sheet	04 September 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

Appendix F: Letter of ethical approval of second ethics amendment from NHS REC



NRES Committee London - Central

Skipton House
80 London Road
London
SE1 6LH

Tel:
Fax:

23 January 2014

Miss Jessica Howells
University of London, Royal Holloway
Egham
Surrey
TW200EX

Dear Miss Howells

Study title: Delayed HIV testing in HIV-positive sub-Saharan Africans.
REC reference: 13/LO/1092
Amendment number: 2
Amendment date: 10 January 2014
IRAS project ID: 129814

The above amendment was reviewed at the meeting of the Sub-Committee held on 21 January 2014

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	7	10 January 2014
Covering Letter	email from J Howell	14 January 2014
Participant Information Sheet	5	10 January 2014
Notice of Substantial Amendment (non-CTIMPs)	2	10 January 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/LO/1092:	Please quote this number on all correspondence
-------------	--

Yours sincerely



**Dr Andrew Hilson
Chair**

Enclosures: List of names and professions of members who took part in the review

Appendix G: Email of approval of first and second ethics amendment from RHUL DEC

Ref: 2013/077R1 Ethics Form Approved

 DELETE  REPLY  REPLY ALL  FORWARD 



Psychology-Webmaster@rhul.ac.uk

Tue 10/12/2013 10:32

mark as unread

To: nwjt084@rhul.ac.uk; Evangeli, Michael;
Cc: PSY-EthicsAdmin@rhul.ac.uk; Leman, Patrick; Lock, Annette;

Application Details: View the form click [here](#) Revise the form click [here](#)

Applicant Name: **Jess Howells**

Application title: **Delayed HIV testing in HIV-positive sub-Saharan Africans.**

Ref: 2014/077R3 Ethics Form Approved

 DELETE  REPLY  REPLY ALL  FORWARD 



Psychology-Webmaster@rhul.ac.uk

Thu 23/01/2014 19:01

mark as unread

To: nwjt084@rhul.ac.uk; Evangeli, Michael;
Cc: PSY-EthicsAdmin@rhul.ac.uk; Leman, Patrick; Lock, Annette;

Application Details: View the form click [here](#) Revise the form click [here](#)

Applicant Name: **Jess Howells**

Application title: **Delayed HIV testing in HIV-positive sub-Saharan Africans.**

PARTICIPANT INFORMATION SHEET, Version 5 [10.01.14]

Study title: Delayed HIV testing in HIV-positive sub-Saharan Africans.

Invitation to participate in the study

We would like to invite you to take part in a research study. Before you decide whether you would like to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. If you would like to ask any questions, have more information on the study or if something is not clear, please contact me using the contact details at the end of this sheet.

What is the purpose of this study?

The main aim of the study is to understand the psychological factors (such as thoughts, feelings and behaviour) that sub-Saharan African individuals experience while delaying a HIV test. Delaying a HIV test is when an individual perceives some risk of HIV infection but does not take a HIV test immediately (within one week of perceiving risk). It aims to explore and understand how these psychological factors change over time before someone decides to take an HIV test.

Who is organising and conducting the research?

The research is being overseen by Dr Stuart Gibson, Lead Clinical Psychologist and Dr Michael Evangelii, who is a Clinical Psychologist and Senior Lecturer at Royal Holloway University of London. The study is being carried out by Jessica Howells who is a Trainee Clinical Psychologist at Royal Holloway, University of London.

Why have I been invited to take part?

We would like to speak to people of sub-Saharan African origin with HIV who delayed their HIV test (i.e. perceived some risk of HIV before their diagnosis but did not take a HIV test within one week of perceiving some risk of HIV). The HIV diagnosis needs to have been made since 1996 but not within the last 3 months. This is so we can better understand the difficulties that people may experience when they think they may have HIV, that then causes them to delay taking a test immediately.

Do I have to take part?

No. Taking part in this study is entirely your decision and will not affect the care that you receive from the NHS as it is separate from this. If you decide that you would like to take part, you will be asked to sign a consent form to show you have agreed to be involved and you will be given a copy of this. We will also ask for your consent for the researcher (Jessica Howells) to access your medical records so we can obtain information such as CD4 cell count at diagnosis etc if you are unable to provide this information at the interview. You can change your mind about taking part in the study at any time and stop participating in the study. You do not need to give us a reason for this. This would not in any way affect any care that you receive.

What will happen to me if I take part?

If you decide that you would like to take part, you will need to meet on one occasion for approximately 60 to 90 minutes with the researcher (Jessica Howells). The length of the interview will vary depending on how much you wish to say. The interview will take place at the XXXXXX Unit at a time that suits you and the researcher. The interview can be arranged to take place before or after a routine appointment that

you may have at the XXXXXX Unit to save on travel. However, if this is not possible, out of pocket travel expenses will be covered.

At the meeting, you will be given the opportunity to ask any further questions and will need to complete the consent form. Then you will be asked to fill in a brief form about some background information about you if we were unable to get this from your medical records (e.g. country of birth, relationship status, religious beliefs) and your HIV diagnosis (e.g. where this was made). Then an interview will take place, in which you will be asked questions about your experience of deciding to take a HIV test from the point at which you first perceived some risk of HIV until the time that you tested for HIV. There are no right and wrong answers, and you are free to not answer any question you do not feel happy to answer. With your consent, the interview will be audio recorded. The recording is used to help the researcher remember what has been said, so that nothing is missed, and will be destroyed after the research is finished. Some of your comments may be directly quoted when the research is written up for a doctorate thesis or journal article; however, each comment will be completely anonymised such that it will not be identified as coming from you. You can choose on the consent form if you would like to be sent a summary of the results of the study. This will be when the study has finished in August 2014.

