A Model of Sibling Relationships in Young People with Perinatally Acquired Human Immunodeficiency Virus (HIV)

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Abstract

Significant HIV-related stressors affecting young adults with perinatally acquired HIV (PHIV+) and their siblings can include parental ill-health or death, sibling ill-health or death, HIV disclosure, stigma and discrimination. Young people are more likely to disclose their HIV status to family members than externally, highlighting that siblings can provide important peer relationships and potential sources of support. Research into the sibling relationships of young people with PHIV+ is currently limited.

The aim of this study was to develop a model of sibling relationships in young people with PHIV+. The sample consisted of 10 young people with PHIV+. Participants aged between 16-25 years old were recruited from two London NHS HIV clinics. Four male and six female participants (median age 20.5 years) each took part in a semi-structured interview. Interviews were recorded, transcribed and analysed using Grounded Theory. Participants also completed a measure of the perceived sibling relationship and of subjective well-being.

Data analysis led to a theoretical model comprising four theoretical codes: 1) Personal adjustment to PHIV+ diagnosis; 2) PHIV+ disclosure in the sibling relationship; 3) Patterns of communication about PHIV+ between siblings; and 4) Patterns of coping and support in the PHIV+ sibling relationship. Key findings include a PHIV+ young person’s perceived lack of control around disclosure of their HIV status to sibling(s) and variations in levels of HIV support and communication between siblings based on their experiences of disclosure. It is hoped that the resulting model will inform therapeutic interventions with this population, to improve levels of well-being and coping with the psychosocial challenges associated with PHIV+ in affected families. Possibilities for future research are also presented.

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CHAPTER 1: INTRODUCTION

Overview of the study

Despite evidence that perinatally acquired Human Immunodeficiency Virus (PHIV+) impacts not only the individuals with the virus but the whole family (DeMatteo, Wells, Goldie, & King, 2002), there remains a limited understanding of the impact of PHIV+ on sibling relationships. In recent years, medical advances have changed the prognosis of PHIV+ from a terminal diagnosis to a chronic one (Sherman, Bonanno, Wiener, & Battles, 2000). Young people born with PHIV+ are now living longer, healthier lives and the psychosocial impact of living with PHIV+ on relationships and well-being requires urgent investigation. Findings in paediatric chronic illness populations have shown the sibling relationship to be affected by sibling ill-health, illness disclosure and parental differential treatment (Weiss, Schiaffino, & Ilowite, 2001). Unlike many chronic illnesses, PHIV+ also remains a highly stigmatised condition that is transmitted from mother to child. PHIV+ young people and their HIV-negative (HIV-) siblings have been found to have poorer psychological health than their general population peers (Gadow et al., 2010). These additional factors warrant specific examination of the nature of sibling relationships in PHIV+.

This Grounded Theory study (Charmaz, 2014) aimed to explore PHIV+ young people's experiences of their sibling relationships. It is hoped that the resultant theoretical model might be used to inform therapeutic interventions with this population, by highlighting potential sources of support or functional and dysfunctional family processes. This introduction will summarise the literature relevant to PHIV+ in young people, sibling relationships in the general population and chronic illness and HIV-related stressors experienced by young people and families with PHIV+. Research questions are outlined to guide the qualitative investigation of sibling relationships in young people with PHIV+.

Human Immunodeficiency Virus (HIV)

The Human Immunodeficiency Virus (HIV) attacks the body's immune system by reducing the number of CD4 blood cells, which increases susceptibility to infection and disease. In the final stages of HIV infection, an individual is diagnosed with Acquired Immunodeficiency Syndrome (AIDS) when their CD4 count drops to a level that they are more likely to develop terminal opportunistic illnesses (usually below 200 cells per ml of blood). Without treatment, people with AIDS typically survive about three years (CDC, 2016).

There is currently no cure for HIV. Current treatments for HIV include antiretroviral (ARV) drugs, which control the replication of the virus and help prevent its transmission. HIV can be well managed with strict adherence to combination antiretroviral therapy (ART), consisting of three or more ARV drugs. Infants, young people and adults with HIV should begin taking ART at the point of diagnosis, regardless of their CD4 count (WHO, 2015; BHIVA, 2016).

HIV Globally

According to the World Health Organisation (WHO, 2014), HIV/AIDS is the number one cause of death among adolescents (10-19 years old) in Africa and the number two cause of death globally in this age range. There are an estimated 36.7 million people worldwide currently living with HIV (WHO, 2016). An estimated 25.8 million of those people live in sub-Saharan Africa (UNAIDS, 2015). There are subsequently

10.9 million children living in sub-Saharan Africa who have lost one or both parents to AIDS; more than 80% of the worldwide total of 'AIDS orphans' (UNICEF, 2016).

Increased availability of highly active ART has led to children with PHIV+ living longer and entering young adulthood in large numbers for the first time (Mellins & Malee, 2013). As such, the global HIV epidemic includes an increasing adolescent and young adult epidemic.

HIV in the UK

There are an estimated 101,200 people living with HIV in the UK (Public Health England [PHE], 2016). In the UK, the HIV epidemic exists largely among gay, bisexual and other men who have sex with men (MSM), as well as heterosexual people of black African ethnicity. Free and accessible HIV treatment in the UK and care available through the National Health Service (NHS) has led to large-scale treatment coverage, with an estimated 78% of all people living with HIV having an undetectable viral load (less than 200 copies/UL) (PHE, 2016). Viral load is the term used to describe the amount of HIV in a person's blood.

Perinatally Acquired HIV (PHIV+)

Perinatally acquired HIV describes the vertical transmission of HIV from a mother to her child during pregnancy, labour, delivery or through breastfeeding. Without intervention, the rates of HIV transmission from mother-to-child are between 15-45% (WHO, 2016). Increased access to effective medical interventions (antenatal HIV screening, ART during pregnancy and for the new-born baby, non-vaginal delivery, safer breastfeeding practices or no breastfeeding) has resulted in significant reductions in mother-to-child transmission of HIV. Transmission rates for PHIV+ declined by an estimated 48% between 2009 and 2014 in low and middle income countries (UNAIDS, 2015). Mother-to-child transmission rates have also declined in the UK, from approximately 20% in the 1990s (Duong, Ades, Gibb, Tookey, & Masters, 1999) to a rate of 0.27% in 2014 (seven transmissions among 2580 infants born to HIV+ mothers) (Peters et al., 2017).

Notable features of PHIV+ include it being a perinatally acquired transmissible condition, highly stigmatised and at least in the US and UK, present mainly in minority ethnic groups, residing in inner-city areas (Kang, Mellins, Ng, Robinson, & Abrams, 2008). In the UK and Ireland at the end of April 2016, the Collaborative HIV Paediatric Study (CHIPS) identified approximately 905 young people living with HIV, of whom 93% were known to have been infected through mother-to-child transmission (CHIPS, 2016). The proportion of this cohort aged ≥15 years was 48% in 2016 and 53% identified as female. Additionally, 50% were born abroad, 78% were of black African ethnicity, and 46% were being seen at clinics in London (CHIPS, 2016).

An alternative route of HIV transmission is ‘behaviourally acquired’ HIV (BAH), which is transmitted via unprotected sex, exchange of bodily fluids or intravenous drug use. There are found to be distinct differences between the BAH and PHIV+ populations (Conner et al., 2013). With particular relevance, PHIV+ is a disease which has a significant impact on the whole family, as mother, possibly father, and one or more children will have the virus (DeMatteo et al., 2002). PHIV+ is therefore also more likely to have an impact on sibling relationships in these families. The PHIV+ young person will have grown up with the stigmatised, chronic illness from birth, had to manage treatment regimens and both siblings may have experienced HIV-related bereavements (Bauermeister, Elkington, Brackis-Cott, Dolezal, & Mellins, 2009).

PHIV+ in Young People

The introduction of highly active ART in 1996 has led to a substantial reduction in HIV-associated mortality and morbidity in paediatric populations in recent years. PHIV+ children born before the availability of ART in the treatment of HIV+ pregnant women and in low-resource countries with poor ‘prevention of mother to child transmission programmes’ (PMTCT) are now entering young adulthood. This cohort of PHIV+ young people pose new challenges as they transition through adolescence and young adulthood with varied and complex physical and mental health needs. Concerns regarding treatment adherence in adolescence are common among both HIV and other chronic diseases (Foster et al., 2009).

Medication Adherence

High levels of adherence to ART (>95%) are crucial to treatment success. Poor adherence may result in viral drug-resistance to medications, which limits treatment options available to adolescents with HIV as they progress into adulthood (Paterson, 2000). In a meta-analysis and systematic review of studies reporting adherence in young adults living with HIV, adherence to ART was found to be lower among European adolescents than adult populations (Kim, Gerver, Fidler, & Ward, 2014). In the same study, rates of treatment adherence in European young adults were much lower at 62% than those in Africa (83.8%) or Asia (83.9%). In a sample of 537 young people with PHIV+ in the UK and Ireland who had ever started ART, almost one tenth were off therapy due to poor adherence/ refusal (Foster et al., 2009). Poor adherence in young people living with HIV has been associated with perceived difficulty of medication routine, substance use and forgetting (Chandwani et al., 2012). Non-adherence was also associated with lower positive affect and lower levels of behavioural skills in a UK sample of 29 PHIV+ young people (Hawkins et al., 2016). Alongside adherence concerns, PHIV+ young people are also exposed to physical health risks as a result of long-term ART, including increased risk for cardiovascular disease, reduced bone density and central nervous system abnormalities (Hazra, Siberry, & Mofenson, 2010).

Neurodevelopment

Whilst treatment with ART has significantly reduced incidence rates of severe neurocognitive diseases, such as HIV encephalopathy, PHIV+ young people may still experience less severe neurocognitive complications (Vreeman, Scanlon, McHenry & Nyandiko, 2015). HIV disease progression, exposure to HIV/ART in utero and ARV neurotoxicity have all been suggested as contributing factors to observed deficits in general cognition, processing speed and visual-spatial abilities in some PHIV+ young people (Laughton, Cornell, Boivin, & Van Rie, 2013). Along with additional deficits in expressive language, the impaired cognitive development of some adolescents living with PHIV+ may have an impact on learning, quality of life and social relationships (Cruz & Cardoso, 2015; Vreeman et al., 2015). However, a recent comparison of 296 PHIV+ and 97 HIV-affected adolescents in the UK (who are HIV-negative but may have been perinatally exposed to HIV and/or live in a household with an HIV-positive mother or sibling) indicated no difference in cognitive scores between groups (Judd et al., 2016). This suggests that PHIV+ children who avoid severe disease (e.g. HIV encephalopathy) before starting ART are at a similar risk of cognitive problems as their HIV- peers (Judd et al., 2016).

Young Adulthood

Despite acknowledgement in the literature that sibling relationships play a significant role in the lives of individuals throughout the lifespan, limited knowledge exists about the influence of siblings among the ‘emerging adult’ population (Milevsky, 2005). Arnett (2000) suggests emerging adulthood as a term to describe the post-school years between adolescence and adulthood (ages 18-25) in which increased autonomy, self-exploration and changing roles are unique characteristics. He argues that this period is distinct from adolescence and young adulthood as an individual has left the dependency of adolescence but has not yet undertaken the responsibilities of adulthood. This is demonstrated in five main features of emerging adulthood; identity exploration, instability (in relationships, work and home), self-focus, feeling in-between (neither adolescent nor adult) and possibilities/optimism (for the future) (Arnett, 2007). The age distinctions and nature of emerging adulthood (developmental stage vs. process) has been widely debated (Arnett, 2011; Bynner, 2005), with evidence that the brain continues to mature until young adulthood (Casey, Tottenham, Liston, & Durston, 2005). For the purposes of this review, individuals transitioning between adolescence, emerging adulthood and young adulthood will be referred to as ‘young adults’ (or ‘young people’) wherever possible.

Developmental Tasks

As indicated, the normal developmental trajectory for young adults in the West involves identity formation, behavioural experimentation, risk taking, alcohol and drug use, romantic relationships and sexual behaviour (Arnett, 2007). Young adulthood represents a time of rapid physical, psychological and social developmental change. The psychological tasks of young adulthood include developing more complex thinking skills, peer and intimate relationships, adopting a personally meaningful value and belief system, separation of identity from birth family, renegotiating relationships with parents and meeting the demands of vocational and economic goals (Kennedy, Sloman, Douglass, & Sawyer, 2007).

A significant life event for most young adults in Western countries is moving out of the family home, either to attend university, move in with a romantic partner/friends and/or create distance and assert financial independence from their existing family unit. In the UK and Ireland, particularly in inner-city areas, this transition is occurring later than it used to, with young adults living at home while starting work or pursuing higher education. Young adults are also having children and getting married older than ever before, with the average age of marriage in England and Wales now at 37 years for men and 34.6 years for women (ONS, 2014).

For individuals with a chronic illness, their healthcare is largely the responsibility of their parents on entering adolescence, but will be almost entirely their own responsibility as young adults. Chronic illness can also disrupt adolescent development due to repeated hospital admissions and poor health status limiting time spent with peers and in education (Taylor, Gibson, & Franck, 2008). Conversely, young people with a chronic illness may experience emotional maturation ahead of their healthy peers due to increased adverse experiences of ill-health and loss (A. Kennedy et al., 2007).

The Nature of Sibling Relationships

Globally, the majority of individuals are raised with at least one sibling, making the sibling relationship often the most enduring and a key source of support. Sibling relationships are unique due to their proximity in age, life-long duration, shared genetics, strong emotional ties and shared family experiences. Recent research has recognised the developmental importance of the sibling relationship and its ability to shape and be shaped by the family context it exists within.

Systemic Framework

The experiences of siblings have been viewed from a number of different psychological theoretical perspectives including social learning theory, attachment theory and family-ecological systems. A broad systemic perspective of the sibling relationship and family will be taken here as it is a position widely taken in sibling research, encompasses elements of alternative perspectives and values the role of social context. The ecological systems perspective (Bronfenbrenner, 1979, 1986) highlights the interaction within and across multiple subsystems, which shape the development of sibling relationships. The microsystems that an individual exists within refers to immediate contexts of daily living and relationships such as family, peers, health services, school or work. The mesosystem represents the connections between microsystem contexts (e.g. the school-home interface) and the exosystem refers to contexts that indirectly impact on the sibling relationship (e.g. parental absence increasing older siblings' caregiving responsibilities). Finally, the macrosystem includes the broader societal contact of political, economic and cultural influences. The presence of HIV in a child's social ecology is likely to disrupt variables at every level of the system. Research using this ecological framework encourages a move away from deficit-based models to a strengths-based perspective which finds resources in the system (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013).

Based on the principles of general systems theory (Bertalanffy, 1968), a family systems framework describes siblings as interdependent individuals who are reciprocally influential as part of a wider family context (Bowen, 1993). Family members and the subsystems they exist within continually affect one another directly and indirectly (Minuchin, 2002). Dynamics within the hierarchy of family subsystems and characteristics of individual family members contribute to siblings' attitudes, roles and interactions towards one another. The sibling dyad must therefore be understood within the transactional nature of interactions in the larger family system and not independent of this context.

Sibling Transition to Adulthood

The systemic family life cycle (Carter & McGoldrick, 1988) considers the changing role of sibling relationships, with young adulthood representing departure from the family home and a decrease in sibling conflict as interactions become more voluntary (Stewart et al., 2001). During adolescence, individuals spend more time with siblings than with their parents, equivalent to a peer relationship (Stocker, Burwell, & Briggs, 2002). A model of family systems development describes the system as oscillating between periods of family closeness, enmeshment and distance (Combrinck-Graham, 1985). The close periods are called "centripetal" and occur around childbirth and child-rearing. The distant, or disengaged, periods are called "centrifugal" and occur at times when family members differentiate from one another, such as adolescence. During this centrifugal period, adolescents are working on individual issues of personal identity and goals, which are affected by family processes and often contribute to the creation of new family structures. Adequate disengagement and individuation is necessary during adolescence, to allow the coming together of the family system in subsequent centripetal periods, without the young person fearing for their autonomy (Combrinck-Graham, 1985).

Young adult siblings report higher intimacy and more warmth than adolescent siblings, with increased emotional exchanges (Scharf, Shulman, & Avigad-Spitz, 2005). However, sibling social support has also been found to decrease in early adulthood as proximity between siblings increases and they spend less time together (White, 2001). Scharf and colleagues (2005) found that sibling relationships seemed to be less related to the quality of parental relationships in young adulthood than in adolescence.

Quality of Sibling Relationships

Sibling relationship literature throughout the lifespan consistently refers to dimensions of warmth, conflict and rivalry that characterise the quality of sibling relationships. Sibling warmth refers to positive aspects of the sibling relationship including affection, support, intimacy, acceptance and admiration (Stocker, Lanthier, & Furman, 1997). Conflict between siblings reflects negative attitudes or interactions such as quarrelling, antagonism, dominance and competition. Sibling rivalry is closely related to perceptions of differential treatment (Brody, 2004) and highlights the importance of fairness and equality in the sibling relationship. Parental differential treatment (PDT) describes an individual’s perception that their parents behave differently towards them than towards their sibling, often favouring one sibling over another (Jensen, Whiteman, Fingerman, & Birditt, 2013). Young adults who report receiving less support relative to their sibling and greater differential treatment also reported more depressive symptoms and less sibling intimacy (Jensen et al., 2013).

Positive sibling relationships have been found to be protective, independent of the quality of the relationship between mother and child (Gass, Jenkins, & Dunn, 2007). Sibling affection moderates the relationship between highly stressful life events and later child adjustment, indicated by less change in symptoms of anxiety and depression over time. Affectionate siblings may increase coping by providing a sense of safety and security. Alternatively, they may be better able to distract and provide alternative explanations for adverse life events. In a sample of African American families, parental spirituality was linked with higher sibling warmth and lower ethnic identity in the children was linked with sibling emotional distance (McHale, Whiteman, Kim, & Crouter, 2007). Birth order and age differences between siblings may also affect the type and quality of the sibling relationship, creating a hierarchical dynamic in which older siblings often take the role of model, caregiver and advisor to younger siblings (Tucker, McHale, & Crouter, 2001).

Gender influences

Gender differences have been found in the quality of sibling relationships, indicating that mixed-sex dyads exhibit increases in intimacy from middle adolescence, whereas sisters report more intimacy overall (Kim, McHale, Wayne Osgood, & Crouter, 2006). In a study of 170 adolescents, male sibling dyads reported lower levels of positive relationship qualities including caring, intimacy and conflict resolution than other gender compositions (Cole & Kerns, 2001). Interestingly however, most research suggests that it is not structural features (e.g. gender, age spacing, biological relatedness) that explain sibling relationship outcomes but the dynamics of the relationship (e.g. levels of conflict and warmth) (Furman & Lanthier, 2002).

Sibling Relationships in the context of Chronic Illness

With increased efficacy of ART, living with PHIV+ now resembles a chronic illness trajectory and HIV+ youths and their families increasingly face many of the same psychosocial challenges as people living with chronic illness (Battles & Wiener, 2002). Chronic illness may result in siblings becoming closer because they offer more help and are more isolated from the community. Alternatively siblings may have less in common and identify less with one other (Weiss et al., 2001). Family communication about a child's chronic illness is also often limited and siblings may feel angry at perceived exclusion from disclosure or the burden of keeping a family secret (Fanos, Fahrner, Jelveh, King, & Tejeda, 2005).

Parental differential treatment also cannot always be avoided when a child is chronically ill (Sharpe & Rossiter, 2002), with increased time and care required by the unwell child. A review of qualitative research regarding siblings of children with cancer found that having a sibling with cancer can lead to jealousy and resentment of parental attention, but may also enhance sibling closeness and development of personal coping skills (Wilkins & Woodgate, 2005). Healthy siblings are often observed to put the ill sibling's needs before their own (Sharpe & Rossiter, 2002). However, among young people with juvenile chronic arthritis, severity of illness was positively associated with perceived sibling conflict (Weiss et al., 2001).

Although chronic illness literature is helpful in beginning to understand the potential impact of PHIV+ on the sibling relationship, PHIV+ has unique psychosocial components that make it unlike other chronic conditions. Research specific to the sibling relationship in PHIV+ is therefore required to accurately represent the impact of the illness.

