

**Understanding friendships and disclosure decisions in young people  
living with Behaviourally Acquired HIV**

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## **Abstract**

The development of friendships is particularly important in adolescence and emerging adulthood. Young people living with behaviourally acquired Human Immunodeficiency Virus (BAHIV) face important decisions about whom to disclose their HIV status to. Disclosing one's HIV status to different people (e.g. friends, family, or sexual partners) is likely to involve different processes. Social support may help people adjust to living with HIV. While previous research has investigated disclosure decisions and social support in people living with HIV, most studies have involved quantitative methods and none have looked at the unique role of friendships for young people living with BAHIV. This Grounded Theory study aimed to identify the factors that impact on the development of friendships in young people (aged 16-26) living with BAHIV and the factors influencing HIV disclosure to friends. It also aimed to understand the role of friendships post-diagnosis in young people living with BAHIV. A final aim was to develop a theoretical model of friendships and disclosure decisions in young people living with BAHIV.

Ten participants were recruited from two inner city London HIV clinics and interviewed about their experiences of friendships, and disclosure decisions within friendships. All participants had been living with BAHIV for at least one year. The sample varied in terms of gender, ethnicity, and sexual orientation. Data analysis led to a theoretical model comprising four theoretical codes: 1) Personal factors influencing HIV disclosure decisions in friendships; 2) Social factors influencing HIV

disclosure decisions in friendships; 3) Disclosure decision outcomes in friendships; and 4) Post-diagnosis experiences of friendships in the context of other aspects of life. The findings highlight a number of suggestions for supporting young people living with BAHIV. These are presented alongside possibilities for future research.

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## **CHAPTER 1: INTRODUCTION**

### **Overview**

The study explored how young people (aged 16-26) living with behaviourally acquired Human Immunodeficiency Virus (BAHIV) experience friendships and HIV disclosure decisions within friendships. It also investigated the role of friendships post-diagnosis in young people living with BAHIV. To provide an overall context for the study information about HIV and the potential challenges of living with the HIV will be presented, followed by psychological models of adjustment to chronic illness. Information about young people living with BAHIV will then be introduced. Developmental aspects of adolescence and emerging adulthood, including the significance of friendships, will be discussed to understand the potential impact of living with BAHIV as a young person. Current literature on the potential challenges facing young people living with BAHIV will be presented, particularly studies investigating HIV disclosure and social support. Finally, the rationale for the study will be presented alongside the research aims.

### **Human Immunodeficiency Virus (HIV)**

#### **HIV: A global perspective**

HIV destroys or impairs the function of cells in the immune system. As the infection progresses, the immune system becomes weaker and the person becomes less able to fight infections and disease (WHO, 2015a). In 2014, an estimated 36.9 million people worldwide were living with HIV (UNAIDS, 2015a). The largest proportion of

people living with HIV is in sub-Saharan Africa, estimated at 25.8 million (amfAR, 2015). While the number of people living with HIV continues to rise, greater global access to antiretroviral therapy (ART)<sup>1</sup> has helped reduce HIV transmission rates and resulted in people living longer, healthier lives. In June 2015, an estimated 15.8 million people were accessing ART (UNAIDS, 2015b). Similarly, improvements in healthcare and education have resulted in a notable reduction in the number of new diagnoses globally, with a 35% decrease between 2000 and 2014. This was particularly significant in sub-Saharan Africa, with a drop of 41%. In western and central Europe and North America, the number of new diagnoses has remained fairly stable, with an estimated 87,000 people in 2000 and 85,000 people in 2014 (UNAIDS, 2015b).

### **HIV in the UK**

In 2014 an estimated 103,700 people were living with HIV in the UK (PHE, 2015a). In line with global trends, the number of people living with HIV in the UK continues to rise and 85,489 people were seen for HIV care in 2014 (PHE, 2015). A total of 6,151 people (4,611 men and 1,540 women) were newly diagnosed with HIV in 2014, with almost half (2,671) in London (PHE, 2015b). While prevalence now extends to other populations gay, bisexual and other men who have sex with men (MSM) continue to be the group most affected by HIV infection in the UK. In 2014, an estimated one in 20 MSM aged 15-44 years were living with HIV in the UK. This figure was higher in London, with a prevalence of nearly one in 11 (PHE, 2015a). Another significant group

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<sup>1</sup> The combination of several antiretroviral medicines used to slow the rate at which HIV makes copies of itself (multiplies) in the body.

of people living with HIV in the UK are those of black African origin. In 2014, over half (55% of men and 62% of women) of an estimated 54,000 people living with HIV acquired through heterosexual sex, were of black African ethnicity (PHE, 2015a).

## **Living with HIV**

### **Potential challenges**

Since the introduction of effective ART in the mid-1990s in resource rich contexts, HIV has been conceptualised as a chronic manageable health condition rather than a terminal illness. Nonetheless, similar to other long-term conditions, many aspects of living with HIV are potentially stressful. Bravo, Edwards, Rollnick and Elwyn (2010) suggest that people living with HIV face three key decisions: whether or not to disclose their status to others (and if so, to whom, when, why, and how); whether to follow recommended medical treatments; and whether or not to maintain an active sex life (and if so, how to manage it).

The decision to disclose one's HIV status is not straightforward and is likely to be experienced differently by people living with HIV. A key factor associated with HIV disclosure decisions is fear of stigma and discrimination (Bravo et al., 2010). Despite advances in public knowledge and attitudes to HIV (NAT, 2011), stigma continues to be a significant problem for people living with the virus. Stigma can be defined as a deeply discrediting attribute that reduces a person "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p.3). In the context of HIV, stigmatisation is a process that devalues people living with the virus (Miller &

Forehand, 2007). Research has highlighted at least three stigma mechanisms for the person living with HIV: *internalised stigma* (the incorporation of negative prejudicial attitudes into one's self-concept); *enacted stigma* (perceived actual experiences of stigma and discrimination); and *anticipated stigma* (fear or anticipation of discrimination and rejection, and internal sense of shame [Earnshaw, Smith, Chaudoir, Amico & Copenhaver, 2013]). Experiences of stigma in people living with HIV have the potential to operate at different levels of HIV disclosure, for example anticipated stigma may prevent someone from disclosing their HIV status and enacted stigma may be a consequence of disclosure. Studies have demonstrated that disclosing one's HIV status can result in stigmatising reactions such as avoidance, rejection, exclusion, blaming, physical distance, and awkward social interactions with others (Shamos, Hartwig, & Zindela 2009; Stutterheim et al., 2009; 2012).

The stigma associated with HIV not only has the potential to influence the process of HIV disclosure but also the way that people understand themselves in terms of their new identity, as a person living with HIV. Identity theorists suggest that individuals have multiple identities that combine to form a coherent sense of self (Ryan & Deci, 2011). Individuals diagnosed with chronic illness face the task of integrating an illness identity in to their self (Whitehead, 2006), which has the potential to disrupt other established identities and roles, such as sexual identity (Kralik, Koch & Eastwood, 2003) and role as a mother (Reynolds & Prior, 2003). Flowers et al. (2007) interviewed 30 Black African people living with HIV in the UK and identified feelings of a damaged sense of self following HIV diagnosis, which was largely related to

experiences of enacted and anticipated stigma. The process of constructing a new identity as a person living with HIV is likely to be an on-going process engaged in by the person living with the virus, as well as family members, friends, healthcare professionals, and other people living with HIV within the broader social context (Roth & Nelson, 1997).

While the introduction of ART has dramatically improved health outcomes for people living with HIV, its success relies on good medication adherence. Some people may adapt easily to the daily task of taking medication, whereas others may struggle. Research suggests that ART adherence in people living with HIV is associated with factors such as self-efficacy (one's beliefs in one's ability to adhere to recommended medication regimes), concerns about adverse effects of ART, beliefs about the necessity and usefulness of ART, as well as current substance misuse, trust or satisfaction with HIV care providers, depressive symptoms, HIV-related stigma, and social support (Langebeek et al. 2014).

### **HIV disclosure decisions**

Given the public health interest in reducing HIV transmission rates and the potential benefits of HIV partner disclosure on reducing onward transmission, research in HIV disclosure has predominantly focused on sexual partners. Researchers have attempted to identify potential barriers to disclosing to sexual partners (e.g. Cissé et al., 2016), as well as answer questions around whether disclosure rates are different for men and women (e.g. Geary et al., 2014), and MSM and heterosexual people

living with HIV (e.g. Przybyla et al. 2013). Some researchers have compared disclosure rates for different members of the social networks of people living with HIV. For example one study in the US involving adults (233 men and 98 women, 72% African American) living with HIV found that HIV status was disclosed significantly more often to friends than family members (Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003). Serovich, Esbensen and Mason (2007) compared disclosure to friends and family over a 15-year period in 116 MSM (aged 21-53 years old, 70% Caucasian). Their findings were consistent with Kalichman and colleagues (2003), where overall disclosure was significantly higher to friends than family in MSM living with HIV. Interestingly, their analysis demonstrated that within the first year of HIV diagnosis family members were disclosed to more often than friends, however friends were disclosed to more quickly than family members and “longest” friends (friends known for longer than 2 years).

Serovich and colleagues (2007) hypothesised that there may be important distinctions between how different members within the same social network “category” are perceived by people living with HIV and this, in turn, may influence their disclosure decisions. Studies that measure disclosure rates using forced choice measures may overlook important data relevant to individual friends and family members, and are unlikely to accurately represent the complexity of people’s experiences of close relationships. For example it is possible that a close friend known for many years may be perceived similarly to a family member. It is equally possible that individuals within the social networks of people living with HIV may belong to

more than one category, for example a friend may also be a sexual partner and a family member may also be regarded as a friend. Qualitative research has the advantage of exploring different aspects of HIV disclosure and gathering rich data on individuals' experiences. Studies using qualitative methods have been conducted to explore barriers and motivators to HIV disclosure (e.g. Lee, Li, Iamsirithaworn & Khumtong, 2013), as well to explore experiences related to stigma and disclosure (e.g. French, Greeff, Watson & Doak, 2015). It is worth noting that interpretation of existing research on HIV disclosure is further complicated by the shifting role of the disclosure process over the course of the HIV epidemic. As little as 10 years ago (20 years in resource rich contexts), learning that one is HIV-positive meant a substantially shortened lifespan and disclosure was likely to have a very different meaning from the situation confronting people living with HIV today.

A number of models of HIV disclosure have been developed in an attempt to explain the disclosure decision-making process in people living with HIV (e.g. Arnold, Rice, Flannery & Rotheram-Borus, 2008; Bairan et al., 2007; Bird & Voisin, 2010; Derlega, Winstead, Greene, Serovich & Elwood, 2004; Gaskins et al., 2012; Iwelunmor, Sofolahan-Oladeinde & Airhihenbuwa, 2015). One model that has received significant attention in the literature is the Disclosure Process Model (DPM) put forward by Chaudoir and Fisher (2010). The model proposes that disclosure must be conceptualised and examined as a single process that necessarily involves decision-making and outcome processes, however the model can be applied repeatedly as people living with HIV engage in different disclosure events throughout their life. The



DPM suggests that approach goals (aimed at pursuing a positive outcome) and avoidance goals (aimed at preventing a negative outcome) underlie disclosure behaviour. The model outlines the disclosure event itself, mediating processes and associated outcomes, and a feedback loop, where people living with HIV who have positive disclosure events become increasingly open about their HIV status and people who have negative disclosure events become increasingly concealed. Chaudoir, Fisher and Simoni (2011) suggest that the DPM provides a useful framework within which to interpret existing findings in HIV disclosure, as well as guide new research in this area. The main advantage of the model is that it takes a broad approach, covering a wide variety of domains and drawing attention to the interrelations among important aspects of the disclosure process.

Dima, Stutterheim, Lyimo and de Bruin (2014) emphasise the importance of the DPM in highlighting issues with existing literature in terms of how HIV disclosure is operationalised, measured, and analysed in quantitative studies. They argue for the importance of the feedback loop element of the model and state that HIV disclosure should be conceptualised as a multidimensional process consisting of multiple related events, involving different members of individuals' social networks. Dima et al. (2014) contend that existing studies in HIV disclosure overlook important data relating to two key areas, namely the disclosure target (who people disclose to) and the discloser's intention (the reasons they disclose). Preau et al. (2015) expand on ideas relating to the latter and distinguish between three different types of HIV disclosure: *direct disclosure* (the person with HIV personally disclosing to a target); *indirect*

*disclosure* (a target being informed their HIV status by someone else); and *guessed status* (a target guessing the person's HIV status). It is likely that the causes and consequences of disclosure for people living with HIV are different depending on who is disclosed to and how the disclosure event is experienced.

### **Social support and living with HIV**

Various studies have investigated the psychological impact of living with HIV and identified elevated rates of depressive symptoms in people living with the virus compared to the general population (e.g. Anderson & Weatherburn, 2004; Ciesla and Roberts, 2001; Heywood & Lyons, 2016; Miners et al., 2014; Lowther, Selman, Harding & Higginson, 2014). Researchers have attempted to identify factors that might contribute to the development of mental health problems in people living with HIV, such as higher levels of self-reported stigma (e.g. Heywood & Lyons, 2015; Logie & Gadalla, 2009). As well as potential risk factors, researchers have attempted to identify factors that might help people living with HIV manage the potential challenges associated with the virus, such as social support. Social support can be defined as information or actions (actual or potential) that lead individuals to perceive that they are cared for or receive aid, assistance, and comfort from others when they need it (MacGeorge, Feng, & Burleson, 2011). Social support can involve specific interactions with others, whereby one person receives advice, instrumental (physical or tangible) support, or emotional support from another, or it can be experienced primarily through the perception that help and support is available from others (perceived social support). Studies have identified positive associations

between self-report measures of social support and health related quality of life, which incorporates factors such as physical, cognitive, emotional, and social functioning (Jia et al., 2004), and emotional wellbeing in people living with HIV (Cowdery & Pesa, 2002; Liu et al., 2013; Reich et al., 2010; Rueda et al., 2012). Based on these findings researchers have hypothesised that social support either directly influences physical and psychological health outcomes in people living with HIV, or serves as a buffer to reduce the influence of HIV-related stressors on health outcomes.

The relationship between social support and HIV disclosure in people living with HIV is not straightforward and different types of social support are likely to influence different stages of the HIV disclosure process. For example perceived social support might facilitate a person to disclose their HIV status and instrumental and emotional support may be positive outcomes of HIV disclosure. Dima et al. (2014) attempted to explore the relationships between HIV disclosure, stigma, and social support in 158 people living with HIV in Tanzania (48% male, mean age 43.8 years). They used a comprehensive list of 21 potential discloser targets (recipients), which included different members of the same social network category (e.g. brother, sister, mother, father). They found that self-reported stigma and social support was experienced differently depending on who was disclosed to and whether the disclosure was voluntary or involuntary (i.e. indirect disclosure and guessed HIV status). For example, participants reported increased perceived stigma only if they disclosed their HIV status voluntarily to people in the wider community, or involuntarily to close

friends and neighbours. Additionally, participants reported more instrumental support if they disclosed (voluntarily) to their partner/spouse, and less if they disclosed to their close family. Overall, these findings highlight the complex relationships between HIV disclosure, stigma, and social support, and suggest that stigma and social support may play different roles in disclosure decisions involving intimate partners, friends, and the broader community (Bairan et al., 2007). The findings further suggest that the consequences of HIV disclosure may differ when disclosing to different people (Greeff et al., 2008), which may influence future disclosure decisions involving members of one's social network (Chaudoir & Fisher, 2010; Chaudoir, Fisher & Simoni, 2011).

### **Psychological models of adjustment**

As mentioned previously, people living with HIV face potentially challenging decisions related to HIV disclosure, medical treatments, and sexual activity (Bravo et al., 2010). While it is reasonable to suggest that HIV-related stressors are largely similar for most people living with the virus, the way in which people experience them will be different, particularly in terms of individual thoughts and feelings about HIV diagnosis, and the strategies they use to cope. Conceivably, there are numerous ways of coping with chronic illness, however researchers have largely focused on cognitive, emotional, and behavioural processes, such as those outlined by the self-regulation model (Leventhal, Meyer & Nerenz, 1980; Cameron & Leventhal 2003).

The self-regulation model (Leventhal, Meyer & Nerenz, 1980) suggests that individuals are active problem solvers who try to make sense of a threat by developing a cognitive representation of the threat (the illness). It is a “parallel-processing” model in that people typically make simultaneous cognitive and emotional representations of their illness. Illness representations cause coping responses that, in turn, influence health outcomes. Coping responses include avoidance or denial, cognitive reappraisal, expressing emotions, problem-focused coping, and seeking social support. Broadbent, Petrie, Main and Weinman (2009) outline six cognitive illness representations that lead to these responses: *identity* (the name of the illness and its associated symptoms); *timeline* (the perception of how long the illness will last); *consequences* (patients’ perception of how serious the illness is in terms of physical, emotional, and social consequences); *emotional representation* (the negative reactions such as fear, anger, and distress); *cure/controllability* (a belief about whether the illness can be cured or managed); and *comprehensibility* (an evaluation of whether the illness makes sense). Overall, the self-regulation model argues that how a person perceives their illness determines how they cope. Two main categories of coping strategies can be identified: functional coping (which leads to a more favourable outcome), and dysfunctional coping (which causes further distress). Pala and Steca (2015) investigated the association between cognitive illness representations and coping strategies in 248 people (80.2% men, mean age 39.6 years) living with HIV. They identified three latent profiles that differed on perceived *consequences* of HIV (the perception of HIV’s influence on the participants’ lives), which they labeled low, moderate, and high illness perception.

Their findings demonstrated that a low/moderate perception of illness influence corresponded to greater avoidance (dysfunctional coping) compared to the high influence perception profile. Interestingly, the authors also identified an association between HIV viral load<sup>2</sup> and the three latent profiles, where participants with greater (detectable) viral load were more likely to perceive the negative influence of HIV on their lives and emotions (based on the dimensions of *consequences* and *emotional representation*). These findings highlight the importance of understanding the psychological aspects of HIV in the context of health-related behaviours, such as ART adherence.

Moss-Morris (2013) argues that existing models of adjustment, such as the self-regulation model, offer only a partial insight in terms of understanding how people adjust to chronic illness as a whole. She presents a multifaceted model of adjustment that can be adapted through different areas of emphasis for specific health conditions. The model proposes that background personal (e.g. early life experiences), social (e.g. experiences of close relationships), and environmental (e.g. availability of health and social care) factors influence how people respond and adapt to various illness-related stressors. In line with the self-regulation model, stressors have the potential to disrupt individuals' emotional stability and quality of life. According to Moss-Morris (2013), good adjustment to chronic illness is represented by less distress, less interference or impact on life roles and relationships, good illness management, and positive affect.

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<sup>2</sup> Refers to the number of HIV virus particles in one millilitre of blood, called "copies". Viral load is typically deemed undetectable (too low to be measured) when it is below 50 copies/ml.

Overall, models of adjustment in health psychology provide a useful framework to understand the ways in which people adjust to and cope with living with HIV, in terms of individual responses to diagnosis as well as on-going HIV-related stressors. It is important to note that adjustment is not viewed as a single event but rather an on-going process. By definition, the process of adjustment implies returning to the same level of psychological, social, and physical functioning than before, referred to by Moss-Morris (2013) as equilibrium. It is therefore important to consider people's experiences as a whole, including those that predate diagnosis. A key adjustment challenge is maintaining and building on close relationships in the context of living with HIV, which includes difficult decisions related to HIV disclosure, such as who to tell and why. It would be useful to understand the impact of living with HIV on people's close relationships as well as the role of specific relationships, such as friends, in shaping how people adjust to living with the virus.

### **Treatment and care for people living with HIV**

It is important that if people living with HIV do experience psychological difficulties that they are adequately supported, particularly as research suggests that experiences of low mood inhibit the capacity of people living with HIV to maintain their health (Boarts, Sledjeski, Bogart & Delahanty, 2006). The British HIV association (BHIVA) and British Psychological Society (BPS) state that people living with HIV should receive psychological care that is sensitive to the unique aspects of living with the virus (BHIVA, 2013; BPS, 2011). Published guidelines recommend that people living with HIV should have timely access to psychological support, including

evidence-based psychological intervention if appropriate, using a stepped care model. In particular, the BPS (2011) guidelines emphasise the importance of appropriate psychological support at the time of HIV diagnosis and state that clear service pathways should be established for onward referral.

## **HIV in young people**

### **The current picture**

In 2010, young people aged 15-24 accounted for 42% of new adult (aged 15 and older) HIV diagnoses worldwide (UNAIDS, 2012). Among young people living with HIV, nearly 80% (4 million) live in sub-Saharan Africa (UNAIDS, 2012). Young people are vulnerable to HIV in two distinct stages of their lives: the first decade of life when HIV can be transmitted from mother-to-child (perinatally acquired HIV; PAHIV), and the second decade of life when adolescence brings new vulnerability to HIV through sexual and drug-use risk behaviour (behaviourally acquired HIV; BAHIV). In 2014, 12% of all new HIV diagnoses in the UK were in people aged 15-24 and an estimated 2,776 people aged 15-24 were seen for HIV care (PHE, 2015c). MSM are the group most likely to acquire HIV between the ages of 15-24 and in 2014 they accounted for approximately 60% of all UK new diagnoses in this age range (PHE, 2015c). In 2014, measures of CD4 count<sup>3</sup> taken within 91 days of diagnosis suggested that 29% of people living with HIV aged 15-24 had a CD4 count of less than 350; the threshold historically used to determine when to begin ART. This figure is lower than in all newly diagnosed adults (aged 15 or older) in 2014, which fell at 40% (PHE, 2015c).

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<sup>3</sup> Measures the number of CD4 T lymphocytes (CD4 cells) in a sample of blood. CD4 count gives an indication of the health of a person's immune system.



## **BAHIV and PAHIV**

While the vast majority of people living with HIV worldwide are living with BAHIV, greater access to ART has resulted in children born with the virus living longer and a new cohort of people living with PAHIV moving into adolescence and young adulthood (Sohn & Hazra, 2013). It is reasonable to suggest that there may be differences between young people living with BAHIV and those living with PAHIV, particularly in terms of HIV-related risk behaviours. Studies have shown that young people living with BAHIV have higher rates of alcohol and drug use, number of sexual partners, and sexually transmitted infections than those living with PAHIV (Setse et al., 2011; Koenig et al., 2010). The majority of heterosexual people living with HIV in the UK are Black-African (PHE, 2015a), whereas the majority of MSM living with HIV in the UK are white-British (NAT, 2015). While MSM are the group most likely to acquire HIV behaviourally, individuals of black-African origin are the group most likely to acquire the virus perinatally. Taken together, it is likely that young people living with BAHIV will differ to those living with PAHIV in terms of sexuality, ethnicity and sexual behaviour. They will also differ from the general BAHIV population in terms of the age and stage of life they are diagnosed, given that most new diagnoses of HIV in the UK are aged 25-34. In 2014, there were 2,044 new diagnoses of HIV aged 25-34 compared to only 727 aged 15-24 in the UK (PHE, 2015c).

## **Characteristics of young people**

### **Definitions: Adolescence and emerging adulthood**

The World Health Organisation defines adolescence as the transitional period in human growth and development that occurs between childhood and adulthood, from ages 10 to 19 (WHO, 2015b). Adolescence is a crucial time for physical, cognitive, and social development. Kennedy, Sloman, Douglass and Sawyer (2007) outline seven key tasks of adolescence, to: develop and apply a more complex level of thinking skills; develop a capacity for deeper relationships with peers; adopt a meaningful value and belief system to guide decisions and behaviour; establish key aspects of identity; meet the demands of vocational and economic goals; renegotiate relationships with parents; and develop the skills for intimate relationships. Developmental psychologists distinguish three stages of adolescence: early (12–14 years), middle (15–16 years), and late ([17-19 years] Erikson, 1968; Muuss, 1988; Piaget, 1975).