Will what I talk about be kept confidential?

What you talk about in your interview is private and will be kept confidential. However there may be some instances where the researcher, Jessica Howells, might need to discuss an issue or concern with your clinical team in accordance with NHS protocol. A discussion might take place if:

- There are concerns for your safety and well-being
- You say that you are having unprotected sex with someone who is not aware that you have HIV
- A sexual partner needs to be traced so that they can receive medication to reduce the chance that they become HIV positive (for example if the unprotected sex took place in the last 72 hours and you tell us who the partner is)

If the researcher felt that additional support would be beneficial, this would be discussed with you and the researcher would help facilitate a referral to the Psychology service at the XXXXXX Unit. The researcher would always try to discuss these concerns with you first, before doing anything.

Expenses and payments

Taking part is voluntary and you will be paid £10 for participating. You will be reimbursed for travel expenses related to attending the unit for an interview at a time that does not coincide with a scheduled routine appointment.

What are the possible risks and benefits of taking part?

Risks:

There are no direct risks from taking part in this study, although some people may become upset when talking about experiences that were difficult for them. However this is understandable when talking about difficult times and experiences. However you do not have to say anything that you do not want to. If you become distressed at any time, you can decide to take a break or stop the interview altogether. If this was the case you could continue the interview at another time or withdraw from the study completely. The researcher, Jess, is a trainee clinical psychologist and has

experience in talking to people about sensitive issues from her experience of working in the NHS. She will give you some time at the end of the interview to compose yourself before you leave, if needed. If you feel you need to speak to someone after the meeting, suggestions will be made to help you with this. The researcher will discuss whether a referral to see someone from the psychology team at the XXXXX Unit would be helpful.

Benefits:

We cannot promise the study will help you directly but it is hoped that by taking part in this research, you will be providing valuable information regarding your experience of deciding to take a HIV test when perceiving some risk of HIV. People often find taking part in research is an interesting and useful experience as they can get their experiences 'heard'. Finding out about your experiences would be very beneficial and important because if we can understand the difficulties that meant you delayed your HIV test, it may help us to find ways to help others with these difficulties so that they do not delay their HIV test. This is important because of the health implications of delaying a HIV test.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to either Jessica Howells (researcher) or Dr. Stuart Gibson (Clinical Psychologist) who will do their best to answer your questions [contact details provided at the end of this information sheet]. If you remain unhappy and wish to complain formally, you can do this. You can contact the XXXX Health Patient Advice and Liaison Service (PALS) via telephone on xxxxxxx or via email on pals@xxxxxxxxxxxxxx.nhs.uk.

Will my taking part in this study be kept confidential?

All the information collected is kept strictly confidential in accordance with the Data Protection Act (1998). All of the data (e.g. questionnaires, audio recordings, transcribed interviews) during the study will be anonymised and identifiable only by a number, not by your name. All data used in any future publications, including the use of participant quotes, will also be anonymous with no identifying details included in any publication of this research. Any information collected in this study will be stored on a secured network drive that is encrypted. On completion of transcription, the audio recordings will be deleted.

What will happen to the results of the research study?

The results of the study will be written up as part of a Doctorate degree in Clinical Psychology. Anonymised quotes from your interview may be used in the final report to help explain the key findings. The research may also be published in a journal or presented at a scientific conference. You will not be able to be identified in any of these. You will be able to get a summary of the findings from the staff at the XXXXXXXXXXXX Unit if you wish to see these.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people to protect your safety, rights, wellbeing and dignity. This study has been approved by the Central London Local Research Ethics Committee and the Research Ethics Committee at Royal Holloway, University of London.

Contact details for further information:

Jessica Howells

Researcher, Trainee Clinical Psychologist

Email: jessica.howells.2011@live.rhul.ac.uk or Telephone: 01784 414012 (Royal Holloway University of London, Doctorate in Clinical Psychology Administration Office – ask for Jessica Howells.)

Dr Stuart Gibson

Clinical Psychologist

Email: Stuart.Gibson@XXXXXXXX.nhs.uk or Telephone: xxxxxxxxxxxxxxxx (Ask for Stuart Gibson)

If you are interested in taking part?

If the researcher is on-site today (which your clinician will have told you), you can take part in the study today. Please let the receptionist know and the researcher will meet with you. Alternatively, if you would like to take part, you can complete the opt-in slip and give this in to reception so that Jessica Howells, the researcher, can contact you. You can also contact Jessica Howells using the contact details above so she can answer any questions you may have and find out if you are interested in participating. You can leave a message with the admin staff and the researcher will get back to you.

Thank you for taking the time to read this information sheet.

Appendix I: Participant consent form

Patient Identification Number:

CONSENT FORM, Version 3 [08.08.13]

Title of Project: **Delayed HIV testing in HIV-positive sub-Saharan Africans.**

Name of Researcher: **Jessica Howells (Trainee Clinical Psychologist)**

- | | Yes | No |
|---|--------------------------|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated 08.08.13 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I understand that the data collected during the study will be looked at by the researcher and her supervisors (at xxxx Unit and Royal Holloway University of London). This will be anonymised before they see it. I give permission for these individuals to have access to the anonymous data collected during the interview. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I understand information will be stored confidentially according to the NHS code of ethics. | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I agree to the audio recording of the interview. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I agree to the use of anonymised quotes in publications. | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. If new information arises involving risk to another person that requires action, I agree that the researcher may communicate with my clinical team in accordance with NHS protocols. | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I agree for the researcher (Jessica Howells) to have access to my medical records so they can obtain information relating to my HIV diagnosis. | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I would like to be sent a summary of the results of the study when it finishes in August 2014. | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. I agree to take part in the above study. | <input type="checkbox"/> | <input type="checkbox"/> |

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

Appendix J: Participant screening sheet

SCREENING SHEET [Version 2, 14.08.13]

Title of Project: **Delayed HIV testing in HIV-positive sub-Saharan Africans.**

Name of Researcher: **Jessica Howells (Trainee Clinical Psychologist)**

You have been given this sheet as you may be eligible to participate in the study.