Subjective Well-being

Subjective well-being is a term widely used in research with both general and HIV+ populations. It is typically considered to have three ‘hedonic’ components; positive affect, negative affect and life satisfaction (also referred to as cognitive appraisals of one’s life) (Diener, 2012). Closely related to subjective well-being is an individual’s psychological well-being, which has been described as optimal functioning in individual and social life (the ‘eudaimonic’ perspective). The measurement of emotional states (affect) or ‘happiness’ in subjective well-being is often characterised by the presence or absence of negative mental health outcomes such as anxiety and depression. Particularly in HIV+ populations, a focus on psychiatric disorders has been taken as an indication of well-being (Mutumba et al., 2015), along with levels of coping and psychological adjustment.

Influence of Sibling Relationships on Well-being

Given that sibling interactions can be associated with strong positive (warmth and intimacy) and negative (conflict and rivalry) qualities, it is not surprising that these relationships have been associated with emotional and behavioural health outcomes. A meta-analysis of 34 studies of sibling relationship quality and psychopathology of adolescents showed that more sibling warmth, less sibling conflict and less differential treatment were significantly associated with less internalising (e.g., social withdrawal, anxiety, depression) and externalising (e.g. delinquency, aggressive behaviour) problems (Buist, Deković, & Prinzie, 2013). The presence of warmth in the sibling relationship, even if accompanied by significant conflict, is associated with less aggression and fewer internalising symptoms (Buist & Vermande, 2014). Several studies have also found a clear link between sibling conflict and internalising problem behaviours (Kim, McHale, Crouter, & Wayne, 2007; Vogt Yuan, 2009) as well as increased involvement in antisocial behaviour (Aguilar, O'Brien, August, Aoun, & Hektner, 2001) and substance use (Yeh & Lempers, 2004).

Psychopathology in Young People with PHIV+

Elevated levels of psychopathology have been shown in both PHIV+ adolescents and HIV- siblings when compared with general population controls (Gadow et al., 2010). Rates of depression and anxiety have been found to be higher in HIV-affected adolescents than PHIV+ young people (Mellins et al., 2011). In a longitudinal study of 166 PHIV+ and 114 perinatally HIV-exposed but uninfected (PHEU) youth in the US, almost 70% met criteria for at least one psychiatric disorder at either baseline or follow-up (18 months), with few group differences (Mellins et al., 2012). Additionally, there was a significant decrease in the prevalence of psychiatric disorders over time in the PHIV+ group, while rates of disorders among PHEU young people remained stable and mood disorders increased. These findings suggest that contextual factors (e.g. negative life events and neighbourhood stressors), rather than HIV status, impact the mental well-being of PHIV+ and PHEU youths (Mellins et al., 2012; Mutumba et al., 2015). PHIV+ young people are also likely to more easily access a support system of health professionals, allowing them to address mental health problems as they arise. These findings are not consistent however, as researchers have also reported higher rates of mental health problems among PHIV+ youths compared to PHEU youths (Mellins et al., 2009) and others have found no difference at all (Mutumba et al., 2015).

In line with the systemic model of families, the macrosystem of an HIV-affected family is known to be vulnerable to multiple environmental stressors such as increased levels of poverty, stigma (a set of negative beliefs or discrediting label that society or a social group hold about something) and victimisation (Latkin, German, & Vlahov, 2013). The microsystems of these families in the US are often characterised by substance abuse, familial conflict, parental mental health problems and parent and/or sibling ill-health/death. In a UK sample of 295 PHIV+ and 90 HIV-affected young people (aged 13-23 years), parental death was associated with higher rates of anxiety and depression in both groups but being female and having higher self-esteem were protective (Le Provost et al., 2017). PHIV+ adolescents are also significantly more likely than behaviourally infected youths (BIY) to report school-related problems (e.g. prolonged absences and school relocation) (Lewis, Abramowitz, Koenig, Chandwani, & Orban, 2015), which may further limit available support for these young people.

Existing literature predominantly focuses on risks to mental health of youth with PHIV+, rather than protective factors that could inform interventions (Mellins & Malee, 2013). A greater understanding of which aspects of the sibling relationship might be protective will allow tailored interventions for young people living in families affected by PHIV+. Additionally, it would be valuable to explore whether levels of anxiety and depression are related to features of the sibling relationship in this unique sample.

Psychological Models of Adjustment

Coping is defined as the use of cognitive and behavioural efforts in managing challenging life events that may exceed a person’s resources (Lazarus & Folkman, 1984). Coping styles mediate the relationship between stressful events and psychological adjustment. In their Stress and Coping Theory, Lazarus and Folkman (1984) propose that coping serves two major functions: to regulate stressful emotions (emotion-focused coping) and alter the relationship with whatever is causing distress (problem-focused coping). Problem-focused coping includes problem solving and interpersonal efforts to alter the source of distress, while emotion-focused coping minimises distress through seeking social support, accepting responsibility and distancing. In people living with HIV, problem-focused coping and lower threat appraisals (but higher challenge and controllability appraisals) are associated with better adjustment (Pakenham & Rinaldis, 2001). In a study of 36 US children with PHIV+, approximately 25% were experiencing significant adjustment problems, with those who endorsed more emotion-focused coping strategies at higher risk (Bachanas et al., 2001). Wallander and Varni's (1998) model of child adjustment to paediatric chronic physical disorders indicates risk (e.g. disability, functional independence, psychosocial stressors) and resistance (e.g. family environment/ adjustment, social support, coping strategies) factors which contribute to adjustment in this population.

Coping with a chronic illness has also been described through the cognitive, emotional and behavioural processes involved in adjustment. The Self-Regulation Model (Leventhal, Meyer & Nerenz, 1980) hypothesises that individuals create schematic 'illness representations', which determine how they make sense of and manage their condition. The individual is an active problem solver in forming emotional disease representations alongside these cognitive appraisals. Illness representations are structured around five key concepts; the nature and labelling of the disease (*identity),* predicted time-course (*timeline),* causal factors *(cause),* personal impact *(consequences)* and the possibilities of control or cure (*control/cure).*

Emotional representations may include feelings of anxiety, guilt, shame, sadness or anger that are a response to a threat (illness symptoms). Together, these representations lead to functional or dysfunctional coping strategies and favourable or unfavourable health outcomes. In reference to HIV populations, higher perceptions of illness influence (consequences) were found among 248 adult HIV+ patients with high viral loads and were associated with dysfunctional coping strategies including passive coping and alcohol use (Pala & Steca, 2015).

Moss-Morris (2013) suggested that existing theories of adjustment offered only limited explanations regarding the process of adjustment as a whole. Her overarching 'Model of Adjustment to Chronic Illness' identifies cognitive and behavioural factors that either aid or impact negatively upon psychological, physical and social adjustment. Cognitive factors helpful for adjustment include acceptance of illness and high perceived social support. Similarly, helpful behavioural coping strategies are problem-focused and seek social support, whereas avoidance is unhelpful. The maintenance of important roles and relationships (such as those with siblings) is a key element of good adjustment. Additional variables include illness-specific factors such as managing ongoing treatment regime/ side effects, threats to mortality and change in identity. Illness stressors and background factors specific to HIV are likely to cause a greater disruption to an individual's quality of life than other chronic illnesses due to high levels of stigma, parental bereavement and risk of transmission. Perceived stigma is strongly associated with mental health outcomes of people living with HIV and has a negative effect on adjustment (Mak, Poon, Pun, & Cheung, 2007).

Models of adjustment in chronic illness and health psychology provide a framework for understanding the cognitive, emotional and behavioural challenges facing young people living with HIV. The ability to draw on both internal and external resources and coping mechanisms is central to returning to a state of equilibrium after critical illness events or stressors (Moss-Morris, 2013). Siblings have the potential to be a useful resource in this process, as a stable presence throughout an individual's illness trajectory and a source of support.

Influence of Sibling Relationships on Coping and Adjustment

Gender-based differences have been found in the value and importance assigned to sibling relationships in adolescents (Oliva & Arranz, 2005). For girls, the quality of sibling relationships is consistent with parent and peer relationships and is related to good psychosocial adjustment (e.g. life satisfaction and self-esteem). In boys, a similar quality of sibling relationship has not been found to be related to other family or personal variables (Oliva & Arranz, 2005). Older siblings are also found to be more likely to offer advice and practical support to younger siblings than vice versa (Voorpostel, van der Lippe, Dykstra, & Flap, 2007). Social learning theory (Bandura, 1977) suggests that siblings are salient models for learnt behaviours, particularly in siblings that have the most similarities. Consistent with this, externalising behaviour in older siblings is associated with increased externalising behaviour in younger siblings (Shortt, Stoolmiller, Smith-Shine, Mark Eddy, & Sheeber, 2010).

It has been suggested that the impact of sibling relationship quality on disease adjustment is increased for youths with more severe and stigmatising illnesses (requiring complex medication regimens and frequent hospitalizations) (Weiss et al., 2001). Adjustment and coping with HIV in young people may therefore be more likely to be affected by the quality of sibling relationships and the subsequent use of internalising or externalising coping behaviours.

Coping Styles in Young People with PHIV+

Children in HIV-affected families report using a range of both emotion and problem-focused coping strategies including self-soothing, problem solving, seeking social support and fantasy/wishful thinking (Mellins & Ehrhardt, 1994). Religious beliefs are also used within families to help young people frame HIV infection and are associated with lower levels of depression (Kang, Mellins, Dolezal, Elkington, & Abrams, 2011).

A questionnaire study with 30 PHIV+ UK adolescents (ages 11-17) found levels of psychological adjustment to be within normal ranges (Sopeña, Evangeli, Dodge, & Melvin, 2010). Psychological adjustment among this sample was significantly related to two coping styles; ventilating feelings and being humorous. Among a sample of siblings of HIV+ children, internalising behavioural symptoms of adjustment were significantly associated with HIV+ maternal maladjustment (Bettoli-Vaughan, Brown, Brown, & Baldwin, 1998).

Research on coping with stigma suggests that use of engagement coping strategies (e.g. adaptation, cognitive restructuring) results in less psychological distress than disengagement coping strategies (e.g. avoidance, denial, wishful thinking) (Varni, Miller, McCuin, & Solomon, 2012). HIV+ adolescents at highest risk of depression report use of passive coping strategies and low social support (Lewis et al., 2015). Access to family resources and social support are important factors in coping with chronic illness. HIV+ children express resilience through engaging with protective factors such as their relationship with their sibling or caregiver (Evans, 2005). It remains unclear, however, which aspects of the sibling relationship are perceived as supportive and might aid adjustment to living with HIV. Additionally, there may also be aspects of the sibling relationship that are maladaptive and hinder adjustment and coping.

Therapeutic Interventions for Young People living with PHIV+

Young people with PHIV+ who experience psychological difficulties should be offered adequate support by specialist services. The British HIV Association (BHIVA) published standards of psychological care guidance for adults living with HIV (2011). Eight quality standards represented a 'minimum' standard of care and included support at the time of diagnosis, screening for psychological support needs and access to evidence-based psychological interventions. Similarly, the UK-based Children's HIV Association (CHIVA) outlined six quality standards that should be met by services offering psychological support to children and young people with HIV (2014). These include engagement of young people and their families, support in understanding HIV and sharing information about HIV and access to psychological approaches to manage HIV treatment. CHIVA recognise the specific concerns and support required by young people with PHIV+ and offer a range of support programmes including an annual summer camp, peer support groups and counselling for individuals and families. A support group specifically for siblings of young people with HIV is also run by UK charity Body and Soul in London.

In support for specialist interventions, a 24-week manualised, combination cognitive behavioural therapy and medication management treatment for depression for young adults living with HIV in the US was found to be more effective than treatment as usual (TAU) at HIV care clinic sites (Brown et al., 2016). The

Collaborative HIV/AIDS Adolescent Mental Health Project (CHAMP; McBride et al., 2007) is a family-based intervention aimed at promoting mental health and reducing sexual risk behaviour in inner-city, uninfected adolescents in the US. This intervention was adapted by McKay and colleagues (2007) to produce CHAMP+; a family program for young people with PHIV+ and their carers aimed at increasing family communication while supporting and encouraging the development of healthy children. A version of this intervention adapted for use in South Africa (VUKA Family Program), led to improvements in mental health, adherence to medication, stigma and communication in 65 pre-adolescents and their families (Bhana et al., 2014).

Whilst the mental health and well-being needs of this population might be met by evidence-based interventions available to the general population (e.g. Cognitive Behavioural Therapy, Family Therapy), there are few family-based interventions specifically for families affected by HIV and none with a focus on sibling relationships.

Sibling Relationships in the context of PHIV+

Previous studies of family relationships with this population have focused almost exclusively on the HIV-related challenges facing the caregiver/mother-child relationship (e.g. Elkington et al., 2011; Murphy, Roberts, & Herbeck, 2013). Significant HIV-related stressors affecting both PHIV+ and HIV- siblings include HIV disclosure, stigma/ discrimination, parental ill-health/death and sibling ill-health/death (Malee et al., 2011). These stressors are also likely to impact the sibling relationship and are therefore a focus of this review.

Disclosure

Direct (or onward) disclosure describes the process or act of telling others of your own HIV status. Indirect disclosure refers to an individual’s HIV status being revealed by others, with or without the index person's consent (Préau et al., 2015). Guessed disclosure is when someone guesses the HIV status of an individual. Finally, paediatric HIV disclosure describes the process of telling a child or young person their HIV positive status. It is often health care workers that are tasked with informing a young person of their status, or at least in supporting the family to do so. The WHO (2011) guidelines on paediatric HIV disclosure recommends that children of school age (those with the cognitive skills and emotional maturity of a normally developing child of 6-12 years) should be told both their HIV positive status and that of their parents/caregivers.

Disclosure of PHIV+ is particularly sensitive as the nature of the condition also discloses the status of an individual’s mother and potentially other family members. Young people living with PHIV+ often experience high levels of family pressure not to reveal their HIV status, particularly to people outside the family (Michaud et al., 2009). Children who are asked to conceal and lie about their HIV status, to protect both themselves and other family members, may develop a sense of shame around their disease (Sherman et al., 2000). HIV-negative siblings may also be excluded from this family secret, for fear that they may tell others or that they themselves may be affected by the stigma attached to the condition (Bettoli-Vaughan et al., 1998).

Anxiety about onward disclosure across HIV+ populations is high (Evangeli & Wroe, 2017) and rates of onward disclosure in young people with PHIV+ remain low (Evangeli & Foster, 2014). Young people are more likely to disclose their HIV status to family members, suggesting that siblings are a particularly important peer relationship and source of support (Lam, Naar-King, & Wright, 2007). The Disclosure Processes Model (DPM; Chaudoir & Fisher, 2010) considers the disclosure decision-making process in terms of approach-focused and avoidance-focused goals, which lead to a 'disclosure event'. The disclosure event is described in terms of content (depth/breadth/duration and emotional content) and the reaction of a confidant (supportive vs. unsupportive). The DPM suggests that individuals with approach-focused goals, whose motivation to disclose is in pursuit of anticipated rewards rather than avoidance of negative states, have better and more supportive disclosure outcomes (Chaudoir & Fisher, 2010).

The context and route of disclosure is therefore likely to have a significant impact on the consequences of this disclosure and the HIV+ individual's quality of life. Disclosure can have beneficial effects including improved self-esteem, closeness in relationships and improved access to HIV services (Préau et al., 2015). Chaudoir and Fisher (2010) describe mediating processes post-disclosure, such as alleviation of inhibition and increased social support, that have an impact on long term outcomes. Alternatively, disclosure can also lead to stigmatisation, discrimination, shame and rejection from close relationships (Brashers, Neidig, & Goldsmith, 2004). Direct disclosure is associated with increased self-efficacy and fewer functional limitations, whereas indirect disclosure is associated with increased social exclusion and more negative social consequences (Préau et al., 2015).

Experiences of disclosure in the sibling relationship are likely to give messages about the acceptability of talking about HIV, onward disclosure and levels of shame and stigma related to the diagnosis. HIV- siblings may hold fears that they will be infected, that their mother and sibling will die and that their family will suffer if they disclose the secret to others (Fanos & Wiener, 1994). Secrecy within families is also common due to the stigma associated with HIV and young people with PHIV+ may feel that they cannot disclose to their siblings or have little control over the disclosure process.

HIV Communication

In a qualitative study of HIV+ Ugandan children aged 8-17 years old, communication about HIV in homes was limited to issues about medication and was directive (e.g. "Have you taken your medicines?") (Kajubi, Bagger, Katahoire, Kyaddondo, & Whyte, 2014). Information about HIV/AIDS was controlled by caregivers at home and often children were instructed never to tell anyone about the diagnosis. Corona and colleagues (2008) interviewed siblings in families of parents with HIV and found that they generally did not talk to each other about HIV, for fear of upsetting the other or their sibling unintentionally disclosing the parent's illness to others. Sibling communication was dependent on factors such as similarity in age or gender, living together and knowledge of parental HIV status.

Level of knowledge and communication about PHIV+ between siblings may relate to the quality of the sibling relationship and their ability to discuss fears or hopes for the future. Communication about HIV may also be restricted by parents sharing limited information with healthy siblings, often leaving them feeling excluded and uninformed (Fanos & Wiener, 1994). With perceived stigma limiting opportunities for disclosure, siblings may be the only peer a PHIV+ adolescent has to talk to about sensitive issues related to HIV such as puberty, sexuality and illness (Fernet et al., 2007).

Stigma

Stigma “represents a construction of deviation from some ideal or expectation” (Alonzo & Reynolds, 1995, p. 304). According to sociologist Goffman (1963), stigma is a powerful and discrediting social label with the ability to reduce an individual’s identity from accepted to discounted and in doing so isolating this individual from self and others.

Earnshaw and Chaudoir’s (2009) HIV Stigma Framework identifies three stigma mechanisms elicited in people living with HIV, which lead to harmful psychological, behavioural and health outcomes. The first of these stigma mechanisms is ‘enacted stigma’ and describes the perceived degree of prejudice and discrimination experienced from others in their community. ‘Anticipated stigma’ refers to the degree that an individual with HIV expects to experience prejudice and discrimination from others in the future. Finally, ‘internalised stigma’ is the extent to which someone believes the negative attitude and feelings associated with HIV about themselves. In a review of the literature, Earnshaw and Chaudoir (2009) found all three stigma mechanisms were related to lower mental health outcomes and lower levels of social support in people with HIV.

The significant stigma associated with HIV/AIDS results in secrecy, limited onward disclosure and communication about HIV status, restricting available social support and resources (Fair & Albright, 2012). Secrecy regarding HIV disclosure and treatment due to social stigma was perceived to impact adherence to ART among a study of 29 French adolescents (Trocmé, Vaudre, Dollfus, & Leverger, 2002). In focus groups, HIV+ youths described offensive comments made by peers about HIV+ individuals and their subsequent efforts to conceal their status and medication from peers (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). Young people also report distancing themselves from friends to avoid rejection or possible stigmatised reactions to their HIV status (Hosek, Harper, & Domanico, 2000). Young people affected by HIV also reported experiencing stigma from being associated with parents who were HIV+ (Chama & Ramirez, 2015). In the absence of other trusting peer relationships, siblings may provide one of few close relationships available for support.

Loss

Families affected by PHIV+ are likely to experience the serious illness or death of a caregiver, sibling or both. Of the PHIV+ young people in the UK CHIPS cohort, 35% had lost at least one parent to HIV/AIDS (Le Provost et al., 2017). HIV- siblings in these families may experience multiple losses of immediate family members in their lifetime to HIV (Cluver & Gardner, 2007). The loss of a parent to AIDS is likely to increase the remaining family's awareness of the progression of the illness and the morbidity of HIV+ siblings. This may lead to healthy siblings distancing themselves from HIV+ siblings to protect themselves from the pain of these losses (Fanos & Wiener, 1994).

Within the family, the illness and cause of death may not be openly discussed and may be kept secret, even from extended family members, due to stigma and shame (Siegel & Gorey, 1994). Lack of open family communication, poor quality care and support from a primary caregiver following a death and an unstable living environment all increase the risk of maladjustment in children to parental loss (Siegel, Mesagno, & Christ, 1990). These are all factors likely to affect siblings who lose a parent to AIDS. Additionally, siblings may be separated following a parent's death or the oldest sibling may be expected to assume the role of primary caregiver (Evans, 2012). Youth-headed households are common in families affected by HIV, particularly in sub-Saharan Africa, however siblings may not feel they have a choice in assuming this caring role (Dijk & Driel, 2012). Oldest siblings described unresolved grief over their parent's death and feelings of uncertainty and anxiety about being able to care for their younger siblings.