In westernised countries such as the UK, certain milestones typically associated with adulthood are occurring later than before, for example the average age of marriage in England and Wales increased from 22 years for women and 24.1 years for men in 1970, to 34 years for women and 36.5 years for men in 2012 (ONS, 2012). As a result, previously well-defined pathways from adolescence to adulthood are less clear-cut and the years from late teens through to the early twenties can be conceptualised as a distinct developmental period, referred to as “emerging adulthood” (Arnett, 2000; Cohen, Kasen, Chen, Hartmark & Gordon, 2003). Arnett (2014) outlines five characteristics that distinguish emerging adulthood from other age periods. He

suggests emerging adulthood is the age of: identity explorations (understanding one's self, capabilities, limitations, beliefs, and values), instability (exploring possibilities in love and work, and moving residences), self-focus (developing knowledge, skills, and self-understanding), feeling in-between (the subjective feeling of being in a transitional phase in life), and possibilities (having hopes and expectations for undecided future directions). While there is no agreed definition of the age at which adolescence ends and emerging adulthood begins, both involve similar developmental tasks, particularly in terms of identity development.

### **Developmental changes in friendships**

Friendship is a diverse, multifaceted phenomenon that may be experienced differently depending on a number of personal and social factors (Keller, 2004). While peer interactions form a significant part of social and cognitive development in childhood, relationships with parents are the most influential during this period (Benson & Haith, 2010). As children enter in to adolescence and become more autonomous, they spend more time with peers and less time with parents and other adults. Important changes in relational networks take place, where friends gradually come to occupy just as central a position as parents (Furman & Buhrmester, 1992). Research demonstrates that perceived social support changes during adolescence, where parental support declines and support from friends increases (Helsen, Vollebergh & Meeus, 2000). Developmental theorists argue that individuals' perceptions of friendships, particularly friendship intimacy, change throughout adolescence and emerging adulthood as a result of changing social needs and

relational roles. Friendship intimacy can be broadly defined as the subjective perceptions of closeness and intimacy, as well as the intimate behavioural exchanges of self-disclosure and coping / support (Reis & Shaver, 1988). In early adolescence the need for intimate exchange begins to emerge (Sullivan, 1953), where individuals begin to share their secrets, problems, and feelings with friends. As individuals progress through adolescence they become more skilled at building and maintaining close friendships and engage in intimate exchanges of self-disclosure with friends (Berndt, 1982; Buhrmester & Furman, 1987; Fehr, 2004). Carbery and Buhrmester (1998) argue that the features and functions of friendships change in emerging adulthood as a result of the broader organisation of individuals' networks of close relationships including those with parents, romantic partners, and possibly their own children. As emerging adults begin to commit to different relational roles, the amount of time and emotional energy available to invest in friendships decreases, which in turn influences the degree of interdependence and intimacy between friends. Research suggests that emerging adults get together with their friends less frequently (Reis, Lin, Bennett, & Nezlek, 1993) but continue to consider their friendships as important (Hartup & Stevens, 1997).

### **The importance of friendships**

Most adolescents and emerging adults have close relationships in the form of friends and romantic partners (Collins & Madsen 2006). While these relationships are likely to be similar in many ways, for example both are typically voluntary and have the potential to make people happy, friends and romantic partners may serve distinct

functions (Furman and Buhrmester, 1992). Research suggests that friendship support uniquely predicts adolescent self-worth over and above support from parents and romantic partners (Laursen, Furman & Mooney, 2006). Similarly, emerging adults feel closer to, engage in more activities with, and discuss more subjects with their friends than with their siblings (Pulakos, 2001). Emerging adults also talk to friends about things they might withhold from their parents, such as dating and sexual behaviours (Lefkowitz, E. S., Boone, T. L., & Shearer, 2004). Engaging in intimate relationships can help adolescents and emerging adults adjust to key developmental tasks, such as identity development. Research suggests that emerging adults with strong friendships display few negative internalising behaviours and express high feelings of self-worth (Barry, Madsen, Nelson, Carroll & Badger, 2009; Pittman & Richmond, 2008). Receiving social support from friends has further shown to facilitate adjustment to important transitions in life, such as beginning university (Friedlander, Reid, Shupak & Cribbie, 2007).

### **Gender variations in friendships**

Research has identified potential gender differences in people's experience of friendships, particularly in terms of how men and women view and interact with their friends. In a meta-analysis of 37 studies Hall (2011) found that friendship expectations of symmetrical reciprocity (e.g. loyalty, genuineness), communication (e.g. intimacy, self-disclosure) and solidarity (e.g. mutual activities, companionship) were higher in females, whereas agency (e.g. physical fitness, status) was higher in males. In addition, Barry et al. (2009) found that females (aged 18-26) reported

greater levels of nurturance, affection, intimacy, and emotional support from their best friends compared to males. For both genders, men appear to be the preferred friends for pursuing activities whereas women are preferred for deep conversations (Baumgarte & Nelson, 2009). While both men and women share personal information with friends to achieve intimacy, men also achieve intimacy by engaging in activities with friends (e.g. playing sport, Radmacher & Azmitia, 2006).

## **Young people living with HIV**

### **Unique challenges faced by young people living with BAHIV**

Young people living with HIV not only face the major developmental changes and challenges associated with adolescence and emerging adulthood, but also face a multitude of emotional, physical and psychological difficulties associated with living with a long-term health condition (Hosek, Harper & Domanico, 2000; Suris, Michaud & Viner, 2004). Receiving a diagnosis of HIV in adolescence or emerging adulthood not only has the potential to disrupt normative development but also comes with the unique risk of experiences of HIV-related stigma (Swendeman, Rotheram-Borus, Comulada, Weiss & Ramos, 2006). This may be particularly significant for young people, as feeling accepted by peers is a key concern for most adolescents (Morrison-Valfre, 2012). Adjustment to HIV in late adolescence or emerging adulthood may present unique challenges in terms of feeling “in-between” (Arnett, 2014), whereby individuals might feel autonomous in some ways but dependent in others. Hosek et al. (2008) conducted a qualitative study involving newly diagnosed (12-24 months previously) young people living with BAHIV, aged 16-24 years. The authors used

Bronfenbrenner's (1979, 1986) ecological systems model to conceptualise their data and found that newly diagnosed young people living with BAHIV described a range of stressors within multiple social-ecological systems, which included interactions with their families, sexual partners, health care providers, work, and school. Interactions within participants' microsystem (the system that young people interact with directly) were perceived as the most stressful, particularly issues related to the actual HIV diagnosis (e.g. thoughts of death and hopelessness about the future) and disclosure of their status to others. Hosek et al. (2008) suggest that the first year after HIV diagnosis may be particularly challenging for young people living with BAHIV.

HIV-related stressors may be experienced differently by young people living with BAHIV compared to those born with the virus, largely because young people living with PAHIV have been living with the virus for longer. In the case of ART, young people living with PAHIV may face issues related to long-term use of medication (Koenig, Nesheim & Abramowitz, 2011), whereas young people living with BAHIV may struggle to incorporate new medication regimes in to their existing lives. MacDonnell, Naar-King, Huszti and Belzer (2013) conducted a study comparing young people living with BAHIV (N=236) and young people living with PAHIV (N=217), aged 12-24 years, in terms of self-reported barriers to ART medication adherence. They found that the top barriers (forgetting, not feeling like taking it/needing a break, and medication reminds me of HIV) were similar for both groups, although young people living with BAHIV identified fewer barriers than those who acquired the virus perinatally. In particular, young people living with BAHIV were reported to be more worried about

stigma, or about other people finding out about HIV, than those with PAHIV. This could in part be explained by the fact that most of the young people living with BAHIV in the study were male (69.9%) and identified as a sexual minority (sexual orientation other than heterosexual [71.6%]). Young MSM may be at risk not only of HIV-related stigma but also stigma related to negative perceptions and treatment due to their sexual orientation (Jeffries et al., 2015a). For young MSM, revealing one's HIV status may also bring up questions about how they acquired the virus, which may be particularly difficult for those who have not disclosed their sexual orientation to all members of their social network (Latkin et al., 2012).

Researchers have attempted to understand the psychological impact of living with HIV during adolescence and emerging adulthood, for example Brown et al. (2015) investigated the presence of mental health symptoms in a sample of young people living with BAHIV (N=1404) and PAHIV (N=628), aged 12-24 (mean age 20.3 years). Participants living with BAHIV were mostly male (77.5%) and of these participants the most frequently reported route of infection was through sex with another man (74.1%). Based on scores from the Brief Symptom Inventory (BSI [Derogatis & Melisaratos, 1983]), Brown et al. (2015) found that 17.5% of young people living with HIV reported psychological symptoms greater than the normative threshold. Interestingly, young people living with BAHIV reported more clinically significant psychological symptoms than those with PAHIV and this was not associated with the length of time knowing their HIV diagnosis. Other studies have consistently demonstrated elevated symptoms of psychological distress for young people living



with BAHIV compared to those with PAHIV (e.g. Abramowitz et al., 2009; MacDonnell Naar-King, Huszti & Belzer, 2013). A potential limitation of studies looking at differences between young people living with BAHIV and young people living with PAHIV is whether age is controlled for, as individuals born with the virus are likely to be younger than those living with BAHIV. There may be other important differences between these two populations that could be associated with increased emotional distress, such as higher levels of substance misuse (MacDonnell et al., 2013) and unique experiences of stigma in young MSM related to sexual orientation (Jeffries et al., 2015a).

### **Identity development and HIV**

The formation of a sense of identity is considered by many theorists to be a primary developmental goal of adolescence and emerging adulthood (Adams, Gullotta & Montemayor 1992; Erikson, 1968; Arnett, 2000; 2014). Erikson's (1950) psychosocial theory of development conceptualises identity as a dynamic interaction between *identity synthesis* (a coherent and internally consistent sense of self over time and across situations [Dunkel, 2005]) and *identity confusion* (a fragmented sense of self). Marcia (1966) expanded on Erikson's ideas and put forward an Identity Status theory, which identifies *exploration* (sorting through various potential identity alternatives) and *commitment* (selecting one or more alternatives to which to adhere) as the defining dimensions of identity. Based on this theory Hosek, Harper and Robinson (2002) conducted a mixed methods study to investigate identity development in young people (aged 17-21 years, 63% African American) living with BAHIV for

between 2 months and 4 years. They used a combination of standardised self-report measures and open-ended interviews, and identified two opposing identity statuses within the sample: *Identity Achievement* and *Identity Diffusion*. Identity achievement represents a set of commitments enacted following a period of exploration, whereas identity diffusion represents an absence of commitments coupled with a lack of interest in exploration. Identity achievement has been associated with balanced thinking and mature interpersonal relationships (Krettenauer, 2005), and identity diffusion has been associated with low self-esteem and an absence of self-direction and agency (Schwartz et al., 2005). The authors hypothesised that for some young people, HIV diagnosis may in fact facilitate and expedite the identity development process (e.g. if they perceive a potentially shortened life-span), whereas for others it may inhibit exploration of identity issues and prevent identity commitment. They emphasised the importance of understanding other contextual factors, such as family and sexual orientation to better understand the relationship between identity development and HIV.

While British attitudes towards homosexuality have changed significantly since the emergence of HIV in the 1980s (Park et al., 2013), identity development in young MSM may be further complicated by experiences of heterosexism (discrimination or prejudice against homosexual people on the assumption that heterosexuality is the normal sexual orientation), stigma, homophobia and prejudice (Harper & Schneider, 2003). Harper et al. (2013) investigated the relationship between different aspects of identity and adherence to medical appointments in young MSM living with BAHIV,

aged 16-24. Ethnic identity, sexual orientation identity, and identity as a young man living with HIV were measured using self-report questionnaires. They found that young MSM living with BAHIV with more negative attitudes towards gay/bisexual people in general were more likely to have missed an appointment in the past three months. In contrast, attitudes to one's own gay/bisexual orientation, whether positive or negative, were not associated with missed appointments. Young MSM who identify as gay or bisexual but do not affiliate themselves with members of their respective groups may have accepted their own sexuality but do not feel comfortable enough to connect with other gay or bisexual individuals (Fassinger & Miller, 1997). For some young people, HIV diagnosis may involve not only acceptance of a long-term health condition but also acceptance of sexual orientation. This might be particularly difficult for individuals who do not feel psychologically ready to do so (Harper et al., 2013).

### **HIV disclosure decisions in young people**

As outlined above, the causes and consequences of HIV disclosure are likely to be different depending on who is disclosed to as well as the type of disclosure event that is experienced (Dima et al., 2014), for example whether disclosure is planned or spontaneous, direct or indirect. Experiences of disclosing one's HIV status may also be experienced differently depending on the route of HIV transmission, for example young people living with BAHIV face the additional challenge of deciding whether to disclose to parents, whereas those with PAHIV have to navigate potential difficulties around disclosing parental HIV status as well as their own. Young people living with

BAHIV face potentially challenging decisions in terms of who to disclose to and when. Some young people may perceive that they lack the skills to initiate and execute disclosure conversations if they do choose to disclose (Forsberg, King, Delaronde & Geary, 1996).

While the literature involving young people is not robust, researchers have begun to ask questions relating to when, how often, and to whom HIV disclosure occurs as well as identify the potential barriers to young people living with HIV sharing their status with others. Thoth, Tucker, Leahy and Stewart (2014) conducted a literature review of 31 studies of HIV disclosure in young people living with HIV, most of which were quantitative (N=21 studies). They found that reported rates of HIV disclosure varied depending upon the methodology, samples, and relationships to the person with whom the disclosure occurs. Research suggests that when compared with older adults, young people living with HIV are less likely to disclose their HIV status to friends (Lam, Naar-King & Wright, 2007; O'Brien et al., 2003). One study involving young people with PAHIV identified disclosure rates to close friends as low as 22% (Lee & Oberdorfer, 2009), whereas another study involving both young people living with BAHIV and PAHIV identified rates of 65% (Michaud et al., 2009). These differences could in part be explained by the study samples, as Abramowitz et al. (2009) found that young people living with BAHIV (N=67) reported a significantly higher number of friends knowing their HIV status (mean = 4.7 friends, SD=4.9) than young people living with PAHIV ([N=99] mean = 1.7 friends, SD=3.9). The relatively big standard deviation for young people living with BAHIV implies some degree of

variation between participants and it would be useful to understand the factors that influence some young people to disclose to more friends than others. It would also be useful to understand any potential within participant factors that influence HIV disclosure to specific friends, given that participants are likely to have disclosed to some friends and not others.

Similar to the adult literature, one of the main barriers to HIV disclosure identified in young people is fear of stigma and discrimination (e.g. Michaud et al., 2009). Martinez, Lemos and Hosek (2012) conducted qualitative interviews with 14 Latino young people (aged 16-24) who had been living with BAHIV between 12 and 24 months. They found that disclosure to friends was unlikely, unless it was indirect disclosure, where young people described a fear of feeling rejected if they disclosed their HIV status. While no published UK guidelines exist for working psychologically with young people living with HIV, the WHO (2013) recommend that adolescents should be informed about the potential health benefits and risks of disclosure of their HIV status to others and empowered and supported to determine if, when, how and to whom to disclose.

### **Social support and young people living with HIV**

Social support from others may be particularly significant for adolescents or emerging adults living with HIV who, given their stage of development, may lack the maturity or experience to cope with HIV diagnosis. Similar to the adult literature, research suggests that social support may act as a buffer to mental health symptoms in young

people living with HIV. For example, Lam et al. (2007) identified a negative association between self-reported social support, measured using a shortened version of the Social Provisions Scale (Cutrona & Russell, 1987), and general psychological distress in young people (aged 16-25) living with HIV. While these findings are useful, the study is cross-sectional and it is possible that young people's perceptions of social support change over time. McFadden et al. (2014) looked at trends in changes in social support in young black MSM (YBMSM) aged 18-30 years, at three time periods shortly after HIV diagnosis. They used social network surveys to investigate sources of instrumental and emotional support, referred to as "social confidants" (SCs). At each time point, SCs were ascribed a role (e.g. friend or family member) and participants identified whether they had or had not disclosed their status to them. Network measures included: size (number of SCs in the network), density (the degree to which SCs know each other), constraint (the degree to which SCs are connected to one another), and betweenness (the degree to which participants are able to monitor the flow of information between SCs in their network). The findings identified three main patterns of change in participants: high gain (increased network size), high turnover (gained and lost approximately the same number of network members), and stable networks. While this study provides useful findings in relation to changes in support networks in YBMSM newly diagnosed with HIV, it does not explain the reasons behind these changes. Furthermore, participants were limited to only one role per SC however it is possible that members of their support network could fulfil more than one (e.g. sexual partner and friend). Friends may be a particularly important source of support for young people living with HIV, as

research suggests that young people are most likely to seek help from people who they are closest to first before accessing professional services for physical or mental health needs (Barker, 2007). Based on the findings from McFadden et al. (2014), it would be useful to understand the social and psychological correlates of why young people may gain or lose friends following HIV diagnosis.

Abramowitz et al. (2009) examined the nature and type of support available to young people living with HIV (N=166, 53% female, 60% PAHIV and 40% BAHIV). They identified significant differences in perceived social support between young people living with BAHIV and those born with the virus. In particular, young people living with BAHIV had lower levels of instrumental support, less friends overall and less friends living with HIV, despite disclosing their HIV status to more friends than those living with PAHIV. In addition, participants that acquired HIV behaviourally demonstrated higher scores on self-report measures of depression than those born with the virus. Interestingly, young people living with BAHIV rated satisfaction with friendships reasonably high. Based on these findings it would be useful to understand the perceived importance of support from friends in young people living with BAHIV and whether friends provide other kinds of support not investigated by this study. Existing research on social support has found positive associations between perceived social support and emotional wellbeing (e.g. Liu et al., 2013) in people living with HIV. Given that participants living with BAHIV demonstrated higher depression scores yet they disclosed to more friends than participants living with PAHIV, it would be useful

to understand the unique psychological processes involved in their friendships, including HIV disclosure to friends.

### **Rationale for the study**

The reviewed literature highlights several important issues and findings that inform the rationale for the current study. Firstly, friendships are particularly important in late adolescence and emerging adulthood. Studies involving young people living with HIV have seldom differentiated participants by route of infection however there are likely to be differences between young people living with BAHIV and those living with PAHIV. Young people living with BAHIV face a number of potential challenges, including whether or not to disclose their HIV status (and if so to whom, when, why, and how). Receiving a diagnosis of HIV presents the unique risk of experiences of stigma. It also has the potential to impact a person's sense of self and bring about new challenges within close relationships. Adjustment may be particularly difficult for young people diagnosed with HIV, who also have to navigate the normal changes and challenges associated with late adolescence and emerging adulthood.

HIV disclosure is a multidimensional process consisting of multiple related disclosure events, involving different members of individuals' social networks. The causes and consequences of HIV disclosure are likely to be different depending on who is disclosed to and how the disclosure event is experienced. Social support from others may help people living with HIV manage the potential challenges associated with the virus. Experiences of stigma and social support are likely to be influential at different



stages of the HIV disclosure process, for example perceived social support may facilitate disclosure whereas anticipated stigma may hinder disclosure in people living with HIV.

While previous research has investigated social support in young people living with BAHIV, no studies have used qualitative methods to look specifically at friendships. Qualitative research has the advantage of exploring different aspects the HIV disclosure process and gathering rich data on individuals' experiences. Existing research has mostly investigated between participant differences in HIV disclosure, however it would also be useful to understand potential within participant differences (e.g. the factors influence disclosure to some friends but not others). In addition, very little is known about the ways in which friendships influence how young people adjust to living with BAHIV.

### **Research aims and questions**

The study aims to develop a theoretical model of friendships and disclosure decisions within friendships in young people living with BAHIV. The study also aims to answer the following research questions:

- What factors impact on the development of friendships in young people living with BAHIV?
- What factors influence disclosure of HIV status to friends in young people living with BAHIV?

- What is the role of friendships post-diagnosis in young people living with BAHIV?

## **Chapter 2: Method**

### **Research Design**

The study adopted a qualitative cross-sectional design. A Grounded Theory approach was used (Charmaz, 2014).

### **Inclusion and exclusion criteria**

Young people were eligible to participate in the study if they were:

- Aged 16-26. This was to form a coherent group of young people with similar developmental features, particularly in terms of close relationships.
- Living with behaviourally acquired HIV (BAHIV)
- Diagnosed for at least one year at the time of interview. This was to allow for adequate time to process and adjust to their diagnosis, and to allow opportunities for HIV disclosure to friends to take place.
- Fluent enough in speaking and comprehension of English to allow the interview to take place without the use of an interpreter. This was to avoid the validity of the study being compromised if direct or accurate translation was not possible.

Young people living with BAHIV who were deemed by their clinical team to be experiencing emotional problems and / or actively using substances to a degree that might impact their ability to engage in the interview were excluded from the study. This included young people who were identified as significantly high risk (e.g.

evidence of suicidal ideation or active self-harm). These decisions were made to ensure participant safety and reduce the risk of undue distress. The term young person refers to a particular period of life between childhood and adulthood with varying definitions of specific age ranges. Studies investigating young people living with HIV have included participants of different age groups, ranging from 12 (e.g. Michaud et al., 2009) to 30 years old (McFadden et al., 2014).

### **Research sites**

Participants were recruited from two inner city London hospitals between August 2015 and February 2016. The prevalence of HIV is high in both London boroughs of the research sites. In 2014, the prevalence of HIV diagnoses per 1,000 people (aged 15-59) was 15.08 and 5.29 for the primary and secondary research sites, respectively (PHE, 2015d). At the primary research site most eligible participants attended the Young Adult Clinic (YAC). This clinic provides support for young people (aged 18+ with no strict upper age limit) who are either newly diagnosed (young people living with BAHIV) or transitioning from paediatric services (young people living with PAHIV). The team consists of specialist HIV doctors and nurses, a dietician and health advisor. The YAC also has links to specialist support services, such as pharmacy and counselling. Data on the number of eligible participants at the primary research site at the time of recruitment was unavailable. At the secondary research site one participant was recruited from the YAC and another was recruited from a general adult HIV clinic. The YAC team at the secondary research site consists of the same team members as primary research site, although the attendees are typically (more than 95%) young

people living with PAHIV. At the secondary research site 27 eligible participants attended for HIV clinic appointments in 2015. The DNA rates for the YACs at both research sites are high. Between April 2015 and April 2016 the DNA rate for the YAC at the primary research site was 28.4%. The DNA rate for the YAC at the secondary research site was 32% in 2015.

## **Choice of Methodology**

### **Qualitative analysis**

The study aimed to develop a theoretical model to understand and represent the social and psychological processes involved in the friendships of young people living with BAHIV. A qualitative approach was deemed appropriate because it lends itself best to understanding individuals' perspectives and allows participants to elaborate on areas that feel most important to them (Elliot, 1995). While quantitative methodology is used to explore the "reality" of the world, qualitative methodology can allow generation of theory based on individuals' constructed meaning (Forrester, 2010).

### **Grounded Theory**

Grounded Theory originally emerged from the work of sociologists Glaser and Strauss (1967) as a method of qualitative analysis that aimed to move qualitative inquiry beyond descriptive studies towards abstract theoretical explanations of social processes. It offered an inductive approach in which data is gathered and analysed systematically and recursively, using a set of rigorous strategies to guide the research

and emergent theory (Charmaz, 2014). Grounded Theory was novel in allowing researchers to stick closely to the data rather than forcing it to fit pre-existing ideas (Glaser & Strauss, 1967).

Grounded Theory was selected in line with the aim of the study to develop a theoretical model of friendships in young people living with BAHIV. It enables the development of a theory that is “inductively derived from the study of the phenomenon it represents” (Strauss and Corbin, 1990, p.23), thus the term Grounded Theory refers to both the methodology and the theoretical product of the research (Charmaz, 2014). Grounded theories are closely informed by actual events and interactions of participants and their communication with others (Holloway, 2005), which is particularly useful for exploring the concept of friendships.

### **Exploring other qualitative methods**

Other qualitative approaches were considered in the early stages of design, however Grounded Theory was deemed to be best suited to the aims of the study. A brief description of these approaches and reasons for not selecting them are outlined below:

### ***Interpretive Phenomenological Analysis (IPA)***

IPA is an approach to qualitative research that attempts to understand lived experience and how participants make sense of these experiences (Pietkiewicz & Smith, 2014). IPA combines ideas from phenomenology and heuristics, resulting in a

method that is both descriptive and interpretive. It involves rich in-depth analysis of individual experiences of participants in their unique contexts, focusing on the particular rather than universal (Smith, Harré, & Van Langenhove, 1995). The degree of interpretation by the researcher found in this approach does not lend itself to the development of a theory grounded closely in actual experience, as aimed by the study. Given the social relevance of friendships and HIV-related stressors Grounded Theory was deemed to be more appropriate than IPA, which focuses heavily on the individual (Pietkiewicz & Smith, 2014).