Many people do not take an HIV test straight away even if they think there may be a chance that they are HIV positive. The main aim of this study is to understand the psychological factors (such as thoughts, and feelings) that individuals experience if they delay taking a HIV test. Delaying a HIV test is when an individual perceives some risk of HIV infection but does not take a HIV test immediately (within one week of perceiving risk). Therefore we need to check that you meet the criteria of having delayed a HIV test as this is what we want to explore and understand. **Please answer the questions below by ticking the appropriate box.**

1) Before being diagnosed with HIV, which of these did you believe to be true:

(Please tick one)

- 0%** - Certain I would test negative
- 25%** - Thought I would probably test negative
- 50%** - Unsure if I would test positive or negative
- 75%** - Thought I would probably test positive
- 100%** - Certain I would test positive

If you ticked a square, please answer question two:

2) After thinking that there might be a possibility of being HIV positive, did you have a test immediately (within 1 week)?

Yes

No

If you ticked a **square (instead of a circle) for Questions 1 AND 2**, you are eligible to participate. Attached is a **Participant Information Sheet** which gives more information about the study. There is also information below about how to participate in the study if you are eligible to.

OPTIONS FOR PARTICIPATING

1. Your clinician will have told you if the researcher is in the clinic today. If they are and you want to participate today or just want to ask questions about the study, please let the receptionist know and they will get the researcher so you can meet.
2. If the researcher is not in the clinic and you want to find out more or to take part, you can complete the opt-in slip below and hand this in to reception or send it back in the stamped addressed envelope provided.
3. Alternatively, you can contact Jessica Howells (Researcher/ Trainee Clinical Psychologist) using the contact details below so that you can ask any questions that you may have at your convenience and potentially arrange a date and time to complete the interview.

OPT-IN SLIP- (Leave at Reception)

I would like the researcher to contact me (within the next 7 days) to answer any questions I may have about the study and to potentially arrange a date and time to complete the interview.

My contact details are: Name: _____

Telephone number (home and/or mobile): _____

Email address: _____

CONTACT DETAILS: Email: jessica.howells.2011@live.rhul.ac.uk or Telephone:

01784 414012 (Royal Holloway University of London, Doctorate in Clinical Psychology Administration Office – ask for Jessica Howells. If not available, please leave your details and I will get back to you.)

Appendix K: Participant demographic information sheet

**Study Title: Delayed HIV testing in HIV-positive sub-Saharan Africans.
Demographic Information Questionnaire, Version 3 [08.08.13]**

Participant ID Number:	
Gender:	Male _____ Female _____
D.O.B:	
Country of Birth:	
Relationship status- Are you currently:	Married/ Civil partnership (partner living abroad) _____ Married/ Civil partnership _____ Widowed/separated/ divorced _____ Living with partner _____ In a relationship (not living together) _____ Single _____

Date of when you first became aware of HIV risk:	
Date of HIV diagnosis:	
Diagnosis setting:	Sexual health/GUM/HIV clinic _____ At your GP _____ In hospital (on a ward) _____ During routine medical tests (e.g. pregnancy) _____ At Accident and Emergency (A+E) _____ Other: _____ (Please provide details)
CD4 count at diagnosis:	
Number of HIV tests taken before positive diagnosis:	

Appendix L: Excerpts from researcher's reflective diary

20.11.13

....Also, as part of being aware of my interactive role with the data and to minimise undue influence of my assumptions on the analysis, it is important for me to outline my prior assumptions about the experiences of these individuals.

When reading the literature on barriers to testing, I have been able to connect to this idea of not wanting to know if something is wrong or what is wrong and I imagine that this is something that will come up with my participants. I remember when I first had symptoms of my inflammatory bowel disease, which at the time I didn't know was Crohn's Disease. I hoped that they would go away and when they didn't, I tried to rationalise and explain them. However, there was a part of me that knew that something wasn't right. The 'not-knowing' is difficult as deep down, I was in a constant state of worry and I knew that something was not right with my body. But actually being told this was the case and having confirmation of this was just terrifying. And more terrifying than being in a limbo almost- especially had I had thoughts that maybe it was cancer when they found a lump in my abdomen. And cancer means death and I'm so young and so on. All sorts of catastrophic thoughts. I guess this what I would call denial as a coping mechanism. If you don't know then it's not real. Looking back, I am able to say- why didn't I just go and get help? Of course it makes sense to see a doctor as soon as possible. But obviously at the time it didn't. I guess that shows just how scary it felt to be told that you had something wrong with you. I imagine that most people may know, intellectually, as I did that the sooner you treat something, the better. But the hope that it will go away and the denial that it is anything serious almost overrules any rationality of seeking any help. I just thought I'll wait a little longer and see if it goes away. If you suspect having HIV, I anticipate that having ideas about HIV meaning certain death for example could definitely put them off testing. Because of the history of the disease, people do think about death and suffering. To know (or think) this is your future must be terrifying....

17.12.13

I met with my academic supervisor today to review my interviewing style after interviewing my first participant. One important thing that he picked up on was that I could have got the participant to reflect on emotions a bit more at various points rather than moving on to another question. I can see that I could have done more of this. He also picked up on trying to clarify with participants when things happened along the time line from perceived risk to testing. I also could have clarified some incidents for the first participant such as when she spoke to her friend about getting a HIV test. Did she initiate the conversation or did her friend? Small details like this are important when trying to understand how individuals who delay testing eventually decide to take a test. He was pleased with the summarising that I did throughout the interview and it seems doing this will ensure that I have understood what the participant is telling me.