Among a sample of adults whose sibling had died of AIDS, levels of grief were found to be higher on all subscales in comparison to a combined bereavement group (Robinson, 2001). These findings support the view that bereavement following a death from AIDS is prolonged and intensified (Mallinson, 1999) The mourning process is likely to be complicated by the stigma and discrimination associated with AIDS restricting access to social support (Wood, Chase, & Aggleton, 2006).

Social Support

It has been argued that social support is a key component of an individual's subjective well-being and adaptive coping. Ryff's (1989) multi-dimensional construct of psychological well-being includes 'positive relations with others', which emphasises the importance of warm, trusting interpersonal relationships. Social support can contribute to the psychological adjustment of people with HIV by helping them to manage psychological distress and the uncertainty associated with their condition. This may be through assistance with information seeking, providing instrumental support, giving acceptance or validation, or encouraging a different perspective (Brashers et al., 2004). AIDS orphans in China with higher levels of perceived social support reported lower scores of depressive symptoms and higher scores of self-esteem (Hong et al., 2010).

Emotional support refers to an individual’s ability to show empathy, provide love, trust and care (Cummings et al., 2014). Instrumental support is more practical and broadly refers to the provision of concrete assistance or aid (Casale, Wild, Cluver, & Kuo, 2015). Abramowitz (2009) found PHIV+ youth received high levels of instrumental support from family members and rated satisfaction with family support higher than that of their friends. However, the types and sources of social support among young adults affected by HIV remain ill-defined and under-researched concepts (Wang et al., 2012). Most research is concerned with the relationship between perceived quality of support and psychological well-being (Cheng et al., 2014; Okawa et al., 2011; Wang et al., 2012).

Compensatory processes of sibling social support

Siblings might be a particularly important social resource in the absence of other sources of support. Furman and Buhrmester (1985) argued that social needs may be obtained from multiple individuals and that if a relationship is not supplying the desired provisions, individuals will compensate for this by turning to a different relationship to fill the void. In the presence of low levels of parental or peer support, sibling support has been found to moderate levels of self-esteem, loneliness and depression in a population of emerging adults (Milevsky & Levitt, 2005). Children with emotionally or physically absent parents or those with high levels of distress have been found to care for each other to compensate for a lack of parental involvement (Brody, 1998). Despite evidence towards a compensatory pattern of support in siblings, there are mixed findings amongst adolescent relationships (Seginer, 1998). This may be because the significance of friendships in this age group minimises the effect of any sibling support in the absence of meaningful friendships

(Milevsky, 2005). The concept of compensatory support may be particularly relevant to siblings affected by HIV however, as their mother may have periods of HIV-related illness and be away from the home, or support from peers may be limited due to non-disclosure.

Siblings as a source of social support in PHIV+

Supportive relationships and increased involvement of family and peers leads to better psychological adjustment, coping and medication adherence in PHIV+ adolescents (Mellins & Malee, 2013). Kenyan AIDS orphans who cohabited with biological siblings reported higher perceived social support from both a special person outside the family and friends (Okawa et al., 2011). Barriers to support in PHIV+ sibling relationships may include disclosure, jealousy, resentment and guilt. Mellins and Ehrhardt (1994) found that whilst HIV-infected children said they sought support from family, friends and professionals, uninfected siblings discussed having no one to talk to about HIV and relying on themselves.

Sharer, Cluver, Shields and Ahearn (2016) explored how family social support related to depression, anxiety and post-traumatic stress in a cross-sectional sample of 1380 children affected by HIV/AIDS in South Africa. The authors found that when siblings provided instrumental and high quality support, children were less likely to experience negative symptoms of mental health. Interestingly however, higher levels of sibling emotional support were related to higher numbers of reported mental health symptoms. It is possible that as siblings are also affected by HIV/AIDS, the shared experiences of grief and distress may impact their ability to provide quality emotional support. Alternatively, high sibling support may have been a consequence of existing mental health symptoms in children with HIV. In an unpublished qualitative study of five matched pair siblings (one PHIV+ young person and their HIV- sibling) in the UK (McLaughlin, 2016), HIV appeared to have a bonding effect on the sibling relationship, with some families uniting together in support of each other. However, lack of communication about HIV within families also resulted in siblings feeling unable to express their emotional needs and therefore relying on distancing themselves from HIV to cope. Although this study has begun to explore the impact of PHIV+ on siblings, the focus of the research was not on the sibling relationship (particularly not in the PHIV+ group) and the sample size was very small. Levels and types of support between siblings was unclear and the role of the sibling relationship in adjustment and well-being unanswered.

To date, studies that focus on social support for PHIV+ young people mostly explore the support provided by adults (e.g. parents, teachers, healthcare professionals) or peers, overlooking the role of siblings as both a peer and family member. Particularly for young people with a chronic illness, the sibling relationship is likely to serve an important interpersonal function, unmet by parents or peers (Nielsen et al., 2012). If present, the type of support provided by siblings may vary in its nature (instrumental vs. emotional support) within the same relationship. The current study is interested in what types of sibling support might aid adjustment to a diagnosis of PHIV+ and increase coping and well-being. The research will also investigate how growing up in a family affected by HIV impacts the nature of the sibling relationship and reciprocal levels of support.

Rationale for Current Study

Researchers have highlighted the need for more child-centred, qualitative research on the psychosocial effects of HIV/AIDS on young people (Cheney, 2015).

Although quantitative research has begun to explore the impact of PHIV+ on infected and affected siblings (Mellins et al., 2012), detailed exploration of the experiences of siblings and the influence of PHIV+ on the sibling relationship is required. The documented impact of other chronic illnesses on sibling relationships (Weiss et al., 2001) and the unique challenges of HIV on the affected family (DeMatteo et al., 2002) indicate the potential value in this area of research. As a qualitative study, the current research will allow rich data to be gathered on aspects of the HIV disclosure process within families and subsequent levels of communication about HIV between siblings.

As previously indicated, research to date has focused predominantly on risk factors for mental health and well-being in HIV-affected siblings. Betancourt and colleagues (Betancourt et al., 2013) note that the evidence base would greatly benefit from identifying protective processes that contribute to resilience in young people with PHIV+, to inform the design of psychosocial interventions. This may include reinforcing existing familial relationships and strengthening naturally occurring support mechanisms within families (Sharer et al., 2016). The role of siblings in psychological adjustment to living with HIV as a chronic illness has also not been a focus of research to date, despite findings that siblings play an important role in therapy management and care for people with HIV (Merten, 2016). The current study investigates levels of support offered and received by siblings in PHIV+ families.

Finally, existing research often combines PHIV+ and BAH young adult populations (Sohn & Hazra, 2013) and a focus on the sibling relationship in PHIV+ young people is necessary to inform family-oriented care and interventions with this population. A UK sample of PHIV+ young people will contribute to the lacking evidence base surrounding the experiences of the sibling relationship in families affected by PHIV+ in the UK. Whilst research from sub-Saharan Africa and the US provides a basis for understanding the role of siblings in HIV care and adjustment, the differences in access to economic and medical resources means that the characteristics and types of relationships between siblings are likely to raise quite different challenges and needs.

Research Aims and Questions

The aim of this qualitative study is to develop a model of the sibling relationship in young people with PHIV+ to inform therapeutic interventions with this population, improving levels of well-being and coping with the psychosocial challenges associated with HIV. A greater understanding of which aspects of the sibling relationship might be protective will allow tailored interventions for young people living in families affected by PHIV+.

An in-depth qualitative design will offer insight into individuals' feelings, thoughts and experiences by identifying significant factors and processes in the sibling relationship (Barker, Pistrang, & Elliott, 2015). Grounded theory is considered the most appropriate qualitative method to suit the research aims, as it allows development of a theoretical model of the sibling relationship from the lived experience and perspective of PHIV+ young people.

Research Questions

1) How does HIV disclosure affect sibling relationships in young adults with PHIV+?
2) Which HIV-related factors influence the perceived quality of sibling relationships in young adults with PHIV+?

3) Which aspects of sibling relationships are perceived as supportive and how are these perceived to influence coping and well-being in young adults with PHIV+?

CHAPTER 2: METHOD

Research Design

The study adopted a qualitative, cross-sectional design. The design, recruitment, analysis and discussion of the findings were guided by Grounded Theory methodology (Charmaz, 2014).

Sampling, inclusion and exclusion criteria

The sample consisted of ten young people with PHIV+ who had at least one sibling. Participants were recruited using convenience and then purposive sampling, to enable testing of the developing model as recommended by Grounded Theory (Charmaz, 2014).

Participant inclusion criteria were as follows:

1) *Aged between 16-25 years old;*

2) *Fluent in speaking and comprehension of English*: to understand interview questions and to give a detailed response without the use of an interpreter. The use of interpreters may have compromised the validity of the study if content was not directly or accurately translated;

3) *Diagnosed with perinatally acquired HIV (PHIV+);*

4) *Knowledge of their PHIV+ diagnosis for at least one year prior to recruitment*: to allow adequate time for adjustment to the diagnosis and to allow opportunities for onward disclosure;

5) *Have at least one sibling that shares the same biological mother and that they have lived with in the same household for at least 5 years in their lifetime (but may be living apart at present)*: to ensure that the participant will have a sibling with the joint

experience of having an HIV+ mother and who will be considered either a biological sibling or a half sibling (with a different father). The participant will also have lived in the same household as their sibling for a significant period of time, allowing the opportunity for a sibling relationship to have developed.

Participant exclusion criteria included:

1) Individuals deemed by the clinical team to have emotional problems to a degree that might impact their ability to engage in the interview;

2) Individuals identified by the clinical team as significantly high risk (e.g. actively suicidal or engaging in self-injurious behaviour).

The exclusion criteria were necessary to minimise the risk of undue distress to participants during the interview and to ensure participant safety.

Research sites

Participants were recruited from two inner city London HIV clinics between September 2016 and January 2017. As specialist services, both clinics also accept patients from outside the London area.

The team at the primary research site consists of specialist HIV doctors and nurses and a clinical psychologist. This service provide care for HIV-positive young people (primarily aged 16 to 24 years) who are either newly diagnosed or transitioning from children’s services to adult services. The service is one of the largest transitional care services for young people living with HIV in Europe, with a cohort of approximately 120 patients. The team provide medical, psychological, contraceptive, sexual health and peer support for young adults living with HIV and their partners. The service offer a walk-in clinic and patients are also reviewed approximately every four months, depending on their needs. The approximate size of the eligible population at this site was 50 participants.

The team at the secondary research site also consists of specialist HIV doctors, nurses, health advisors and a clinical psychologist. This service provides a range of services for HIV-positive teenagers and young people including specialist HIV care, sexual health advice and screening and psychological support. This site has a cohort of approximately 80 patients that are reviewed in clinic every three to four months. The approximate size of the eligible population at this site was also 50 participants. The average DNA rate for appointments at this site is approximately 50%.

Choice of methodology

Qualitative analysis

Although quantitative research has begun to explore the impact of PHIV+ on infected and affected siblings (Mellins et al., 2012; Gadow et al., 2010), detailed exploration of the experiences of siblings and the influence of PHIV+ on the sibling relationship was required. An in-depth qualitative design offers insight into individuals' feelings, thoughts and experiences by identifying significant factors and processes in the sibling relationship (Barker et al., 2015).

Grounded Theory

Grounded theory was considered the most appropriate qualitative method to suit the research aims, as it allows development of a theoretical model of the sibling relationship from the lived experience and perspective of PHIV+ young people. The model is grounded in the data, does not require over-interpretation of findings and allows the suggestion of causal links (Charmaz, 2014). The model can be used to aid clinicians' understanding of the role of the sibling relationship in coping and well-being, to guide psychosocial interventions. Grounded Theory lends itself to the study of individual processes and interpersonal relationships, with consideration of the interaction between these and wider social processes (Charmaz, 2014).

Grounded Theory starts as an inductive approach, but becomes increasingly deductive through theoretical sampling, allowing points of interest or gaps in the data to be targeted based on an emerging theory. The findings from ongoing data analysis and constant comparison of categories within and between individuals guides further data collection. In this sense, data collection and analysis are interrelated processes which allow the theory to be grounded in the reality of the data (Corbin & Strauss, 1990). This method is considered to guard against researcher bias or subjective inclusion of categories and is supported through the use of memo-writing in revising hypotheses throughout the research process. Grounded Theory therefore provides a systematic, discovery-oriented method for development of a model of the sibling relationship with implications for psychotherapeutic intervention.

Exploring other qualitative methods

Alternative qualitative methods were considered before Grounded Theory was selected as the approach best suited to the research aims of this study. Two other qualitative approaches are described below, along with the reasons they were not pursued.

Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA) requires interpretation of the data and extends what is actually said by participants to hypothesise meaning (Forrester, 2010). The aim of IPA is to explore how participants make sense of their personal and social world, with cognition as a key analytic indicator of an individual’s mental and emotional state (Smith, Flowers & Osborn, in Yardley, 1997). Although IPA is concerned with the lived experience of participants, it does not allow for the development of a theoretical model for comparison with existing literature; a key aim of this study.

Discourse Analysis

Discourse Analysis (DA) focuses on the construction and function of language (Forrester, 2010). It aims to understand how people use language to create and shape identities, activities and relationships in the context of multiple discourses (Smith, Flowers & Osborn, 1997). Whilst the current study endeavored to take a constructionist position, DA does not lend itself to the exploration of individual experiences within wider social narratives, which again was a primary aim of this study.

Divergent methods in Grounded Theory

Glaser and Strauss (1967) developed Grounded Theory as a systematic, qualitative analysis to construct abstract theoretical explanations of social processes, assuming the researcher’s neutral stance throughout. These authors subsequently developed the theory in different directions, with Glaser (1992) staying close to the original discovery-orientated methodology while Strauss and Corbin (1990) incorporated principles of verification and increasingly technical analytic strategies. Grounded Theory has since evolved further from its positivist, objectivist foundations (Glaser & Strauss, 1967) to a constructivist position that considers the researcher’s perspective and interactions an inherent part of the research (Charmaz, 2014).

Rationale for using Charmaz's constructivist Grounded Theory

Retaining its inductive approach, Charmaz's (2014) Grounded Theory allows the development of a theory heavily grounded in the data, whilst acknowledging that meaning occurs within social and cultural contexts. Constant comparison ensures a reliable representation of the individual's experience, whilst examining their differences and similarities.

This approach was chosen as it encourages the researcher to use Grounded Theory strategies flexibly as guidelines for analysis (Charmaz, 2014). This was particularly relevant to this study, which was conducted within the constraints of a doctoral programme and required an early literature review (prior to data collection) for the purposes of ethical and departmental approval. Charmaz's approach also acknowledges that the researcher is "a part of the world we study, the data we collect, and the analyses we produce" (p. 17, Charmaz, 2014). The researcher felt particularly aligned with this assumption and the need to account for her own position and interaction with the data in the construction of a resulting theoretical model.

Reflexivity

It is important to address the researcher's background assumptions and disciplinary perspective by acknowledging any prior experiences or knowledge that may have influenced the research process (Charmaz, 2014). As the researcher for this study, I am a 30-year-old female Trainee Clinical Psychologist with an interest in working in Clinical Health Psychology. Although having never worked in a specialist HIV clinic before, I have spent time in South Africa and witnessed the HIV epidemic among young Africans while volunteering in a secure government-run mental health hospital. These experiences helped me to understand some of the issues that may be facing this group, such as concerns around disclosure, social stigma/ discrimination and managing a chronic health condition. I also had some previous knowledge of HIV, having attended sexual health academic lectures and being required to submit a literature review and research proposal for this project. Additionally, I had experience working clinically from a systemic perspective and theoretical background, so have an awareness of the potential impact of family relationships and communication on emotional distress and well-being (Dallos & Draper, 2010). It was therefore crucial that I remain neutral during the interviews, despite being aware of my belief that open communication among families often allows greater opportunities for accessing support.

In 2016 in the UK and Ireland, 50% of young people living with PHIV+ were born abroad and 78% were of Black African ethnicity (CHIPS, 2016). Consideration of my personal background as an HIV-negative, UK-born, Caucasian woman also highlighted the differences between myself and participants. Information shared by participants in this study may have been influenced by their assumptions about what I may or may not understand about their experiences, because of these differences. Additionally, it was essential to bring awareness to any preconceptions that may originate from my standpoint as the researcher (Charmaz, 2014), to enhance the credibility of the findings (Mays & Pope, 2000).

With reference to the specific research topic, I also have a younger brother and therefore was likely to bring my own assumptions about what a sibling relationship might resemble. To encourage reflection on these issues and my position as the researcher, I kept a reflective diary and regularly discussed relevant thoughts, preconceptions and observations with the academic supervisor. Peer supervision with other trainees undertaking Grounded Theory also allowed opportunities for reflection, particularly during analysis, to avoid forcing the data into preconceived categories or ‘common sense theorising’ (Schutz, 1967).

Procedure

Ethical approval

The study was given ethical approval from an NHS Research Ethics Committee in August 2016 (Appendix 1) and from Royal Holloway University of London Research Ethics Committee (Appendix 2). Health Research Authority (HRA) Approval was subsequently granted in August 2016 (Appendix 3). Site specific confirmation of Capacity and Capability (R&D approval) was gained from both research sites in August 2016 (Appendix 3 and 4). The key ethical considerations of this study are discussed in brief below:

Voluntary basis of participation: Participation in this study was voluntary and did not affect participants’ care at either site. Participants were also informed of their right to withdraw from the study at any time and were informed how to do so.

Informed consent: Informed consent was sought from all participants. An information sheet was provided to every participant, with the opportunity to consult with others and ask any questions. Written consent was collected using a consent form and uploaded to the patient medical file for each participant.

Minimising distress: Field supervisors at both sites agreed to uphold a clinical duty of care to their patients for the purposes of this study. During the interview debrief, participants were asked about their experience of the interview and provided with a named member of staff from whom they could seek further support, if required.

Confidentiality: The boundaries of confidentiality were explained to all participants prior to the interview and were reflected in the participant information sheet. Anonymity of participants' identities was maintained at all times.

Recruitment process

Engagement with the team

Following ethical approval and prior to recruitment, the researcher met with the field supervisor at the main recruitment site and attended multi-disciplinary team (MDT) meetings at both recruitment sites. Meeting with the wider MDT allowed any questions about the study to be answered and for clinicians to be briefed about their potential involvement in the study. Written materials were provided to aid recruitment (Appendix 7).

Identifying participants

PHIV+ participants eligible for the study were initially screened and approached by their clinician to take part during their routine clinic appointment. Only participants deemed by the clinical team to have capacity to consent were approached by staff for participation.

Introducing the study

Clinical staff gave eligible PHIV+ participants an overview of the study and a participant information sheet during their routine clinical appointment. If they were interested in participating, they were offered the choice of meeting with the researcher after their appointment (if on site) or permission was taken for the researcher to contact the participant to answer any questions that they might have and arrange a time to meet.

At this meeting, the researcher explained the nature of the study, ensured the information sheet had been received and read and gave the opportunity to ask questions.

Informed Consent

Written informed consent was obtained from each participant (Appendix 8). The boundaries of confidentiality were verbally explained. Participants were shown a copy of the "Participant Health Information" sheet (Appendix 15) to give consent for specific HIV-related medical information to be collected from their records (including most recent viral load and CD4 count), via a clinician.

Measures

Immediately prior to the interview, participants were asked to complete a short demographic questionnaire (including ethnicity, household occupants), an adapted measure of perceived sibling relationship quality (Adult Sibling Relationship Questionnaire- short form; ASRQ-S, Lanthier et al., 2000) and a measure of subjective mental well-being (Hospital Anxiety and Depression Scale; HADS, Zigmond & Snaith, 1983).

Interview and debrief

One-off, semi-structured interviews were carried out with each participant on an individual basis. The researcher allowed time at the end of the interview to debrief and reflect on the participant's experience of the interview. Signposting to a member of the clinical team for further support was provided if required. Each participant was reimbursed £10 for their time (in high street vouchers). Participants were asked if they would like to be contacted at the end of data collection for consultation on the theoretical model and feedback on the findings.