### ***Discourse Analysis (DA)***

DA is a way of conceptualising and analysing language (Charmaz & McMullen, 2011). There are many varieties of DA with roots in philosophy, sociology, linguistics, psychology, and literary theory (Wood & Kroger, 2000). In psychological research, DA focuses on the way language is used to construct the reality of participants' worlds (Giles, 2002). The assumption is that multiple realities exist and that these are influenced by prior experience, knowledge and assumptions, i.e., discourses. While a social constructionist positioning to knowledge is consistent with the study's approach, it was felt that the outward focus on broader societal narratives in DA would not allow for sufficient exploration of individual experience and meaning, as aimed by the study.

### **Divergent methods in Grounded Theory**

Since Glaser and Strauss' early work (1967; Glaser, 1978) they have taken Grounded Theory in somewhat different directions. In line with their original conceptualisation, Glaser regards Grounded Theory as "a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area" (Glaser, 1992, p. 16). In contrast, Strauss and his co-author, Corbin (1987; Corbin & Strauss, 1990; Strauss & Corbin, 1990; 1998), put forward a more linear approach to the methodology and define Grounded Theory as a method of verification. Glaser (1992) argues that Strauss and Corbin's approach contradicts fundamental principles of Grounded Theory and forces data and analysis into preconceived categories, resulting in "full conceptual description". Despite their differences, both Glaser and Strauss remain faithful to the positivist belief that the researcher holds a neutral position in analysis. More recent researchers have argued against this assumption and instead suggest that social reality is multiple and constructed, formed by social processes rather than discrete events (e.g. Clarke, 2012; Charmaz, 2014). They believe that the researcher's position, privileges, perspective, and interactions must be taken into account as an inherent part of the research reality. This constructivist approach views research as constructed, rather than discovered, which in turn fosters the researcher's reflexivity about their actions and decisions (Charmaz, 2014).



### **Rationale for using Charmaz's Constructivist Grounded Theory**

The constructivist approach was deemed appropriate for the study in line with the researcher's own ontological, epistemological, and methodological orientations (Jeon, 2004). In agreement with Charmaz (2014), the researcher believed that their position and involvement in the construction and interpretation of the project must be accounted for. Unlike earlier versions of Grounded Theory, this approach allowed for more methodological flexibility in acknowledging that a literature review may need to be conducted before data collection for the purpose of ethical approval (Charmaz, 2014).

### **Reflexivity**

In the study the researcher was a Trainee Clinical Psychologist with an interest in working in clinical health psychology. It was anticipated that the researcher would differ from participants in several ways, particularly in terms of ethnicity and sexuality. The majority of young people living with BAHIV in the UK are MSM (PHE, 2015c), followed by those of black African origin (PHE, 2015c). The researcher was a 28-year-old white-British, heterosexual female without a diagnosis of HIV. It was important that any personal or intellectual assumptions were reflected on throughout the research process to enhance the credibility of the findings (Mayes & Pope, 2000).

The researcher had some previous knowledge of HIV having attended sexual health academic lectures and being friends with someone living with HIV. These experiences

are likely to have been significant in the researcher's open and accepting attitude towards people living with HIV and other sexually transmitted diseases. The researcher also had experience of working psychologically with young people (aged 18 and over) living with Sickle Cell Disease (SCD), who were largely of black African and black Caribbean origin. Similar to HIV, young people living with SCD are at risk of experiencing health-related stigma (Jenerette & Brewer, 2010). These experiences helped the researcher to understand some of the potential challenges facing young people living with a long-term, stigmatised health condition. The researcher kept a diary so that thoughts, reflections and responses could be recorded throughout the research process. These were also discussed regularly with the academic supervisor. As well as reflecting on values and assumptions, the diary offered an opportunity for the researcher to document any initial concerns about the study and how these could be overcome, sampling decisions, thoughts on the quality of the data gathered, and observations about the context of data collection (Henwood & Pigeon, 1992).

## **Procedure**

### **Ethical approval**

The study was granted ethical approval from an NHS Research Ethics Committee in April 2015 (Appendix 1) and from Royal Holloway, University of London Psychology Departmental Ethics Committee (DEC) in June 2015 (Appendix 2). Research and Development (R&D) approval was gained from the primary research site in May 2015 (Appendix 3) and the secondary research site in June 2015 (Appendix 4).

Consideration was given to possible ethical implications of the research, particularly due to the potentially sensitive nature of the data. Full details of how ethical considerations were addressed are included in the Participant Information Sheet (Appendix 5). The main ethical considerations for the study were:

- **Voluntary basis of participation:** Participation in this study was voluntary and did not affect participants' care at either research site.
- **Confidentiality:** Anonymity of participants' identities was maintained at all times and participants were informed about the limits of confidentiality if any significant risk was disclosed.
- **Informed consent:** Information was provided to enable informed consent to be obtained. Participants were given opportunities to ask questions or consult with others before taking part.
- **Right to withdraw:** Participants were given the right to withdraw from the study up to a specific date and were given clear information on how to do so.
- **Emotional distress:** Following all the interviews participants were asked about their experiences of being interviewed by the researcher. No participants required further psychological support, although three said they might consider it in the future.

#### **Recruitment process: Primary research site**

##### ***Step 1: Engagement with the team***

Before beginning recruitment the researcher attended several meetings with the lead Consultant (Field Supervisor) of the Young Adult Clinic to discuss the project. The

researcher also attended a clinical team meeting to discuss the project with other clinic staff and to distribute written materials to aid recruitment (Appendix 6).

### ***Step 2: Identifying participants***

At the beginning of each clinic a patient list was reviewed and staff identified any potential participants.

### ***Step 3: Introducing the study***

Recruitment only took place when the researcher was on site. The clinic staff introduced the study to potential participants during their appointment. Only eligible participants were informed about the research. Those who were interested were given an information sheet and given the opportunity to meet with the researcher on site. On meeting the researcher the information sheet was reviewed and participants were given the opportunity to ask questions.

### ***Step 4: Arranging participation***

If they wished to take part, participants could opt to either complete the interview on the same day or arrange an alternative time to come back (during clinic hours only). Ethical approval was granted to interview participants on the same day as they were informed about the research. Participants who were interested but unable to meet the researcher that day were asked permission by clinic staff for their contact details to be passed on to the researcher.

### ***Step 5: Informed consent***

Written informed consent was obtained from each participant before the interview took place (Appendix 7).

### ***Step 6: Interviewing and debriefing***

After the interview all participants were given the opportunity to reflect on their experience of the interview with researcher and, if appropriate, informed of ways to access further psychological support. Participants were reimbursed £15 in high street vouchers for their time. Those who interviewed at a time outside of their routine clinic appointment were also reimbursed travel expenses. All participants were asked if they would like to be contacted at the end of data collection to discuss feedback on the results. Three participants volunteered.

### **Recruitment process: Secondary research site**

Recruitment at the secondary research site followed the same process as the primary research site, with the exception of step 2. Rather than attending the same clinic regularly for recruitment, the researcher targeted different clinics to attend based on the inclusion criteria. The researcher made contact with a Data Quality Analyst at the secondary research site who produced an anonymous list of appointment dates and times for eligible participants. The lead Consultant sign-posted the researcher to the relevant clinical teams to discuss exclusion criteria. Decisions to attend certain clinics were made based on participant eligibility and the researcher's availability.

### **Response rate**

A response rate of 77% was achieved for recruitment, where three people declined participation after speaking directly to the researcher. Two did not give a reason and one raised concerns about confidentiality. The same response rate was achieved for feedback on data analysis. The three participants who volunteered were contacted (via e-mail) at the end of data collection. Two participants (7 and 8) responded however Participant 8 was unable to arrange a suitable time to speak on the telephone within the allocated time frame.

### **Interview schedule**

Semi-structured interviews were selected as the method of data collection. An initial version of the interview schedule (Appendix 8) was drafted in collaboration with the academic supervisor, prior to data collection. The questions were developed based on the research questions and previous literature. Interview questions were generally open-ended and non-judgemental to encourage unanticipated statements and stories to emerge (Charmaz, 2014). Questions were framed with the intention to explore, not to interrogate (Charmaz, 1991). The interview schedule was structured so that participants were initially asked about themselves (e.g. *What sorts of things are you interested in?*) and their HIV diagnosis (e.g. *What is it like living with HIV?*) before moving on to talk about friendships. The order of questions was guided by participants' responses. Participants were asked about their perceptions of friendships over time and the factors that motivate them in HIV disclosure decision-making to friends. They were encouraged to think about friendships in the context of

other members of their social network (such as family, sexual partners, and romantic relationships).

Feedback on the draft interview schedule was sought from two service-users (people living with HIV) who were not eligible for the study but who were diagnosed between the ages of 16 and 26. The first service-user, a white-British male (aged 37), was known personally to the researcher and volunteered their participation. The second service-user, a 26-year-old middle-eastern male (diagnosed less than one year ago), was recruited through the primary research site. Service users were consulted separately by the researcher, face-to-face. The researcher met with the first service user before data collection and the second service user between participants 4 and 5. Service-users were given written information to guide their feedback (Appendix 9). Upon collating both sets of feedback, a number of small changes were made to the interview schedule (Appendix 10, changes are underlined) to incorporate some of the ideas discussed. The changes consisted of additional questions relating to HIV disclosure decisions.

### **Data collection**

Prior to data collection a pilot interview was conducted with the academic supervisor. This helped the researcher to familiarise herself with the interview schedule and gain confidence in adapting the order of interview questions based on the interviewee's responses. During data collection the interview schedule was used as a guide. General topics were covered across all interviews while specific additional or prompt

questions were asked based on participants' responses. Questions were occasionally repeated or paraphrased to confirm participants' understanding. Throughout the interviews the researcher provided participants with summaries of their narrative to ensure that they had been understood and interpreted correctly (Forrester, 2010). All participants were asked about their experience of the interview afterwards. Most participants commented that they had enjoyed talking to the researcher and all participants described it as a novel experience. Although some of the questions touched on potentially sensitive topics, none of the participants became noticeably distressed during the interviews.

The researcher carried out all interviews. Eight were conducted at the primary research site and two were conducted at the secondary research site. All interviews took place during clinic hours. The researcher ensured that there was a private room available where the participant could talk openly about their experiences. All interviews were audio recorded. Observations about the setting and personal reflections on the interview were recorded in the research diary at the end of each interview (Mills, Bonner & Francis, 2006). Interviews lasted between 30 minutes and one hour, although the majority lasted approximately 50 minutes.

### **Theoretical sampling**

Charmaz (2014) defines theoretical sampling as the process of "seeking and collecting pertinent data to elaborate and refine categories in your emerging theory" (p.192). The aim of theoretical sampling is conceptual and theoretical development of



analysis; it is not about representing a population or increasing the statistical generalisability of research findings. The process of theoretical sampling ensures that the researcher constructs full and robust categories and helps to clarify the relationships between categories (Charmaz, 2014). In the study the researcher used theoretical sampling by adapting the interview schedule to ask about experiences not covered in earlier interviews. The researcher regularly reflected on participants' responses with the academic supervisor and any ambiguities and key areas of interest were identified. These were then added to the interview schedule to be explored with subsequent participants. A list of additional questions can be seen in Appendix 11.

### **Participant characteristics**

There were ten participants in the study. Table 2 outlines relevant demographic characteristics of participants, to situate the sample and help provide context for the research. Prior to beginning the interview participants were asked to complete a demographic questionnaire (Appendix 12). After the interview, with consent, participants' doctors were asked to complete a health information sheet (Appendix 13). Nine participants were taking Anti-retroviral therapy (ART) and the remaining participant (Participant 9) was due to begin ART on the day of interview. Participants consisted of five UK born and five non-UK born young people living with BAHIV. English was a second language for three participants and four participants received a HIV diagnosis outside of the UK. Data was collected for participants' most recent CD4 count and viral load. All CD4 counts were taken within 12 months of interview and

viral loads were taken within 6 months. Participant 7 had recently undergone a course of chemotherapy for lymphoma, which can dramatically lower CD4 count.

**Table 1. Participant characteristics**

Ppt. No.	Sex	Age	Age at diagnosis	Ethnicity	Country of birth	Sexual orientation	Relationship status	Employment status	CD4 count <sup>7</sup>	Viral load	Clinician rated ART adherence
1	M	22	20	Latino	Ecuador	MSM	Co-habiting	Employed PT	375	Und. <sup>8</sup>	>90% (good)
2	M	25	24	Black African	Nigeria	Heterosexual	Regular partner (not co-habiting)	Unemployed	492	Und.	>90% (good)
3	M	25	21	White British	England	MSM	Single	Employed FT Education PT	585	Und.	>90% (good)
4	F	23	16	White British	England	Heterosexual	Single	Employed FT	500	Und.	>90% (good)
5	F	26	16	Black British	England	Heterosexual	Single	Unemployed (FT mother)	261	Und.	>90% (good)
6	M	25	15	Black African	Eritrea	MSM	Single	Unemployed	358	Und.	>90% (good)
7	M	23	21	Black Caribbean	England	MSM	Co-habiting	LT sick leave	45	Und.	>90% (good)
8	M	25	22	Black Caribbean	Trinidad & Tobago	Bisexual	Regular partner (not co-habiting)	Education FT	629	Und.	>90% (good)
9	M	23	22	Spanish	Spain	MSM	Single	Employed FT	444	64865	N/A
10	M	25	24	Black Caribbean	England	MSM	Regular partner	Employed FT	183	740	>90% (good)

<sup>7</sup> A CD4 count ranges from 500–1,200 cells/mm<sup>3</sup> in healthy adolescents/adults (without HIV)

<sup>8</sup> Undetectable viral load

## **Analysis process**

### **Transcription**

The researcher transcribed all interviews verbatim within one week of the interviews taking place.

### **Coding**

In Grounded Theory coding means attaching labels to segments of data to describe what each segment is about. Charmaz (2014) suggests that it is through coding the researcher raises analytic questions about the data from the very beginning of data collection. Coding gives the researcher an opportunity to refine and sort data, and make analytic comparisons between data segments (Charmaz, 2014). In Charmaz's constructivist Grounded Theory there is a minimum of two stages of coding: initial coding and focused coding. The researcher followed the method of analysis outlined below.

#### ***Phase 1: Initial coding***

The researcher ensured that initial coding stuck as closely to the data as possible. It was important for the researcher to view initial codes as provisional so that other analytic possibilities could be considered (Charmaz, 2014). Codes were also viewed as provisional in the sense they were occasionally reworded to improve their fit with the data. Charmaz (2014) identifies four questions that initial coding should seek to answer:

- "What is the data a study of?" (Glaser, 1978, p. 57; Glaser and Strauss, 1967)

- What do the data suggest? Pronounce? Leave unsaid?
- From whose point of view?
- What theoretical category does this specific datum indicate? (Glaser, 1978)

Initial coding prompted the researcher to see areas in which data was lacking and identifying these gaps formed part of the analytic process. An advantage of using a Grounded Theory approach is that gaps and queries identified in the early stages of analysis can be later explored through subsequent data collection (Charmaz, 2014). The researcher adopted a reflexive approach to initial coding and discussion with the academic supervisor generated new ideas and insights into the data.

Line-by-line coding was conducted to prompt the researcher to remain open to the data and to gain a closer look at what participants had said, including implicit concerns as well as explicit statements. A label or short summary was coded for each line of data. The use of gerunds (nouns made from verbs, i.e. verbs ending in “ing”) was employed to capture processes (Charmaz, 2014), for example “feeling uncertain” as opposed to “he did not know his HIV test result”.

A key component of initial coding is the use of comparative methods (Glaser and Strauss, 1967) to establish analytic distinctions between data. At the first level, the researcher compared data with data to find similarities and differences in how individual participants spoke about their experiences. Secondly, data between participants was compared to explore similarities and differences in participants’

interpretations and descriptions of their experiences. The use of constant comparison is helpful in working towards “theoretical saturation”, or data satisfaction. Data is regarded as saturated when no new categories or theoretical insights emerge (Charmaz, 2014). This concept is controversial among qualitative researchers and Dey (1999) instead argues for “theoretical sufficiency” to describe how researchers conduct Grounded Theory.

### ***Phase 2: Focused coding***

Focused coding involves making decisions about which initial codes make the most analytic sense to categorise the data inclusively and completely (Charmaz, 2014). Focused codes are more conceptual than initial codes and help form the theoretical direction of the research (Glaser, 1978). A key aim of focused coding is to determine the adequacy and conceptual strength of initial codes. During focused coding the researcher looked back on initial codes to consider their meaning and the comparisons made with and between them. It was important for the researcher to take a critical and measured stance towards focused coding (Charmaz, 2014), to avoid over-interpretation or forcing data in to preconceived categories.

### **Writing memos**

Memo-writing is a crucial part of Grounded Theory (Charmaz, 2014). During both initial and focused coding the researcher wrote memos to explore reflections, ideas, and concepts arising from the data (Appendix 14). Charmaz (2014) states that memo-writing provides a space for the researcher to become actively engaged in the data,

develop ideas, fine-tune subsequent data-gathering, and engage in critical reflexivity. Memos allowed for the comparison of data and were vital in linking each stage of coding towards the final development of conceptual categories. The researcher stored memos electronically so that they could be added to over the course of analysis.

### **Theoretical coding and diagramming**

The purpose of theoretical coding is to help the researcher create relationships between focused codes and move the analysis in a theoretical direction (Charmaz, 2014). Theoretical coding allowed the researcher to develop focused codes in to concrete and specific categories before integrating them in to a model. Memo-writing was vital to this process and it was through memos that categories were tentatively developed. The emergent theory was made up of theoretical codes, each made up of a selection of focused codes. Initial codes and direct participant quotations were also used to provide further explanation. A diagram was used to provide a visual representation of codes and their relationships (see Figure 1, Chapter 3). Diagrams have the advantage of demonstrating the relative power, scope, and direction of theoretical and focused codes, as well as the connections between them (Charmaz, 2014).

### **Quality assurance in qualitative research**

Published guidelines on good practice and quality in qualitative research were adhered to (Elliot, Fischer & Rennie, 1999). This included:

### **Owning one's perspective**

As explained, the researcher kept a diary to make their own thoughts and values explicit and used supervision to reflect on how these might influence the collection and interpretation of data. Extracts from the diary are included in Appendix 16.

### **Situating the sample**

To situate the sample and provide context for the research relevant demographic characteristics of participants have been provided in Table 1. This also provides an opportunity for the reader to assess the generalisability and applicability of the findings.

### **Grounding in examples**

The researcher included direct quotations from participant interviews in the memos to illustrate any developing codes. Extracts from one interview transcript is included (Appendix 15) to demonstrate the interview process and the process of initial and focused coding.

### **Providing credibility checks**

A peer supervision group was set up with several other Trainee Clinical Psychologists who were also adopting a Grounded Theory approach. This was extremely useful in allowing for discussion about methodology and analysis, particularly as one of the Trainees was also carrying out a study involving young people living with HIV. Peer supervision entailed looking at and commenting on one another's codes, categories



and models. The academic supervisor provided feedback on two participant transcripts (commenting on the researcher's interview technique and initial coding), two draft tables of focused and theoretical codes, and a draft model.

### **Coherence**

The researcher aimed to achieve coherence by naming the theoretical codes appropriately and providing a clear and integrated summary of analysis. This was achieved by mapping out the emergent theory using a diagram, as well as providing a narrative account to understand the categories and the relationships between them.

### **Resonating with readers**

At the end of data collection, final draft versions of the table of codes and diagram were discussed with one participant (Participant 7) to check that the analysis accurately represented their experiences and made sense overall. The relevant documents were sent via e-mail and discussed on one occasion over the telephone.

## Chapter 3: Results

The analysis is presented below alongside direct quotations to illustrate the focused codes comprising each theoretical code. All identifying details of participants have been removed to maintain confidentiality. Participants are referred to using numbers 1-10 to maintain anonymity (see Table 1.).

Four theoretical codes were identified and are presented in Table 2. These theoretical codes comprise 12 focused codes, each containing a number of specific properties developed during the initial stages of coding. A summary table in Appendix 17 documents the presence of focused codes across all participants. A diagrammatic model is presented at the end of this chapter, demonstrating the interrelationships between the theoretical codes and focused codes.

Five of the ten participants had disclosed their HIV status to friends. Out of these five, all participants had disclosed to more than one friend. The five that had not disclosed to any friends had disclosed to other members of their social network, including parents, siblings, and intimate partners. Participants that had disclosed to friends tended to disclose to some friends and not others, which enabled them to reflect on factors facilitating and hindering disclosure within different friendships.

**Table 2. Theoretical codes, focused codes and initial codes**

THEORETICAL CODES	FOCUSED CODES	PROPERTIES OF CODES (INITIAL CODES)
<b>1. Personal factors influencing HIV disclosure decisions in friendships</b>	<b>1.1. Identifying pre-diagnosis knowledge and beliefs about HIV</b>	Being uneducated about HIV
		Believing that HIV means you are going to be really unwell or die
		Understanding HIV through friends living with HIV
		Wanting to avoid people living with HIV
	<b>1.2. Identifying personal beliefs about friendships</b>	Wanting to maintain boundaries between self and friends
		Being true to oneself within friendships
	<b>1.3. Thinking about the consequences of disclosing to friends</b>	Wanting emotional support from friends
		Believing there is nothing to gain by disclosing to friends
<b>2. Social factors influencing HIV disclosure decisions in friendships</b>	<b>2.1. Considering the nature of friendships</b>	Knowing other people with HIV
		Identifying positive personal qualities of friends
		Considering longevity of friendships
	<b>2.2. Difficulty trusting friends</b>	Predicting friends will intentionally disclose HIV status to others
		Predicting friends will unintentionally disclose HIV status to others
	<b>2.3. Not wanting to burden friends with HIV</b>	Believing HIV is one's own problem
		Not wanting to distress friends
	<b>2.4. Identifying pre-existing negative beliefs about HIV held by friends</b>	Thinking HIV is taboo
		Predicting that friends would be worried about contracting HIV
		Witnessing friends reacting negatively to other people living with HIV

		Predicting being judged by friends
		Predicting being rejected by friends
<b>3. Disclosure decision outcomes in friendships</b>	<b>3.1. Positive outcomes following HIV disclosure to friends</b>	Feeling more valued by friends and valuing friends more
		Feeling supported by friends to live well with HIV
	<b>3.2. Complications associated with non-disclosure to friends</b>	Hiding / lying to friends about HIV medication
		Hiding / lying to friends about hospital appointments
<b>4. Post-diagnosis experiences of friendships in the context of other aspects of life</b>	<b>4.1. Friendships being unchanged by HIV</b>	Doing normal things with friends
		Not feeling different to friends
	<b>4.2. Receiving HIV-related support elsewhere</b>	Receiving support from a partner over friends
		Receiving support from professionals over friends
	<b>4.3. Comparing friends to other important things</b>	Valuing God more than friends
		Valuing work or hobbies more than friends

## **1. Personal factors influencing HIV disclosure decisions in friendships**

All participants described personal factors that influenced their decision to disclose to friends. These included individual beliefs about HIV and their friendships, as well as beliefs about the consequences of disclosure within friendships.

### **1.1. Identifying pre-diagnosis knowledge and beliefs about HIV**

Participants varied in their knowledge of HIV before they were diagnosed. All participants identified a process of acquiring knowledge following diagnosis, mostly through being educated by health professionals, seeking information independently online, or meeting other people living with HIV through charity support groups. Overall, participants described a shift in their perspective of HIV from their initial reactions to the weeks and months following diagnosis, resulting from direct experience of living with the virus. Five participants identified being uneducated about HIV before being diagnosed. For some participants this meant having inaccurate beliefs about HIV transmission, whereas others identified knowing little about the virus or how it is treated.

*“...We used to feel that even when you handshake HIV would be transmitted, so we kind of were horrible...so like, once you have it, everybody around you can get infected” (P2)*

*"I never really heard about it. I never, like – because even in school when we done sex education class we were never told much on STDs or STIs, it was more about how to use a condom. And like, falling pregnant" (P4)*

When reflecting on their own pre-diagnosis knowledge and beliefs about HIV some participants spoke collectively about their experiences by using the term "we". For Participant 2 this referred to a shared identity of being Nigerian, as most of his friends were also from Nigeria. Participant 4 used the term "we" to describe herself and her peers of the same age. While participants described a shift in their own perspective of HIV, it is possible that they believed that their friends (who are not living with HIV) held similar knowledge and beliefs to themselves before they were diagnosed. This may have, in turn, influenced their subsequent disclosure decisions.