25.02.14

After interviewing participant 4 today, I have realised that the interview schedule is really geared towards asking people's thoughts about testing. Whereas what is coming up is that sometimes, people aren't necessarily considering testing and some people even stop worrying about HIV despite feeling really concerned about it initially. The participating have spoken about having doubt about HIV which means that at some points, they dismiss HIV completely. Therefore I think I need to further

explore the shifts and changes in peoples risk perception of HIV as this is something that has come up in all 4 interviews so far. Perhaps when people are thinking more that they may have HIV, asking about thoughts/feeling about testing may be more relevant then.

10.03.14

I have just interviewed participant 6. As this process has gone on, I have become more aware of the interactive role between me and the research. As the interviews have gone on, I have picked up on reoccurring themes which are coming up across interviews and it has been important to explore these further while remaining open to new ideas. I feel like my developing theoretical sensitivity has allowed my interviewing style to become more fluid and I am exploring things in more detail which I failed to do in earlier interviews. There is the balance however between developing theoretical sensitivity and not forcing the data. I am keeping in mind to not ask misleading questions so that I am not forcing the data.

25.03.14

What has been coming up in the analysis is that some people have a desire not to think or believe that they could HIV. It seems like although they may have also had genuine doubt, they were able to reflect that there was a part of them that just didn't want to believe they could have HIV and this influenced the doubt that they had. This also seems to be linked to the 'preferring not to know' that is coming up in the interviews also- that they don't want to believe they could have HIV because they are so scared of what it would mean to be HIV positive.. After transcribing interview 8 today, I can really see in my comments/answers how I was reflecting with the participant on how it made sense for her to not want to think about HIV. She had a terrible and traumatic experience in Africa which led her to first consider HIV but this was a time where there was no access to HIV testing or medication. I was trying to explore with the participant if for her, not worrying about HIV was a conscious process, which she felt it was at times. But it felt important for this not to feel blaming for the participant. Many of the participants have described feeling foolish or ignorant when they reflect back on their experiences, after they have been diagnosed as HIV positive. It is understandably difficult for people to look back, perhaps with some regret about what they did or didn't do about their worries about HIV. But in this interview, given the participants really terrible experiences, I noticed in the transcription that I was really empathising with her due to her difficult experiences and reflecting on the fact that her responses made sense for her at that time because of the position she was in. I think that she was also trying to get this across to me while also having some regret about her actions perhaps.

Appendix M: Final interview schedule

Interview schedule

How are you today?

I'd like you to take your mind back to the time when you first thought that there was a chance that you might have HIV.

1. When did you first think that there was a chance that you may have HIV?

PROMPT: What was happening in your life at that time? Can you say what exactly led you to think you might have HIV? Relationship status at that time?

2. What happened after you thought that you might have HIV?

PROMPTS: What did you do? What thoughts/images went through your mind? How did you feel?

3. How did you feel about taking a HIV test at that time?

PROMPTS: What did you know about HIV, HIV testing, HIV transmission? What did you know about accessing a HIV test? What did you think other people's views about testing were?

4. What did you think might happen after taking a HIV test?

PROMPTS: How did you think a diagnosis may impact on your life? What did you think might need to happen in terms of medical care? How confident did you feel about being able to deal with an HIV positive diagnosis?

5. What do you think stopped you from taking a HIV test immediately?

6. How did things such as your thoughts and feelings about taking a HIV test change from when you first thought that you might have HIV up until the test that resulted in the HIV positive diagnosis?

7. Why do you think your thoughts and feelings about taking a test changed?

PROMPTS: What happened around that time? Relationships/ talking from others/info that you came across/being ill

8. Who or what was helpful when making the decision to take the test that resulted in the HIV positive diagnosis?

What was unhelpful in the process?

9. What led you to first consider having a HIV test?

PROMPTS: What thoughts did you have? What feelings did you experience

at this time?

10. How did you feel when you decided to take a HIV test?

PROMPT: how did you decide to have a test? How did you feel beforehand?
What was it like having the test?

11. What was it like taking the test? How did you feel when you were eventually diagnosed with HIV?

12. What, if anything, did you learn from your experiences?

13. Looking back on these experiences, what would have been helpful to know or have?

14. Is there anything else related to your experience of testing that we have

Appendix N: Example initial coded interview transcript

Participant 6	Initial coding	Thoughts for memo
<p><i>I: Good. Okay, so as I said, what I'd like to do is just take your mind back to 1998. You said that was the point when you first starting thinking that HIV was a possibility. Can you tell me a bit about what was going on for you at that time?</i></p>		
<p>2. Um, I had come in to this country and I thought initially I had some funny skin rashes.</p>	<p>Having unusual skin rashes</p>	
<p>3. Actually my skin became, it was like eh, bloated skin with dark patches and um, I having like, fungal infections which were very unusual.</p>	<p>Having unusual symptoms and infections</p>	<p>It seems that it was the unusual aspect of the symptoms is what worried her</p>
<p>4. And um...that's the time when I really got worried.</p>	<p>Becoming worried about symptoms</p>	
<p>5. And I went to my GP and eh, he said my uh, my protein levels were very high. He just said your protein levels are very high.</p>	<p>Being told by GP protein levels are high</p>	
<p>6. And uh, he said uh, I could um, it could be due, maybe you could be having myeloma or something.</p>	<p>GP suggesting she could have cancer</p>	<p>Researching/finding out more information isn't something that has come up in other</p>
<p>7. So I just went through all these investigations for myeloma, Bennis-Jones syndrome, urine protein, all sorts of things.</p>	<p>Having investigations done</p>	<p>interviews- only 1 person asked the advice of others about symptoms</p>
<p>8. And I went to read about it myself to say why would your protein be raised.</p>	<p>Researching why she was ill</p>	