Response rate

At the primary research site, two individuals refused participation in the study due to “lack of time” on the day of recruitment. One potential participant was not suitable for the study as he did not acquire HIV perinatally. Another participant had agreed to take part in the study but was then admitted to the ward and chose not to take part due to health problems. At the secondary research site, one individual also refused participation due to lack of time. The overall recruitment rate was approximately 70% (10/14 potential participants who met the inclusion criteria).

Interview guide

The draft interview guide (Appendix 9) was developed with the intention to use probing open questions, whilst allowing the participant to lead the conversation (Bernard & Bernard, 2012) and with consideration of the research questions. An initial version of the interview guide was drafted in collaboration with the academic supervisor, based on existing literature. The interview guide was structured so that participants were first asked to describe their family and constructed a genogram of their family structure with the researcher. They were then asked more general questions about their HIV diagnosis (e.g. *How does having HIV affect your life now?*), before talking about their sibling relationships and how HIV might impact on these (with consideration of factors such as disclosure of HIV status, levels of support and relationships over time). Participants were first asked about their relationship with an “identified sibling”, although were also asked about other siblings where relevant. The term “identified sibling” is used to describe the sibling that the participant chose to complete the ASRQ-S about and whom meets the inclusion criteria of the study. The interview guide referred both to siblings who were aware or unaware of the participant's HIV status. Questions were worded sensitively and ordered flexibly, according to participant responses.

The interview guide was adapted based on service user feedback from three PHIV+ young people (all aged 17 years old) on the Children's HIV Association (CHIVA) Youth Committee. The committee meets four times a year and members are all HIV positive. The service users met with the researcher for one hour in the month prior to data collection. Service users were given written information to guide their feedback (Appendix 10). The group were asked to comment on all aspects of the interview guide including its length, questions, language and wording. Following this consultation, changes were made to the interview guide including simplifying the language and asking about HIV more explicitly. These were role played in pilot interviews with the academic supervisor, who offered additional feedback on the interview style and order of questioning.

A second editing process for the interview guide took place after the completion of the first three interviews for this study. In line with Grounded Theory methodology, simultaneous data collection and analysis revealed gaps in the data, areas of interest and new hypotheses to be explored (Corbin & Strauss, 1990). These additional routes of enquiry were added to the interview guide to be pursued in subsequent interviews (see Appendix 11 for an updated interview guide).

Descriptive measures

The Adult Sibling Relationship Questionnaire–Short form (ASRQ-S) and Hospital Anxiety and Depression Scale (HADS) were completed by participants to provide additional descriptive information on the quality of the sibling relationship (with an 'identified sibling') and subjective well-being. These were two key aspects of investigation and the information from these questionnaires informed the interpretation of any findings and helped situate the sample.

The ASRQ-S is a 47-item self-report measure with eight scales, developed from the Adult Sibling Relationship Questionnaire (ASRQ; Stocker et al., 1997). The questionnaire explores features of the sibling relationship from young adulthood (over the age of 17) (Lanthier et al., 2000). Four scales of the ASRQ-S were administered to participants (intimacy, emotional support, quarrelling and antagonism), totaling 23 items (Appendix 12). The scales selected map onto two factors: warmth and conflict. These scales were chosen based on the highest loadings on these two factors and are intended to give a brief overview of the quality of the relationship. The ASRQ-S has been shown to have good reliability on warmth and conflict factors (α= .96 and .93 respectively) in college undergraduates. Aspects of the ASRQ have also been used previously in adolescent and young adult siblings with a chronic illness (McDonald, Patterson, White, Butow, & Bell, 2015).

The HADS is a 14-item self-report measure of subjective mental well-being (negative affect component) (Appendix 13). The HADS has been shown to have good reliability in the general population (α= .83 for HADS-A and .82 for HADS-D subscales; (Bjelland, Dahl, Haug, & Neckelmann, 2002) and has good validity in assessing anxiety and depression in HIV-infected patients (Savard, Laberge, Gauthier, & Bergeron, 1999).

Data collection

Interviews were all carried out in the participant’s HIV healthcare clinic, in private consultation rooms. Interviews lasted between 36 and 59 minutes, with a mean interview length of 46 minutes.

Theoretical sampling

Theoretical sampling involves actively seeking participants or information to illuminate and define the properties of developing theoretical categories (Charmaz, 2014). Initially, convenience sampling of the target population was employed to advance theory development. After completion of the first six interviews, the researcher hypothesised about the role of gender in patterns of communication in sibling relationships and sought to recruit a final two males through theoretical sampling to explore this further.

Theoretical saturation refers to the point at which data collection no longer generates theoretical insights, or reveals new properties of existing theoretical categories (Charmaz, 2014). Dey (1999) argues that emerging categories are only ever suggested by the data, rather than ‘saturated’ by it, and that the term theoretical sufficiency better describes this fit. The specificity of the research questions and sample suggested that theoretical sufficiency would be reached with a relatively small number of participants. The researcher additionally aimed for depth and significance within interviews to provide adequacy of data within a proposed sample size of ten participants.

Participant characteristics

Ten participants took part in the study. Participants consisted of six females and four males aged 17-23 years (median age 20.5 years). One participant had expressive aphasia. Table 1 outlines relevant demographic characteristics of participants. Table 2 outlines the characteristics of participants’ sibling(s), with a particular focus on their ‘identified sibling’. Table 3 outlines participant HADS and ASRQ-S scores. The information in all tables is used to situate the sample, provide a context for the research and inform the analysis. Broadly in line with the CHIPS (2016) cohort, 60% of the sample were born abroad, 90% were of black African ethnicity, 60% identified as female and 30% had lost a parent to AIDS. The participants' scores on the HADS also reflect those of PHIV+ young people in the CHIPS cohort, of whom 17% scored above caseness (>11) for anxiety and 4% for depression (Le Provost et al., 2017).

Table 1: Participant characteristics

Ppt. No.	**Sex**	**Age (years)**	**Age of paediatric disclosure (years)**	**Place of Birth**[1]	**Ethnicity**	**Relationship Status**	**Employment Status**	**CD4 count** [2] **(cells/ mm^3)**	**Viral load (IU/ mL)**	**ART adherence estimate**[3]
1	F	17	12	sub-Saharan Africa	Black African	In a relationship	Unemployed	288	Und.[4]	Good
2	M	19	10	sub-Saharan Africa	Black African	Single	Employed (part time)	760	Und.	Good
3	F	23	15	England	Black African	Single	Employed (full time)	417	Und.	Good
4	F	20	9/10	England	Mixed (White and Black African)	Single	Employed (part time)	270	Und.	Good
5	F	21	12	England	Black African	In a relationship	Employed (full time)	735	Und.	Good
6	M	23	12	England	Black African	Single	Employed (part time)	37	62,176	Poor
7	F	23	11/12	sub-Saharan Africa	Black African	In a relationship	Employed (full time)	440	3802	Patchy
8	F	18	12	sub-Saharan Africa	Black African	Single	Student (full time)	409	524,715	Poor
9	M	21	19/20	sub-Saharan Africa	Black African	Single	Unemployed	36	224	Patchy
10	M	20	8	sub-Saharan Africa	Black African	Single	Student (full time)	40	467,735	Poor

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[1] Regions are used to maintain participant anonymity

[2] A CD4 count ranges from 500–1,200 cells/mm^3 in healthy adolescents/adults (without HIV)

[3] Adherence estimated as: <50% doses taken = Poor; 50-90% doses taken = Patchy; >90% doses taken = Good

[4] Undetectable viral load: <50 IU/mL

Table 2: Characteristics of participant sibling(s)

Ppt. No.	**Identified Sibling Sex**	**Identified Sibling Age (Years)**	**Identified Sibling aware of status (Y/N)**	**Identified Sibling HIV Status (Neg/Pos)**	**Currently living in same household as identified sibling? (Y/N)**	**Relationship to Identified Sibling (Biological/ Half)**	**Total number of siblings**
1	F	27	Y	Neg	Y	Biological	2
2	F	34	Y	Pos	N	Biological	3
3	F	16	N	Neg	Y	Biological	2
4	F	24	Y	Neg	Y	Biological	1
5	F	27	Y	Pos	N	Biological	2
6	M	26	Y	Pos	Y	Biological	2
7	F	30	N	Neg	N	Biological	2
8	F	14	Y	Neg	Y	Half	2
9	M	14	Y	Neg	Y	Biological	7
10	F	10	Y	Neg	Y	Biological	1

Table 3: Participant HADS and ASRQ-S scores

Ppt. No.	**HADS Anxiety Subscale Total Score**[5]	**HADS Depression Subscale Total Score**	**HADS Total Score**	**ASRQ-S Warmth**[6] **(Intimacy & Emotional Support) Mean Score**	**ASRQ-S Conflict (Quarrelling & Antagonism) Mean Score**
1[7]	9	8	17		
2	4	3	7	1.00	1.00
3	5	0	5	3.67	1.91
4	7	1	8	2.67	2.45
5	1	0	1	4.67	1.36
6	5	2	7	2.67	3.55
7	9	7	16	1.58	3.36
8	14	9	23		
9	2	2	4	3.92	1.55
10	6	7	13	3.92	2.91

Table 3 indicates that only one participant (participant eight) scored above caseness for symptoms of anxiety. All other participants scored below the clinical cutoff for symptoms of anxiety or depression, although two others were in the 'borderline' range (participants one and seven). Participants three, five, nine and ten scored above the average level of warmth reported in the sibling relationship in a general population sample of college undergraduates in the US (Lanthier et al., 2000). Participants four, six, seven and ten scored above the average level of conflict reported in the sibling relationship in the general population.

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[5] HADS scores for anxiety and depression: 0-7 = Normal; 8-10 = Borderline; 11-21 = Abnormal

[6] Warmth: *M*= 3.19, *SD*= .93; Conflict: *M*= 2.20, *SD*= .77 in college undergraduates (scores range from 1-5; higher scores indicate higher levels of the factor)

[7] Participants 1 and 8 had missing data on ASRQ-S

Analysis process

Transcription

The interviews were audio recorded using a dictaphone, transcribed verbatim by the researcher at the earliest opportunity and analysed using Grounded Theory. A de-naturalised approach to transcription was taken by the researcher (Oliver, Serovich, & Mason, 2005), which conveys the substance of a conversation, without depicting the details of every utterance, accent or interview noise. This approach is thought to lend itself to Grounded Theory analysis, as the focus is less on the communication of perceptions, but the perceptions themselves (Oliver et. al, 2005).

Coding

Grounded Theory coding consists of three stages: initial coding, focused coding and theoretical coding (Charmaz, 2014). These phases of analysis are linked and underpinned by on-going memo-writing. The coding processes involved in this study are detailed below:

Stage 1: Initial coding

Initial coding (or open coding) develops a provisional “analytic framework” (p. 113, Charmaz, 2014), from which the analysis is shaped. The aim of initial coding was to remain open to the possible theoretical directions of the data whilst making sense of the content and staying close to the interview data. To aid this process, initial codes were constructed as actions and coded as gerunds (verbs with ‘-ing’ endings) (Glaser, 1978). The researcher conducted detailed, line-by-line coding of the transcript in this manner, which led to the recognition of emerging focused codes.

Stage 2: Focused coding

Focused coding involves attending to how initial codes account for the data and the constant comparison and refinement of codes, concepts and categories (Charmaz, 2014). Focused coding aimed to retain the detail contained in the data, whilst acknowledging the researcher's interaction with and perspective of the analysis. The researcher began to identify emerging themes by considering which initial codes held the most "analytic power" (p. 140, Charmaz, 2014), either due to frequency or significance. These were labelled with focused codes that were more abstract, but which allowed initial codes to be collapsed into larger categories that adequately conceptualised the data.

Stage 3: Theoretical coding and diagramming

Theoretical codes specify possible relationships between these categories and allow application of an emerging theoretical model to the data (Charmaz, 2014). The researcher used memos to link the focused codes, describe the properties of categories and sort and integrate categories into theoretical codes. Initial codes and direct participant quotations were also used as further explanation of theoretical codes. A diagrammatic theoretical model was constructed to map out the content and direction of connections between categories. The emergent theory was then compared to existing literature.

Writing memos

Memos were written throughout the coding process as analytic notes to record thoughts, ideas and hypotheses emerging from the data (Birks & Mills, 2011). Memos were particularly useful when raising focused codes to conceptual categories and specifying the relationships between them (Charmaz, 2014). They also encouraged the researcher to adopt a critically reflexive stance by making her standpoints and assumptions more visible.

Quality assurance in qualitative research

The quality standards the researcher followed are those indicated by Elliott, Fischer and Rennie (1999) for qualitative research and those by Henwood and Pidgeon (1992) for grounded theory. These standards were referred to throughout the study to increase the validity of the data.

Owning one's perspective

As already mentioned, the researcher kept a reflective diary throughout the research process to recognise the potential impact of any preconceived or emerging assumptions, values or interests on her understanding of the data (Elliott et al., 1999). An extract from this diary can be found in Appendix 16.

Situating the sample

Demographic and health information was collected from all participants (Table 1), along with measures of the quality of the sibling relationship and subjective well-being (Table 3), to provide basic descriptive data about the sample. This allows the sample to be situated, compared with others and determines the transferability of the findings and the contexts in which they might be applied (Henwood & Pidgeon, 1992).

Grounding in examples

To allow evaluation of the 'fit' between the data and conceptual classifications (Henwood & Pidgeon, 1992), the researcher provided direct quotations to illustrate her interpretation of emerging themes and categories. An extract from an interview transcript is provided (Appendix 17) to demonstrate the interview and analytic processes, including the labelling of initial and focused codes. Examples of memos written during data generation are also provided (Appendix 18) to enhance the reader’s insight into the researcher’s understanding of the emerging data.

Providing credibility checks

To enhance the credibility of the study, the researcher set up and facilitated a peer supervision group, consisting of two other trainee clinical psychologists also using Grounded Theory analysis. The group provided a valuable forum for testing codes and increasing theoretical sensitivity (Corbin & Strauss, 1990). Two coded interview transcripts were reviewed by group members, allowing for independent verification and validation of emerging themes, categories and models.

Alongside this resource, the researcher’s academic supervisor also checked two interview transcripts and one set of open codes early on in the research process. This provided necessary feedback on the researcher’s interview style and questions, as well as helping to illuminate any gaps in the data or initial coding. The supervisor also provided feedback on two draft tables of focused and theoretical codes and a draft model. Finally, the field supervisor verified the content of the theoretical model and supporting data to confirm that it fitted with his clinical experiences. These examples of analytical triangulation (Patton, 1999) reduced systematic bias in the data, whilst theoretical triangulation allowed a variety of theoretical perspectives to be drawn upon in the interpretation of the data.

Coherence

The resulting theoretical model is presented in both figurative form and verbal narrative to clearly illustrate the relationships among categories (Elliott et al, 1999).

Codes and categories were clearly labelled in a way that was coherent to others and fitted the data.

Resonating with readers

The researcher was aware of the need to capture the experiences of participants in the interviews and analysis, before relaying this accurately to the reader. The language of participants was examined closely and prioritised in the formation of codes and categories to support the validity of the resulting theoretical model.

CHAPTER 3: RESULTS

The analysis is presented below, with direct quotations provided 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 4. These theoretical codes comprise 14 focused codes, each containing a number of specific properties developed during the initial stage of coding. A summary table is presented in Appendix 19, which documents the presence of focused codes across participants. A diagrammatic model is presented at the end of this chapter, demonstrating the relationships between theoretical codes and properties across a chronological timeline of disclosure events and the sibling relationship over time.

Only one of the ten participants had no siblings who were aware of her HIV status. All other participants had at least one sibling who knew that they had HIV. Four participants had siblings who were also living with PHIV+.

Table 4: Theoretical codes, focused codes and initial codes

Theoretical codes	Focused codes	Initial codes
1. Personal adjustment to PHIV+ diagnosis	**1.1 Learning about HIV**	Learning about HIV at CHIVA youth camp
		Learning about HIV at school
		Learning about HIV from health professionals
	1.2 Impact of stigma	Experiencing stigma at school
		Stigma in romantic relationships
		Expecting to face HIV stigma in social situations
		Feeling that stigma makes it harder to live with HIV
	1.3 Medication adherence	Not taking medication
		Disliking the quantity/taste of medication
		Medication being part of a routine
2. PHIV+ disclosure in the sibling relationship	**2.1 Growing up as HIV+ siblings**	Feeling closer to sibling because of both having HIV
		Having shared experiences relating to HIV
		Learning from sibling’s experiences of HIV
	2.2 Direct/ indirect sibling disclosure	Disclosure from family member to sibling
		Telling your sibling that you have HIV
		Lacking power/control in sibling disclosure decision and process
	2.3 Guessed/ non-disclosure to sibling	Thinking sibling doesn’t know about their diagnosis
		Not thinking about disclosing to sibling
		Sibling guessing that they have HIV
3. Patterns of communication about PHIV+ between siblings	**3.1 Finding ways to talk about HIV**	Being asked limited, direct questions about HIV
		Making a joke of HIV
		Not calling it HIV
	3.2 Times of increased	Increased communication about HIV after disclosure

	sibling communication	Increased communication about HIV at times of sibling bad health
		Hoping to increase communication with sibling in future
	3.3 Keeping the secret	Keeping HIV diagnosis a secret
		Hoping sibling will keep the secret
		Fear of exposing family secrets
		Not talking to sibling(s) about HIV
		Limiting who you tell
	3.4 Not knowing	Not knowing who in the family has/had HIV
		Not knowing what sibling thinks/ knows about HIV
4. Patterns of coping and support in the PHIV+ sibling relationship	**4.1 Feeling normal**	Believing that HIV hasn’t had an impact on family relationships
		Thinking that life is still the same
		Putting HIV to the back of your mind
		Doing normal things with sibling
	4.2 Valuing the sibling relationship	Feeling close to sibling
		Talking frequently to sibling
		Sharing similar characteristics/ interests to sibling
		Feeling that the sibling relationship is one of the most important in life
	4.3 Perceptions of sibling coping	Sibling seeking support outside the family
		Sibling worrying about brother/sister’s health
		Thinking HIV doesn’t affect sibling
	4.4 Sources of support	Supporting sibling (practical, non-HIV related support)
		Supporting sibling (emotional, non-HIV related support)
		Receiving support from friends
		Receiving support from mum
		Receiving HIV-related support from sibling
		Relying on yourself

1. Personal adjustment to PHIV+ diagnosis

Most participants (7/10) were made aware of their HIV status by a health professional at around twelve years old (see Table 1). All participants described a period of personal adjustment following their experience of paediatric disclosure. This period of adjustment seemed to be initially an individual experience that included learning more about HIV and the stigma attached to HIV, as well as adjusting to medication regimes and the new importance assigned to these for maintaining good health. Adjustment to HIV was also described as an ongoing process that got easier over time and gradually included people close to them as they felt able to draw on these relationships.

> *"I think it gets easier [...]*[13] *you just get used to it after a while I guess. You just have to learn to accept it"* (P7)

1.1 Learning about HIV

Three participants mentioned learning about HIV at a residential youth camp they attended for young people with HIV, run by the Children's HIV Association (CHIVA). They talked about how this helped them understand more about the condition and learn from other young people about how they manage living with HIV. There was also a sense of normalising their experiences and emotions associated with being HIV positive.

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[13] A string of dots […] denotes that a section of the extract has been removed to promote the clarity of the quote.

> *"there was a camp that I did go to, called CHIVA, and that did help my understanding and now I do understand it, completely."* (P1)

> *"I did go to umm, this camp, it's a CHIVA camp for like, other young people who have it and so that was like a lot of fun. And I think it kind of like, helped me as well, just kind of being there with other people and seeing how they deal with it."* (P8)

Three participants talked about learning about HIV at school. It seemed that paediatric disclosure often coincided with the time at which HIV is covered in the UK secondary school curriculum. This was therefore often the first experience participants had of hearing people talk about HIV away from health settings and the home.