Three participants identified believing that being diagnosed with HIV meant becoming really unwell or dying. Two participants related this belief to their cultural background and one participant described being influenced by the media.

*"So the kind of picture every African has in mind of HIV is like, once get you get it, you are dead" (P2)*

*"Where I come from, HIV positive you're not, like, a normal person. You got a picture of you know bony, like that, a zombie image, you know, in my head" (P6)*

*"I guess my experience of HIV was that you see in certain movies about people that get HIV and then die or get depressed or, you know, there is always tragedy after that. After the diagnosis, yeah" (P8)*

For these participants being diagnosed with HIV meant extreme negative consequences and therefore something they feared. Participants 2 and 8 appeared to believe that death or other negative consequences would happen imminently following HIV diagnosis. All participants that identified thinking HIV meant becoming really unwell or dying were black-African or black-Caribbean males.

Five participants that self-identified as MSM identified being friends with people living with HIV at the time of diagnosis. Two of these participants described understanding HIV through these friendships.

*"Before I used to be like 'urgh'... then I thought... I used to think 'I want to avoid that person, dah dah dah dah', like the stereotypical... but then when I knew the people and they'd tell me they had it, it wasn't an issue at all. I didn't feel any different towards them" (P3)*

*"Well... 'Cause – my friend was – I seen him living his life and he was alright, um, I always knew that there was always things about HIV, especially in London, and how you can still live well and healthy" (P10)*

For Participant 3 being friends with people living with HIV helped to alter previous beliefs about wanting to avoid people with the virus (which he identified as stereotypical), by reflecting on his own positive reactions to friends' diagnoses. Given that Participant 3 disclosed to some friends and not others, he may have perceived that certain friends shared a similar view to his own in the past. Participant 10 described feeling reassured by seeing a friend living well with HIV, which helped him to realise that HIV can have little impact on one's daily life.

Two participants who had not disclosed to friends identified thoughts of wanting to avoid people living with HIV in the past. Both participants referred to actual instances of meeting people with the virus and reflected on their reactions.

*"So that is like the picture they have, so I wouldn't blame them. It has happened to me also, when I heard that someone had HIV I was like "Wow! That man! I'm not going near"" (P2)*

*"Yeah. Um... um... 'cause that's kind of, that's kind of what I... somebody I had met – I knew – I had met before... um, told me they had HIV and I, kind of, pushed – ignored them – after that. So when I found out that I had it I felt really bad about that..." (P7)*

Participant 2 described feeling certain that his friends would share this view and identified feelings of empathy towards them. Participant 7 spoke hesitantly when



recalling his reactions and identified feelings of guilt. This demonstrates that being diagnosed with HIV changed his beliefs about the virus.

### **1.2. Identifying personal beliefs about friendships**

Participants spoke about their decisions to disclose to friends in the context of more general beliefs about friendships. Participants who had not disclosed to friends described their decisions based on beliefs about the extent to which personal information should be shared between friends. All of these participants were black-African or black-Caribbean males.

*“But as I’ve said earlier, there are some friends, there are certain things... although transparency is good [...] <sup>6</sup> no one is 100% transparent, that’s why we wear clothes. There is still something you have to cover” (P2)*

*“Yeah, because I’m alright. I don’t mind they know it because they’re my friends but friends shouldn’t know everything about you, there are some things – boundaries – with friends as well” (P6)*

Some participants reflected on their own personal traits or qualities when describing their disclosure decisions. This was evident for two participants who had disclosed to friends as well as one participant who had not. For these participants the decision to

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<sup>6</sup> A string of dots [...] denotes that a section of the extract has been removed to promote the clarity of the quote.

share or withhold their HIV status was consistent with how they perceived their identity within the context of friendships.

*“Yeah... I think it’s just because I’m an open person” (P4)*

*“No, I’m very quiet. Like, my friends didn’t even know I was coming here [the UK]<sup>7</sup> until – I told them – the last minute. Yeah... so, yeah I think I’m generally a very, very private person. And my friends, they know that and they’re just like, OK that’s just who he is” (P8)*

*“Well I would say I’m... I’m “outgoingly shy” [...] I’m very outgoing but I don’t like people to know me. Well, I don’t like them to know, um, that side of me... the deep, personal stuff. ‘Cause I like to keep things to myself and to have protection over me” (P10)*

For some participants the decision to withhold their HIV status from friends appeared to be a natural decision in line with how they saw themselves. For Participant 10, it appeared to be a way of avoiding a feared outcome, such as feeling exposed or vulnerable within friendships. While Participant 10 had disclosed to some friends, he identified a tendency to withhold personal information from friends more generally. It is possible that participants chose to present themselves differently with individual friends or friendships groups depending on their perceptions of them. In addition, it

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<sup>7</sup> Words placed within square brackets have been added by the researcher so that the extract can be easily understood.

may be that the factors driving HIV disclosure decision were prioritised differently with different friends, for example in the case of Participant 10 the desire to seek social support from friends (discussed in more detail in 1.3.) may have been more important than being true to his identity within certain friendships.

### **1.3. Thinking about the consequences of disclosing to friends**

Eight participants identified the perceived consequences of friends knowing their HIV status as a factor in their disclosure decisions. This appeared to centre on the extent to which they believed disclosing to friends could benefit them personally. Two participants that had disclosed to friends described doing so as a way of receiving social support, in the form of talking to friends about HIV.

*“I told her pretty much straight away, yeah. Pretty much straight away. I’m a person – I can’t keep things in – I’ve gotta speak to someone. Because if I don’t I’d probably go crazy. And I knew that she would be a really good person to talk to about it” (P4)*

*“‘Cause I know I need someone to talk to and I know she was a great person to speak to, and everything that we’ve spoken about recently, they’ve been more serious things, so I just know that she is going to be there to support me” (P10)*

Both friends identified by participants were female. For Participant 4 there was a real sense of obligation and urgency in her decision to disclose, where she considered the

potentially distressing consequences of non-disclosure. Both participants reflected on self-perceptions in their decision-making and identified feeling certain about positive disclosure outcomes. In contrast, five participants described withholding their status from friends because they anticipated little personal gain from disclosing. Participant 3 identified HIV as having little impact on his life and therefore perceived no particular reason to disclose to friends. Another participant described weighing up the consequences of disclosing to friends, where negative consequences within friendships were anticipated as more likely.

*“Don’t feel the need to tell them. Because, like, it’s always in the back of my mind but I’m never really thinking about it. It’s not really a problem for me. I forget I have it sometimes” (P3)*

*“No I don’t think it would add any benefit to me and there is the risk that it might make things awkward, and there is the risk of negative things happening if I tell them. So... no. ‘Cause I don’t see, like, the positives of telling my friends. Yeah” (P8)*

Participant 8 described feelings of uncertainty related to potentially damaging outcomes within friendships. His friendships appeared to be extremely important given that he identified even “awkwardness” between friends as something he is not willing to risk.

Two participants anticipated little personal gain from disclosing to friends due to believing that they were either managing independently or receiving sufficient support elsewhere (discussed in more detail in 4.2.).

*“Yeah, I’ve wanted to, but I’ve just thought ‘do you know what? I’m handling it by myself’. So I just do it by myself” (P5)*

*“Yeah – I think – I could tell him HIV, he would be alright with it. He would support me, but at this stage I don’t feel like I need support from people because I have the strongest support I can get” (P6)*

Both of these participants had been living with HIV for approximately 10 years. Participant 5 described wanting to disclose and contemplated the possibility of receiving at least some kind of support from friends, although stopped herself from doing so. It may have been that the feared outcomes of disclosing were greater than the perceived benefits, which influenced her decision to withhold her status. Similar to participants 4 and 10 (above), Participant 6 identified feeling certain about positive disclosure outcomes however the anticipated support from friends seemed incomparable to support he was receiving from professionals, which included a HIV charity as well as the clinic.

Despite anticipating little personal gain from disclosing to friends now, two participants contemplated changing their disclosure decisions in the future.

*“...let’s say I’m in hospital or I’m bed in the house. I’ll let them know, like, ‘guys, you know, from now on I need help. I need this, this, and that’, ‘I need you to be in hospital with me, or go to hospital with me, or give me company’. Yeah. At that stage obviously I have to tell everyone, but now it’s like I’m OK, you know. Let me just have that moment, you know. That peace. And enjoy it” (P6)*

*“Um... for the moment I’m just, I’m quite content with nobody knowing. I don’t really see the point. Um, in the future... in the future that might change. Um, but I don’t think I’ll ever necessarily bring it up, just to tell somebody that I’m positive. Unless I HAD to tell them” (P7)*

Participant 6 described wanting practical support from friends in the future if his health deteriorated. He identified the decision to disclose under these circumstances as obligatory, which implied a perceived sense of control to withhold his status now. Participant 6 anticipated negative changes in his friendships (i.e. disruption to the peace) following HIV disclosure and expressed a desire to maintain his friendships as there are. Participant 7 also acknowledged the possibility of feeling obliged to disclose in the future but described little intent to initiate disclosure conversations otherwise.

## **2. Social factors influencing HIV disclosure decisions in friendships**

All participants described social factors that influenced their decisions to disclose to friends, although the majority came from the five participants that had not disclosed to anyone. These factors related to participants' perceptions of individual friends, friendship groups, and the nature of their friendships in general.

### **2.1. Considering the nature of friendships**

Four of the five participants who had disclosed to friends identified specific characteristics of both individual friends and friendship groups that helped them initiate disclosure conversations. Participants 3 and 9, who self-identified as MSM, appeared to categorise friends quite distinctly according to whether or not they were involved in certain aspects of their lifestyle. Both participants described engaging in a "party" lifestyle (involving recreational drugs) in the past and identified sharing this with friends. In particular, they described disclosing to friends who were part of that lifestyle and therefore knew other people living with HIV, or friends that were living with HIV themselves. Both participants perceived that HIV would be considered more acceptable to these friends compared to other friends who had less experience of the virus and the "party scene" they associated it with.

*"Yeah... Yeah, exactly. I think she's more accepting, that's why. Like she don't have a problem at all [...]. Because she already had friends that had it. So it was, like, what's one going to be a problem?" (P3)*

*“Because the two friends that I told about this, they are like me. And we were since I moved after to Madrid in the same group of friends, and one of my friends also have this [HIV] and it is normal” (P9)*

Both participants seemed to affiliate themselves with these particular friends or friendships groups in identifying a shared accepting attitude towards HIV.

Two participants that had disclosed to friends described doing so because of the type of people they perceived their friends to be. They identified positive personal qualities in certain friends that gave them reassurance that they would respond favourably to disclosure.

*“My friends are open minds so they are not like... they don’t have any problem about... I don’t know, maybe yes some people is more... “What are you doing?”, “what did you do for have this [HIV]?”. No, my friends are not like this” (P9)*

*“She’s just great, she’s so – yeah – she’s just kind hearted and she accepts everything and she’s not a judger” (P10)*

Their decisions seemed to centre on anticipating that these friends would be accepting of their diagnosis. Participant 10 reflected on positive personal qualities of a recently acquired friend when considering people he might disclose to in the future.



Nine participants identified having close friendships, which they had maintained for many years. No participants described losing friends as a result of their HIV diagnosis. Two participants who had disclosed to friends reflected on the duration of their friendships when deciding whom to disclose to.

*“Like, if I know – if I have – a big feeling that they’re quite permanent in my life then I’ll, like, tell you. But... yeah, like, if I don’t, like, with colleagues, like, what’s the point? I could go and get another job tomorrow, so I just don’t see the point” (P4)*

*“Well it’s not possible because the people that I think that they are not going to react good, I am not going to tell. I know my friends since 5 years and the other one since 17... so I knew they would react OK” (P9)*

## **2.2. Difficulty trusting friends**

All participants that had not disclosed to friends identified feeling scared or worried about friends sharing their HIV status with other people. Four of these participants perceived that friends sharing their status would be intentional. Difficulties trusting friends tended to represent beliefs about other people generally rather than characteristics of individual friends. Participants appeared to trust friends in other ways and described positive experiences of friendships overall.

*“Because.... I don’t feel as confidence... many confidence, I am scared because they live in Spain. They are in the gay world in Spain. The gay Latin people in Spain, you know. I worry about that because I... if I explain they, they maybe explain to other people...” (P1)*

*“I just thought like – ‘cause you – I imagine if I was to ever tell you then, if I was to tell you I had it [HIV] you would have dropped my friendship and then you would have told it to whoever” (P5)*

Participant 5 anticipated friends sharing her HIV status repeatedly and carelessly after being rejected by them (discussed in more detail in 2.4.). Unlike all other participants, Participant 5 identified very few close friendships and appeared to hold quite fixed beliefs on trusting others, where she described feeling that nobody in her social network could be trusted.

One participant recalled an experience when a friend outside of her close friendship group shared her status with others, making her re-evaluate future disclosure decisions.

*“I’m more, like... conscious. Like... I mean, sometimes, because I’m such an open person and I think that I can trust everyone I’m like ‘uhhh’, but now I know like, no. I won’t saying nothing to anyone.*

*Interviewer: And what are your main concerns, is it that you'll think they'll....*

*Yeah, that they'll pass it on. Definitely. You can't trust anyone these days [laughs]" (P4)*

Participant 4 demonstrated black and white, or "all or nothing", thinking in completely ruling out the possibility of telling additional friends in the future. She spoke light heartedly about this decision, which could either imply some flexibility in her thinking (perhaps she did not really mean it) or that she was not particularly distressed by what happened.

Two participants who had not disclosed to friends identified concerns that friends would share their HIV status unintentionally. One participant linked this to the behaviour of his friendship group generally, whereas another participant described individual traits of a specific friend.

*"Something will happen tomorrow and it might just fuck it up, and all my friends are drinking, you know, they might get drunk and talk rubbish and like 'wahh...fuck you' and 'wahh... he's got HIV' and, you know, and everything" (P2)*

*"No, 'cause he's got a big mouth [laughs].*

*Interviewer: [laughs] OK, so you worry he might tell other people?*

*Um... probably not intentionally, but he'd probably be a bit like me and one day he'll accidentally let it slip" (P7)*

Both participants described feeling uncertain about the consequences of disclosing to friends. While they did not know for sure that friends would share their HIV status, the perceived consequences were bad enough for them not to risk it. In this sense, they were trying to gain control over an uncertain situation by withholding their HIV status. Neither participant seemed to consider an alternative, more positive, outcome of HIV disclosure. Participant 2 anticipated an inability to cope if friends shared his HIV status.

*"That's... I know that it [HIV] won't kill me, I can cope with that. But spreading the news, I won't be able to cope with that" (P2)*

It seemed that for Participant 2, other people discovering his HIV status outside of his control was one of the worst aspects of living with HIV and one that he feared the most.

### **2.3. Not wanting to burden friends with HIV**

Four of the five participants that had not disclosed to friends described withholding their status as a way of protecting friends from HIV. Most participants described an accepting attitude towards their diagnosis however they seemed to perceive that friends might think differently. Two participants who reported living well with HIV

identified feeling able to manage independently, although both had disclosed to their partners. Participant 1 described living well with HIV in terms of emotional wellbeing, whereas Participant 8 emphasised physical wellbeing.

*"You know, because I have this problem and it's my problem... it's not my friend's problem, no. It's my problem. I don't worry about it but all of the people around me they don't need it" (P1)*

*"It's just like, I mean why tell them anyway, it's nothing to them whether they know or they don't know. It's actually just about me and my personal life, and it's about me keeping myself healthy. So I don't see the reason to burden them with that" (P8)*

Some participants described withholding their status to avoid distressing friends, where disclosure decisions were made to avoid potentially negative consequences for friends rather than participants themselves. These participants seemed to value their friends in trying to protect them.

*"...they wouldn't be like "oh, go away!" but I feel like they would be sad for me"*  
(P6)

*"And, for that reason I don't like to explain to many people, because I don't want to worry... they [them]" (P1)*

#### **2.4. Identifying pre-existing negative beliefs about HIV held by friends**

Seven participants described withholding their status from friends due to anticipating that friends would either think or act differently towards them. All participants identified their friendships being largely unchanged by HIV and a big part of this was perceived as being the result of friends not knowing their status. In other words, for some if not all friendships, participants chose to withhold their HIV status as a way of avoiding potentially negative outcomes with friends. Two black-African male participants described witnessing friends being shocked by HIV and insinuating that it is a taboo subject.

*“Yeah. The kind of picture that everybody have in mind, that “HIV, wow!” (P2)*

*“...all my friends were like [whispers] ‘oh my god! He’s HIV positive’, you know. I was like guys, you gonna say that to me as well” (P6)*

Four participants perceived friends as having little understanding of the ways HIV is transmitted and therefore identified concerns that they would be worried about contracting it.

*“So if I use a cup everyone might not want to use that cup, so they will just be like sceptical of everything I do” (P2)*

*“Yeah. And they, like, sometimes joke about it, saying like ‘oh like, be careful you don’t get HIV’ and all those things” (P3)*

*“Yeah, that’s what saying, through other ways. Now, like, I get a cuddle. I get cuddle even in like Christmas I stay with them, it’s like, we sleep in the room happy together. They wouldn’t be that happy, if I tell them [...] They’d be like ‘urgh, I can’t sleep with him...’” (P6)*

For participants 2 and 6 withholding their HIV status seemed to serve as a way of avoiding negative consequences within their friendships. Participant 2 identified concerns about what his friends thought of him whereas Participant 6 anticipated potential changes in what he does with friends, in particular activities involving physical contact.

Four participants recalled actual experiences of friends reacting negatively to other people living with HIV, which made them think that they would react similarly towards them if they knew their status.

*“It’s like, like, when I’ve heard – for example – I heard someone actually sayin’, ‘if I knew someone with it [HIV] I wouldn’t talk to them’. Like, you’re just gonna drop your friendship because of the person’s sickness, it’s not like the person intend to have it” (P5)*

*“I have known one person to describe somebody else with HIV as dirty” (P7)*

All participants witnessed their friends’ reactions towards people living with HIV who they did not know well or had just met. Despite such differences in the duration and quality of their relationships, participants felt certain that their friends would react in the same way towards them if they disclosed their status.

Three participants that self-identified as MSM predicted being judged by friends if they disclosed their HIV status. Two of these participants had disclosed to some friends and one participant had not disclosed to any. In particular, participants predicted being judged about how they acquired HIV, in terms of past behaviour and lifestyle choices. Similarly to identifying positive aspects of friends that facilitated disclosure (described in more detail in 2.1.), participants 3 and 10 seemed to categorise their friends depending on whether they were also MSM and / or part of a particular “party” lifestyle associated with higher rates of HIV transmission. Accordingly, they described withholding their HIV status from the friends they perceived as either being heterosexual or outside of the “party scene”, due to feeling as though these friends would not understand their behaviour and therefore hold judgements about it.



*“Interviewer: So you think it might bring up stuff about your past and how you acquired HIV?”*

*Yeah... and I don't wanna explain all that. I don't want all the grief from people that's the problem” (P3)*

*“I don't have many gay friends. So obviously growing up around straight people I know the mentality, even though time has gone on, it's still the stigma behind gays and homosexuality, and HIV. And I just feel that, um, especially with my family and my childhood friends, it would be, um... I kind of – they'll look at me different – and everything would just be different” (P10)*

Both participants identified feeling certain about how their friends would react. Their perceptions of what it means to others to be MSM and living with HIV appeared to be related to broader societal beliefs, particularly for Participant 6.

Two participants predicted that they would lose friendships if they disclosed their status. For Participant 3 this was restricted to a particular group of friends whereas Participant 5 believed this to be true for all friends.

*“I won't tell them... Um. I dunno. I think that they would probably lose contact. That's what I think, yeah” (P3)*

*“He was like, ‘you can tell me anything, we’re good friends’, and I really wanted to tell him, it’s like I had to slap myself like, ‘really!’ I said, ‘right, if I might tell you, you must run a mile’. So... I just... thought, ‘there’s nothing to say’” (P5)*

Both participants seemed definite in their decisions and said that they would not consider changing their mind in the future, although Participant 5 described a clear desire to want to tell at least one friend. Both participants appeared to cope with disclosure decision-making by having a fixed rule to apply to either a particular group of friends or all friends. They adopted a coping strategy of avoidance to manage the anxiety (fear) associated with the anticipated negative consequences of disclosing to friends.

### **3. Disclosure decision outcomes in friendships**

Seven participants reflected on the impact of disclosure decisions on their experience of friendships. These related to positive outcomes for participants that had disclosed to friends, as well as complications associated with concealing HIV for participants that had not disclosed to friends.

#### **3.1. Positive outcomes following HIV disclosure to friends**

Two participants described positive changes in their friendships as a result of disclosing their HIV status, in terms of feeling more valued by friends or valuing friends more compared to before they were diagnosed.

*“Umm... My friends now is more... more sensitive. More care. I think maybe they love me more [...] because the reason is they don’t know when I die and for that reason they want to stay with me more time they can, you know. And my relation with my best friend is very nice now...” (P1)*

*“When you go through something like that you know who your true friends are!” (P4)*

Three participants that had disclosed to friends described feeling supported by their friends to live well with HIV, in providing a positive outlook towards their health. For two participants these included friends that were also living with HIV themselves.

*“I think the ones that had it – have HIV – like, I told them and they were like ‘it’s fine, it’s just normal. Just carry on <participant name>’” (P3)*

*“We had this, like, biggest heart to heart ever and he was like, ‘you just need to just do it, like, do what you need to do’” (P10)*

It may have been that participants felt a sense of being understood and accepted by these friends because of the shared experience of living with HIV. Both participants identified feeling reassured by friends.

### 3.2. Complications associated with non-disclosure to friends

Six participants identified complications with hiding their HIV status from friends, particularly in terms of medication and healthcare. For most participants these complications seemed to be relatively minor and did not appear to have a significant impact on their lives. Some participants described lying to their friends about HIV medication.

*“I’m crafty, I’ve got it in a little box, so they just think it’s multi-vitamins. So whenever I stay at their house... ‘I’m just taking my tablet’” (P3)*

*“Yeah. I suffer with sinusitis anyway so, my tablets, I told them it’s for my sinus. Or I suffer really bad migraines, or I’m depressed” (P5)*

Participant 5 described lying to friends about HIV medication using alternative health conditions. By seemingly feeling more comfortable disclosing other potentially stigmatising conditions, such as depression, to friends this suggests that HIV is perceived as an exception. This was similar for Participant 7 who made comparisons between HIV and cancer (he also had a diagnosis of lymphoma). While he acknowledged difficulties talking about cancer with friends, he described HIV as being significantly worse.

*“Um, cancer is awkward but I can manage it. HIV is just a no-go. I think it’s...[pause]... I think it just kind of makes you feel a bit dirty” (P7)*

Participant 7 identified feeling certain that he would not disclose his HIV status to friends, which appeared to be due to internalised stigma. The only other participant that described experiencing stigma in this way was Participant 3, who also self-identified as MSM. Interestingly, he used the same term as Participant 7 in describing how he felt being diagnosed with HIV.

*“I: And what did it mean to you when you were diagnosed, what did HIV mean to you?”*

*I just felt a bit dirty” (P3)*

Both participants believed that at least some of their friends would share the belief that HIV is “dirty”, which they described as being a key factor in their disclosure decisions.

One participant identified significant complications within friendships in trying to manage unpleasant side effects of HIV medication.

*“Before it was hard, ‘cause I was sharing flat with 4 people, like, 5 people. It was hard. They kinda like – that’s why I was – I keep moving house, because of my treatment. They kinda judge you, sometimes, they see you after 8 [after taking medication]... they see you act stupid...” (P6)*

For Participant 6 it seemed that the side effects of HIV medication were making it difficult for him to present himself positively to friends. Rather than disclosing his HIV status, he felt it was easier to repeatedly move house to avoid embarrassment. This suggests that the risk of disclosing his HIV status was greater than the perceived disruption to his life associated with moving.