<p>9. And the point, it was either cancer or HIV.</p> <p>10. So that's when I started thinking, this could really be HIV.</p> <p>11. But then I didn't want to think about it in that way because I was hearing stories about insurance, that maybe if the insurance people knew that I was HIV, they would um, not give me like insurances.</p> <p>12. And then there comes a time when you are well and you just forget about it, you think oh, maybe it was just my mind.</p> <p>13. I was just um... uh confusing myself.</p> <p>14. So there was a time when I was okay and nothing happened.</p> <p>15. But each time I had an illness or some fever or something, and then I would think again about, it could be this.</p> <p>16. But I never wanted to hear the word HIV.</p> <p>17. And because I'd nursed so many people in Zimbabwe who had died and the knowledge of being HIV, once they didn't know that they were HIV, they were okay but the moment that they were given the diagnosis, they would just go so down y'know...deteriorate so quickly and the next minute you hear that they are dead.</p> <p>18. But then there wasn't medication then.</p>	<p>Finding that symptoms could be HIV</p> <p>Thinking symptoms could be due to HIV</p> <p>Not wanting to think that symptoms could be HIV because of impact on insurance</p> <p>No longer worrying about HIV when well again</p> <p>Believing she was confusing herself</p> <p>No longer worrying about HIV when well</p> <p>Thinking that symptoms could be due to HIV</p> <p>Not wanting to think it could be HIV</p> <p>Seeing people deteriorate quickly and die after being diagnosed with HIV</p> <p>Medication not being available</p>	<p>After researching her symptoms, she thought she could have HIV but she really did not want to believe it. She was worried about the impact of a HIV diagnosis on her home insurance.</p> <p>Line 11- It seems like this wish to not believe that she had HIV meant that she almost talked herself out of thinking it could be HIV to the point where she stopped worrying completely.</p> <p>Line 15- Here she is feeling uncertain again when her symptoms returned.</p> <p>It seems that seeing others deteriorate when they were diagnosed when working as a nurse was a great source of fear.</p>
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<p>19. But as I said, I kept on thinking that maybe it was just my mind and being a nurse you diagnosis yourself a thousand times a day.</p> <p>20. And you think I've got this and I've got that but then at the end of the day, you think maybe it's nothing.</p> <p>21. I was well, there wasn't anything to...it's only when I got really unwell in 2012 that um, that maybe I should have had it earlier.</p> <p><i>I: Okay, so you went to your GP initially and they suggested some things. And you said you did your own sort of research and you thought it could be cancer or HIV. But you didn't ever bring that up to your GP?</i></p> <p>22. I didn't bring it up to my GP.</p> <p>23. Uh, I was more concerned about cancer than HIV.</p> <p>24. And when he said oh some people have just naturally got a high protein levels in their blood and that...it just sort of um and I was well, I wasn't having any problems, I just though ah, maybe.</p> <p>25. It sort of, it sort of um...the proteins sort of like came down and I just was thinking that maybe if it was HIV, it wouldn't have gone down now that it's gone down.</p> <p>26. I should not worry about it at all.</p>	<p>Reassuring self that symptoms were not due to HIV</p> <p>Believing that symptoms are probably nothing serious</p> <p>Doubting HIV as she was not unwell</p> <p>Not mentioning concerns to GP</p> <p>Being more concerning about cancer</p> <p>Doubting HIV due to GP's explanation</p> <p>Doubting that proteins would reduce if it was HIV</p> <p>Deciding she should not worry about HIV</p>	<p>Line 22- Perhaps this is 'denial'- not bringing it up because she is so scared of what it would mean to have HIV.</p> <p>She gets an non-HIV explanation for her symptom and this reassures her and thus makes her doubt HIV.</p> <p>Line 25- Here she is doubting that her symptoms are due to HIV due to her evaluation of them which then results in her not worrying about HIV.</p> <p>Line 27- Again, it seems like this doubt is actually driven by this wish for things to be okay and for her not to have HIV</p>
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<p>27. So you know at times you want to assure yourself that there's nothing wrong and you want very much for things to be right, that's how I was feeling.</p> <p><i>I: Yeah. And you said that, those symptoms would go away and then...</i></p> <p>28. I would forget about it and live life normally.</p> <p>29. But then if I became a bit unwell, it would be in, at the back of my mind, it would think, could it be, could it not?</p> <p>30. And that's the worst thing that you go through.</p> <p>31. And then you see other patients that uh, being a nurse, I would see patients with HIV being very unwell.</p> <p>32. And then I would say, I don't get that unwell so I should be okay.</p> <p>33. But I was just assuring myself that I should be okay.</p> <p>34. But uh, obviously I wasn't, I wasn't okay.</p> <p><i>I: Okay, and you said that you'd seen people deteriorate, when you when you back in Africa., when they knew they had HIVis that something you were afraid of happening to you?</i></p> <p>35. I was afraid of that happening to me, that uh, maybe the knowledge of um, me being HIV, maybe it would just strike me so hard that it would affect me, I would deteriorate.</p>	<p>Reassuring self that things are okay</p> <p>Wanting things to be okay</p> <p>Forgetting worries about HIV</p> <p>Feeling undecided about HIV</p> <p>Feeling unsure was difficult</p> <p>Seeing people with HIV being very unwell</p> <p>Doubting HIV when comparing herself to patients with HIV</p> <p>Reassuring herself that she is okay</p> <p>Reflecting that she was not okay</p> <p>Fearing that knowing would cause her to deteriorate</p>	<p>Line 29- Again, the uncertainty would come back when she became ill again but she was not sure either way if it was or was not HIV</p> <p>Line 35- This has come up in other interviews- that knowing would be intolerable. But for this participant, there was a fear that knowing would impact on her physically</p>