> *"I think I was in school and we were in a citizenship lesson and they were talking about it and I was like (laughs), I was like "whaaat?".* (P5)

> *"I think the time when I found out. We was learning about it at school, as well."* (P1)

Most participants identified learning about HIV from health professionals at the specialist HIV clinic where paediatric disclosure took place. Although they were given information at the time of paediatric disclosure, they described not often fully understanding it all or taking it all in.

> "*…most I learnt was like coming here [to the clinic]*[14]*. I don't think I researched anything on my own really*." (P6)

> "*I think it just didn't hit me, because I was what like 11, so when someone tells you you have HIV it's like "ok"*." (P7)

Participants seemed to be selective about how they sought information about HIV, with no participants reporting independently seeking information in the public domain (e.g. on the internet), possibly for fear of encountering false or stigmatising material.

1.2 Impact of stigma

Eight participants talked about the impact of stigma on their ability to cope with and adjust to living with HIV. Participants described becoming aware of the stigma associated with HIV in different ways and experiencing stigma in different settings or relationships.

Alongside learning about HIV at school, three participants discussed the stigma they experienced at school, both from teachers and peers. This stigma was experienced from people who were not aware of the participants' HIV status. Their experiences included being bullied by peers, peers making jokes about HIV and misinformation from teachers and peers about the nature of HIV. It appeared that there were a variety of different emotional responses to these experiences, including shame and anger. These early experiences of stigma also seemed to predispose participants to secrecy and silence about their HIV status.

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[14] Words placed within square brackets (i.e. [*to the clinic])* have been added by the researcher so that the extract can be easily understood.

> *"Because they thought that I had it, and I did, but, I would always say that I didn't. And because like, they was learning about it, it was just like a thing that was like, oh look, let's bully her and say she has it."* (P1)

> *"when I was growing up and in school that was a bit harder. Because you get like teenagers that talk about it like, in a bad way. Not that's it's a good thing, but, and then, you just feel like well, they don't know what it's kind of like and they made fun of, there were jokes about it as well. I don't remember the jokes but, they used to make jokes about it, I remember that much."* (P3)

> *"Oh no, school tells you you die from it, so [...] I remember arguing with my teacher about it."* (P7)

Half the participants also went on to describe stigma in romantic relationships. This included predicting a partner would react negatively to potential disclosure and worrying about sharing their HIV status because of fears of judgement and rejection.

> *"I worry about like, getting into a relationship where I'd have to tell the person, and like how that person would receive it. Yeah, I suppose that's my main worry, yeah."* (P6)

Participant seven had disclosed to two romantic partners and talked about how her current partner's views about HIV are influenced by his African culture. The first partner she disclosed to had left the relationship because of her HIV status, so this was a sensitive and difficult topic for her to talk about and was the only time a participant cried in an interview.

> *"…he's still scared. He's still scared himself, I mean he's still trying to understand it. Because he's African himself and obviously in Africa as soon as they hear that they probably think AIDS, they don't probably think, oh there's two different types [HIV and AIDS]. So, he's still terrified himself of it."* (P7)

Participant ten had not yet had a romantic relationship and talked about waiting until his last year of university to have a relationship as a result of the stigma attached to HIV. He also planned to disclose to any potential partners at an appointment at the HIV clinic, so that a health professional could answer any questions and facilitate sharing his HIV status.

> *"the stigma is there, the condition's not going and because you know how it's transmitted and you know how it impacts the body, I think, it's better to have a medical appointment to discuss it with your partner than to discuss it in person and not know what to do."* (P10)

Six participants described expecting to face HIV stigma in wider social situations. They talked about the impact of anticipating stigma on mood and how they are treated by other people. They also seemed to have generalised their experiences of stigma to believing those views are held by the wider population. There was a sense of adjustment to and acceptance of other people's views of HIV.

> *"…if we listened to what other people say, it would kind of make us like depressed and stuff."* (P5)

> *"…some people don't understand it and the way they think of it, it could affect, like how they treat me and stuff like that."* (P1)

> *"…in my head I thought this is how everyone will probably see it. But, eventually I got used to it. Sort of like, I knew some people would accept it, some won't."* (P7)

Participant ten also considered the impact of stigma in the workplace and potentially having to disclose to colleagues. He seems unsure about how to manage this and alluded to feeling uneasy about both disclosing and not disclosing.

> *"I think, it's very personal and it feels awkward when you have your first job because I haven't worked at all, having a first job and just say that you have this, and they know the stigma behind it. And, what do you do?"* (P10)

When asked if there was anything that made it "harder to cope", five participants mentioned that stigma makes it harder for them to live with HIV. They associated stigma with the perception that 'you die from HIV' and misinformation about the condition or ease of transmission.

> *"Umm, stigma I guess. When you hear people, like talking about AIDS like it's a death trap kind of thing."* (P3)

> *"What doesn't help? The media I think, the way they portray it. It's like, once you have it you can pass it on to someone that's it. Or you die from it."* (P7)

> *"I feel like there's a lot of people that are ignorant about it and don't know what it is and they sort of have opinions on it […] it's like, it's quite disheartening."* (P6)

Participant four compared HIV to other chronic illnesses (like diabetes) that her friends could talk freely about and gain sympathy for. She felt annoyed that she felt she had to be secretive and lie about what her medication was for, due to the fear that they would treat her differently if she disclosed.

> *"…obviously the stigma doesn't help, umm because the fact that I do have to take pills, I wish I could just be like "oh yeah, I'm taking it for this" and not have to worry."* (P4)

1.3 Medication adherence

All participants discussed medication as being a key issue related to their HIV status. Six participants referred to a time after paediatric disclosure when they either stopped taking medication or were taking it intermittently. Many of the participants had taken this medication from a young age with no previous adherence issues. However, they seemed to be adjusting to their new understanding of their diagnosis, the importance of medication for maintaining good health and increasing independence in managing their medication regimes.

> *"Yeah, quite soon after I found out about the diagnosis and I think, there was, I think not last year, the year before, I did struggle a bit as well […] wasn't really taking my medication properly, kind of stopped. But, now I'm just fully back on track"* (P1)

> *"I don't know, I just went through like, bad phases, I just I think I was like depressed for a while and when I was 17 I stopped taking my meds completely and I only started to, like, resume, like a few months ago."* (P3)

> *"Umm, my health has been quite bad, yeah. I mean I'm kind of like, I kind of go in and out of spells in hospital like, I'd say every 1.5 years. I just end up in hospital due to not taking medicine and things like that, like just not looking after myself."* (P6)

Participants also talked about going on controlled breaks from medication at the advice of health professionals, to prevent resistance at times when adherence was poor. In relation to difficulties with HIV medication adherence, eight participants mentioned disliking the quantity of tablets or the taste of medication as factors contributing to this.

> *"I didn't even like the taste of them, I had 3 I think at a time. So, I didn't like them, so I just stopped taking them."* (P3)

> *"…they didn't give me tablets so it was the liquid ones. And I used to throw it in the sink. Because it was just really disgusting. And then they changed me to tablets."* (P5)

Participants also talked about medication being part of their daily routine. This was mentioned as an aid to medication adherence in helping them remember to take it, as well as making the process less effortful.

> *"But obviously, I'll always remember to take my meds, but that's because it's routine so…"* (P3)

> *"…so I just used to take it and I got into the habit of it and it was just something I used to do. So I didn't really question it, I just did it and got on with it."* (P8)

2. PHIV+ disclosure in the sibling relationship

Regarding disclosure between PHIV+ participants and their 'identified siblings', three out of ten participants talked about growing up with a PHIV+ sibling with both being aware of each other's HIV status. Four out of ten 'identified siblings' were made aware of their brother/sister's HIV status from a family member. Two out of ten 'identified siblings' were not aware of their brother/sister's HIV status. Only one participant directly disclosed to his 'identified sibling'.

2.1 Growing up as HIV+ siblings

Participants who chose to talk about an “identified sibling” who was also PHIV+, described feeling close to their sibling because they both have HIV.

> *“I think we just like started getting closer, I think we realised we had more in common or something, so we just got closer like that.”* (P5)

> *“It’s just another thing, if anything it’s another thing that makes us a little bit closer, because it’s another thing that we’ve been through together.”* (P6)

Participant seven was the exception to this finding. She chose to talk mainly about her close relationship with her older sister (who is HIV-), but also had a younger sister (whom she lives with) who is PHIV+. When reflecting on her distant relationship with her younger sister, she wondered whether it was because HIV did not change them as people and that they had little else in common with each other.

> *“You would have thought that it would have made us closer, because we both have it, but no, pretty much. Whether we had, I had or it or I didn’t, she’s just the same. Nothing different about her, so no.”* (P7)

Participants who grew up with a PHIV+ sibling referred to having shared experiences relating to HIV, including medical appointments and medication. As children, they would either share appointments or be taken together on the same day by their parent(s).

> *"…we kind of went through the same thing, it was just a case of, when we were kids we had our doctor's appointments at the same time*" (P6)

Participants with a PHIV+ sibling also described taking their medication at the same time when they were younger. It was through these shared experiences that participants were made aware of their sibling's HIV status. Participant five was the only person who talked about their sibling being involved when they were first told about their HIV diagnosis.

> *"…we'd always like take our medicine at the same time, so, like, he just knew."* (P6)

> *"I think I was like around 12 or 13 when the umm, I think some psychologist woman, she came to my house and they sat with me, my sister and my mum, I think my sister already knew from when she was a bit younger"* (P5)

Two participants talked about how growing up with a PHIV+ sibling allowed them to learn from their older sibling's experiences of HIV. Participant five felt reassured by her sister's knowledge and advice about HIV.

> *"I just asked my sister, because obviously she knew more about it, so yeah… She was just like, as long as you just take your medicines every day you'll be fine, like, you're not gonna die."* (P5)

Participant six described problems taking his medication and how his PHIV+ older brother used to try and support him with this when they were younger by modelling the behaviour. As these difficulties continued however, his older brother grew increasingly frustrated at his sibling's inability to do something that he might have perceived to be routine.

> *"There's been many occasion when he's tried to coach me through taking medication, but when I can't get it, he just gets angry, he's not a very good teacher."* (P6)

2.2 Direct/ Indirect sibling disclosure

In four out of ten participants, 'identified siblings' became aware of their brother/ sister's HIV status from another family member. In three participants, this disclosure came from their mother and in one instance from an aunt. Participant one described an accidental disclosure from her aunt, who thought that her older sister already knew about her HIV status when she started talking to her about it.

> *"…my aunt had thought that my sister knew. But she hadn't known. So, she was just telling my sister how she thinks that I'm very strong and how I'm coping and how I don't let it affect me and stuff like that, and then my sister was like "how what doesn't affect her?" and she was like "oh, her HIV" and she was like "Oh, I didn't know"."* (P1)

In the instances where the participant's mother disclosed their HIV status to their sibling, the participant was not aware that the disclosure was going to take place.

In one example, this disclosure took place when participant four's sister confronted her mother and asked what it was that they were keeping from her. She felt annoyed that she had not been present when her sister was told about her status.

> *"…my sister confronted my mother saying "I know that you and [participant's name] are keeping something", so she just like confessed and told her."* (P4)

In another example, the disclosure took place while the family were praying together and came as a shock to the PHIV+ young person.

> *"…my mum was making us pray so we were praying, and then my mum just randomly came out with it and then my sisters were both, they kind of looked at me and they were both like "what?"."* (P8)

In this scenario and all other experiences of indirect disclosure to siblings, participants appeared to feel a lack of power or control in the sibling disclosure decision and process. They talked about feeling hurt and annoyed by the way in which it was disclosed. There was also a sense of wanting to do it "properly" or in the right way, with more planning and consideration.

> *"…it was just really random, like the way my mum just kind of told them. And, I don't know, like I felt kind of hurt by it, because she didn't tell me she was gonna tell them. And I would have like wanted to do it properly."* (P8)

> *"I wasn't there, which I was annoyed about. Because umm, my doctor kept asking me "does your sister know yet?" and I said "no", umm, "I'll find the right time for when I want to tell her"."* (P4)

Although only one participant directly disclosed to their 'identified sibling', there were two experiences of direct disclosure to siblings in the sample overall. Participant one chose to disclose to her half-sibling (sister), but not to her biological sister whom she lived with. Although she did not see her half-sister often, she described their relationship as being a lot closer than with her other sister. They had met for the first time five years ago, are the same age and talk "all the time". When describing this sibling relationship, it seemed to closely resemble a positive peer relationship.

> *"I told her [...] It was kind of scary, but she was very cool about it."* (P1)

Participant nine also directly disclosed to all of his seven siblings. His experience of HIV diagnosis and disclosure was markedly different to all other participants. He described being diagnosed with HIV age 19 or 20 years old, after also being given a diagnosis of cancer. He had been previously unaware of his HIV+ status and had not been taking ART. His mother had died in the year before his diagnosis and his father when he was a child, leaving him and his siblings orphaned. He said it felt easy disclosing to his siblings while he was in hospital being treated for cancer because he knew they would not judge him and their reaction was positive and consoling.

> *"I told them, yeah, I felt like I needed to tell them because having a doctor tell my sibling something that I've got, you're not really gonna believe it until they actually hear it from the horse's mouth himself"* (P9)

2.3 Guessed/ non-disclosure to sibling

There were two participants who had not disclosed to their 'identified siblings', who believed that this sibling did not know about their HIV status (participants three and seven). However, participant seven also had a younger sister who was PHIV+ and was aware of her sister's HIV status. This meant that only participant three had no siblings who were aware of her HIV status.

In addition to growing up with an older brother with PHIV+, participant six also had a younger brother who he had not disclosed to and who he believed was unaware of his, his father's and his older brother's HIV+ status. Of the three participants whose 'identified sibling' they believed was unaware of their HIV+ status, none of them had thought about disclosing to their sibling.

> *"…it's not a conversation I like having. It's not something I want to bring up."* (P6)

Although he had never talked about his diagnosis with his youngest brother, participant six thought that his brother might have guessed that he has HIV. He said that he's never hidden the fact that he takes medication from his brother and his brother is often present when his father speaks to him and his older brother about "staying healthy" and "taking your medication".

> "*I feel like he might have put two and two together, by now. Because he knows that I have to take medication every night, he's seen me in hospital a few times, so, he definitely knows there's something different between me and him, but he might not just know what it is*." (P6)

Participant two was adopted from sub-Saharan Africa as a child after his parents died and his oldest sister was left to care for him and his two brothers. He considered whether his brother might have guessed that he has HIV because he had seen him taking medication with their older sister, who also later died of AIDS. They had never spoken about his diagnosis explicitly.

3. Patterns of communication about PHIV+ between siblings

3.1 Finding ways to talk about HIV

Eight participants referred to ways in which they tended to talk to their sibling about HIV-related issues. The first of these was being asked limited, direct questions by their sibling about aspects of HIV such as medication and medical appointments. Participants gave the sense that this allowed their sibling to check in with them about their HIV-related health, without having to engage in deeper discussion, which they appreciated.

> "*…she really randomly asked how my appointment went. And then I was like "yeah, my viral load is down" and she was like "good", and then like walked off*" (P4)

> “*…when I come for appointments she’ll be like, ‘good luck’ and stuff like that and as soon as I get home, she’s like “how did your appointment go?”. I’m like, “it’s good, it’s all good”, and she’s like “yessss”.*” (P1)

Participants also commented that their siblings do not refer to HIV specifically and that this was something they favoured. Most participants preferred to be able to give a brief response to questions from siblings about their health, without having to go into any detail or think about HIV too much.

> “*…we don’t talk about it specifically, but they’ll be like “oh, (name), you’re not well, you should take medication” or they’ll like notice something and be like “oh, are you ok?”* (P8)

> “*…it will probably be “how did the appointment go?” but not be specific and say “how did the HIV appointment go?”… so it’s, we’re touching the topic but we’re not opening the book. So, yeah it’s a case of it’s ok, the questions that she’s asking ‘cos I’m not thinking about it too much, it’s a quick answer, she knows how I’m feeling, I know how she’s feeling, that’s it, conversation done.*” (P9)

Four participants discussed not ever naming HIV with their siblings in their communication about it. Participant six reflected on never saying the word ‘HIV’ at home with his family. Participant eight mentioned that he does not use the word ‘HIV’ because of the way it makes him feel and two participants discussed having another word for HIV at home or with their sibling.

> "*I don't like saying it as well. It's just, I don't know, makes me feel weird."* (P8)

> "*…they always referred to it as 'the virus', like from when I was a kid growing up*" (P4)

> "*…we just call it "the club". So, even when we're in public we just go "yeah, got to go to the club […] we'll just be like "oh yeah, I just went like to the club today and you know, same old, same old*". (P5)

Participant five talked about how referring to HIV as "the club" with her sister allowed them to talk about it in public without other people knowing what they were talking about. Their mother also had a different word she used to refer to her HIV. The use of the "the club" also has connotations of being in a secret or exclusive 'club' with her sister that no-one else is a part of. Two participants also referred to making a joke about HIV with their sibling, which seemed to make it easier to talk about together.

> "*Like we just make jokes about it like, we kind of just make fun of ourselves […] If I'm with my sister and it comes up, we just laugh, 'cos it's just funny. It's like an inside joke, kind of thing.*" (P5)

> "*…she kinda, I don't know, takes it, tries to make it seem like light-hearted… I don't know, it's kinda like, it's kind of our thing so she makes it seem like, I*

> *don't know, not as bad as it actually is… she's just there, just trying to make jokes out of it. And so, yeah, that kinda helps because, not having to take it seriously all the time*." (P8)

3.2 Times of increased communication

Six participants referred to distinct periods of increased communication about HIV with their sibling(s). Four participants noticed that they spoke about HIV more with their sibling soon after their sibling had found out about their status. They tended to need to reassure their sibling and contain their emotional reaction to finding out their brother/sister was HIV positive.

> "*And then obviously she came, and she came and talked to me about it […] she left it I think about two weeks before coming to me*." (P1)

> "*I do know that like, a few months after, just she like came to me and she was like crying and she was like really upset and telling me how she was, it made her really sad that I had HIV.*" (P4)

Three participants found that their siblings talked to them more about HIV when they were unwell. Participant six discussed how his brother tries to encourage him to take his medication when he gets unwell because of poor medication adherence.

> "*I don't know if he gets annoyed but, like I said before I think it puts a real burden on the family when I get ill. So, it like, it's just like, "get on with it", you know*." (P6)

Participant eight commented that her younger sisters have noticed that she has been more unwell recently and asked her about what might be causing this. Their questions seemed to encourage increased communication about her HIV status and how she was managing her health.

> *"…they've noticed changes and so I've kinda, I had to tell them like I haven't been feeling well, this and this have been happening. And so, they were like, "oh why do you think that is?", and I was like "I don't know, it could be a number of things"*." (P8)

Six participants also talked about their hope to talk to their sibling(s) more about both HIV and their personal lives in future. They hoped that their sibling would talk more openly with them and that they would be able to share more with their sibling. This suggests that the majority of participants may not be satisfied with their current levels of openness or communication with their sibling and would like to improve this over time.

> "*I'd like for her to talk to me more. And know she can talk to me. I'd like her to be able to actually talk to me and my mum, about her problems*." (P1)

> “*I’d like to like, just talk to her more about me, so she kind of has like a better understanding* [*of HIV*].” (P8)

3.3 Keeping the secret

Five participants referred to feeling it was best to keep their HIV diagnosis a secret. They were aware that their parent(s) and family did not talk openly about HIV and recalled knowing that it was not something they should tell people about. Some participants’ parent(s) had told them to be careful about who they shared their status with.

> “*…she was like “why didn’t you tell me?” and I said I wasn’t really allowed to tell anyone*” (P1)

> “*I guess maybe it’s like having to keep a secret as well. That’s changed my life”* (P4)

Participants also spoke about hoping that their sibling would keep their HIV status a secret. Some participants explicitly asked their sibling not to tell anyone about their HIV status, while others felt that they did not need to ask for it to be kept confidential.

> “*So, I asked her not to tell people and she said “ah, ok”*.” (P1)

> *"Interviewer: and did you ask your siblings not to tell anyone else? No, I didn't have to. 'Cos I know that, the way we are if it's in the house, it stays in the house. If it's in the room, it stays in the room."* (P9)

Two participants talked about their fear of exposing family secrets. Participant eight expressed a desire to explain more about HIV to her younger sisters, but felt that her mum would not want this because it would involve talking about her estranged father. Participant six preferred not to talk about HIV or ask his dad questions about it because he was concerned about what he might find out. He talked about not knowing how his parents contracted HIV, wanting someone or something to "*blame*" for his illness and feeling "*resentment*" towards his father for not knowing the whole picture.