Two participants that had not disclosed to friends described hiding or lying to friends about hospital appointments. These included close friends as well as colleagues who were labelled as friends.

*“But then, sometimes I have to go to the hospital and he’s like ‘why? You are not sick. What are you going there for?’ So, I tell him that the jaundice I had when I was in Nigeria, they still find traces in my blood, so I need to go for some antibiotics” (P2)*

*“I remember one time I had to go to the doctors, the hospital, and I was late to get to work and it was, like, I didn’t know how to tell them. Because I didn’t obviously want to tell them it was, um... yeah so things like that are kind of awkward” (P10)*

While Participant 2 did not appear to feel particularly distressed about lying to friends, Participant 10 identified feeling uneasy with the situation. He described

hinting at some kind of “taboo” appointment (a sexual health check-up) without disclosing completely.

*“I was like, “yeah, you know”... sort of went [winked]. Yeah, they were trying to ask if I was OK and if everything was all right and I just told them it was a check-up and gave a cheeky smile, like that it was at the sexual health clinic. But yeah, that was about it” (P10)*

It may have been that his feelings of uneasiness related to the act of lying, because it conflicted with his values or beliefs about friendships, therefore he tried to give as much information as possible without disclosing his HIV status. Alternatively, Participant 10 may have believed that by mentioning something related to sexual health this would prevent his friends from asking further questions (because of the “taboo” nature of the subject) and effectively put an end to the conversation.

#### **4. Post-diagnosis experiences of friendships in the context of other aspects of life**

As mentioned above, most participants identified their friendships as being largely unchanged by HIV. Participant 7 described changes within some friendships, namely withdrawing from friends at college due to feeling isolated or perceiving himself as being different to others because of his diagnosis. These changes were not described within his close friendships. Participant 5 described longstanding difficulties with trusting others and therefore identified few close friendships, however this seemed

to be mostly related to factors preceding HIV diagnosis. Participant 5 described particularly distressing experiences from childhood and adolescence, with regards to how she was treated by adults close to her as well as her peers. She identified being diagnosed with chronic depression by a Psychiatrist at the time of the interview and it is possible that the negative thoughts she identified about friendships and HIV were part of on-going difficulties with low mood. It is also possible that her diagnosis of HIV, on top of other distressing experiences in the past, precipitated these problems.

#### **4.1. Friendships being unchanged by HIV**

Participants did not describe any significant changes in their social activities as a result of HIV and identified doing normal things with friends, which at least in part seemed to be related to feeling healthy at the time of interview. Some participants acknowledged that this had not always been the case and identified problems with either adhering to medication regimes (Participant 5) or experiencing unpleasant reactions to medication (Participants 3 and 6) in the past.

*“We do... we go out together, we go clubbing. Drink. Every normal thing that friendship does” (P2)*

*“No, not at all. I still do everything the same. We still do the same stuff. Yeah. Like, nothing’s changed” (P4)*



Two participants described feeling similar to friends who are not living with HIV. While Participant 6 acknowledged some differences in living with HIV compared to her friends, these appeared to be related to more practical health-related behaviours rather than something within herself that set her apart from her friends.

*“I feel, I don’t feel... different much from them. Obviously, I’ve got to think more about things, like, if I want a baby I can’t just, like, go and have a baby. I have to, like... obviously they have to plan it as well if they want to, but, they haven’t got to be so protective of when they’re having sex, whereas I do. So... that’s the only difference in it” (P6)*

Participant 9 identified himself as similar to his friends in discussing adverse health behaviours, such as drinking alcohol excessively and smoking. He seemed comfortable engaging in these behaviours with friends in the same way as before he was diagnosed with HIV.

*“No, because it’s like... if you are smoking and you start to read about smoking, I know that it’s no good, but... what can we do? [...] I know that I’ve got to take care of myself, but I’m not always thinking, ‘oh my god, I have this [HIV]’. No. I have this and that’s all [...]. It’s the same for me as it is for my friends who do not have this [HIV]” (P9)*

Participant 9 described not wanting to dwell on his diagnosis of HIV and expressed a more accepting attitude towards it. On the other hand, he also identified wanting to avoid thinking about the potential risks associated with smoking and drinking alcohol, which could suggest an element of fear. In other words, perhaps it was too scary for him to think about the potential damage to his health and it was more important for him to engage in activities, such as drinking alcohol excessively, that are normal within his friendship group.

#### **4.2. Receiving HIV-related support elsewhere**

Overall, participants' experiences of living with HIV seemed to be similar regardless of whether or not they had disclosed to friends. As mentioned previously, the majority of participants described an accepting attitude towards HIV and identified living well at present. Two participants described elements of feeling distressed about their diagnosis, for example labelling themselves as "sick" (participants 1 and 5), describing feeling beaten by HIV (Participant 10), and wishing they could turn back time (Participant 5). In addition Participant 7 was living with a cancer diagnosis, which he perceived as being potentially related to HIV, and identified fears about further health complications in the future. All participants described receiving some form of HIV-related support and made comparisons between different members of their social networks. Three participants who identified being in a relationship described receiving support predominantly from partners rather than friends.

*"Interviewer: Are friends more helpful than family? Who is the most helpful out of everybody?"*

*Umm. My boyfriend [...] He is my... my major support. Yeah" (P1)*

*"What made it easier for me to tell my girlfriend is because she is the one I want to spend the rest of my life with, so I didn't... I need her support. So that's why I have to tell her" (P2)*

Participant 2 described feeling obliged to disclose to his girlfriend but not to friends. It may be that he held different beliefs about the importance of telling the truth to friends compared with partners, or he may have felt more of a responsibility to tell her in terms of risk of HIV transmission (given that he described them as being sexually active).

Participant 8 described a period of feeling depressed immediately after being diagnosed with HIV. He identified his partner as his major source of support during that time, particularly in terms of instrumental support.

*"I: How did you pull through that? What helped?"*

*Well, uh, my boyfriend at the time, he helped me a lot. In terms of like coming to appointments with me and doing anything I needed. Because I guess he felt bad about it as well" (P8)*

Participant 8 identified potential feelings of guilt by his partner whom he acquired HIV from. It is possible that he found support from his partner the most helpful due to the shared experience of living with HIV, which was not the case within his friendships. Participant 8 may have felt more easily understood by someone who has gone through the same process and receiving support from friends would have inevitably involved disclosing his HIV status, which he may have perceived as difficult or stressful. Participant 8 also identified receiving HIV-related support from health professionals, in terms of offering advice about HIV and feeling reassured about his health.

*“I guess talking to the clinicians and stuff and being reassured from them that I wasn’t gonna die suddenly. And yeah, researching and finding stories and finding more information about the virus and realising that OK, it is possible that I can have a healthy, normal life with the disease” (P8)*

For Participant 8 it appeared that distressing thoughts about the potential negative consequences of HIV at least in part fuelled his experience of feeling depressed. Participants 5 and 6 that had not disclosed to friends also described feeling supported by health professionals rather than friends. For Participant 5 this included staff at the clinic whereas Participant 6 emphasised support from a HIV charity organisation.

*“No. From the hospital, that’s it [...] They’re just really – they just listen and understand – and give me advice” (P5)*

*“Friends are very important. But what supports me now is [HIV Charity], they support me with a lot of things” (P6)*

#### **4.3. Comparing friends to other important things**

Three participants described prioritising other important things in life over friends.

One participant identified his religious faith as a protective factor in living with HIV.

*“Well, God is the number one. As far as I’m concerned, without God, I would not be able to live through it. Because, it’s got easier because God has put the strength in me. So God is the number one. In everything I do, God first” (P2)*

Two participants identified work and hobbies as priorities over friends. For Participant 3 this appeared to take over his life making little time for anything else, however Participant 7 described the emotional benefits of exploring his creativity in coping with HIV.

*“Well it’s a bit bad at the moment, because if I’m gonna go meet someone, I’ll blow them off straight away to do an extra class. Or do something at the gym, it’s like that for me. Work – straight away” (P3)*

*“But I guess more important than friends would be – I mentioned before that I study computer game arts – so I do spend a lot of time making things like that,*

*um, and drawing a lot. Um, I guess... being able to do that, it kind of helps me escape from anything else that's going on" (P7)*

Participant 3 appeared to prioritise work over all social relationships, which included intimate partners as well as friends. Participant 7 described the benefits of being creative as a private experience that allowed him to take time out from potentially distressing thoughts or emotions associated with living with both HIV and lymphoma.

### **A model of friendships and disclosure decisions in young people living with BAHIV**

The main aim of the study was to develop a model of friendships for young people living with BAHIV. Figure 1 below outlines how the theoretical and focused codes interact in relation to HIV diagnosis and disclosure decisions. The focused codes that were identified most frequently across participants (discussed in this chapter) have been included within the model. The model is set out chronologically moving from left to right. It begins with pre-diagnosis knowledge and beliefs about HIV (box 1.1.). The arrow from this box to social factors influencing HIV diagnosis in friendships (box 2.) represents the idea that participants may believe that their friends hold similar knowledge and beliefs to themselves before they were diagnosed, which could in turn influence how they anticipate their friends will react to HIV disclosure. For example, if they perceive that friends believe HIV means you are going to be really unwell or die, they might not want to burden them with disclosure. Similarly, the arrow from box 1.1. to box 1.3. demonstrates that participants' pre-diagnosis

knowledge and beliefs about HIV may influence the perceived consequences of disclosing to friends. Box 1.2. runs from the beginning to the end of the model to illustrate that participants held personal beliefs about friendships both pre- and post-HIV diagnosis. Participants' beliefs about friendships appeared to influence disclosure decisions, which included wanting to maintain boundaries between self and friends, and being true to oneself within friendships.

When participants were diagnosed with HIV they faced important disclosure decisions within friendships, such as whom to disclose to and when. Their friendships were experienced in the context of living with HIV, which included how they think and feel about friendships as well as what they do with friends. Participants' friendships were also experienced in the context of other relationships (e.g. intimate partners) and aspects of life (e.g. religion, work, and hobbies). These processes are demonstrated by the two large grey arrows from the box labelled HIV diagnosis to disclosure decision, and to box 4.

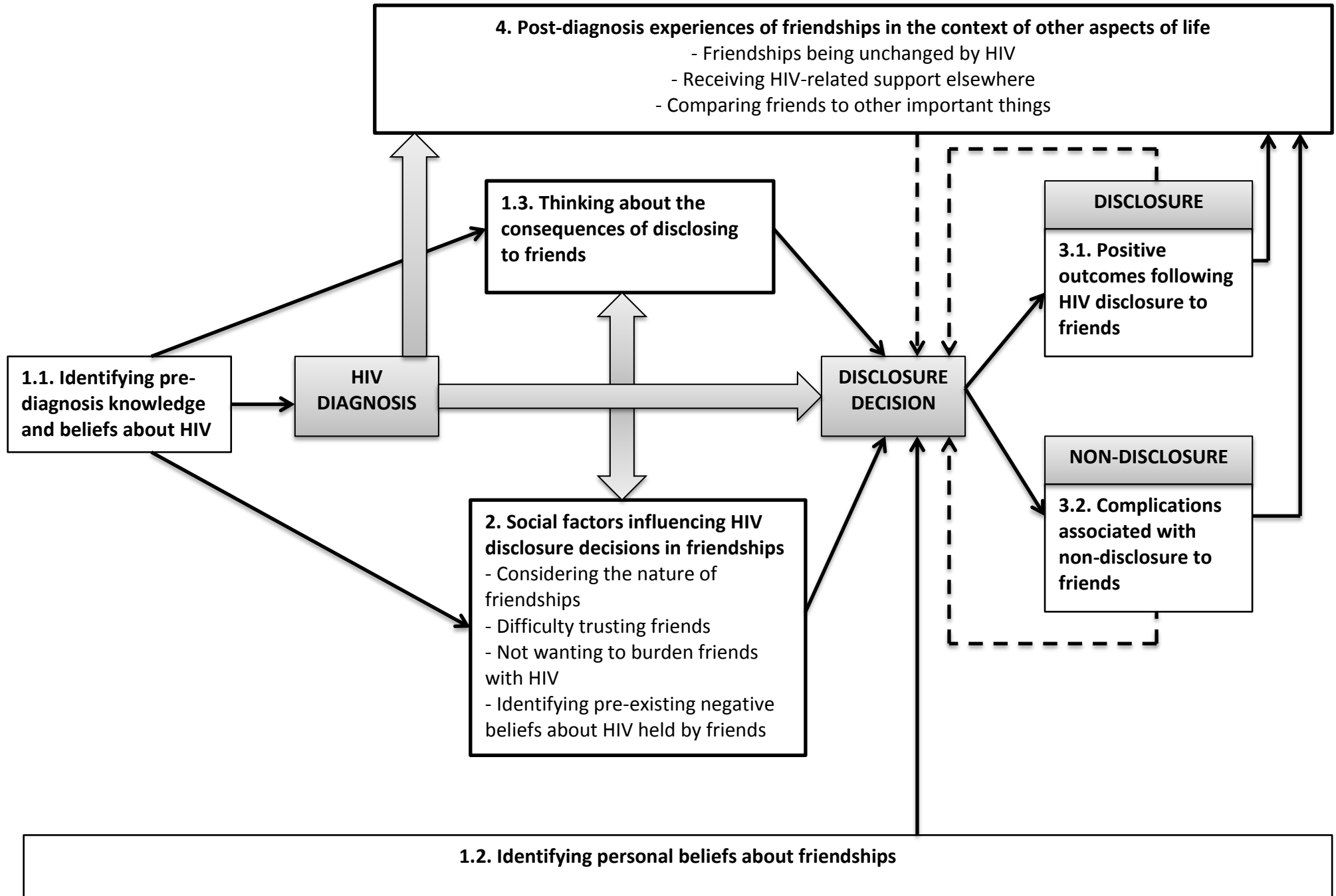
Participants described thinking about the consequences of disclosing to friends when making disclosure decisions (box 1.3.), which included wanting emotional support from friends (leading to disclosure) or believing there is nothing to gain by disclosing to friends (leading to non-disclosure). Participants also identified social factors that influenced their disclosure decisions in friendships (box 2.). These mainly included barriers to disclosure, although some participants described positive aspects of friendships that facilitated disclosure.

Participants' disclosure decisions (disclosure or non-disclosure) led to disclosure outcomes within friendships, represented by the black arrows to boxes 3.1. and 3.2. Participants described positive outcomes following disclosure and complications associated with non-disclosure in friendships, however they also described a perceived absence of negative outcomes following non-disclosure. This is represented by the arrow from box 3.2. to box 4., where disclosure decision outcomes influenced participants' experience of friendships (for example, some participants described their friendships being unchanged by HIV because their friends did not know their status). Some participants that had disclosed their status described being supported by friends to live well with HIV, which helped them to continue to do normal things with friends (friendships being unchanged by HIV). This is represented by the arrow from box 3.1. to box 4.

The dotted arrows from boxes 3.1., 3.2. represent feedback loops, where disclosure decision outcomes influenced future disclosure decisions. For example, participants who felt more valued by close friends following disclosure may be more likely to disclose again in the future. The other feedback loop from box 4. demonstrates the potential influence of post-diagnosis experiences of friendships on future disclosure decisions. For example some participants identified their friendships being unchanged by HIV because of their decision to withhold their HIV status and these experiences may encourage them to continue to withhold their status from others in the future.



**Figure 1. A model of friendships and disclosure decisions in young people living with BAHIV**



## **Chapter 4: Discussion**

The study explored experiences of friendships in young people, aged 16-26, living with behaviourally acquired HIV (BAHIV). A Grounded Theory methodology (Charmaz, 2014) was used. Ten participants were interviewed to answer the following questions:

- What factors impact on the development of friendships in young people living with BAHIV?
- What factors influence disclosure of HIV status to friends in young people living with BAHIV?
- What is the role of friendships post-diagnosis in young people living with BAHIV?

### **Overview of findings**

The findings suggest that a number of social and psychological factors influence how young people living with BAHIV experience friendships, particularly related to HIV disclosure decisions. Four theoretical codes were identified and mapped on to a model of friendships, highlighting the relationship between these codes and the focused codes comprising them. The four theoretical codes identified were:

1. Personal factors influencing disclosure decisions in friendships.
2. Social factors influencing disclosure decisions in friendships.

3. Disclosure decision outcomes in friendships.
4. Post-diagnosis experiences of friendships in the context of other aspects of life.

These codes will now be examined in the context of the three research questions outlined above. Relevant literature will also be presented, incorporating existing research and psychological theory. The strengths and limitations of this study will then be discussed, followed by the researcher's personal reflections. Suggestions for future research and the clinical implications of the study will be proposed.

## **1. What factors impact on the development of friendships in young people living with BAHIV?**

### **4.1. Friendships being unchanged by HIV**

Most participants identified having close friendships that predated HIV diagnosis, which they had maintained for many years. They described their friendships as being largely unchanged by living with HIV and feeling satisfied with their friendships overall. It seemed that participants felt able to maintain their friendships due to little perceived impact of HIV on their lives. Participants described doing normal things with friends and feeling healthy (apart from one participant who was also living with lymphoma). Existing research has identified associations between HIV viral load and cognitive representations of HIV, where people with greater (detectable) viral load were more likely to perceive the negative influence of HIV on their lives and emotions (Pala & Steca, 2015). All nine participants on ART had undetectable viral load, which

may have influenced their perceptions of the consequences of HIV (i.e. they may have been less likely to consider negative physical, emotional, and social consequences).

Some participants in the study speculated that changes in their health in the future might bring about new challenges in friendships. It is possible that participants felt able to maintain their friendships due to few perceived HIV-related stressors. Moss-Morris (2013) outlines possible on-going stressors in living with a chronic health condition, which include managing social relationships and relationships with health professionals, uncertainty about the future, preserving autonomy, acknowledging limits, and managing illness-specific symptoms, treatments, lifestyle changes, disability, and disfigurement. None of these stressors seemed to be particularly significant for participants in the study. While some identified fears around shortened life expectancy immediately following diagnosis, they described feeling reassured by acquiring knowledge about HIV over time, through the help of health professionals. One participant identified some uncertainty about possible health complications in the future following a secondary diagnosis of lymphoma. No major HIV-related symptoms or associated lifestyle changes were described, although some participants did identify unpleasant side effects of medication. According to Moss-Morris (2013), “good adjustment” to chronic illness involves less distress, less interference or impact on life roles and relationships, good illness management, and positive affect. Overall, most participants demonstrated good adjustment to living with HIV in these areas. Good illness management was represented by good ART adherence, with eight

participants achieving HIV viral suppression (see Table 1.). Other aspects of the Moss-Morris (2013) model can be used to explain evidence of emotional distress in two participants, one of which identified a current psychiatric diagnosis of chronic depression. In line with the model, certain personal background factors (e.g. a history of bullying and sexual abuse) and key critical events (e.g. death of a friend living with HIV) described by these participants may have interacted with HIV-related stressors (e.g. managing friendships), resulting in potential adjustment difficulties (e.g. thoughts of resisting HIV diagnosis).

### **3.1. Positive outcomes following HIV disclosure to friends**

Participants that had disclosed to friends identified positive outcomes within their friendships, such as feeling more valued by friends, which was in line with their expectations of disclosure. Previous research has demonstrated similar findings. For example Hult et al. (2012) found that most adults living with HIV who disclosed selectively within their social network (disclosing to some people but not others) achieved the desired result of feeling supported. In addition, a study in the US involving young people (aged 16-24) newly diagnosed with HIV found that participants identified an improvement in the quality of their social relationships following HIV diagnosis. This was interpreted in the context of a particular cognitive coping strategy, which involved finding a better appreciation for life and clarity for what really matters (Martinez et al., 2012). While it is certainly possible that HIV disclosure is not always responded to favourably, negative reactions from friends were not evident in participants' experiences.

Participants that had not disclosed to friends identified an absence of negative outcomes through non-disclosure, which was perceived as being an effective way of maintaining their friendships. In other words, participants felt happy that their friendships remained unchanged by HIV due to their friends not knowing their status. For these participants, the decision to withhold their HIV status could have facilitated adjustment as they achieved a sense of control of managing the potential challenges of living with HIV (Moss-Morris, 2013). These findings can be further explained by gender, given that eight of the ten participants were male. Research suggests that friendship expectations of symmetrical reciprocity (e.g. genuineness) and communication (e.g. self-disclosure) are higher in females compared to males (Hall, 2011). Research also suggests that while both men and women share personal information with friends to achieve intimacy, men also achieve intimacy by engaging in activities with friends (e.g. playing sport, Radmacher & Azmitia, 2006). It is possible that participants who had not disclosed to friends perceived an absence of negative outcomes because they were able to achieve intimacy with friends through continuing to do normal things. It is also possible that females may be more likely than males to perceive non-disclosure to friends negatively, whereby non-disclosure may affect their expectations of symmetrical reciprocity and communication.

It is worth noting that participants largely described friendships that were established pre-HIV diagnosis, with little emphasis on the perceived impact of living with HIV on developing new friendships. Half of the sample was newly diagnosed (living with BAHIV for 1-2 years) and these participants may have had little opportunity to meet

new friends, given the relatively short time frame. Equally it may have been that, in general, participants did not experience certain life transitions (e.g. changes in education or employment) that could have fostered new friendships. One participant moved to the UK following HIV diagnosis, however he mostly spoke about his partner when referring to newly acquired relationships.

## **2. What factors influence disclosure of HIV status to friends in young people living with BAHIV?**

Most of the factors described by participants that influenced disclosure decisions within friendships were related to the disclosure recipient, that is, their thoughts and feelings about individual friends or friendship groups. This is in contrast to existing models of HIV disclosure, which mainly focus on individual cognitive factors (e.g. Bird & Voisin, 2010; Chaudoir, Fisher & Simoni, 2011; Gaskins et al., 2012; Arnold, Rice, Flannery & Rotheram-Borus, 2008). These models can be further critiqued in that they do not consider the influence of affect (e.g. guilt and anxiety) in HIV disclosure processes (Evangeli & Kagee, 2016).

Two participants that had been diagnosed the longest (10 years) had not disclosed their HIV status to any friends. Given that non-disclosure to friends was maintained over a relatively long period of time, this could indicate that these participants held fixed or entrenched beliefs about HIV disclosure. Alternatively, it may be that other factors influencing HIV disclosure (e.g. perceptions of health status) had not changed over time. In contrast, another participant who was also diagnosed aged 16 had

disclosed to friends. While there were no notable differences in disclosure decisions within friendships for the older and younger participants, it is possible that factors relating to the timing of diagnosis played a part in participants' decision making, particularly in terms of societal representations of HIV. In 2008, a Swiss HIV advisory committee formulated "The Swiss Statement" (Vernazza, Hirschel, Bernasconi & Flepp, 2008), which suggested that a person living with HIV who is virally suppressed (through effective ART) is not sexually infectious. This statement was influential in initiating discussion around viral load as a legitimate HIV prevention measure. While the statement produced widespread concern amongst some public health advocates, it also helped to challenge potentially inaccurate and unhelpful beliefs about HIV transmission. The way HIV is constructed in society has changed dramatically over time and this may have influenced how confident participants felt disclosing their status to friends.

Some participants, of black-African and black-Caribbean origin, made reference to perceived cultural beliefs about HIV when describing their thoughts and feelings about being diagnosed, as well as their disclosure decisions. The PEN-3 cultural model (Airhihenbuwa & Webster, 2004) provides a framework to examine the role of culture in addressing beliefs and behaviours that contribute to health-related decisions, such as HIV disclosure (Iwelunmor, Sofolahan-Oladeinde & Airhihenbuwa, 2015). The model references three interconnected domains of cultural empowerment, relationships and expectations, and cultural identity. The domain of relationships and expectations includes the role of different members of individuals'



social networks (such as friends and family) in influencing health-related decisions. One participant from Nigeria spoke about perceived inaccurate beliefs about HIV transmission and HIV-related life expectancy by friends, which he conceptualised as being part of African culture. Given the cultural significance of these beliefs, he described feeling unable to challenge them and therefore preferred the “easier” option of withholding his HIV status from friends. Similarly, two black-Caribbean MSM participants spoke about the role of family members in shaping potentially stigmatising beliefs about what it means to be homosexual and living with HIV. In particular, they reflected on the power of religious beliefs within their family systems. While these participants did not appear to believe that their friends necessarily shared these views, it is possible that perceived familial beliefs led to experiences of internalised HIV stigma (Earnshaw et al., 2013), which in turn influenced their decision to withhold their HIV status from friends.