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<p><i>I: And when you say the fear of the unknown, what do you mean by that?</i></p> <p>46. Not knowing what I would have, what could have happened if I'd been told without me being sick.</p> <p>47. Because right now I had no choice, when I was diagnosed in 2012, I didn't have much choice but I was very very unwell.</p> <p>48. But if I had just been told when I walking like maybe being well and somehow I got a blood test and it came, it would maybe have affected me in a different way than it affected me now.</p> <p>49. Because I was already, very unwell and I was prepared for anything because anything could have happened.</p> <p>50. I was unconscious for a long time, I lost my memory, everything was so bad.</p> <p>51. My children were called to come and say their goodbyes to me because I was that bad so I didn't have a choice as it were.</p> <p><i>I: So the symptoms that made you think it could be HIV would go away, and you'd think...</i></p> <p>52. I'm just like any other person, people get colds, people get headaches and all that.</p>	<p>Worrying about what would happen if diagnosed when not unwell</p> <p>Feeling that she had no choice about knowing her status</p> <p>Fears that knowing would affect her differently if she knew when not unwell</p> <p>Being prepared for any result</p> <p>Being extremely unwell when in hospital</p> <p>Feeling that she didn't have a choice as she was so unwell</p> <p>Believing that symptoms were normal</p>	<p>Line 48/49- This is interesting- that she was worried that knowing she was HIV positive when she wasn't unwell would affected her more than when she was ill. This has to do with being prepared and is perhaps why it seems that other participants have described a process of preparing themselves for a positive result. She feared finding out without being able to do this. Whereas when she did find out, she was really unwell and prepared for any outcome.</p> <p>Line 52- The symptoms going away made her feel that they</p>
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<p>54. And then you, you know you would just try to assure yourself, I think I should be okay yeah.</p> <p><i>I: But you said, that when the symptoms did come back, you were then thinking maybe it is HIV?</i></p> <p>55. Hmm-hmm.</p> <p><i>I: And how did it feel to be thinking maybe it's HIV?</i></p> <p>56. I would fear, I had a fear, a very big fear.</p> <p>57. And anger in the sense that I knew on my own, I wouldn't have had HIV.</p> <p>58. But the anger that you trust somebody that they are behaving themselves and they are going out with other women.</p> <p>59. And you think that even though they would go out with other women, you'd think, they'd use protection.</p> <p>60. So that anger really, is the one that uh, was um...I was engulfed with anger more than anything.</p> <p><i>I: So that was anger at your partner?</i></p> <p>61. Yes.</p> <p><i>I: And can you tell me a bit about what happened there?</i></p> <p>62. Yeah because, there was a time when I went back to Zimbabwe just to</p>	<p>Reassuring herself that she will be okay</p> <p>Feeling afraid when thinking about HIV</p> <p>Feeling angry about possibly having HIV</p> <p>Feeling anger about being betrayed</p> <p>Expecting that husband would protect himself</p> <p>Feeling engulfed with anger</p> <p>Feeling angry at partner</p> <p>Going back to Africa to see family</p>	<p>were 'normal'- doubting HIV.</p> <p>There were mixed emotions- both fear but also anger towards her husband for putting her in this position</p>
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<p>visit because my children were with him.</p> <p>63. And my children would tell me y'know things like uh, on Friday, dad doesn't come home.</p> <p>64. So he goes away on Friday and nobody knows where he is and comes back on Sunday for work on Monday.</p> <p>65. And you think I'm working very hard in England to support everybody back home and he was busy doing that.</p> <p>66. So when I went home, the reception, y'know the reception that he would normally give me, the attention and all that, it wasn't there anymore.</p> <p>67. It was like he didn't care about me anymore and you could see that there was something more interesting in Zimbabwe than, he didn't care, of my presence.</p> <p>68. Yet usually he would be very excited that I'm home and everything would be nice and I would happy, we would be this happy family.</p> <p>69. But, at that time when I went back, you could see that um, even the y'know, our intimacy had changed, he wasn't keen on me anymore.</p> <p>70. So, I really became, really concerned.</p>	<p>Being told that her husband had not come home</p> <p>No-one knowing where her husband is going</p> <p>Feeling annoyed about her husband being away all weekend</p> <p>Feeling that her husband was reacting differently to her</p> <p>Feeling that her husband no longer cared about her</p> <p>Seeing a difference in her husband's reaction to her</p> <p>Husband no longer being intimate towards her</p> <p>Becoming concerned about the change in her husband's behaviour</p>	<p>Line 70- She was concerned about her partner being unfaithful and therefore this was another reason why she considered HIV as a possibility</p>
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Appendix O: Example memos