> "*I don't know where like this illness came from, like in my family, we've never spoken about like how it got there, but all I know is that, it's not on my mum's side of the family… I don't ever want to have that conversation, I just feel like I'd open so many stuff*" (P6)

> "*I feel like my mum wouldn't want to. Because then it would involve me like talking about my dad and then that kind of thing, and I don't think my mum likes talking about that.*" (P8)

The secrecy surrounding HIV and how it was contracted seemed to lead to participants not talking to their sibling(s) about HIV at all. Eight participants spoke about HIV as being something that is not ever talked about in their family.

> "*…it's not something we bring up. It's not something we've ever said, "oh, let's sit down and talk and discuss this", it's never happened*." (P7)

Participant nine made the comparison between cancer and HIV, as he had experience of both illnesses. He felt able to talk about cancer to his siblings as it was more socially acceptable and more commonly encountered in the public domain (such as on television), which gave him a platform to discuss it.

> "*… you can talk about cancer, you can't really talk about HIV. It's like, they're two different things*." (P9)

Another way in which participants kept HIV a secret was by limiting who they told about their status. Disclosure to wider family, friends and romantic partners was restricted, with some participants not having told anyone about their HIV status. Half the participants had no-one in their personal support system outside close family who knew about their status and four participants had never directly disclosed their status to anyone. Participants often seemed to feel that there was no need for anyone other than their siblings and close family to know about their HIV status.

> *"I feel like, it's an in-house thing. There's no need for everyone else to know really"* (P9)

3.4 Not knowing

Throughout all the interviews, there was a sense from participants of 'not knowing' a lot of the details surrounding their HIV status and that of other family members. Six participants described both themselves and their siblings not knowing who (else) in the family has HIV.

Three participants had lost one or more parents to AIDS and another participant had lost her father due to a sudden medical crisis. Participants who had lost a parent to AIDS either did not openly discuss the cause of death or said that they did not know the cause of death of their parent. Participant two also talked about not knowing how his older brother and sister died, but suspected they died of AIDS. He also did not know if his only living biological brother knows if he has HIV, but thought that he did.

> "*…my mum had it but I'm not sure, yeah, my mum had it but I'm not sure if she died of it*" (P2)

> "*…my other [brother] that passed away in 2010, he, I don't know how he died, I think he was sick but I'm not sure if he died of [HIV] or if he was just like very sick.*" (P2)

> *"I'm not sure if my other brother now, if he knows I have it. I don't know but, I think he does.*" (P2)

Seven participants did not know what their sibling thinks about HIV or how much they know and understand about the condition. Participant eight hoped that she and her mum could explain more about the condition to her sisters in future.

> "*I don't know what my mum's told them [about HIV]*". (P3)

> "*I don't think they have any clue what it actually is or how I got it, because I don't know, umm, I would like for me and my mum to kind of explain it to them*" (P8)

4. Patterns of coping and support in the PHIV+ sibling relationship

4.1 Feeling normal

One aspect of coping with HIV referenced by all participants was to feel normal. This seemed to be contributed by a number of different beliefs and actions, which included believing that HIV has not had an impact on family relationships. Nine participants described feeing that HIV had not affected their relationships with family, including their sibling relationships. Participants equated a normal sibling relationship to both supporting each other and feeling irritated or annoyed with one another at times.

> "*…it's like a normal relationship, we're there for each other.*" (P3)

> "*…we still obviously like get on each other's nerves and stuff, so that obviously hasn't changed. So, yeah it's just kind of normal, the way it always has been.*" (P8)

All participants talked about their lives generally being the same as pre-paediatric disclosure. Alongside the belief that HIV had not changed things, was the notion that participants did not see themselves as being different to others or changed by HIV. It seemed that they were communicating that HIV is not a central part of their identity, but just an added challenge for them to manage in life.

> "*…it hasn't changed my life, as drastically as I thought it would. So, my life's pretty much still the same*". (P1)

> "*…it never bothers me like, I never see myself as being different*." (P7)

Six participants described coping with HIV by putting it to the back of their minds and not thinking about it. Similarly to not thinking about HIV, participants also described maintaining a 'normal' relationship with their sibling(s) by doing 'normal' things with them. This may also have acted as a distraction from thinking about HIV.

> "*I don't really think about it, it's at the back of my mind*" (P9)

> "*We'll watch a movie, sometimes we'll make dinner together, or we'll make my mum's breakfast together while she gets ready for work. Play with my nephew together, kind of, do some online shopping*" (P1)

> "*Umm, yeah, to like bars, pubs, clubs, umm, and maybe like watch a film on tellie, umm, I don't know just like, sit and chat, occasionally make pancakes*" (P4)

4.2 Valuing the sibling relationship

All participants described feeling that the sibling relationship is one of the most important relationships in their life. They considered their sibling relationship more important than friends and referred to it being a lifelong relationship, as both a family member and confidant.

> "*It's very important to me because, you know I've grown up with her. She used to change my nappies and stuff like that and it's just something I feel like it should, it's very important. It should be very important to like a lot of people. And to be close to your siblings, or at least try to be close with them.*" (P1)

> "*Very, I think she's one person who I couldn't have her mad at me. Literally, like, not speaking to her or my nieces, it feels weird so, we speak near enough every other day*." (P7)

Participant four recognised that although she felt she was not as close as she would like to be to her sister at the moment, she still considered the relationship important. She said that she felt closest to her parents and friends at present because her sister was in a relationship and less emotionally available than she had been in the past.

> "*I think it's important but in reality it's not very high on the list at the moment. Umm, just because of circumstances*." (P4)

Eight participants described feeling close to their sibling and many indicated feeling closer to their siblings than friends. Participants described knowing that their sibling would be there to support them, even when their friends were not.

> "*…with her it's more important 'cos obviously you have friends, but then like, even if I didn't have friends I'd still have my sister, kind of thing*." (P5)

> "*…she's my sister, but she's also kind of like my best friend, in a kind of clichéd way. But, she is because, I don't know, when I need her she's there basically. When we need each other we're there for each other… I'm just a lot closer to her than I guess anyone in my life*." (P8)

> "*Like, I could have been, like when I got diagnosed with cancer, I didn't call my friends, I called my sister and my brothers, so it's a case of, that's way more important to me*" (P9)

Participants with more than one sibling also referred to feeling closer to one sibling than another. This was not fixed however and they acknowledged that the sibling they feel closest to changes at times and may change for their sibling too.

> "*I spend more time with my older sister. Yeah, me and the younger one, we don't often get along. She annoys me a lot, so, yeah*." (P8)

> "*Even now, he's like, if we see each other, we're just like strangers, even my sister doesn't talk to him anymore like they're not close. So, like if all of us are*

> *in the same room, it will just be and my sister talking, like he will just walk past*." (P5)

Nine participants suggested a relationship between talking frequently to their sibling and feeling close to them or valuing the relationship. Conversely, those participants that did not talk to their sibling often or spend time with them frequently regarded their relationship as less close or valued.

> "*It's pretty good, we talk near enough every day. I spoke to her before I came here*." (P7)

> "*…they tried contacting me and calling me and when they did see me they were like really happy*" (P8)

> "*I don't really see her that often, I don't really talk to her as often and so our relationship isn't as close as it was.*" (P4)

Eight participants also indicated that sharing similar characteristics or interests to their sibling made them feel closer. Sharing the same interests (such as skateboarding, art or chess) seemed to make participants feel more connected to their sibling and may have led to them spending more time together or feeling like they had more in common.

> "*We're kind of alike but I think people say I'm more mean (laughs). Yeah, I think because we're kind of similar, 'cos we're both like blunt and stuff*" (P5)

> "*…we laugh a lot together, we kind of have the same sense of humour. He reminds me like a little version of me, sort of.*" (P6)

> "*She's got very similar interests to me, we both like doing arty things*" (P4)

4.3 Perceptions of sibling coping

Alongside references to their own ability to cope with living with HIV, nine participants indicated ways in which their sibling might be affected by HIV or cope with having a sibling with a HIV. These insights seemed to be limited by a lack of communication about HIV in families and relied on participants' levels of attention to and awareness of their sibling's emotional states and help-seeking behaviours.

Three participants noticed that their sibling was seeking support outside of the family, from either friends or a romantic partner.

> "*I would really like it if she could actually talk to us instead of going out and talking to other people, as much. Or, I'd prefer if she has problems, we hear about them from her and not from someone else, like we normally do. Or if something's happened, we hear from her and not someone else*." (P1)

> "*I think when she has problems in her life, it's what she discusses with her partner*" (P7)

Half of the participants also noticed their sibling worrying about their brother/ sister's physical and mental health, particularly at times of HIV-related illness.

> "*So, I've not been feeling well at all. And it's been kind of affecting my mood, and yeah, like my parents are a bit worried and I think my sisters are as well*." (P8)

> "*…start to like over-worry about it, which I think my sister did at one point*" (P4)

The majority of participants however (nine participants in total) still thought that their HIV does not affect their sibling.

> "*I think she's, she's got over when she was really upset, and I think she's, it doesn't really bother or affect her anymore*." (P4)

> "*I don't think he, like I don't think he was really bothered about it, you know*" (P5)

Participant eight was the only one to consider how HIV-related illness required her mum to spend extra time with her when she was in hospital or at appointments. This directly impacted her younger sisters, who were cared for by their father in their mum's absence.

> *"…my mum will have to stay with me while I get better and so, my mum will be with me and then my sisters will have to be like with my stepdad*." (P8)

4.4 Sources of support

All participants talked about different sources of practical, emotional and HIV-related support. Reciprocal support between siblings took the form of both emotional support (talking and listening about problems or concerns) and practical support (offering help or assistance in a tangible and/ or physical way).

Participants described practical, non-HIV related support between themselves and their sibling(s), which included helping with household chores, childcare and running errands.

> "*…we're always like a team kind of, in that sense. Whereas, obviously you don't have that with your friends. We kind of team up when it comes to like, either looking after my [younger] sister or like the house, like maintaining the house or cleaning and stuff.*" (P3)

> "*Whenever I can tell that she's going through something, I do let her know that I'm here for her. I do little things to help her out when I can tell she's struggling [...] just little things. If she's been busy the whole day taking care of my nephew I'll make dinner for us two, so, like that.*" (P1)

It seemed that practical support was more commonly offered between siblings when they were younger or offered from a younger sibling to an older sibling. Participants also reflected on there being more conflict in their sibling relationship when they were younger.

> "*…we just used to clash anyway, 'cos I was like the annoying one, so I used to just annoy her all the time, so, that's why we didn't used to get along*" (P5)

Eight participants described reciprocal emotional (non-HIV related) support between themselves and their sibling. Again, this seemed to mainly be older siblings offering younger siblings emotional support or advice and the level of emotional support between siblings seemed to increase as they got older. This may have been due to increased warmth in the sibling relationship, which was evident in the way participants described their sibling relationship now, versus when they were younger.

> "*…he's young, so he's not, number one he's not gonna have much advice that's gonna help me, and I don't really wanna burden him with what I'm going through, I kind of just want him to do that to me, not the other way round.*" (P6)

> *"…whenever I need to talk to her, she's always there. She may call an hour later (laughs), but she's always there if I need to talk to her."* (P7)

The four participants who had experienced parental death talked about the emotional and practical support between themselves and their sibling(s) immediately following their loss. Participant two remembered his brother being with him when his mum died and talked about his older sister raising him when they were orphaned as young children.

> "*I know, I remember my mum passed away, I was with my second brother, he was with me next to me*." (P2)

Participant six talked about not being able to offer his brothers emotional support because of his own grief. Instead, he reflected on how he and his older brother had supported his youngest brother practically, by looking after him.

> "*…when it happened I wasn't thinking about him, I was going through it myself, so and I think the same for him, like, we kind of looked out for my little brother a lot, because obviously he was really, young*" (P6)

Participant three mentioned that her middle sister was most affected by her father's sudden death and that she supported her by being emotionally available when she needed her.

> "*…just being there. That's kind of all you can do. But she's a lot better. Well, she's coping a lot better now*" (P3)

Five participants talked about receiving support from their friends over their sibling.

> *"Interviewer: Yep, so if you had a problem or something that you wanted to talk to someone about, who would you go to?*
>
> *I'd probably go to one of my friends more than anyone"* (P6)

> *"Interviewer: who do you go to if you have an issue or something that you wanna talk about, that's a bit emotional?*
>
> *I normally go to one of my close friends. Yeah, one of my best friends, I'll go to.*
>
> *Interviewer: Yeah, and if it's HIV-related?*
>
> *One of my close CHIVA friends"* (P1)

Here, participant one makes the distinction between going to friends for HIV-related support or non-HIV related support. This affects her decision about which friends to go to as she seeks HIV-related support from one of her HIV+ friends. Participant three discussed going to her friends for support without being specific about what she is feeling "sad" about. This allows her to maintain secrecy around her HIV status while still being emotionally supported by her friends.

> "*I just go to my friends and say I'm sad, and then they just cheer you up. They don't ask questions*." (P3)

Six participants mentioned receiving support from their mum over their sibling. Much of the support provided by mothers was related to managing HIV, ill-health or emotional well-being.

> *"Interviewer: who gives you the most support, would you say?*
>
> *My mum [...] like when I was in hospital she was bringing me lots of stuff, to keep me occupied. I enjoy drawing so she brought me my pencil case and she brought me paper. And she brought me food that I really enjoy.*" (P1)

> "*…she was trying to get me to take my meds she talked about it a lot. And she was saying how like, I could live a healthy life and it's for the best and ummm, could live a life without pain kind of thing*." (P3)

> "*…because we don't really talk as much anymore, it's not as much as it used to be. Umm, I feel like I'm going to my parents a lot more than I would go to her*." (P4)

Five participants talked about receiving HIV-related support from their sibling. This included both emotional and practical support. Participant one talked about her sister doing the dishes, making her food and doing her washing for her when she is unwell.

> "*Yeah, like when I'm sick, she will help look after me. She cooks for me sometimes, not cooks for me but she gives me food, so yeah*." (P3)

Emotional HIV-related support from siblings was particularly valued by participants when their sibling was aware of their status, but their friends were not. This allowed participants to have a peer-like figure who they could talk to about having HIV, without having to disclose to friends if they chose not to. Siblings offered their PHIV+ brother/sister encouragement and understanding to support them in living with HIV.

> "*…well obviously because she knows about it, so obviously you can like talk to each other about it, but with other people it's not really, yeah.*" (P5)

Finally, five participants also referred to relying on themselves to manage difficulties or problems. This was alongside other sources of support, but seemed to be a default position for many of the participants, before support was sought from either siblings, friends or family.

> "*I tend to just keep things in and just go like, ride with it and just go, yeah*" (P6)

> "*I've always been someone who keeps stuff to myself. Works out better somehow.*" (P7)

> "*…my problems are for my business*." (P10)

Model of sibling relationships in young people with perinatally acquired HIV (PHIV+)

The aim of the study was to develop a model of sibling relationships in PHIV+ and assess how this model related to previous findings from the literature. Figure 1 below outlines how the main themes are hypothesised to interact in sibling relationships following paediatric disclosure of PHIV+. Focused themes that were felt to be particularly relevant to the sibling relationship in PHIV+ were included in the model alongside the four theoretical themes.

The model depicts features of the ‘HIV journey’ of a PHIV+ young person post-paediatric disclosure, in relation to aspects relevant to the sibling relationship. The four themes are plotted across a timeline, beginning at paediatric disclosure and running throughout adolescence, emerging adulthood and young adulthood (indicated at the top of the model). This timeline provides a context to the experiences of siblings in PHIV+, as illustrated in the main model. The first theme in the centre of the model refers to a period of personal adjustment to PHIV+ diagnosis, directly following paediatric disclosure. This stage is ongoing and includes both an initial response as well as ongoing adjustment into young adulthood (illustrated by the dashed arrow line running across the top of the model). Following this period of personal adjustment, PHIV+ young people experience decisions and events related to disclosure of their HIV status to a sibling. They may have grown up with a PHIV+ sibling and are likely to both be aware of one another’s HIV status. Alternatively, this stage may take the form of either direct/ indirect disclosure or guessed/ non-disclosure. The type and experience of HIV disclosure to sibling(s) affects patterns of communication about PHIV+ between siblings, as does their adjustment to their diagnosis. Certain patterns of communication are more likely to be experienced than others, depending on a sibling’s awareness of their brother/ sister’s HIV status. For instance, siblings who are aware of their brother/sister’s HIV status will find ways to talk to each other about HIV and have times when they talk about it more than others. Siblings who it is believed do not know about their brother/sister’s HIV status or who find out unintentionally are less likely to communicate openly about HIV. The relationships indicated between PHIV+ disclosure in the sibling relationship and communication about PHIV+ between siblings are illustrated in the intersecting circles of the diagram. Levels and types of communication about PHIV+ between siblings also influence patterns of coping and support in the sibling relationship.

Patterns of coping and support with HIV in the sibling relationship are formed primarily post-paediatric disclosure and run alongside the ‘HIV journey’ of young people with PHIV+. Siblings support one another and influence coping strategies at each stage of the model. The evolution of reciprocal support between siblings is observed from practical support when younger, to emotional support when older, with increasing levels of warmth described between siblings as they enter young adulthood. The solid arrows in the model show how one theme may feed into and influence another. These relationships between themes may be one-way or bi-directional. An example of a bi-directional relationship is that of personal adjustment to PHIV+ diagnosis and levels and types of sibling support, which may help or hinder this process.

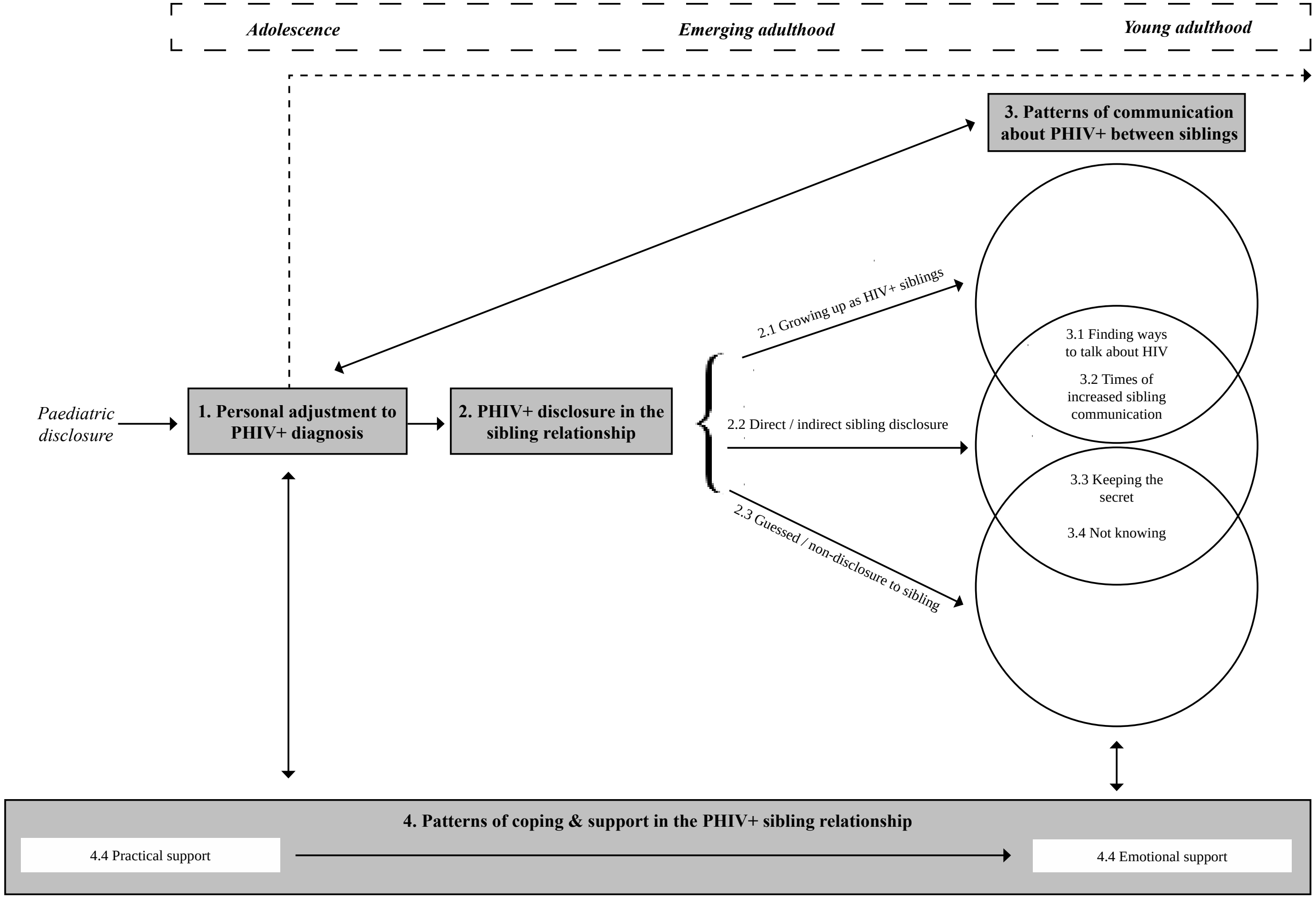

Figure 1: A model of sibling relationships in young people with perinatally acquired HIV (PHIV+)

CHAPTER 4: DISCUSSION

This study explored sibling relationships in young people living with PHIV+. Ten young people, aged 17-23, with PHIV+ were interviewed about their experiences. Data was collected and analysed using Grounded Theory methodology (Charmaz, 2014). The research aimed to answer the following questions:

1) How does HIV disclosure affect sibling relationships in young adults with PHIV+?
2) Which HIV-related factors influence the perceived quality of sibling relationships in young adults with PHIV+?
3) Which aspects of sibling relationships are perceived as supportive and how are these perceived to influence coping and well-being in young adults with PHIV+?