### **1.1. Identifying pre-diagnosis knowledge and beliefs about HIV**

Most participants reported feeling uneducated about HIV or having inaccurate beliefs about transmission, or HIV-related life expectancy, before they were diagnosed. Two participants who knew other people living with HIV described having a better understanding of the virus. These findings are similar to a study involving African American men living with HIV, where many participants knew few other people living with HIV and talked about their lack of understanding of the virus when diagnosed (Gaskins et al., 2012). In addition, the authors found that men were unlikely to disclose to friends unless they were very close to the participant or also living with

HIV themselves. Conceivably, one of the main ways for young people to acquire knowledge about HIV is through the education system. One participant described learning little about HIV as part of school sex-education and recent media publications in the UK suggest that additional training for teachers may be required (Moorhead, 2015). The Children's HIV Association (CHIVA) recently put forward guidelines to promote "HIV friendly" schools in the UK (CHIVA, 2015). Such guidelines have the potential not only to promote HIV prevention but also raise awareness of HIV (in both staff and pupils), which could in turn reduce HIV-related stigma.

Participants that had not disclosed to friends perceived marked differences between themselves and friends without HIV, in terms of knowledge and beliefs about the virus. Identity development is a key part of adolescence and emerging adulthood (Adams et al., 1992; Erikson, 1968; Arnett, 2000; 2014). Young people diagnosed with BAHIV are faced with the potential challenges of integrating living with HIV in to their identity, although research suggests that living with HIV might actually facilitate and expedite the formation of identity for some adolescents, particularly if they perceive a potentially shortened life-span following HIV diagnosis (Hosek, et al., 2002). Participants spoke about acquiring knowledge about HIV through engaging with health professionals. It is possible that some participants chose to withhold their status from friends due to perceived differences in identity between themselves and friends, in terms of being a person living with BAHIV (with good knowledge about the virus) compared to a person without BAHIV (with poor knowledge about the virus).

This is likely to have contributed to participants' beliefs about how friends would respond to HIV-disclosure.

### **1.2. Identifying personal beliefs about friendships**

Some participants described their disclosure decisions in the context of their self-perceptions (e.g. being an "open person"). These findings are similar to Hult et al. (2012) who demonstrated that preconceived perceptions of identity (e.g. being a "private person") hindered disclosure of HIV status in adults newly diagnosed with HIV. The findings are also comparable to a model of disclosure put forward by Arnold et al. (2008), which emphasises the importance of social identities and role relationships in disclosure behaviours. The authors argue that in any social context there are implicit, socially shared expectations of behaviours related to social identity (e.g. a person living with HIV, heterosexual woman) and role relationships (e.g. a friend, sexual partner). These expectations inform the creation of individual decision rules that motivate disclosure behaviour. Some of the MSM participants appeared to make clear distinctions between groups of friends that they had and had not disclosed to and it is possible that they had different decision rules for each group. For example Participant 2 identified two groups of "party friends" and "gym friends". It is possible that he identified himself predominantly as a fun and out-going MSM living with HIV with his party friends, compared to a healthy and hard-working MSM with his gym friends. The decision to disclose or withhold his HIV status to friends may therefore have been informed by these different social identities. While the role of being a friend seemed to be the same for both groups, there may have been

different expectations attached to this role, based on the social norms of the friendship groups (e.g. being someone to go clubbing with versus someone to exercise with).

Some participants described withholding their HIV status in the context of wanting to maintain boundaries between friends, all of who were black-African or black-Caribbean males. It is possible that these participants held particular beliefs about friendships that were influenced by their cultural background. Research suggests that friendship is not a universal form but rather takes different forms in different cultural worlds (Adams & Plaut, 2003).

### **1.3. Thinking about the consequences of disclosing to friends**

The perceived consequences of HIV disclosure appeared to influence participants' disclosure decisions within friendships. Participants that had disclosed to friends wanted (and anticipated) social support from friends, whereas participants that had not disclosed to friends believed that there was nothing to gain. In both cases, participants seemed to weigh up possible positive or negative outcomes before making disclosure decisions. These findings provide support for a consequence-based model of HIV disclosure, which has been previously investigated in quantitative studies of men and women living with HIV (Serovich, 2001; Serovich, Lim & Mason, 2008). The positive consequences identified by participants were mostly self-oriented, in the form of having someone to talk to about HIV, although it is possible that friends perceived mutual benefit (e.g. wanting to be there to support them). One

participant spoke about her friends researching HIV online so that they could understand the virus better.

### **2.1. Considering the nature of friendships**

Participants that had disclosed to friends identified positive personal qualities of friends (e.g. being non-judgemental and accepting) that facilitated HIV disclosure. Some participants disclosed to friends they had known for a long time. As mentioned previously, participants that self-identified as MSM appeared to categorise their friends as belonging to distinct groups, according to whether they knew other people living with HIV (including friends living with HIV themselves) or not. These participants tended to disclose their status to the former, the “in group”, and withhold their status from the latter, the “out group”. In this sense, they demonstrated a positive bias towards the in-group in terms of HIV disclosure. This is consistent with Social Identity Theory (Tajfel, 1978), which suggests that individuals develop a collective, depersonalised identity based on positive perceptions of group membership (Islam, 2014).

### **2.2. Difficulty trusting friends**

All participants that had not disclosed to friends identified fears that friends would share their status with others. This finding is consistent with previous research, including a qualitative study investigating disclosure processes in rural African American men (mean age 38 years) living with HIV (Gaskins et al., 2012). Participants did not identify difficulties trusting their friends in other areas (e.g. with other

personal information), which suggests that there was something unique about their perceptions of HIV. The cognitive model of anxiety put forward by Beck, Emery and Greenberg (1985) can help to understand these findings. The model proposes that anxiety is the result of an increased perception of likelihood of danger, which interacts with the specific meaning the person assigns to the danger. In this case, the perceived danger was the risk of friends sharing their HIV status with others. The meaning assigned to the danger would depend on the individual, although it would cause distress (e.g. fear of discrimination from others). It is likely that participants' perceived ability to cope with these consequences was low, as described by Participant 2, and that rescue factors (e.g. help from other people) would not be present. This led to a state of anxiety and the coping behaviour of avoidance (withholding their HIV status) to reduce the likelihood of danger, and in turn reduce the anxiety.

### **2.3. Not wanting to burden friends with HIV**

Participants identified wanting to avoid burdening or distressing friends as a reason for non-disclosure. This finding has been demonstrated in existing qualitative (Hult et al., 2012) and quantitative (Derlega, Winstead, Greene, Serovich & Elwood, 2002) HIV disclosure research. The latter study involved adults living with HIV, where the authors identified a relationship between self-reported perceptions of stigma (in the form of public opinions of HIV) and protecting others, where the greater the perceived stigma the greater the desire to protect friends as a reason not to disclose. Protecting friends was measured using a self-report scale that included items such as

“I didn’t want my friend to worry about me” and “I didn’t want my friend to experience any pain over things I was going through”, which are similar to the experiences described by participants in the current study.

#### **2.4. Identifying pre-existing negative beliefs about HIV held by friends**

Participants perceived pre-existing negative beliefs about HIV by friends, which meant that they anticipated that friends would think or act differently towards them if they knew their status. This led participants to withhold their HIV status to avoid potentially negative outcomes within their friendships, such as being judged or rejected by friends. Existing qualitative research involving young people living with HIV (aged 17-21) identified similar barriers to HIV disclosure, where participants identified fears around the impact of disclosure on close relationships (Hosek, Harper & Domanico, 2000). These findings can be interpreted in the context of anticipated stigma (Earnshaw & Chaudoir, 2009), which has been similarly identified in previous studies of young people living with HIV (Bakeera-Kitaka, Nabukeera-Barungi, Nostlinger, Addy & Colebunders, 2008; Martinez et al., 2012). Two MSM participants further expressed feelings of internalised stigma, where they described feeling “dirty” living with HIV. It is possible that young MSM are potentially more vulnerable to experiences of internalised stigma than other young people living with HIV, due to stigma also related to being a sexual minority (Deacon, Stephney, & Prosalendis, 2005). Jeffries et al. (2015b) conducted qualitative interviews with 28 young MSM (aged 13-29) living with HIV in America and found that participants described self-stigmatising sentiments, such as feeling “poisonous,” “nasty,” and “like the leper”.

### **3. Disclosure decision outcomes in friendships**

Participants described positive outcomes in friendships following disclosure, such as feeling more valued by friends. Complications associated with concealing HIV medication and hospital appointments from friends were identified with non-disclosure. It is possible that if a young person living with HIV feels more valued by one friend following disclosure they may choose to disclose to another friend to enrich their relationship in the same way. Likewise, if concealing HIV medication from friends is perceived as relatively straightforward (not stressful) then this might encourage future non-disclosure. In other words, it is likely that post-disclosure experiences within friendships influence the likelihood of subsequent disclosure to friends. This idea is consistent with the feedback loop in the Disclosure Process Model (Chaudoir, Fisher & Simoni, 2011).

### **3. What is the role of friendships post-diagnosis in young people living with BAHIV?**

#### **4.2. Receiving HIV-related support elsewhere**

While friendships appeared to be very important to most participants, they identified receiving little HIV-related support from friends. Two participants that had disclosed to friends described being accompanied by friends to clinic appointments, although only one of them found it helpful. These findings are similar to Abramowitz et al. (2009) who demonstrated that despite being satisfied with friends' help, young people living with BAHIV reported little instrumental support from friends. No participants in the study described wanting additional support from friends, therefore



it is possible that instrumental support within friendships is not perceived as particularly important. As mentioned previously, participants demonstrated good adjustment to HIV based on the dimensions outlined by Moss-Morris (2013). Given that participants spoke about doing normal (and fun) things with friends, it is possible that an important role of friendships is helping young people living with BAHIV maintain positive affect, which can be experienced regardless of whether friends are aware of ones' HIV status. Some participants described feeling supported by health professionals, particularly in terms of being educated (and reassured) about HIV. This may have facilitated adjustment to HIV in terms of maximising autonomy and promoting good illness management (Moss-Morris, 2013).

Three of the five participants in romantic relationships described receiving HIV-related support from a boyfriend or girlfriend over friends, mostly in the form of emotional support. It may have been that they perceived emotional support from a partner as more important than from friends. This can be explained in terms of participants' age and stage of development. Research suggests that when adolescents and young adults become involved in romantic relationships (have a boyfriend or girlfriend) they become less intimate and involved with friends. In particular, intimacy with partners is rated significantly higher than intimacy with friends (Salas & Ketzenberger, 2004) and emotional closeness in a romantic relationship is perceived as more important than in friendships (Fuhrman, Flannagan & Matamoros, 2009). An alternative suggestion is that, for some MSM participants (namely 7 and 8), emotional support was received from a partner over friends as a

direct result of HIV disclosure (they disclosed their partner but not to friends). Most participants described receiving emotional support from at least one of their close relationships and it is possible that if participants 7 and 8 were without a partner then they may have turned to friends instead. In support of this idea Heywood and Lyons (2016) found that the type of support received, in particular emotional support, was more important than the source (relationship partner, friends, family, or agencies) in MSM adults living with HIV.

#### **4.3. Comparing friends to other important things**

Some participants identified prioritising other things in life over friends, such as work, hobbies, or religion. Participant 7 described the benefits of being creative (drawing) as a way of distracting himself from potentially distressing thoughts or emotions associated with living with both HIV and lymphoma. Gilligan (2000) suggests that spare time activities, such as hobbies, are particularly important in helping young people develop resilience (the capacity to do well despite adverse experience). Participant 2 described his relationship with God as the most important compared to other close relationships. This is consistent with existing qualitative research involving Latino young people (aged 16-24) living with BAHIV, where participants emphasised the presence of God in coping with the virus. While Participant 2 identified God as a source of strength, Participant 6 expressed feelings of being punished by God immediately following HIV diagnosis. The role of religion in coping with chronic illness may depend on both individual and cultural factors. While the exact nature of participants' religious beliefs were not discussed in detail, both participants that

referred to God were of black-African origin. Existing research suggests that religion is extremely important for black-African men and women living with HIV (Ridge, Williams, Anderson & Elford, 2008). In line with the self-regulation model (Cameron & Leventhal 2003; Broadbent et al., 2009) religion may affect coping by influencing a person's cognitive appraisal of the illness, which in turn determines how they cope. For example, religion may influence *comprehensibility* by providing a framework to allow a person to make sense of illness.

## **Strengths and limitations**

### **Strengths**

A key strength of the study is that it addressed a gap in the literature by focusing specifically on friendships in young people with BAHIV. Most HIV research involves adults and does not differentiate by route of transmission (Sohn & Hazra, 2013). Whereas previous studies have often grouped different disclosure targets in people's social networks (Dima et al., 2014), the study allowed for an in-depth exploration of the processes involved in disclosure decisions specifically with friends. The study further allowed exploration of both between and within participant factors in HIV disclosure decision-making.

The issue of generalisability in qualitative research continues to be debated among researchers. Lewis and Ritchie (2013) argue that qualitative research can be assessed on *representational generalisation*, which refers to whether the findings can be generalised to, or held to be equally true of, the population from which the sample is

drawn. Representational generalisation is assessed based on two main issues: the quality of the research (discussed in more detail below) and the degree to which the sample is representative of the wider population. It is likely that study sample is representative of young people living with BAHIV in the UK on ART. In 2014, 95% of all people living with HIV in the UK on ART achieved viral suppression (PHE, 2015b). All of the nine participants in the study on ART had undetectable HIV viral load, which is in line with international guidelines (UNAIDS, 2014). Another strength of the study is that despite a heterogeneous sample (with regards to gender, ethnicity, and time since HIV diagnosis) most participants described similar experiences in terms of their friendships being unchanged by living with HIV. Participants that had not disclosed to friends also identified similar barriers, such as difficulty trusting friends. This suggests a degree of transferability of the research to other young people living with BAHIV in the UK (Lewis & Ritchie, 2013).

Charmaz (2014) identifies the criteria of fit, work, relevance and modifiability (Glaser and Strauss, 1967; Glaser, 1978) to evaluate Grounded Theory research. “Fit” refers to the extent to which analytical codes emerge from the data rather than preconceived ideas relating to existing theory. A theory “works” if it is able to explain behaviour in a substantive area, as well as predict future behaviour. The “relevance” of a theory refers to whether the theory focuses on a core concern or process, rather than being merely of academic interest. “Modifiability” refers to the theory’s ability to be continually modified as new data emerge to produce new categories, properties or dimensions of the theory. To assess the quality of Grounded Theory research

Charmaz (2014) further recommends the criteria of credibility, originality, resonance, and usefulness. The study will be evaluated in the context of these eight concepts below (the usefulness of the study will be discussed in the clinical implications section).

The study was novel in its detailed and single focus of exploration about friendships in young people living with BAHIV, thus meeting criteria for relevance described above. Previous research on social support in young people living with HIV has largely involved cross-sectional, quantitative approaches. No previous study has used qualitative methods to explore the social and psychological processes involved in the perceptions of friendships and disclosure decisions in young people living with BAHIV. These novel contributions contribute to the originality of the research.

Gaining feedback on the interview schedule from service-users was another strength of the study, as it allowed the researcher to add or refine questions to ensure clarity and sensitivity. It is suggested that the involvement of service users provides evidence for resonance, as the questions being asked were relevant and meaningful to individuals who were diagnosed with HIV aged 16-26. Resonance of the study was further achieved by participant feedback on data analysis. While the involvement of participants beyond data collection is deemed controversial by some qualitative researchers, others argue that co-construction (between participants and researchers) is a fundamental principle of constructivist approaches at all stages of analysis (Nagel, Burns, Tilley & Aubin, 2015). At the end of data collection the results

were discussed with one participant, to ensure that they made sense and to offer potential deeper insights about their lived experience (Charmaz, 2014). During feedback, Participant 7 commented that while not all codes applied directly to his own experience the data made sense overall. He confirmed that the codes that did apply to him were accurately represented and worded sensitively.

External validation of coding and the constructed model was sought from the academic supervisor as well as a peer supervision group of other Trainee Clinical Psychologists adopting a Grounded Theory approach. Both individual and group supervision allowed for the fine-tuning of focused and theoretical code titles, ensuring that these fit the breadth of data they covered. This provides further evidence of fit, work, and credibility. Given that the academic supervisor previously worked clinically in the field of HIV it also provides further evidence of resonance.

Comparative methods were used throughout analysis, which allowed for rigorous comparison both within and between participants (Charmaz, 2014). Memo-writing was completed to draw together the researcher's ideas and facilitate the development of focused and theoretical codes. These techniques ensured that the analysis remained rooted in the data (Charmaz, 2014) and provide evidence for fit, work, modifiability and credibility as described above. The researcher also kept a diary to document useful reflections throughout the research process. The diary was particularly helpful in capturing the researcher's personal views, assumptions, and

experiences, and how these interacted with this data in line with a constructivist approach (Charmaz, 2014).

### **Limitations**

The inclusion and exclusion criteria were deliberately broad to aid recruitment for the study, given the small population of young people living with BAHIV in the UK. This resulted in a diverse sample of participants, particularly in terms of ethnicity and length of time since HIV diagnosis. It was initially anticipated that most participants would be relatively newly diagnosed, however two participants (5 and 6) had been living with HIV for approximately ten years. While white MSM are the group most likely to acquire HIV between the age of 15 and 24 (PHE, 2015c; NAT, 2015) the study included only one white-British MSM. This raises questions about whether the sample is representative of young people living with BAHIV in the UK and therefore limits the representational generalisability of the findings.

Another potential limitation of the study is that CD4 count data was not collected for participants at the time of HIV diagnosis. People who test late for HIV have a lower CD4 count and are therefore more likely to be physically unwell (NAM, 2016). The stage of disease progression at diagnosis for participants in the study was unknown and this might have influenced their experiences of friendships. Furthermore, the recorded CD4 counts for three participants were taken nearly one year prior to the time of interview and it is possible that these figures did not accurately represent participants' current health status. In terms of other additional data collection, it may

have also been useful to assess participants' current emotional wellbeing using standardised measures. While the study did not aim to investigate the presence of mental health problems in the young people living with BAHIV, it may have provided useful information in the context of participants' experiences of friendships.

Due to the demanding and complex nature of the clinical work involved with young people living with BAHIV, it was often difficult to keep track of who attended the clinic and who was approached about the research. This meant that eligible participants were missed. While three potential participants declined taking part after speaking directly to the researcher, the exact number of potential participants approached by the clinical team is unknown. It is possible that those who declined participation did so because of potentially difficult experiences related to living with HIV. It is also possible that clinic staff selected eligible participants to approach that they thought might be particularly suited to, or interested in, talking about friendships. Taken together, this raises questions as whether the findings 'work' (as described above), in that the theory derived may not reflect that of the context it seeks to refer.

English was a second language for three of the participants. Language is central to qualitative research at all stages from data collection to analysis, particularly in terms of how codes are titled. The relationship between participants' perceived experiences and language is a two-way process, where language is used to express meaning and language influences how meaning is constructed. It may be that at times the



researcher misinterpreted participants said. This may have compromised the resonance of the findings, as concepts in one language may be differently understood in another.

The concept of theoretical saturation is interpreted and viewed differently by researchers. Charmaz (2014) argues that saturation is reached when gathering new data no longer reveals new properties of theoretical codes. Some suggest that achieving theoretical saturation is not determined by the sample size but rather the research objective and the quality of the data (Mason, 2010). The researcher was a novice in Grounded Theory methodology and it is possible that a more skilled interviewer may have gathered richer data to achieve saturation. The context of the research may have also limited theoretical saturation. Specifically, the inclusion criteria were deliberately broad due to the small population and the research process was under time-constraints determined by the DClinPsy course requirements. Dey (1999) puts forward the term “theoretical sufficiency” as an alternative to saturation. He argues that researchers are at risk of undermining the value and legitimacy of their analyses by adopting a directive and prescriptive approach as suggested by traditional Grounded Theory (i.e. Glaser and Strauss, 1967; Glaser, 1978). In other words, he suggests that researchers may conduct superficial analyses in an attempt to reach data saturation, which may in fact be unachievable.

## **Personal reflections**

A key challenge that emerged throughout the research process was maintaining the role of the researcher during participant interviews. Prior to the study my experience of working with people living with chronic health conditions was exclusively in a clinical capacity. During the interviews I was mindful of urges to engage in a more therapeutic style, which may have been too interpretive or deviated too far from the interview schedule. Occasionally I found it difficult to keep the focus of the interviews specifically on friendships, particularly when participants seemed motivated to talk about their experiences of other close relationships, such as intimate partners, and I was equally interested to hear them. While this was helpful in considering the importance of different members of participants' support networks, it left less time for more focused questions on friendships, including detailed examples of specific disclosure events. Overall, I found the time-limited nature of the interviews quite challenging in trying to achieve a balance between creating a safe space to talk about potentially sensitive issues and meeting the research aims.

Throughout the research process I reflected on similarities and differences between participants and myself, and the impact of these on data collection and analysis. I reflected on the fact that I am a 29-year-old white-British, heterosexual female without a diagnosis of HIV, and I wondered what it felt like for participants to share their experiences with me. I felt extremely privileged to hear participants' stories, particularly given that some of them had disclosed their HIV status to very few people. One participant acknowledged this in our interview and included me in the

short list of people that were aware of his status. Some of the MSM participants identified beliefs about being judged by others because of their HIV status, which made me wonder whether they also perceived being judged by me. Bell (2005) highlights a potential advantage of being part of the particular group that you are studying, referred to as an “insider researcher”, where participants feel better understood by the researcher and therefore more at ease in their interactions. Despite being unaware of my sexuality and HIV status, I found participants to be very willing and open to discuss their experiences with me.

At times I felt sadness and empathy because of participants’ difficult experiences but also admiration towards their resilience. I noticed feeling particularly connected to one female participant who was white-British and heterosexual, like myself. When hearing her experiences of being diagnosed aged 16 I was particularly impressed with her commitment to taking care of her health at such a young age and her strength to cope with repeatedly being confronted by others about her diagnosis. During the interviews I was aware of feeling frustrated with how HIV is constructed in society, particularly in terms of the apparent lack of knowledge and prejudice that remains today. I reflected on my own experience of hearing friends and others talk about HIV in a way that demonstrates poor knowledge and understanding of the virus, which made me empathise with participants’ disclosure decisions.

## **Suggestions for future research**

Most participants in the study described living with HIV as having little impact on their friendships and this, in part, could be explained by the nature of their friendships. Participants predominantly described friendship that predated HIV diagnosis. One potential avenue for future research would be to conduct a longitudinal study, revisiting participants (e.g. at one and five years post-diagnosis) to see if their experience of friendships and HIV disclosure to friends had changed over time. It may be particularly useful to understand the potential impact of living with HIV on meeting new friends, as well as how friendships change alongside changes in other relationships (e.g. moving in with partners, moving out of the family home), and other areas of life (e.g. starting a new job).

The study involved young people living with BAHIV of different ethnicities, gender, and sexual orientation. Future studies could focus on a specific population within the sample to gain a richer understanding of their experiences of friendships. The participants in the study who self-identified as MSM identified similar factors influencing their disclosure decisions that were unique to other participants, for example whether friends knew other people living with HIV or not. They were also the only participants that described internalised stigma and it would be useful to explore these experiences further through additional qualitative research.

Most participants demonstrated evidence of good adjustment (Moss-Morris, 2013) and this was similar for participants that had and had not disclosed their status to

friends. Two participants identified difficulties within their friendships related to living with HIV (e.g. withdrawing from friends) alongside potential symptoms of distress (e.g. resisting their HIV diagnosis). One area of future research could be to investigate young people living with BAHIV who are accessing mental health services to explore experiences of friendships and disclosure decisions within this population.

The study highlighted significant within participant factors that influenced HIV disclosure to friends, including perceptions of individual friends or friendships groups (e.g. identifying positive personal qualities of friends). One option for future research could be to investigate these factors using quantitative methods, although this may involve the creation of a new scale of HIV disclosure. While existing disclosure scales do exist, most involve single item or very short scales (e.g. Abler et al., 2015) that do not capture the multi-dimensional nature of the disclosure process (Dima et al., 2014). Furthermore, the reliability and validity of these scales has not been established. A new reliable and valid multi-item, multi-dimensional scale of HIV disclosure may be required to enable future quantitative research.