Memo- Needing to get rid of uncertainty- 01.12.13

Participant 1- It seems that trying to be ignorant and avoiding the pain of knowing about her HIV status and embracing her uncertainty was a strategy that became problematic. In the end, she felt that she needed to get the uncertainty about her HIV status off her mind. Intrusive images of her ex-partner being unfaithful were obviously making her think about the possibility that she might have HIV as this is what caused her to first think about it.

Line 89. "the time I thought about the break up and put those images in to my head, definitely pushed me to say, no, I need to get this off my head and get to know".

After talking to her friend, she decides that that testing will make things easier and again it sounds like it's because it will take away the worry. Here she described knowing as better:

Line 201. "Than you sitting down and worrying".

It seems that this was a really worrying time for her, like being on edge and not being sure what to expect.

Line 220. "You keep...looking over your shoulder anything happening".

Added 05.02.11- Participant 2- Similar to participant 1, there came a point where he could no longer tolerate the uncertainty about his HIV status. It sounds like not being sure and both considering that he could be HIV positive and negative was quite mentally exhausting and therefore, he just wanted to know either way and have a definite answer about his status. This participant had described having hope that he could be HIV negative because he started to develop doubt about having HIV, even though he was initially convinced that he had HIV and was going to die. (See memo on having hope about being negative). But it seemed that his want for certainty was to find out which of these was true- was he negative as he had hoped or was he positive. Whereas participant one didn't necessarily talk about wanting to know if she was positive or negative as she didn't describe hope of being negative. It seemed like she was focusing more about being positive but she wanted to get rid of the uncertainty about this.

Line 155. Because I wanted confirmation.

Line 156. Hmm...because that way of thinking you are negative, you are positive, I wanted to get rid of it.

Line 157. I wanted to get one thing. Positive. Negative. Just one.

He describes the pressure that was associated with this uncertainty and that he wanted to cope. Similar to participant 1, he describes wanting to be pro-active and deal with the situation and to not just be passive.

Line 188. I think... I wanted it to, to release pressure Hmm, hmm.

Line 189. I wanted it to release pressure because the pressure was too much.

For him, he wanted to get rid of uncertainty because it was psychologically/mentally exhausting. This participant thought he would die if he was positive so he also spoke about wanting to be able to make a will and to be able ask for forgiveness from God if he was HIV positive before he died as he saw this as a sin. Therefore certainty also allowed him to do this.

Line 153. "So I wanted to confirm that I have sinned and beg God, so that he can forgive me".

Memo- The relationship between stigma on HIV risk perception - contributing to and maintaining uncertainty -15.03.14

An important theme that has been coming out of the interviews so far is that participants' risk perception was fluctuating. The participants are individuals who have delayed testing because before they tested, they perceived risk of HIV. However something I had not anticipated was that this risk perception would be constantly changing and even go away at some points and thus impact on people's decision to test.

This risk perception appears to be linked to participants' experiences and their interpretations of these which results in them either feeling concerned about being infected with HIV or doubting HIV infection. While thinking about the reasons described by participants that led them to feel concerned or doubtful about HIV infection, it seems that stigma is a more subtle, hidden force linked to this fluctuating risk perception but via the mechanisms proposed in Earnshaw and Chadour (2009)'s model of stigma. For example, they note that one stigma mechanism for uninfected individuals are stereotypes which may impact on testing because it reinforces ideas about who is vulnerable to HIV and therefore if individuals feel that they do not fit in to these groups, they perceive themselves as invulnerable.

Despite many of the participants being in situations where one might objectively think that the risk of having contracted HIV is high (e.g. P3 described how his long-term wife with whom he had children and had had unprotected sex with was diagnosed with it), they had doubts about having HIV. Some of the participants talked about not being promiscuous or only having a small number of partners which made them doubt HIV. Therefore it seemed that stereotypes about the type of sexual behaviours that you must engage in, in order to contract HIV impacted on participants initial risk perception. This allowed room for doubt to develop and thus delayed their testing. Having a lack of knowledge which many of the participants have spoken about so far seemed to allow these stereotypes to exist.

One participant describes how his risk perception of HIV was quite dependent on the reactions of others. He felt doubtful and subsequently no longer worried about having HIV. This is because he was being accepted by others and therefore believed that he could not have HIV otherwise he would be rejected. Because HIV was highly stigmatised he seemed to actually be more concerned about what others thought than what he thought. This seems like a sort of denial perhaps?

"And even if you approach a woman and she accepts a date with you, you think, I'm fine, you understand. It's like physical, your physical appearance was the, y'know, main thing. I believed it because as long as you're in the mainstream society, they're accepting you, you're okay". (P4)

People's acceptance of others seemed to be rooted in stereotypes about how someone with HIV would look. For example he reflects on the fact that people had particular symptoms in mind that they thought indicated HIV. For example, for his community, it was swelling behind the ears. It seems that due to lack of information, stereotypes/inaccurate information about HIV existed. This meant he doubted/dismissed HIV as he didn't have these symptoms.

"That's another thing, in Africa whereby, if you see somebody whose...I mean I had, y'know it was very funny whereby in Africa the symptoms people used to think about. Because you got some lymph nodes, at the back of your ears, swelling up. So it was a question of whereby y'know...if you start feeling yourself behind the ears, if I don't

have those swelling up, then I'm fine". (P4)

Participants also expressed a preference not to know about their HIV status. All of them reported fears of discrimination because of the stigma and discrimination around HIV. This makes me think of the term 'pre-stigmatic fear' used by Alonzo & Reynolds (1995). Only 3 of the participants spoke to anyone during the period of delay. For two of these participants, this helped them to make the decision to test as they learnt about available medications. But it seems that the stigma and discrimination anticipated by participants, meant that they were reluctant to talk to people while they were thinking that they may have HIV. I wonder if they would have spoken to other people if it was a less stigmatised disease. Or perhaps it was just their way of dealing with it- some people seek the help of others and some don't. But it is possible that if they had been able to discuss their concerns more openly, they may have had more information about HIV which in turn may have helped them to decide to test sooner. These pre-stigmatic fears, meaning people would prefer to not know their status, also meant that participants stayed in this state of uncertainty and therefore delayed testing. As Alonzo & Reynolds (1995) suggest, they prefer an ambiguous status and just flirt with a stigmatised identity.

Some of the participants spoke about a desire to not believe they had HIV and it seemed that these pre-stigmatic fears, amongst other fears associated with being HIV-positive, motivated this desire. This desire to not believe they had HIV also appears to impact on the doubt they had about HIV. This doubt meant that some participants even stopped worrying about HIV completely, contributing to their delay. This was observed in a study by Siegel et al. (1999). They suggested that because of fearing anticipated stigma, individuals who perceive risk of HIV, may be reluctant to interpret their symptoms as being HIV related.