Overview of findings

The findings suggest that systemic, relational and individual psychological factors influence young people's experiences of sibling relationships, when one or both siblings have a diagnosis of PHIV+. Four theoretical codes emerged from the analysis and were mapped onto a model of the sibling relationship in PHIV+. The theoretical model outlines key features of the sibling relationship in relation to HIV and describes the relationship across time, from pre-paediatric disclosure, through adolescence and emerging adulthood, to young adulthood. The four themes identified were:

1. Personal adjustment to PHIV+ diagnosis
2. PHIV+ disclosure in the sibling relationship
3. Patterns of communication about PHIV+ between siblings
4. Patterns of coping and support in the PHIV+ sibling relationship

These theoretical codes will be discussed in the context of the three research questions, with consideration of existing research and psychological theory. The strengths and limitations of the study will be presented, along with personal reflections from the researcher. Finally, directions for future research will be proposed along with the clinical implications of the findings.

How does HIV disclosure affect sibling relationships in young adults with PHIV+?

As illustrated by the model, participants' experiences of disclosure of their HIV status to their sibling(s) were varied. In line with the literature, the most common experience of participants in this study was for their sibling to have found out about their HIV status from their mother or another close family member (Fielden et al., 2011). Young people seemed to feel a lack of power and control over this disclosure from their family member, who either revealed their HIV status unintentionally or did not seek permission to disclose prior to the event. Participants in the current study were unhappy about not having the opportunity to be involved in telling their sibling that they had HIV and about not being informed in advance that they would be told. Unplanned disclosure experiences are common among families affected by HIV (Kennedy et al., 2010) and children often guess their parent or sibling's HIV status through their observations of health-related behaviours, as described in this study (e.g. observing medication-taking).

A sample of PHIV+ adolescent women in Canada reported feeling that the power to disclose their HIV status belonged to their parents (Proulx-Boucher et al., 2011). The circumstances in which two participants directly disclosed to their siblings in this study may provide support for the hypothesis that a reason for non-disclosure to siblings is the young person's perceived responsibility of their parent(s) in disclosure decision-making (Dematteo et al., 2002). One participant disclosed to her half-sister, who did not have the same biological mother as her. Another participant disclosed to his biological siblings after the death of their mother. Power may have been held by parents because disclosing one's PHIV+ status inevitably leads to disclosure of a parent's HIV status (Abramowitz et al., 2009). It is also possible that an 'authoritative' or 'authoritarian' parenting style (with high levels of control), often found in Black African families (Baumrind, 1972), may have contributed to increased parental authority regarding disclosure. A review of the literature on self-disclosure in HIV+ youth affirms the significant role of family in influencing the disclosure decisions of a young person (Thoth, Tucker, Leahy, & Stewart, 2014). Participants who did not directly disclose to their siblings also talked about either not having thought about telling their sibling or waiting for the right time to tell them. This may be consistent with the 'pre-contemplation' and 'contemplation' stages of the model of behaviour change (Prochaska & Diclemente, 1986). There was a sense that these participants did not feel the need to tell their sibling about their HIV status, possibly because they were satisfied with the nature and quality of the sibling relationship as it currently stood and did not want this relationship to change.

It did not seem that having a sibling who was aware of their HIV status was necessary for participants to perceive the sibling relationship as highly valued and close. Previous unpublished research has indicated that PHIV+ appeared to have a bonding effect on the sibling relationship in young people with HIV- siblings who were aware of their brother/sister's HIV status (McLaughlin, 2016). Although some participants with a PHIV+ sibling commented that having the shared experience of HIV made them feel closer, participants also described close relationships with siblings who were not aware of their HIV status.

As indicated in the model, differences in levels and types of support and communication about HIV were observed based on HIV disclosure in the sibling relationship. Participants with a PHIV+ sibling described talking about HIV more with their brother/sister, but seemed to rely on themselves more than participants with HIV-negative siblings. This may have been because they did not want to additionally burden their PHIV+ sibling or parent, who were also managing their own illness (Proulx-Boucher et al., 2017). Participants with HIV- siblings reported disclosure resulting in increased social support from their sibling, particularly at times of ill-health. This is supported in findings of improved family relationships resulting from disclosure of HIV status from mothers to their children (Murphy et al., 2001). The route of disclosure (direct vs. indirect) did not seem to affect siblings' reactions to learning their brother/sister's HIV status and indirect disclosure did not result in rejection, perceived judgement or other negative social consequences as reported in previous research with an adult HIV+ sample (Préau et al., 2015). Participants did not report feeling that they were treated differently by HIV- siblings who became aware of their diagnosis. These findings are consistent with evidence that existing positive qualities in a relationship were associated with positive disclosure outcomes for HIV+ adults disclosing to romantic partners (Smith, Cook, & Rohleder, 2017).

Participants described a period of increased communication about HIV with their siblings soon after their sibling was made aware of their HIV status. This may have been partly due to an increase in communication about HIV in the family at this time, while potentially difficult emotions were being managed (Bhana et al., 2016). Participants noticed that their sibling was upset and experiencing their own period of adjustment, later than other family members. It seemed that siblings tried to protect one another from these upsetting emotions by limiting subsequent discussion about HIV in the family home. It was only when the participant was visibly unwell that they reported communication about HIV increasing again with their sibling, possibly due to necessity. Times of ill-health may be considered a 'centripetal' force within families, bringing them together between alternative 'centrifugal' periods of distance (Combrinck-Graham, 1985).

Participants with siblings unaware of their HIV status referred to ways in which they continued to keep their HIV status secret, including never talking about HIV. Consistent with previous research in PHIV+ young people (Abramowitz et al., 2009), all participants described keeping the secret by restricting onward disclosure and four participants had never directly disclosed their status to anyone. Participants reported additionally asking or expecting their sibling to keep the secret, indicating a level of trust in their relationship. Secrecy around HIV status has been suggested to serve a protective function in HIV+ individuals who anticipate social stigma (Dorrell & Katz, 2013). Fears of disclosure of the family diagnosis may also be held by HIV-negative sibling(s) and may have resulted in a lack of personal support for both siblings (Malee et al., 2011). Five participants had no one in their personal support system outside close family members who knew about their status. This meant that their sibling was potentially the only peer-like figure aware of their HIV status and is consistent with research suggesting approximately 50 percent of PHIV+ adolescents do not disclose to anyone outside their immediate family (Lee & Oberdorfer, 2009).

Some participants reported feeling that there was no need for friends or wider family to know about their status if their siblings and immediate family were aware and supportive. Being able to talk to siblings who were aware of their HIV status about HIV-related issues allowed participants to access emotional support from a peer-like figure, without having to disclose to friends. For some participants, just knowing their sibling was 'there' for them was enough and they did not want or feel the need to talk about HIV with their siblings.

It was unclear how much the experience of sibling disclosure generalised to participants' future disclosure decisions (e.g. to friends or romantic partners). However, it is likely that the positive, beneficial disclosure experiences described by participants may contribute to likelihood of disclosing again in the future (Chaudoir & Fisher, 2010).

Which HIV-related factors influence the perceived quality of sibling relationships in young adults with PHIV+?

The perceived quality of sibling relationships in this sample seemed to be characterised by levels of support and communication between siblings. Participants' personal adjustment to their PHIV+ diagnosis (both immediately following their paediatric disclosure and longer term) seemed to have an impact on both support and communication in the sibling relationship, as indicated by the model. It seemed that if a PHIV+ young person had difficulties with adjustment to their diagnosis, the sibling relationship was described as closer and more supportive. In line with previous research, one of the main difficulties participants faced in adjusting to their diagnosis was learning about and experiencing the stigma associated with HIV (Mak et al., 2007). These experiences can be understood in the context of Earnshaw and Chaudoir’s (2009) HIV Stigma Framework, which describes how participants’ ‘witnessed stigma’ led to ‘internalised’ and ‘anticipated’ stigma from wider social groups. Stigma is understood as a social construct (Goffman, 1963) and ecological systems theory (Bronfenbrenner, 1979) highlights the influence of societal views and cultural beliefs in the system of an individual with HIV. The sources of societal stigma identified by participants (e.g. school, media, internet) are likely to have also been experienced by their siblings. This did not seem to negatively affect the quality of the sibling relationship and instead the consolidation of family ties aided the adjustment process and management of HIV stigma, as suggested in previous research (Proulx-Boucher et al., 2017). The Model of Adjustment to Chronic Illness (Moss-Morris, 2013) also supports that mitigating the impact of illness stressors (such as HIV stigma) on important relationships is necessary for successful adjustment.

Participants’ discussion of stigma within romantic relationships is likely to be reflective of the age group of this sample, who were entering romantic and sexual relationships for the first time. They reported anxieties around disclosing to potential partners, linked to anticipated stigma and fears of rejection. Fair and Albright (2012) in their study of young adults with PHIV+, echo the experiences of this sample who managed relationships by avoiding intimacy or waiting to have a relationship. In a sample of 11-19 year olds in the general population, interdependence and closeness was found to shift from family members to romantic partners across adolescence (Laursen & Williams, 1997). It is possible that participants maintained a close relationship with their sibling or family for longer than if they had entered into a romantic relationship earlier. All participants in the current study valued their sibling relationship(s) very highly, often over friends and romantic partners.

As previously described, the secrecy and limited communication associated with HIV in families is well documented, particularly in literature relating to PHIV+ (Fielden, Chapman, & Cadell, 2011). Secrecy described by participants in this study was indicated as partly a learnt behaviour for siblings. This is supported in research which emphasises the influence of parents who keep their child's HIV status a secret until paediatric disclosure and then remain reticent to raise the issue of HIV within the family (Fielden et al., 2011). Sherman et al., (2000) highlight the risk of an HIV+ child internalising shame about their HIV status due to family secrecy around the condition. PHIV+ young people in this study reported actively not talking to their siblings or family about HIV wherever possible. Whilst participants referred to a relationship between talking frequently to their sibling and feeling close to them, this communication was not HIV-related and reflected levels of mutual support. Silence in PHIV+ families has also been suggested as an attempt to preserve the family equilibrium and assure family harmony (Proulx-Boucher et al., 2011).

The family secret of HIV left participants fearful of asking their parents questions about their condition, at the risk of exposing further family secrets. Some participants wanted to understand where the condition came from in their family to be able to talk to their siblings about HIV more openly. According to the Self-Regulation Model (Leventhal et al., 1980), these individuals may have been unable to build a mental 'illness representation' regarding the causal factors of their condition due to a lack of information about their illness. Without the barriers of stigma and family secrecy associated with HIV, participants would have been able to problem solve to gather information, make sense of and manage the problem. Instead, they were left with unanswered questions around the origin of their illness which limited communication about HIV between siblings. Dorrell and Katz (2013) reported a context of confusion and mistrust in families with PHIV+ due to lack of communication about HIV.

Three participants had experienced parental loss to HIV/AIDS in this sample and one of these participants had also lost multiple siblings to the condition. The cause of death was not openly discussed in the families of these participants, with two participants never having had their relative's cause of death confirmed. This could be related to social stigma and shame (Siegel & Gorey, 1994) or this information may have been intentionally kept from the young person to protect them from anxiety relating to their own mortality. The shared experience of loss between siblings highlighted the impact of HIV on the exosystem of a young person (Bronfenbrenner, 1986), with parental death increasing older siblings' caregiving responsibilities. It seemed that siblings 'pulled together' to help and support each other during this time, in an example of a 'centripetal' period of closeness (Combrinck-Graham, 1985).

As previously reported in a sample of HIV+ Ugandan youth (Kajubi et al., 2014), communication about HIV between siblings at home was limited to practicalities such as hospital appointments and medication in this sample. This seemed to allow siblings to demonstrate that they were holding their brother/sister in mind and check in with them regarding their health. It may also have been intended to prevent either party feeling uncomfortable or upset by engaging in deeper discussion about HIV, as found in previous research (Proulx-Boucher et al., 2011). Although limited, this communication between siblings also acted as practical support in prompting medication adherence and encouraging attendance at clinic appointments. There were however, other aspects of living with HIV that were not discussed with siblings, such as sex, feelings and telling other people about their HIV status. The topic of HIV has repeatedly been found to be taboo in families affected by the condition (Rydstrom et al., 2013), which is likely to further reduce the frequency of discussion between siblings of what are already sensitive issues.

Participants reported avoiding difficult emotions by not naming HIV in conversation with their sibling or using a different word for it. Having a different word for HIV that was shared with their sibling also became a positive association that encouraged humour and ‘in-group’ status between siblings. Making jokes about HIV with their sibling seemed to bring siblings together and made it easier to talk about. Being humorous has been found to be significantly associated with better psychological adjustment in a sample of PHIV+ UK adolescents (Sopeña et al., 2010). This could also have been a strategy of young people with PHIV+ to feel more in control of their condition.

Participants described hopes about their future relationship(s) with their sibling(s), including a desire to increase the level of communication with their sibling, both about HIV and their personal lives in general. This may have indicated conflicting emotions about what they believe their sibling relationship should resemble versus the current nature of this relationship. Cognitive Dissonance Theory (Festinger, 1962), suggests that an individual may hold conflicting attitudes about something of value which cause feelings of discomfort. According to this theory, participants may have been attempting to reduce their discomfort by voicing an intention or hope to change this area of their lives in future.

Which aspects of sibling relationships are perceived as supportive and how are these perceived to influence coping and well-being in young adults with PHIV+?

All participants referred to the ways in which their sibling relationship helped them to ‘feel normal’ and referenced maintaining this sense of normality as a coping strategy in managing their diagnosis. Participants described maintaining a ‘normal’ relationship with their sibling(s) by doing ‘normal’ things with them (such as cooking together and watching television). This may have acted as a distraction from thinking about HIV, a coping strategy that has been found in research with PHIV+ children and their siblings (Mellins & Ehrhardt, 1994). Feeling normal compared with others also reduces the impact of stigma in young people with PHIV+ (Proulx-Boucher et al., 2011). It follows that feeling normal in their sibling relationship supported the belief of participants that HIV had not changed them as a person. The Self-Regulation Model (Leventhal et al., 1984) suggests that individuals with a chronic illness create ‘illness representations’ surrounding the impact of the disease on their identity. Participants who reported coping well with HIV, did not see themselves as being different to others (including their sibling) and believed HIV was not a central a part of their identity. Participants who were not coping as well with HIV identified recent events which may have highlighted the ways in which HIV made them different from their peers and HIV- sibling(s) (e.g. a difficult disclosure in a romantic relationship, deterioration in their health and hospitalisation).

All participants described reciprocal levels of support in the sibling relationship, which contributed to levels of coping and well-being in the sample. Young people with PHIV+ talked about giving and receiving practical (non-HIV related) support with their sibling which included household chores, childcare and running errands. This is consistent with previous research that family members were a major source of instrumental support for PHIV+ youth (Abramowitz et al., 2009). It was observed that practical support between siblings was more common when they were both younger or was often offered from a younger sibling to an older sibling. This finding contrasts with literature suggesting that older siblings are more likely to offer practical support (Voorpostel et al., 2007). However, it may be explained by emotional support becoming increasingly offered as siblings get older and their need for practical support decreases. Participants reported that with age, levels of warmth also tended to increase in their sibling relationship and levels of conflict decreased. Young adults in the general population describe more warmth and increased exchanges of emotional support with siblings than as adolescents (Scharf et al., 2005). Sibling interactions become increasingly voluntary as they progress into young adulthood and the relationship begins to resemble a peer relationship (Stewart et al., 2001). Increased levels of warmth and emotional support in the sibling relationship as young adults may have contributed to participants' perceived ability to cope better with their HIV diagnosis now than when they were younger. Participants' responses on the measure of subjective well-being (HADS, Zigmond & Snaith, 1983) indicated similar levels of depression and anxiety to the general population, as previously found in a UK sample of PHIV+ young people (Le Provost et al., 2017). Higher levels of warmth reported by participants on the ASRQ-S (Lanthier et al., 2000) seemed to correlate with descriptions of closer and more supportive sibling relationships in young people with PHIV+.

Emotional (non-HIV related) support largely seemed to be offered or received from older to younger siblings in this sample. This hierarchical nature of sibling relationships has been found in birth order research in the general population, with older siblings taking the role of model and advisor to younger siblings (Tucker et al., 2001). Participants also referred to sharing a knowledge of family dynamics and processes with their sibling, which may have been influenced by the presence of HIV. Siblings are also likely to live together in the family home as adolescents and all the participants in this study still lived at home. The continued presence of siblings in the microsystem of a PHIV+ young person (Bronfenbrenner, 1979) may have meant that they were easily accessible for support and that siblings may be more attuned to the needs of PHIV+ young people, especially if they are unwell. Abramowitz and colleagues (2009) found that young people with HIV rated satisfaction with social support from their family higher than that of their friends. Participants in this study described knowing that their sibling would be there to support them, even when their friends were not.

Despite differences reported in the general population (Kim et al., 2006), there was no clear effect observed of gender on either levels or types of support between siblings in this study. This may have been partly due to the small sample size and having fewer male than female participants. Sibling gender combinations seemed equally likely to seek support from either each other, friends or family. There was also no indication that female sibling relationships were closer than males. All participants referred to mutual support and warmth in the relationship, as well as feeling irritated or annoyed with each other at times, in line with descriptions of sibling relationships in the general population (Scharf et al., 2005).

All participants described seeking different types of support from different people. Half the participants reported that they were more likely to receive non-HIV related emotional support from their friends over their sibling. Abramowitz et al., (2009) found that young people living with HIV received more emotional than instrumental support from friends. However, participants were more likely to receive

HIV-related support from their sibling or a parent than friends. It is likely that this was at least in part due to limited levels of HIV disclosure to friends, which has been found to be lower in PHIV+ young people than their behaviourally infected peers (Abramowitz et al., 2009). Participants who grew up with an older sibling with PHIV+ reported learning about HIV and medication regimes by asking their sibling questions and receiving guidance and encouragement. This increased their ability to cope with HIV-related stressors such as stigma and medication adherence by normalising the experience and having a peer-like figure to turn to for support.