### **Clinical implications**

The findings indicate a number of areas where health services could support young people living with BAHIV, particularly in terms of adjustment and HIV disclosure to friends. One of the key determinants of adjusting to chronic illness is minimising the impact on roles and relationships (Moss-Morris, 2013). The community sample of young people in the study demonstrated good adjustment by maintaining friendships

that were established pre-HIV diagnosis. The cognitive and behavioural factors outlined by Moss-Morris (2013) that facilitate returning to emotional equilibrium (successful adjustment) may be useful areas to target in psychological assessment and intervention for young people living with BAHIV. In terms of assessment, questions examining these areas (e.g. perceived sense of control regarding HIV management) could be incorporated in to regular mental health screening interviews. The same areas could also be targeted in psychological intervention using a Cognitive Behavioural Therapy (CBT) approach. CBT has been shown to be effective in reducing symptoms of depression in people living with HIV (Sherr et al., 2011), although no published evidence base currently exists for working specifically with young people. While the study did not examine the presence of mental health symptoms in the sample, there was evidence of experiences of internalised stigma in some of the MSM participants, which has been previously identified as a risk factor for depression in this population (e.g. Dowshen, Binns & Garofalo, 2009). Other research has suggested that internalised stigma is also associated with increased levels of illicit drug use, which may be a way of coping with internalized stigma (Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009). Based on these findings, it is important that regular mental health screening is conducted with young people living with BAHIV.

Psychological support for young people living with BAHIV could be provided at different levels, in line with a stepped-care model (BHIVA, 2013; BPS, 2011). Some young people may prefer to be offered leaflets, self-help booklets, or online

resources detailing psycho-education on adjustment to living with HIV. Given that some participants identified feeling reassured to live well by friends who were also living with HIV, these resources could include quotes or [online] blogs from other young people living with the virus as a form of peer support. Clinical Psychologists could play an important role in training front line staff, such as nurses and health advisors, to provide low-intensity psychological interventions for young people living with BAHIV. Training could also be provided on the factors that might help or hinder successful adjustment in young people living with BAHIV to provide staff with the skills to ask informal questions related to emotional wellbeing during routine HIV clinic appointments, as well to conduct mental health screening assessments.

Structured peer support programmes have demonstrated promising findings in supporting young people living with PAHIV in terms of adjustment and HIV disclosure (Lut & Evangelii, 2015), however there may be less formal support available for people diagnosed with BAHIV in adolescence or emerging adulthood. Support could be provided for young people living with BAHIV in the form of group psycho-education programmes. Groups could be conducted on a drop-in basis with a rolling programme that covers topics such as “HIV and me” (to discuss factors relating to adjustment) and “talking to friends about HIV” (to discuss factors relating to HIV disclosure). In line with published guidelines (BPS, 2011), service-users could be involved in planning and implementing these groups, as well as being given opportunities to provide feedback for service evaluation.

While HIV disclosure interventions exist to support mothers living with HIV to disclose to their children (e.g. RoCHAT, Mkwanazi & Bland, 2013), women living with HIV to disclose to others (Kaaya et al., 2013), and MSM living with HIV to disclose to family (Serovich, Reed, Grafsky, Hartwell & Andrist, 2011) and sexual partners (Chiaasson, Shaw, Humberstone, Hirshfield & Hartel, 2009), no disclosure interventions have been developed to support young people living with HIV. This could be particularly useful in providing guidance for health professionals on how to talk to young people living with HIV about disclosure decisions (involving friends and other close friendships). Health professionals should be guided not only on how to support young people living with HIV to disclose their HIV status, but also on their rights not to disclose, particularly given that non-disclosure seemed to be effective for some participants in maintaining their friendships.

The findings from the study demonstrated evidence of HIV-related stigma in young people living with BAHIV. In particular, participants spoke about the anticipated negative consequences of sharing their HIV status with friends. Reducing HIV-related stigma should not only involve individual factors (i.e. working directly with the young person living with HIV), but should also target peer beliefs and other social or systemic factors. Campaigns promoting HIV-education in schools, such as the “HIV friendly” schools campaign (CHIVA, 2015), could help reduce HIV-related stigma in young people by raising knowledge and awareness of the virus.



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## Appendix 1: NHS ethics approval



### NRES Committee London - Stanmore

Ground Floor  
NRES/HRA  
80 London Road  
London SE1 6LH

Telephone: 0207 972 8932

21 May 2015 – Revised letter reissued with changes highlighted

Miss Evelyn McKenzie  
Royal Holloway University of London  
Egham  
Surrey  
TW20 0EX

Dear Miss McKenzie

**Study title:** Understanding friendships in young people with  
behaviourally acquired HIV  
**REC reference:** 15/LO/0708  
**IRAS project ID:** 177302

The Research Ethics Committee reviewed the above application at the meeting held on 22 April 2015.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Julie Kidd, [nrescommittee.london-stanmore@nhs.net](mailto:nrescommittee.london-stanmore@nhs.net). Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

### Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

### Conditions of the favourable opinion

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

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

A Research Ethics Committee established by the Health Research Authority

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.*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

#### Clinical trial authorisation must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

*The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming clinical trial authorisation or giving grounds for non-acceptance, as soon as this is available.*

#### Notice of no objection must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

*The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming no objection or giving grounds for objection, as soon as this is available.*

The sponsor must ensure that all participants enrolled into the study are registered with The Over Volunteering Prevention System (TOPS).

**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).**

#### **Ethical review of research sites**

### NHS Sites

The favourable opinion applies to all NHS sites taking part in the study 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).

### Summary of discussion at the meeting

#### Informed consent process and the adequacy and completeness of participant information.

The sub-committee agreed that this research had no ethical issues and were content with the design of the study and all related documentation

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity policy]	1	31 March 2015
Interview schedules or topic guides for participants [Draft Interview Schedule]	1	01 April 2015
IRAS Checklist XML [Checklist_01042015]		01 April 2015
Participant consent form [St Thomas'_Consent Form]	1	01 April 2015
Participant consent form [St George's'_Consent Form]	1	01 April 2015
Participant information sheet (PIS) [Guys & St Thomas_PIS]	1	01 April 2015
Participant information sheet (PIS) [St George's'_PIS]		
REC Application Form [REC_Form_01042015]		01 April 2015
Referee's report or other scientific critique report [Research Proposal Memorandum 1]	1	09 January 2015
Referee's report or other scientific critique report [Research Proposal Memorandum 2]	1	10 February 2015
Research protocol or project proposal [Research Protocol]	1	01 April 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	31 March 2015
Summary CV for supervisor (student research) [Academic Supervisor CV]	1	31 March 2015

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### After ethical review

#### Reporting requirement

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

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### **HRA Training**

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

<b>15/LO/0708</b>
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<b>Please quote this number on all correspondence</b>
-------------------------------------------------------

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

Yours sincerely  
Amrita Dhamu



**Mrs Rosemary Hill**  
**Chair**

E-mail: [nrescommittee.london-stanmore@nhs.net](mailto:nrescommittee.london-stanmore@nhs.net)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments*

*"After ethical review – guidance for researchers"*

*Copy to: Ms Sharon Clutterbuck  
Mr Bala Thirugnanabalan, Guy's and St Thomas' NHS Foundation Trust*



**NRES Committee London - Stanmore**

**Attendance at PRS Sub-Committee of the REC meeting on 22 April 2015**

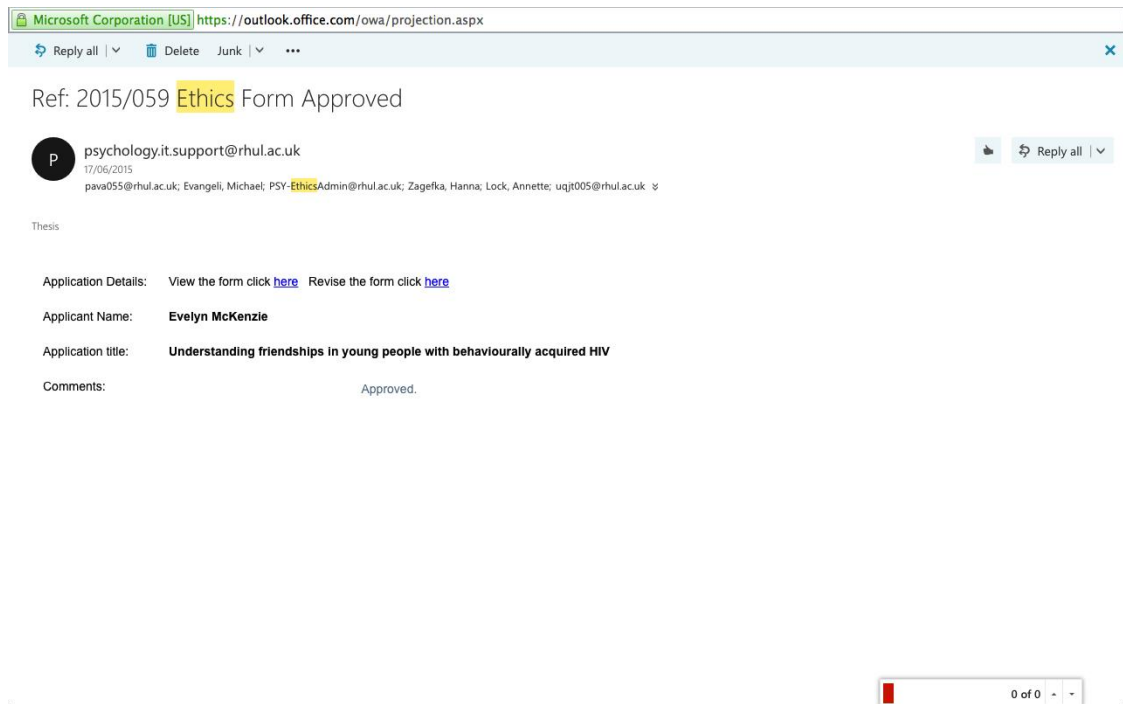
**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Rosemary Hill	Statistician	Yes	
Mrs Elayne Nasr	Retired	Yes	
Dr Carol Pellowe	Senior Lecturer - Infection Control	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Ms Julie Kidd	Committee Coordinator

## Appendix 2: Royal Holloway University ethics approval



## Appendix 3: R&D ethics approval – primary research site

5/24/2016

R&D Approval RJ115/N157 - McKenzie, Evelyn (2013)

### R&D Approval RJ115/N157

Arnold Katie [REDACTED]

Fri 29/05/2015 16:20

To: Conway Katie [REDACTED]

Cc: McKenzie, Evelyn (2013) <Evelyn.McKenzie.2013@live.rhul.ac.uk>;

Dear Dr Conway,

**Title:** Understanding friendships in BAH youth

**REC REF:** 15/LO/0708

**PI:** Dr. Katie Conway

**CI:** Miss Evelyn McKenzie

**Sponsor:** Royal Holloway University of London

Thank you for submitting your study to [REDACTED] Department I am delighted to inform you that NHS Permission has been issued for the above study. We have prepared a site file that will include the R&D approval letter and we will need to meet and explain your responsibilities as an investigator in order to remain compliant under the Research Governance Framework.

**Please let me know when would be convenient to meet at the R&D offices, [REDACTED] Hospital.**

There is a document which requires the PIs signature ([After R&D Registration – guidance for investigators](#)). If you would like someone to attend the site file meeting on your behalf; could you please confirm you are happy for them to sign this document?

As you may be aware, the Trust is working to achieve the national and local ambition of:

- 80% studies recruiting their first participant within **70 days of SSI form submission**
- 80% of studies recruiting the agreed number of participants within the planned study duration

For your study, the targets are recruiting your first participant by **06/07/2015** and recruiting **5 participants** in total by **31/03/2016**. If you are not able to meet these targets please do contact me to discuss an extension to the end date or other options.

You will need to send by email a monthly report of the recruitment numbers to the studies i.e. the numbers of participants recruited to your studies every month. This reporting is now a Department of Health requirement and the Trust is tasked with gathering data on every active study taking place at the organisation.

The accrual notification should be sent to: [REDACTED]

Stating:

1. The R&D number (RJ115/N157) number given to you by the R&D department
2. The REC REF number (15/LO/0708)
3. The Month and year
4. And the number recruited to the study for that month

<https://outlook.office.com/owa/?viewmodel=ReadMessageItem&ItemID=AAMkADRmOWY5ZTQ5LWEzZDAtdNDI4ZS1hZTdhLTk5YjgzMGYwMGM4NwB...> 1/2

5/24/2016

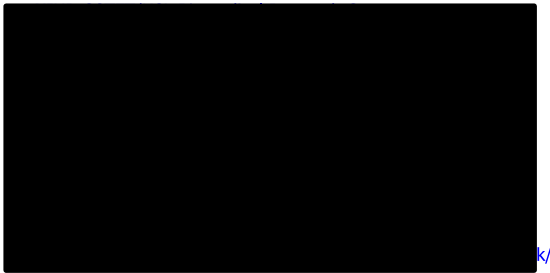
R&D Approval RJ115/N157 - McKenzie, Evelyn (2013)

If you have any queries throughout your project, please do not hesitate to contact me. Meanwhile, may I wish you success in your project.

Best wishes,

Katie



**Katie Arnold**  
**R&D Co-ordinator (non-commercial team)**



 *London working together with our partners to deliver better health through research*

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## Appendix 4: R&D ethics approval – secondary research site



NHS FOUNDATION TRUST

### **Research & Enterprise Office (JREO)**



Direct Line: 0

Email: [frm](#)

24/06/2015

Dr Katia Prime  
Consultant in HIV and Sexual Health  
NHS Foundation Trust

Dear Dr Prime,

PROJECT TITLE	Understanding friendships in BAH youth.
REC Reference	15/LO/0708
JREO Reference	15.0112
CSP Reference (if applicable)	N/A
Sponsor	Royal Holloway University of London
Principal Investigator (PI):	Dr Katia Prime

Notification of NHS Foundation Trust host site permission

Permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed and approved were those specified in the ethics approval letter dated 23/04/2015. The protocol version approved is version 1.0 dated April 2015

This approval also covers the approved amendment and associated documents (received and approved amendment is number 01 dated 29/05/2015)

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, and NHS Trust policies. Permission is only granted for the activities for which a favourable opinion has been given by the REC. The permission may be invalidated in the event that the terms and conditions of any research contract or agreement change significantly and while the new contract/agreement is negotiated.

The research sponsor, the Chief Investigator, or the local Principal Investigator, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The JREO should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The JREO should be notified within the same time frame of notifying the REC.

All amendments to this study (including changes to the local research team) need to be submitted in accordance with the guidance on IRAS. In addition any changes to the status of a study should be notified to the JREO.

Please note that the JREO is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements.

Any intellectual property that is identified should be discussed with the JREO prior to any disclosure of this information by publication or presentations to ensure that all rights are protected.

At study closure, the JREO together with the approving ethics committee should be notified that the study is closed. Study findings should be disseminated as identified in the original ethics application (including participants where appropriate). Study files should be appropriately archived.

Please contact the JREO if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely,

A handwritten signature in cursive script, appearing to read 'mai', written in dark ink.

**CC.** Miss Evelyn McKenzie- Chief Investigator

## **Appendix 5: Participant Information Sheet**

### **PARTICIPANT INFORMATION SHEET**

*December 2015, Version 5*

**Project title: Understanding friendships in young people with behaviourally acquired HIV**

We are carrying out a study exploring the friendships of young people with behaviourally acquired HIV. We would like to invite you to be interviewed by Evelyn McKenzie, a Trainee Clinical Psychologist at Royal Holloway, University of London (RHUL). The interview will take place at XXXXXX, and will last between 45 and 90 minutes. Before you decide whether you want to take part, it is important that you understand why we are doing this study and what will happen if you take part. **Please read this sheet carefully.** If you want to discuss taking part with someone close to you before you decide, please feel free to do so and ask any questions you may have.

#### **Who is conducting the research?**

Evelyn McKenzie is carrying out the study as part of a professional qualification to become a Clinical Psychologist. Dr Daniella Chilton, Consultant in HIV and Sexual Health, is overseeing the research. Dr Michael Evangeli, a Senior Lecturer at RHUL also supervises the study.

#### **Why are we doing this research?**

We would like to find out more about what it is like for young people with behaviourally acquired HIV and their experiences of friendships before and after diagnosis. We are particularly interested in what your friendships are like, whether you talk to your friends about being HIV positive, and whether your friends have influenced how you live with HIV.

#### **Why are you asking me to take part?**

We are asking you to take part because you are a young person aged 16-26, who was diagnosed with HIV at least one year ago, attending XXXXXX.

#### **What will happen in the interview?**

The interview will include a number of questions about your experience of friendships. Some questions will be asked at the beginning about what it was like when you were first diagnosed with HIV. You will be welcome to ask any questions you have before we begin. If you agree to take part, Evelyn McKenzie will also look at your medical records to collect basic demographic information and date of HIV diagnosis. With your consent the interview will be audio recorded. This is to make sure that no important information is missed.

#### **Where will the interview take place?**

The interview will take place in a quiet and private room at XXXXXX. To allow you to be able to speak freely, we would ask that you attend the interview alone.

### **Do I have to take part?**

No, you don't. The study will not affect your care at XXXXXX in any way. If you decide to take part now, you'll still be free to stop taking part at any time, without giving a reason. If you decide to withdraw at any point your care will not be affected.

### **Will the interview be confidential?**

What you talk about with Evelyn McKenzie is private and will be kept confidential. In very rare cases, if you say something during the interview that suggests that you or someone else might be at risk of serious harm (for example, if you say that you are planning on harming yourself or you are having unprotected sex with someone who is not aware that you have HIV), Evelyn may need to speak to your clinical team so that they are able to provide you with support. This would be discussed with you first.

### **What will happen with the information we collect?**

The interview will be recorded on a Dictaphone so that it can be transcribed (written out) and analysed at a later date. The transcribed data will be stored as a word document in a password protected folder on a computer that is also password protected. Once the interview has been transcribed the recording will be deleted. The consent form, which we will ask you to sign if you decide to take part in the study, will be the only document that will have your name written on it. The consent form will be kept separately from the responses you provide, in locked filing cabinets at St Thomas' Hospital. Your responses will have a code written on them, the same code will also be written on the consent form, linking the two together. This is so that if you decide to withdraw your consent after the interview has taken place, we will be able to locate your answers and withdraw them from the study. The consent forms you sign will be kept for two years and then destroyed.

### **Who will be writing up the research?**

Evelyn McKenzie will use the information to write a thesis as part of a professional qualification to become a Clinical Psychologist. Before the thesis is written, you will have the opportunity to look at the main findings from the study and give feedback on these if you wish you. To do this you can contact Evelyn McKenzie (using the details below) **anytime between 13<sup>th</sup> and 27<sup>th</sup> April, 2016**. Equally, if you do not wish to have any further involvement after the interview, you do not have to. We hope that the findings from the study will be used to plan health services in the future. The data collected may be used to write academic papers for publication or may be presented at conferences. All identifying information will be removed.

### **Are there any disadvantages or risks of taking part?**

There are no direct risks involved in taking part in the study, although some people might find talking about their diagnosis of HIV and friendships difficult, sensitive or in some cases upsetting. You will be given the opportunity to reflect on your experience of the interview immediately afterwards with Evelyn McKenzie. Evelyn is a Trainee Clinical Psychologist and has experience of talking to people about sensitive issues in her experience of working in the NHS. If you feel that you need to speak to someone after this meeting, suggestions will be made to help you with this.



**Are there any benefits of taking part?**

You may find talking about your experiences helpful. The information you provide will help to increase knowledge about the experiences of friendships in young people with behaviourally acquired HIV. This knowledge could help to develop better services for people in your situation in the future.

**Will I get anything personally for taking part?**

We will reimburse your time for taking part in the interview to the value of £15 (in high street vouchers). If you decide to attend an interview on a different day to your routine clinic appointment, you will be also be reimbursed for travel expenses.

**What if I feel unhappy with the interview or the way I am treated?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London-Stanmore Research Ethics Committee. It has also been approved by XXXXXX Research and Development and Royal Holloway, University of London Departmental Ethics Committee. This means that these Committees are satisfied that your rights will be respected, that any risks have been reduced to a minimum, and that you have been given enough information to decide whether to take part or not. If you are unhappy with anything to do with the research please contact a member of the research team, using the details below. If you are still unhappy, or you do not wish to talk to a member of the team about it, please contact the Patient Advice and Liaison Service (PALS) at XXXXXX will be happy to listen to you and will help you make a formal complaint. Their number is XXXXXX

**What happens next?**

If you are interested in taking part you will be given the opportunity to meet with Evelyn McKenzie on the same day as your clinic appointment (if she is available on site) to discuss whether you wish to take part. If you do, you will be given the option to be interviewed that day, or attend at a more convenient date. If Evelyn is not available on site on the day of your clinic appointment, you can contact her (using the details below) to arrange a time to meet.

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

## **Appendix 6: Clinician research summary sheet**

### **Project title: Understanding friendships and disclosure decisions in young people living with behaviourally acquired HIV**

#### **Who is suitable?**

- Young people aged 16-26 (*at the time of interview*)
- Diagnosis of HIV acquired through sexual or drug use risk behaviour
- Diagnosis of HIV for at least one year (*at the time of interview*)
- Fluent enough in speaking and comprehension of English to allow the interview to take place without an interpreter

#### **Who is not suitable?**

- Young people deemed to have emotional problems to a degree that might impact their ability to engage in the interview
- Young people identified as significantly high risk (e.g. actively suicidal or engaging in self-injurious behaviour)

#### **Summary of project**

*The following can be read aloud to potential participants...*

Evelyn, a Trainee Clinical Psychologist, is conducting a research project looking at friendships in young people with HIV. She would like to talk to people of your age about their experience of friendships. If you were interested in taking part, it would involve being interviewed by Evelyn for around 45 minutes – 1 hour about what your friendships are like, whether you talk to your friends about being HIV positive, and how HIV has affected your friendships. You would receive £15 for your time (in high street vouchers).

## Appendix 7: Participant Consent Form

1 2 3 4 5 6 7 8 9 10

1

### PARTICIPANT CONSENT FORM December 2015, version 2

Title of the project: Understanding friendships in young people with behaviourally acquired HIV

Name of investigators: Evelyn McKenzie and Dr Michael Evangelidis (Royal Holloway, University of London), Dr Daniella Chilton ( )

Ethics committee reference number: 15/LO/0708

Participant identification number: \_\_\_\_\_

2

The section below is to confirm that you would like to take part in the research and that you know what is involved. Please tick the boxes if you agree with each statement.