Appendix P: Table showing the presence of themes across participants

THEORETICAL CODES		SUB CODES (Focused coding)		Categories and codes raised across participants (Page and line number(s) of quotes)							
				1	2	3	4	5	6	7	8
1	Moving in and out of uncertainty about HIV infection	1.1	Considering HIV infection	1:5 2:13 7:87		1: 2 2:13 16: 168, 169, 170	2: 11, 12 16 5: 41 6: 52 8: 71, 72	1:7,9, 11 4: 48, 49 8: 85, 90, 9: 96, 97 10: 109 15: 167, 171 22: 250 22: 256 24: 290, 291 27: 321	1: 2,3,4, 10 2:15 3: 29 7: 70 12: 111 15: 130	1:7 2:14 15,18, 21 4:26 5: 31,32 13:100 15: 124 16: 133, 134 17: 136 18: 151, 152 19: 156, 158, 159 22: 184	4: 38 5:46 9: 86 10:90, 94 11: 102, 103
		1.2	Doubting HIV infection	5:57	13: 115 116,117	5: 42, 43, 44, 45, 47 6: 53, 54, 55	2:18, 19 8: 68, 69 10: 98, 105, 106 16: 154,	4: 46, 47 7: 84 8: 93 9: 94 10: 108	2: 13, 19 3: 24, 25 3: 31, 32 5: 52, 54 8: 80, 81	5: 33, 34 17: 137 18: 153, 155 19: 157	5: 41, 42, 45 7: 58 8: 74, 75, 76

					16: 171	155	15: 175 21: 243 24: 284 26: 311, 312, 313 27: 327	9: 84, 85, 86, 87, 88, 90 9: 94, 99 12: 112, 113 13: 116, 117 14: 124, 125 15: 130 17: 151,152, 154	20: 176, 177	10:91, 95, 96, 97 11: 104 14: 126, 127
	1.3	Feeling uncertain about HIV infection	1:14 5:58	14: 131	6: 58	6:53 7:63	5: 50, 51	3:29,30 8: 82 12: 115	5: 36 8: 57 12: 95 16: 132 24: 205	3: 22, 29
	1.4	Not wanting to believe or think it is HIV	7:81 16:203			7: 64, 65 67		2:11 2:16 3:27 19: 164, 165, 167		7: 61, 62 8: 67, 68 9: 85, 87 11: 107
	1.5	Feeling more certain about HIV infection		1:2 2:8 6: 45,46 52,59			4: 37, 38, 39, 40 5: 52, 53 7: 76, 78, 79, 80, 81, 82, 83 10: 110, 111 18: 210, 211	4: 33 23: 205 24: 209 26: 224		

							19: 212, 213, 214 21: 239, 241 22: 251 26:304 30: 357, 360			
		1.6	Not worrying about HIV infection				4:37, 38, 39, 40 10: 94 11: 108, 109 14: 133, 134, 135	8: 95 13: 148 14: 149, 150,151 21: 244, 245, 246, 248 22: 254, 255 24: 285, 287, 289 26: 306 27: 324, 328, 329 28: 331	2: 12 2: 26 2:28 13: 119, 122 23: 195, 196 197, 199	3: 23, 28 3:31 4:32
2	Preferring not to know about HIV status	2.1	Fear of facing death			5:39,40 6: 50,51	2: 20, 21 22, 23 10: 87, 88, 89 12: 113, 114	3: 27, 31 24: 278		9: 72,73,74 10: 75, 76 11: 85, 87, 88

									14: 116, 117		
		2.2	Fear of not being able to tolerate knowing				4: 34, 35 12: 116 13: 117 12: 120, 121, 123, 125, 126	5: 55 11: 123, 124, 125 12: 126, 133 13: 144	2:17 4: 35, 36, 39, 41, 5: 44, 45, 46, 48		
		2.3	Fear of experiencing stigma and discrimination	2:26,27, 28 3: 34	5:42,43	5:41	6: 47	3: 28, 29, 30 5: 61, 62, 63, 64 6: 63, 74 14: 155, 156, 157	7: 72, 73 15: 132	6: 45, 46 7: 54, 55 8: 61, 62	16: 138, 140, 142 17: 145
		2.4	Not wanting relationships and lifestyle to change	6: 61,62, 63,64 17: 206, 207			4: 32, 33	6: 71, 72 14: 158			
3	Making the decision to test for HIV	3.1	Having hope about being negative		12: 112 13:121 14:125	17: 175, 178, 179				24: 201,202 24: 206, 209, 212	
		3.2	Wanting certainty about HIV status	8:89	16: 147, 151, 153 17: 155,	9: 82 10:101	18: 169, 171, 172	2: 17,18 9: 100 19: 221	25: 215, 216 27: 229	10: 82, 83 13: 102, 103	

				156, 157 18: 174, 175 19: 188, 189				22: 190		
	3.3	Having hope for medication and for life			7: 65, 66 68, 69, 70 9: 89 10: 93 10: 96, 98,99, 100	8: 76 9: 78, 80, 81 15: 138- 141			24: 206, 208, 210, 211 25: 213	
	3.4	Feeling ambivalent about testing		15: 134- 140	7: 62 11: 112, 113, 114 12: 116, 117			7: 71	9: 68, 69, 71 15: 118	
	3.5	Preparing for and accepting a potentially positive result	8: 90,91, 93 15: 184	17: 158, 159,162, 163,168, 169 19: 184	11: 107, 108	18: 168, 173 19: 175	16: 179, 180 19: 222	5: 49 24: 208 28: 231, 232	25:207 26: 215	