1. I confirm that I have read and understood the information sheet (version 5) for the above study and have had the opportunity to ask questions
2. I understand that my participation is voluntary and I can withdraw at any time up until 13<sup>th</sup> April 2016, without giving any reason, and without my medical care and legal rights being affected
3. I agree to have my interviews with Evelyn audio recorded
4. I agree to take part in the above study
5. I agree to having my anonymous quotations used in the reports for this study
6. I agree to Evelyn McKenzie accessing my medical notes for the purpose of this study

☐
☐
☐
☐
☐
☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature
_____	_____	_____

## Appendix 8: Draft interview schedule

**1. Tell me a bit about yourself.**

*How do you spend your free time?*

*What sorts of things are you interested in?*

*What job do you do / what subjects do you study? [SEE PARTICIPANT DEMOGRAPHIC SHEET]*

**2. Tell me about your experience of attending the clinic.**

*How long have you been attending?*

**3. Tell me about what happened when you were first diagnosed with HIV.**

*How did you find out?*

*What was going on around that time?*

*What did you think?*

*How did you feel?*

**4. How are things now?**

*What is it like living with HIV?*

*In what ways has your life changed since your diagnosis?*

*In what ways is your life the same?*

**5. Tell me about the important friends in your life.**

*How did you meet?*

*How long have you been friends?*

*Who are you closest to?*

*What do you like about your friends?*

*What are your relationships with [INSERT – e.g. your school friends] like?*

*What is your relationship with [INSERT NAME] like?*

**6. Tell me about the friends you have told about being HIV positive (if any).**

*Who did you tell first?*

*When did you tell them?*

*What were your thoughts and feelings about telling them?*

*How did it go?*

*What made it easier to tell them?*

*How does telling your friends affect your relationships with them?*

*How did telling your friends compare to telling other people (e.g. family / partners)?*

**7. Tell me about the friends you haven't told about being HIV positive.**

*What were your thoughts and feelings about not telling them?*

*How does not telling your friends affect your relationships with them?*

*How do your relationships with friends you have told compare to those you haven't?*

*Are there any friends you haven't told who you might tell in the future?*

**8. Tell me about your friendships before you were diagnosed.**

*Who were you closest to?*

*Has your diagnosis changed what you do with your friends?*

*Has it changed how you think about your friends?*

*Have you lost touch with any friends since your diagnosis?*

**9. Tell me about the friends who are the most helpful to you.**

*In what ways are they helpful?*

*Which friends do you turn to for emotional support?*

*Do your friends help you with practical things (e.g. attending clinic appointments)? In what way?*

*How does support from your friends compare to support from other people (e.g. family / partners)?*

**10. How important are your friendships compared to other relationships in your life (e.g. family / partners)?**

*How important are your friends compared to other things in your life (e.g. career / education / employment / hobbies and interests)?*

**11. Tell me about how you see your friendships in the future.**

*Which friends would you like to stay close to?*

*Would you like your friendships to change in any way?*

*Which aspects of your friendships would you like to stay the same?*

**12. Is there anything else you'd like to share?**

*Is there anything important about your friendships that we haven't spoken about?*

## **Appendix 9: Service user feedback guidance sheet**

### **Summary of the project**

Evelyn McKenzie (a Trainee Clinical Psychologist at Royal Holloway, University of London) is carrying out a study exploring the friendships of young people with behaviourally acquired HIV (BAH). Evelyn aims to interview 10 young people, aged 16-26, with BAH about what their friendships are like, whether they talk to their friends about being HIV positive, and whether their friends have influenced how they live with HIV. Participants will be recruited from HIV clinics at St Thomas' and St George's Hospital in London. Evelyn will use the information from the study to write a thesis as part of a professional qualification to become a Clinical Psychologist. It is hoped that the findings will help to plan health services for young people with BAH in the future.

### **How can you help?**

Before conducting the interviews, it would be helpful to discuss the interview schedule with other young people with BAH. The interview is semi-structured. This means that the interview schedule is used as a "guide" to explore certain areas of interest however new ideas can be brought up during the interview based on what the interviewee says. The questions in bold will be asked first, followed up by the prompt questions (underneath) if appropriate. The order the questions are asked will be guided by the interviewees' responses.

Consider the following when looking at the interview schedule:

- **How each question is phrased**
  - **Are they clear / understandable?**
  - **Fair to ask?**
  - **Possible to answer?**
- **Questions to add / other areas to cover.**
- **Questions to remove.**
- **Any other comments?**

## Appendix 10: Interview schedule post-feedback

**1. Tell me a bit about yourself.**

*How do you spend your free time?*

*What sorts of things are you interested in?*

*What job do you do / what subjects do you study? [SEE PARTICIPANT DEMOGRAPHIC SHEET]*

**2. Tell me about your experience of attending the clinic.**

*How long have you been attending?*

**3. Tell me about what happened when you were first diagnosed with HIV.**

*How did you find out?*

*What was going on around that time?*

*What did you think?*

*How did you feel?*

**4. How are things now?**

*What is it like living with HIV?*

*In what ways has your life changed since your diagnosis?*

*In what ways is your life the same?*

**5. Tell me about the important friends in your life.**

*How did you meet?*

*How long have you been friends?*

*Who are you closest to?*

*What do you like about your friends?*

*What are your relationships with [INSERT – e.g. your school friends] like?*

*What is your relationship with [INSERT NAME] like?*

**6. Tell me about the friends you have told about being HIV positive (if any).**

*Who did you tell first?*

*When did you tell them?*

*What were your thoughts and feelings about telling them?*

*How did it go?*

*What made you feel more comfortable telling them?*

*Was your decision to tell them planned or spontaneous?*

*How does telling your friends affect your relationships with them?*

*How did telling your friends compare to telling other people (e.g. family / partners)?*

*Have there been any times that friends have found out your status without you telling them?*

**7. Tell me about the friends you haven't told about being HIV positive.**

*What were your thoughts and feelings about not telling them?*

*How does not telling your friends affect your relationships with them?*

*How do your relationships with friends you have told compare to those you haven't?*

*Are there any friends you haven't told who you might tell in the future?*

**8. Tell me about your friendships before you were diagnosed.**

*Who were you closest to?*

*Has your diagnosis changed what you do with your friends?*

*Has it changed how you think about your friends?*

*Have you lost touch with any friends since your diagnosis?*

**9. Tell me about the friends who are the most helpful to you.**

*In what ways are they helpful?*

*Which friends do you turn to for emotional support?*

*Do your friends help you with practical things (e.g. attending clinic appointments)? In what way?*

*How does support from your friends compare to support from other people (e.g. family / partners)?*

**10. How important are your friendships compared to other relationships in your life (e.g. family / partners)?**

*How important are your friends compared to other things in your life (e.g. career / education / employment / hobbies and interests)?*

**11. Tell me about how you see your friendships in the future.**

*Which friends would you like to stay close to?*

*Would you like your friendships to change in any way?*

*Which aspects of your friendships would you like to stay the same?*

**12. Is there anything else you'd like to share?**

*Is there anything important about your friendships that we haven't spoken about?*



## **Appendix 11: Additional interview questions**

**3.**

*Before you knew you were HIV positive what were your thoughts or beliefs about HIV?*

**5.**

*Do you have any friends who are sexual partners? Tell me about what that is like. Has your diagnosis changed your relationship with them?*

**7.**

*What thoughts or images go through your mind when you think about telling them?  
Have there been any times that you have come close to telling them? What was that like?  
How do you think they would react if you did tell them? How likely do you think that is? What  
would that mean to you? How would you cope?*

**8.**

*Have you made any new friends?*

## Appendix 12: Participant demographic questionnaire

Participant identification number: \_\_\_\_\_

### PARTICIPANT QUESTIONNAIRE

Before your interview it would be helpful to know some basic information about you. You do not have to answer any questions that you do not feel happy to. You will have an opportunity to discuss this form or ask any questions before we begin the interview.

---

1. Age: \_\_\_\_\_

2. Gender: \_\_\_\_\_

3. Ethnicity: *(please circle)*

White British

Irish

Mixed White & Black Caribbean

Mixed White & Black African

Mixed White & Asian

Pakistani

Bangladeshi

Chinese

Indian

Black African

Black Caribbean

Other: *(please state)* \_\_\_\_\_

4. Country of birth: \_\_\_\_\_

5. Sexual orientation: *(please circle)*

Heterosexual / straight

Homosexual / gay

Bisexual

Other: *(please state)* \_\_\_\_\_

6. Relationship status: *(please circle)*

Single

Regular partner (separate residences)

Regular partner (co-habiting)

Married / civil partnership

Other: *(please state)* \_\_\_\_\_

**7. Education / Employment status:** *(please circle)*

Education (Full-time)

Education (Part-time)

Unemployed

Employed (F/T)

Employed (P/T)

Other: *(please state)* \_\_\_\_\_

## Appendix 13: Participant health information sheet

Participant identification number: \_\_\_\_\_

### PARTICIPANT HEALTH INFORMATION

Date of HIV diagnosis: \_\_\_\_\_

Currently attending: *(please tick all that apply)*

Psychiatry ☐

Psychology ☐

Counselling ☐

Other mental health support ☐

Please describe: \_\_\_\_\_

CD4 count *(most recent)*: \_\_\_\_\_

Date: \_\_\_\_\_

Viral load *(most recent)*: \_\_\_\_\_

Date: \_\_\_\_\_

Antiretroviral treatment?

YES

NO

Medication	Adherence estimate >50% doses taken = Poor 50-90% doses taken = Patchy >90% doses taken = Good

## Appendix 14: Example memos

### **Memo – Identifying pre-diagnosis knowledge and beliefs about HIV**

#### *Interviews 1 – 4*

Participants seem to be giving a narrative account of what they knew before being diagnosed with HIV compared to what they know now, in terms of knowledge / education and beliefs about HIV. This seems to influence to their initial reactions to diagnosis to some extent – e.g. Participant 2 being uneducated about HIV compared to Participant 3 knowing more about it due to knowing other people living with HIV before he was diagnosed. Participant 2's initial reaction of feeling stunned and hopeless compared to Participant 3 feeling sad, but choosing to stay on holiday in Brazil on receiving his HIV diagnosis.

*P2 – So like “wow! I just got my death sentence...That was the picture that I had, when the first [...] when I got my result, I was like “wow!”. (Page 3)*

*P3 – Upset for the first... first week, really upset. And then... it kind of died a bit down after that. And then sometimes I forget I have it now. I don't even realise [...] I stayed over there, still [laughs]. For a long time. And then I come back when my plane ticket was to come back. (Page 6)*

Despite Participant 3 knowing other people living with HIV, he also described acquiring knowledge about the virus post-diagnosis, which seemed to facilitate the process of adjustment...

*P3 – Yeah, just sad. Didn't know what to do. Just a bit lost... But now. I know what to do. I'm fine now. (Page 7)*

I almost got the sense that some participants wanted to tell me (assuming that I do not have a diagnosis of HIV myself) how little an impact HIV has on their lives.

Participant 2 spoke about wanting to educate society about HIV and thinking that it would be easier to disclose to friends if people knew more about HIV as a whole. Participant 4 (diagnosed aged 16) reflected on her age in terms of being uneducated about HIV before she was diagnosed. Perhaps being young means little exposure to HIV, or only a certain type of exposure (HIV-related jokes between friends or HIV in the media rather than formal education about HIV). For Participant 2, being uneducated about HIV appeared to shape unhelpful beliefs about transmission – believing it could be transmitted by touch – whereas for Participant 4 her lack of knowledge about HIV was actually a factor that facilitated HIV disclosure to friends...

*I: Did you have any concerns or fears about telling friends?*

*No, not really 'cause I was so not known to what it [HIV] really was that I didn't really feel away from telling them. No, I didn't feel away at all. (Page 12)*

#### *Interviews 5 – 8*

Similar to previous interviews, participants reflected on education / knowledge and beliefs about HIV before they were diagnosed. Participant 6 described his pre-diagnosis beliefs about HIV in terms of his culture, which was similar to Participant 2, who is also black-African...

*Just being, like, where I come from HIV positive you're not, like, a normal person. You got a picture of you know bony, like that, a zombie image, you know, in my head. And I was thinking "I'm gonna be that" and it was really stressful. (Page 3)*

It seems that pre-diagnosis knowledge and beliefs about HIV are influenced by culture and perhaps people of black-African ethnicity have more catastrophic or stigmatising beliefs about HIV than those of British origin? Similar to participants 2 and 3, Participant 7 described wanting to avoid other people living with HIV in the past. Perhaps participants are reflecting on their own beliefs about HIV in the past and anticipating that their friends share similar views to what they did before they were diagnosed. This didn't seem to be particularly distressing for Participant 2, who

seemed to reflect on his past behaviour as a way of empathising with friends, whereas Participant 7 seemed to feel guilty about it...

*Somebody I had met – I knew – I had met before... um, told me they had HIV and I, kind of, pushed – ignored them – after that. So when I found out that I had it I felt really bad about that, and a bit worried that somebody else would do the same. (Page 8)*

#### *Interviews 9 – 10*

Similar to other MSM participants, Participant 10 described knowing other people with HIV before he was diagnosed. He had a unique and tragic experience of being friends with someone with HIV who passed away shortly after he [Participant 10] was diagnosed. Although the death was drug-related, it is possible that Participant 10 made links to HIV – e.g. perhaps he perceived his friend's struggle with substance misuse as a way of coping with his HIV diagnosis? Despite this difficult experience, Participant 10 seemed to be reassured by knowing other people living with HIV in terms of knowing that you can live well with the virus...

*Well... 'Cause – my friend was – I seen him living his life and he was alright, um, I always knew that there was always things about HIV, especially in London, and how you can still live well and healthy. (Page 4)*

Participant 10 seemed to identify tensions between rational thinking about HIV – i.e. knowing you can live healthily – and more emotional thinking about HIV, based on his Christian upbringing...

*But I guess it was – for me – it was, for me, it was a kind of – my upbringing was – Pentecostal Christian, I'm first generation Jamaican, sort of – so my parents are from Jamaica – so that stigma, for me, was, "you're going to hell"... like... you just, "you've sinned, you've got nothing left". So that was my, kind of, shock in the fact that I've lost it all, I've lost everything. And I'm gonna be one of those guys who is going to be*

*on pills all the time, and, infectious – obviously not infectious – but you know, the disease and leprosy. (Page 4)*

Perhaps certain cultural and religious factors may shape unhelpful beliefs about HIV, which could influence internalised stigma. Perhaps black-Caribbean and black-African young MSM may have different pre-diagnosis beliefs about HIV than white-British MSM, which could be related to systemic factors (family influences)?

#### *Initial coding*

Believing HIV could be transmitted easily

Being uneducated about HIV

Believing HIV means you are going to be really unwell or die

Being friends with people living with HIV

Wanting to avoid people living with HIV

#### **Memo – Being true to oneself within friendships**

There seems to be something about the disclosure process as being part of identity – e.g. being an “open person”, or being a “private person”. Participants seem to be making decisions on HIV disclosure to friends based on how they see themselves within their friendships. Perhaps this links to self-determination theory (Deci & Ryan, 1985)? SDT says that individuals’ behaviour is driven by three basic psychological needs: autonomy, competence, and relatedness. But there is also a sub theory of motivation (intrinsic and extrinsic motivation) – there are different depths of motivation and the behaviour change is more enduring the deeper the motivation. Perhaps what participants are describing relates to autonomy – feeling that they are in charge of their decision-making? If young people feel that they have more control over HIV disclosure decision-making it may seem less distressing. This could also link to Moss-Morris’ (2013) model of adjustment to chronic illness (perceived sense of control facilitating successful adjustment).



## Appendix 15: Example interview transcript

PARTICIPANT 2	Initial coding	Focused coding
<p><i>I: And me! Quite right. And me. OK... so, can you tell me about the important friends in your life? So it doesn't matter that you haven't told them... just tell me about the friends who are important to you.</i></p> <p>My friends... I can say my friends are the greatest asset I've got so far.</p> <p>They're kind. They are so nice,</p> <p>but I don't know how they are going to take it, how they are going to react to it when they know that you are HIV positive.</p> <p>The reason being that the kind of picture...</p> <p><i>I: That they might have?</i></p> <p>Yeah. The kind of picture that everybody have in mind,</p> <p>that "HIV, wow!".</p> <p>Like, because there is somebody, who is also Nigerian, he used to run a restaurant, so later people got to know that he is HIV positive and they stopped going to his restaurant. He had to sell the restaurant to someone. Because people stopped going there.</p>	<p>Really valuing friends Describing positive qualities of friends</p> <p>Feeling uncertain about friends' reactions to HIV</p> <p>Identifying a reason for not telling friends</p> <p>Predicting that friends will share the same view of HIV as other people Predicting that friends will be stunned by HIV Witnessing negative reactions to HIV by others in the past Witnessing HIV-related stigma</p>	<p>Characterising friendships</p> <p>Identifying pre-existing negative beliefs about HIV held by others</p>

<p>Simply because, the owner, the owner, not the one that is cooking the food...</p> <p><i>I: The owner...</i></p> <p>The owner who used to be there. He is HIV positive... “Wow! That guy is HIV positive. I can’t go there! I can never go there and drink again!”.</p> <p>So that is the kind of picture the Nigerians have in their mind.</p> <p><i>I: OK. And is that somebody who you know, who owns the restaurant?</i></p> <p>Yeah, I know him, but I don’t talk to him.</p> <p>I knew him to be HIV positive even before I knew my own.</p> <p><i>I: Yeah. And are most of your friends Nigerian?</i></p> <p>Yes.</p> <p><i>I: Yeah?</i></p> <p>Most of them.</p> <p><i>I: So it sounds like you think that they all have a similar view.</i></p>	<p>Believing people’s reactions to HIV are unreasonable</p> <p>Remembering other people wanting to avoid someone with HIV in the past</p> <p>Believing that Nigerians share a negative view of HIV</p> <p>Knowing of someone else with HIV</p> <p>Knowing of someone else living with HIV before being diagnosed</p> <p>Confirming that most of his friends are Nigerian</p> <p>Confirming that most of his friends are Nigerian</p> <p>Confirming beliefs about Nigerians</p>	<p>Identifying pre-existing negative beliefs about HIV held by others</p>
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<p>A similar view.</p> <p>But now that, when I brought my girlfriend in, when I said... when the doctor said to her that “HIV, even when you... even when you both share the same toothbrush you are not going to contract that”.</p> <p>But I never knew that!</p> <p>Even when... they used to... WE used to feel that even when you handshake HIV would be transmitted,</p> <p>so we kind of were horrible...</p> <p>so like, once you have it, everybody around you can get infected.</p> <p>So people they stigmatise...</p> <p>the stigmatisation is really killing people in Africa. Really killing people.</p> <p><i>I: So it sounds like they don't have a lot of education about HIV in Nigeria.</i></p> <p>Yes. Yes, they are trying.</p> <p>But not enough.</p>	<p>sharing a similar view about HIV Describing being educated with his girlfriend about HIV transmission at the clinic</p> <p>Realising HIV is not transmitted as easily as previously believed Believing before that HIV could be transmitted through touch</p> <p>Describing being horrible in the past</p> <p>Believing HIV can be transmitted easily Thinking people stigmatise</p> <p>Believing stigma is really killing people in Africa</p> <p>Believing Nigeria is trying to educate people about HIV Believing HIV education in Nigeria is insufficient</p>	<p>Identifying pre-diagnosis knowledge and beliefs about HIV</p> <p>Identifying pre-diagnosis knowledge and beliefs about HIV</p> <p>Identifying pre-diagnosis knowledge and beliefs about HIV</p>
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<p><i>I: And who would you say that you are closest to out of your friends?</i></p> <p>Yeah, yeah. I am very close to them.</p> <p><i>I: Is it one particular friend that you would say is your best friend, or do you have several?</i></p> <p>Yeah, yeah. Actually, I don't tell people that I have a best friend. I only have close friends.</p> <p><i>I: OK...</i></p> <p>I keep everybody equal, so they are all close friends.</p> <p><i>I: OK. So, how would you describe your close friends? What are they like?</i></p> <p>Hmm. It's a friendship that has been for more than a decade.</p> <p>So we all grew up together in Nigeria.</p> <p>So we found ourselves here, and we continued the friendship.</p> <p><i>I: So they're all in the UK as well?</i></p> <p>Yeah</p>	<p>Feeling very close to friends</p> <p>Identifying having close friends rather than a best friend</p> <p>Keeping friends equal</p> <p>Knowing friends for more than ten years</p> <p>Growing up with friends in Nigeria Maintaining friendships over time</p> <p>Confirming friends are also in the UK</p>	<p>Characterising friendships</p>
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<p><i>I: Do you have friends who you are still in contact with in Nigeria?</i></p> <p>Yes</p> <p><i>I: OK. And what are your relationships like with your friends?</i></p> <p>Great.</p> <p>We do... we go out together, we go clubbing. Drink. Every normal thing that friendship does.</p> <p><i>I: It sounds like from what you were saying earlier that the main reason that you haven't told your friends about your status is because you're worried that they might react negatively, is that right?</i></p> <p>Yes</p> <p><i>I: So what... can you tell me more about that, what are your main concerns?</i></p> <p>The reason is if my friends... see, they take me as a friend, but what about them telling other people about it. Like "Oh... such and such, blah blah blah". It's about spreading the news.</p> <p>That's... I know that it won't kill me,</p>	<p>Confirming being in contact with friends in Nigeria; maintaining long distance friendships</p> <p>Thinking friendships are great</p> <p>Doing normal fun things with friends</p> <p>Predicting friends will react negatively to HIV diagnosis</p> <p>Predicting intentional indirect disclosure by friends</p> <p>Feeling able to survive HIV</p> <p>Feeling able to cope with HIV</p> <p>Feeling unable to cope with</p>	<p>Friendships being unchanged by HIV</p> <p>Identifying pre-existing negative beliefs about HIV held by friends</p> <p>Difficulty trusting friends</p>
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<p>I can cope with that.</p> <p>But spreading the news, I won't be able to cope with that.</p> <p>So that's why.</p> <p>I told... I used to tell my doctor here, I am still going to tell people about it,</p> <p>but once I have the confidence.</p> <p>Now I don't have the confidence.</p> <p>I need to get the confidence first before I can start telling people about it.</p> <p><i>I: What do you think would help you to gain the confidence?</i></p> <p>Actually, knowing my results that I was given,</p> <p>that is why I can come here and talk to you about it, because last time I was told my viral load is less than 20</p>	<p>indirect HIV disclosure</p> <p>Planning to disclose HIV status in the future</p> <p>Hoping to feel more confident in the future</p> <p>Feeling unconfident now</p> <p>Identifying low confidence as a barrier to HIV disclosure</p> <p>Identifying knowing results as helpful</p> <p>Feeling more able to talk about HIV now viral load is undetectable</p>	
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## **Appendix 16: Example research diary entries**

**28.10.15**

Today it hit me how privileged I feel to have been able to listen to participants' stories and experiences, particularly those who have disclosed their HIV status to many people. Initially Participant 2 seemed that he wasn't hugely motivated by the research however at the end of the interview he seemed like a completely different person – really enthusiastic and animated. He spoke a lot about Nigerian beliefs about HIV and seemed passionate to try and change them. Participant 2 made a point of telling [clinic staff member] how much he enjoyed taking part in the research and how much he valued talking to me personally. It was a relief to learn that a safe space had been created for him during the interview. I felt as though the process of talking had been therapeutic for him and one that I am privileged to have been part of. I noticed with Participant 3 the challenges of conducting a research interview when I am more clinically trained. At the end of the interview he was asking advice related to life goals (e.g. meeting a partner) and I found it difficult to know how far to go with this. I tried to normalise his concerns and wondered whether he might be interested in seeking help from primary care psychology. He joked that people often tell him he needs to "go and see someone". I got the impression he had some concerns about his appearance and he talked a lot about going to the gym excessively. I wondered whether in hindsight it might have been helpful to use standardised measures of symptoms of mental health problems (e.g. PHQ-9) as part of my research design, to gain clarity on potential experiences of emotional distress within the sample.

**11.11.15**

I was pleased to interview Participant 4 today for several reasons. She was a young girl who was diagnosed at 16 and I found myself warming to her a great deal. I was particularly impressed with her resilience and the clinic already informed me that she is a good attender. I admired her willingness to take care of her health at such a young age. It was also great to broaden the scope of the study with recruiting a female. The interview also raised other issues associated with HIV – i.e. legal issues relating to intentionally infecting others with HIV. Once again, I noticed with this interview that it was difficult for me to stay focused on the research aims and avoid hearing about other interesting, but not directly, relevant experiences.

### Appendix 17: Summary of focused codes across participants

THEORETICAL CODES	FOCUSED CODES	1	2	3	4	5	6	7	8	9	10
1. Personal factors influencing HIV disclosure decisions in friendships	1.1. Identifying pre-diagnosis knowledge and beliefs about HIV		X	X	X	X	X	X	X		X
	1.2. Identifying personal beliefs about friendships		X		X		X	X	X		X
	1.3. Thinking about the consequences of disclosing to friends			X	X	X	X	X	X		X
2. Social factors influencing HIV disclosure decisions in friendships	2.1. Considering the nature of friendships			X	X					X	X
	2.2. Difficulty trusting friends	X	X		X	X		X		X	
	2.3. Not wanting to burden friends with HIV	X					X		X	X	
	2.4. Identifying pre-existing negative beliefs about HIV held by friends		X	X		X	X	X	X		X
3. Disclosure decision outcomes in friendships	3.1. Positive outcomes following HIV disclosure to friends	X		X	X						X
	3.2. Complications associated with non-disclosure to friends		X	X		X	X			X	X
4. Post-diagnosis experiences of friendships in the context of other aspects of life	4.1. Friendships being unchanged by HIV	X	X	X	X		X	X	X	X	X
	4.2. Receiving HIV-related support elsewhere	X	X			X	X		X		
	4.3. Comparing friends to other important things		X	X				X			X