Although not a direct aim of this study, the perceived coping of HIV-negative siblings was also referred to by participants, who had either not considered the impact of HIV on their sibling(s) or believed that HIV does not affect their sibling. Despite this, participants were aware of their sibling worrying about their physical and mental health, particularly when they are unwell due to HIV-related illness. The lack of communication about HIV in families may have contributed to the observation of some participants that their sibling tended to seek support outside of the family at times of need, from either friends or a romantic partner. It is possible that healthy siblings may not have wanted to additionally burden their sibling, for fear of upsetting them or bringing up difficult emotions (Waite-Jones & Madill, 2008). However, this left PHIV+ young people feeling like their sibling did not want to confide in them and impacted negatively on their perception of the sibling relationship.

Only one participant considered how her HIV-related illness directly impacted on the amount of time her mother spent away from her two younger sisters. Parental differential treatment of siblings is commonly discussed in literature relating to childhood chronic illness (Sein, 2001). It can leave siblings feeling resentful at the amount of time and care required by an ill sibling (Sharpe & Rossiter, 2002), but in the experience of this participant seemed to enhance sibling closeness, with her healthy siblings prioritising her needs.

Strengths and limitations

Strengths

A key strength of this study is the novel contribution it makes to literature on sibling relationships in young people with PHIV+. The research questions had not been asked before and the potential clinical implications of the findings increase the value of the study. The sample of PHIV+ young people in the UK also offers a perspective rarely included in research that largely represents the experiences of HIV+ adults living in sub-Saharan Africa and the US. Although a recent unpublished study interviewed sibling pairs where one young person had PHIV+ (McLaughlin, 2016), the current study investigated the experiences of the sibling relationship from the point of view of the PHIV+ individual in more detail. Specific research questions relating to aspects of the sibling relationship allowed this project to build on and extend the findings of existing research.

An additional strength of this study is that participants could talk about relationships with siblings that do not know about their HIV status. Participants also talked about siblings who were both HIV+ and HIV-, which allowed any themes specific to these potential relationship differences to be investigated. The variety of sibling relationships discussed also increased the degree to which the sample might represent the wider UK PHIV+ population and therefore the generalisability of the findings. Variation in the types of sibling relationships discussed may have provided a less homogenous sample, however the spread of themes resulting from the data across participants indicated that this was unlikely to be the case. The inclusion of criteria that a sibling must share the same biological mother and have lived with them for a minimum of five years (in their lifetime) was also introduced to minimise the heterogeneity in the sample. A balance was sought between the inclusion criteria and variation in the sample, consistent with theoretical sampling.

Participants were encouraged to talk about multiple siblings and to reflect on similarities and differences between these relationships. This strengthened the validity of the analysis as a wider picture of sibling relationships was gathered, alongside a detailed description of the relationship with an ‘identified sibling’. It is also possible that participants may have been more likely to choose to talk about a sibling with whom they had a stronger relationship, but that by enquiring about all sibling relationships, a more accurate and representative picture of sibling relationships was gathered. The use of a descriptive questionnaire measure (ASRQ-S; Lanthier et al., 2000) provided a snapshot of levels of warmth and conflict in the sibling relationship with an ‘identified sibling’, which corresponded to their qualitative description of interactions with this sibling. The ASRQ-S may also have provided a reflective tool pre-interview and seemed to socialise participants to talking about their sibling relationships in terms of levels of support, intimacy and conflict. The questionnaire measures also characterised the sample and aided comparison with other samples and populations, highlighting variations between participants. However, two participants did not complete the whole questionnaire due to double-sided printing, resulting in missing data and a lack of contextual information about the sibling relationship for these participants.

An additional consideration is whether the sample is truly representative of the wider population of PHIV+ young people in the UK. Although the sample was recruited from two inner London clinics (and not across the UK as would be desirable), data from CHIPS (2016) suggests that it was largely representative of the population in the UK and Ireland. Additionally, the inclusion of a participant with expressive aphasia supports the likely representativeness of the sample, given the incidence of neurocognitive deficits in PHIV+ young people (Vreeman et al., 2015). Conversely, the inclusion of this participant may have compromised the quality of the qualitative data gathered, which relied on the participant's recall and verbal expression of their experiences and emotional states. Finally, the descriptive data of adherence to ART in the sample also supports generalisability, with good adherence in 50% of participants. Adherence rates were found to be between 50-60% in HIV+ European adolescents and young adults generally (Kim et al., 2014). The recruitment response rate of around 70% (10/14 potential participants) indicates that the findings are likely to be transferable to other settings.

The use of analytical and theory triangulation (Patton, 1999) allowed additional validation of the theoretical codes and reduced systemic bias in the data. Theory triangulation encouraged the use of different theoretical perspectives to interpret the data. In this case, systemic, developmental, ecological and health psychology theories have been drawn on to represent the data and findings. Analytical triangulation involved having a specialist clinician review the findings to comment on the accuracy, fairness and validity of the data analysis. Service users also commented on the interview guide prior to data collection, providing valuable feedback on the terminology and sensitivity of questioning. Additional credibility checks included the use of internal and external supervision, along with peer review and feedback from fellow trainees using Grounded Theory. Internal and peer supervision ensured that important codes were not missed, that themes were mutually exclusive and that higher order themes included lower order themes. Together, these processes ensured coherence and clarity of the results as well as increasing the quality of the research findings. External supervision utilised the specialist knowledge and clinical experiences of the supervisor validating the theoretical model and key findings post-analysis.

Limitations

A literature review was required prior to data collection for the purposes of ethical approval and to prove a novel contribution to existing research. Grounded Theory methodology historically advocates delaying the literature review until after the analysis to avoid imposing preconceived ideas on your work, known as 'received theory' (Glaser & Strauss, 1967). More recent grounded theorists recognise that a complete lack of awareness of relevant literature is implausible (Henwood & Pidgeon, 2003; Thornberg, 2012) and suggest an alternative, constructivist position which requires a critically reflective view of previous research (Charmaz, 2014). The use of memos (Appendix 16) and a reflective diary (Appendix 17), sought to reduce researcher bias by remaining critically aware of existing knowledge and assumptions and their potential impact on the research questions and analysis. Prioritising the language of participants in codes and categories and constant comparison within and between data also ensured the emerging theory was grounded in the data (Charmaz, 2014).

During recruitment, clinical staff were relied upon to approach all individuals that fitted the inclusion criteria for the study. It is possible however, that staff selection of participants and self-selection of participants who agreed to take part in the research may have introduced a level of selection bias. Only participants who attended their clinic appointments were approached to take part in the research, which may have led to sampling of a group who were functioning at a higher level or had better levels of support and adjustment in comparison to PHIV+ young people who did not attend. Descriptive data from the HADS indicated that only one participant scored above caseness for symptoms of anxiety and no participants scored above caseness for symptoms of depression. Participants who were approached to take part but refused (citing ‘time constraints’) might have chosen not to talk about their sibling relationship and the potential impact of HIV on this relationship, due to particular difficulties in this area. Staff are also likely to have avoided asking individuals with PHIV+ to take part who they knew had particularly difficult family lives or problems adjusting to their diagnosis. This may have led to a sample of individuals who, although seemed to speak openly in the interview about issues relating to HIV and their sibling relationship, might have valued this relationship more than those young people who did not participate. Alternatively, young people who were struggling in their sibling relationship or emotionally adjusting to their diagnosis might have been more eager to participate to have a forum to discuss these difficulties.

In line with Grounded Theory methodology, theoretical sampling should have been conducted as the study progressed to sample participants that would develop the properties of emerging theoretical categories (Charmaz, 2014). This was attempted in the second half of recruitment as the researcher considered the role of gender in sibling relationships, however, overall only two male sibling pairs were recruited in this sample (compared to six female sibling pairs and two mixed gender sibling pairs). Sampling additional male and mixed gender siblings may have provided further insight into levels of communication and support in these relationships, which research suggests may differ from female-only siblings (Kim et al., 2006).

Given the spread of focused codes across participants, it appears that most codes reached theoretical saturation in this sample. As the latter participants were interviewed, there were very few new codes arising, which supports this assertion. The exception to this was the interview with participant nine, whose experience of HIV diagnosis and sibling disclosure was quite different to the rest of the participants. This highlighted the possibility that because of a limited sample size, theoretical saturation may not have been reached regarding experiences of PHIV+ disclosure in the sibling relationship.

Despite the efforts of the researcher, a lack of participant feedback on the codes and theoretical model meant that the results were not validated by young people with PHIV+. Three participants agreed to be contacted after their interview to give feedback on the initial analysis. Two were contacted via email and one via telephone, however there was no response from any participants. This may have been because the participants did not have any comments about the analysis (due to it accurately reflecting their experiences), or they may not have felt comfortable giving feedback that challenged the work of the researcher.

On reflection, there seemed to be a lack of interview questions enquiring specifically about cultural factors affecting beliefs about HIV or sibling relationships. It is surprising that cultural factors were not referred to more explicitly by participants. Despite this, it is important to note that all participants are part of an ethnic minority in the UK and that this cultural context may be important with regards to interpreting the findings. A possible explanation for the lack of explicit cultural references in the data is the role of researcher bias. As a white, middle class female from Western culture, the researcher may have taken an individualistic view and interpretation of participants’ accounts, overlooking any alternative cultural influences in the process.

However, participants and their siblings have largely grown up together in the West. It is therefore possible that their/ their parent's culture of origin does not have as much of an influence as it may have done in previous cohorts of PHIV+ young people who grew up in sub-Saharan Africa. Participants were observed to discuss the impact of Western cultural beliefs (e.g. stigmatising beliefs), which were explored in the analysis.

Researcher reflections

As a qualitative researcher, it is important to consider the role of my own social and cultural background throughout the research process. As a white, female professional who is HIV-negative, I reflected regularly on the lens through which I viewed the experiences of PHIV+ young people. I was aware of both the similarities and differences between myself and participants in age, gender, ethnicity, family life, relationships and experiences of chronic illness and loss.

I was also aware of my dual role as both researcher and clinician. I found it effortful to remain conscious throughout the interviews that although I needed to remain sensitive to the emotional well-being of participants, my role was not as a therapist. It is possible that participants may have perceived me to be aligned with medical professionals or psychologists in the service, as they were recruited by these professionals and the interview took place in a clinical setting. Due to the power assigned to medical professionals, this is also likely to have influenced the type and amount of information that participants may have felt comfortable sharing with me. The use of supervision encouraged additional reflection on these issues.

When interviewing participants, I was also acutely aware of the need to remain focused on the discussion of issues surrounding the impact of HIV on participants' sibling relationships. It was clear early on that there was a wealth of HIV-related experience and knowledge willing to be shared by these young people. One participant commented that it was the first time she had talked to anyone in detail about her experience of paediatric disclosure. It felt important to allow adequate time for this for her to feel heard, whilst also remembering that it was not the focus of the interview but a part of the narrative.

Throughout the course of the research, I was also encouraged to reflect on my own sibling relationship and level of family communication. I value my sibling relationship very highly and feel comfortable sharing personal details about my life with my brother, but the research made me wonder how he viewed our relationship and what goes unsaid between us or what he feels he cannot share with me.

Finally, I was aware of a sense of sadness for participants at having a part of their lives they feel they can tell few (if any) people about. I underappreciated the ongoing perpetuation of perceived stigma towards HIV through schools and media in the UK and admired the resilience and strength of participants in managing this. I also felt sadness for the HIV-negative siblings of participants who were often excluded from the family secret and considered the potential impact of this on their emotional well-being and relationships within the family. I was surprised at the level of 'not knowing' expressed by participants, additionally highlighting the restrictions on open communication in HIV-affected families.

Suggestions for future research

Interviewing a larger sample of PHIV+ young people about their experiences of sibling relationships would allow the findings of this study to be validated further and the theoretical model tested. An emphasis on experiences of PHIV+ disclosure in the sibling relationship would provide additional evidence for the theoretical code entitled “PHIV+ disclosure in the sibling relationship”. The disclosure experiences of participants seemed to vary more than other key themes, both between and within families, so it seems necessary to explore this further in a bigger sample. Interviewing a sample of PHIV+ young people about their siblings is the only way in which relationships with siblings who are unaware of their brother/sister’s HIV status can be explored. It is therefore valuable to extend this aspect of the current study to compare sibling relationships between those who are aware and unaware of their sibling’s HIV status. The Children’s HIV Association (CHIVA) state that “more UK studies are needed to determine how and when to support onward disclosure to personal networks as well as to wider systems” (CHIVA, 2014, p. 30). The findings of this study confirm previous research that siblings can be an integral part of a young person’s personal network (Milevsky & Levitt, 2005; Sharer et al., 2016) and that disclosure to siblings is an area requiring urgent consideration and investigation.

Although McLaughlin (2016) interviewed both PHIV+ young people and their HIV-negative sibling about their experiences of HIV, this was a sample size of only five matched pairs and the focus of questioning for the young person with PHIV+ was not on the sibling relationship. It would therefore be valuable to extend the scope of the current study by interviewing a larger sample of one or more siblings of young people with PHIV+ to gain an alternative viewpoint of the sibling relationship and an insight into aspects of coping with having a PHIV+ brother/sister. It would also be interesting to include both PHIV+ and HIV- siblings of participants in this investigation to allow comparison, particularly around themes of HIV communication and support between siblings.

An additional area for future research would be to distinguish between different types of sibling relationships in young people with PHIV+, for instance biological siblings, step-siblings and half-siblings. The current study encouraged participants to talk about all their sibling relationships, but did not have a large enough sample size to make comparisons between these types of relationships. Participants were also required to have the same biological mother as their sibling to take part in the study. However, some siblings were HIV-negative and unaware of their mother's HIV status (as well as their sibling's HIV status), so the potential impact of knowingly living with an HIV+ mother would not have been captured, even with the criteria in place. Removing this criteria would allow additional exploration of the impact on the sibling relationship of sharing an HIV+ mother, as the findings indicate that there may be more open communication and increased direct disclosure to sibling(s) if this is not the case.

Finally, a question that remains unanswered is whether disclosure to siblings facilitates onward disclosure to friends or romantic partners. It was unclear from this study how much the experience of sibling disclosure (e.g. decision-making, route of disclosure, reaction of sibling, subsequent support, impact on relationship) influenced future disclosure decisions. It would be valuable to explore this further, both qualitatively and quantitatively, in a sample of PHIV+ young people.

Clinical implications

It is hoped that the theoretical model of sibling relationships in PHIV+ produced by this study might be used to inform future therapeutic interventions with this population. Current guidelines for psychological support for adults and children living with HIV in the UK are discussed with relevant suggestions based on the findings of this study.

Onward disclosure

The CHIVA Standards of Care for Infants, Children and Young People with HIV (2013) includes “disclosure of HIV diagnosis to both the infected child and affected children within the family” (p. 29) as a key issue for children with HIV and their families. The findings of this study suggest that PHIV+ young people are not often involved in sibling disclosure decisions. Guidance or support for parents about how to involve the PHIV+ young person and facilitate discussion between the pair prior to sharing the HIV diagnosis with family members would therefore be highly beneficial.

The current study demonstrates the difficulties experienced by young people with PHIV+ in disclosure decision-making, planning and execution, not only to siblings but also romantic partners and close friends. To date, there are no onward disclosure interventions for young people with PHIV+, despite self-reported difficulties (Evangeli & Foster, 2014; Evangeli & Wroe, 2017). Young people with HIV have expressed their need for support in developing the skills to disclose their HIV status (Thoth et al., 2014) and health workers have requested guidance and support regarding HIV disclosure support (Bott & Obermeyer, 2013). The CHIVA Psychological Standards of Care (2014) offer minimal guidance on supporting onward disclosure in both young people with HIV and their HIV- siblings. There remains a critical need for a tailored onward HIV disclosure intervention for those PHIV+ young people (and their siblings) who indicate the need for it (Evangeli & Foster, 2014).

Interestingly, whilst there are regular, limited references to supporting onward disclosure to siblings in CHIVA (2014) guidance, there is no mention in the British HIV Association (BHIVA, 2011) guidance for adult populations. This disclosure guidance for adults only refers to sexual partners in the prevention of onward transmission. It was evident from this research that support for young adults regarding decision-making around disclosure to siblings who remain unaware of their HIV status would be beneficial and is not currently offered. A normative message from clinicians that disclosing to siblings has been found to positively impact or produce little change in the sibling relationship in young people with PHIV+ (as indicated in this study), may also aid this process.

CHIVA (2014) also acknowledge that siblings of children with PHIV+ may be unaware of their parent/ sibling's diagnosis but will still be exposed to HIV-related influences in the family home, such as secrecy, ill-health and loss. Both these siblings and those who are made aware of their brother/sister's HIV status are often left without direct access to services who consider their emotional and psychological needs post-disclosure.

Information and signposting

BHIVA 'Standards for psychological support for adults living with HIV' (2011) suggest a stepped care model for psychological support for people living with HIV (PLWH) in the UK and Ireland. At step one, it recommends that PLWH should be provided with "information, signposting and supportive communication" (p. 4) such as leaflets and websites, as well as access to peer support. Participants in this study reported receiving such information from health professionals at the time of paediatric disclosure, however, it was not clear how much information or signposting is provided to HIV-negative siblings, at any stage of the disclosure process. Peer support groups for siblings of PLWH are currently only available in London in the UK (at Body and Soul Charity). All siblings of children and young people with PHIV+ would benefit from the opportunity to receive peer support, as a space to talk about the impact of HIV on themselves and their family.

Supporting PHIV+ young people to share information about HIV with their siblings post-disclosure may help to encourage communication about the condition in the family home. Providing HIV-affected siblings with reliable information about HIV is also likely to reduce levels of anxiety and uncertainty about the condition. It may also reduce reliance on the internet for information, which may be incorrect or stigmatising. CHIVA has specifically developed its website for young people and parents/ carers by promoting youth and family-friendly information and peer support. Wider dissemination of information about HIV such as this by health professionals may also go some way to reducing the experiences of stigma for PLWH. Contributing to school curriculums or delivering teaching about HIV in secondary schools, for example, may help to challenge the experiences of stigma reported by the participants of this study during adolescence.

Psychological support

At levels two to four of the BHIVA stepped care model, practitioners should screen for psychological distress at key points in the life of PLWH, for example when experiencing family problems including those arising from another family member’s HIV status. The inclusion of family issues as a potential stressor for PLWH is an important consideration when offering psychological support to this population, given the evidence that HIV affects the whole family (DeMatteo et al., 2002). This is also highlighted in the inclusion of ‘family therapists’ as professionals that may be involved in providing psychological support for PLWH. The provision of family therapy is supported by the findings of this study to reduce secrecy and silence surrounding HIV in the family system and facilitate open communication within families. However, family therapy is not currently routinely offered in specialist HIV clinics and would only be indicated if family problems were raised by the PLWH.

BHIVA (2011) guidelines also recognise that “support for PLWH may involve support for other family members who may also have HIV and/or for carers, who in turn can play a valuable psychological support role.” (p. 12). The findings of this study highlight the value placed by PHIV+ young people on their sibling relationships and the reciprocal levels of practical and emotional support between siblings. Psychological interventions with this population would benefit from recognising this unique resource and professionals should routinely enquire about support provided by siblings. In doing this, they reinforce existing familial relationships and strengthen naturally occurring support mechanisms within families (Sharer et al., 2016). Bringing siblings into the therapy room would also increase their perceived involvement in matters relating to the family system and ensure the well-being of the sibling is considered in the system.

CHIVA (2014) recommend involving siblings and family members in actively supporting a child or young person with medicine taking to “integrate adherence support into daily life.” (p. 35). This reflects the findings of the current study, in which participants reported receiving HIV-related practical support from their siblings, particularly at times of ill-health. Moreover, CHIVA (2014) highlight that the needs of children affected by HIV should be held in mind alongside those of their HIV+ sibling(s) and parent(s). The emotional consequences for a child of talking (or not) about HIV and of difficulties in the family system relating to HIV communication may require specific psychological interventions for the child and family, which should be advocated for by health professionals in the system. BHIVA (2011) cite a requirement for evidence-based psychological assessment and interventions which have been “developed, standardised and evaluated for use with HIV and/or other life-threatening long-term medical conditions.” (p. 62). Despite the growing evidence base for family-based interventions in HIV support, there seems to be no specific reference to manualised family interventions such as VUKA (Bhana et al., 2014) or CHAMP+ (McKay et al., 2007). Although these interventions are in the relatively early stages of development, trials in UK populations should be considered to adapt the intervention to cultural and societal differences and investigate their efficacy in UK populations.

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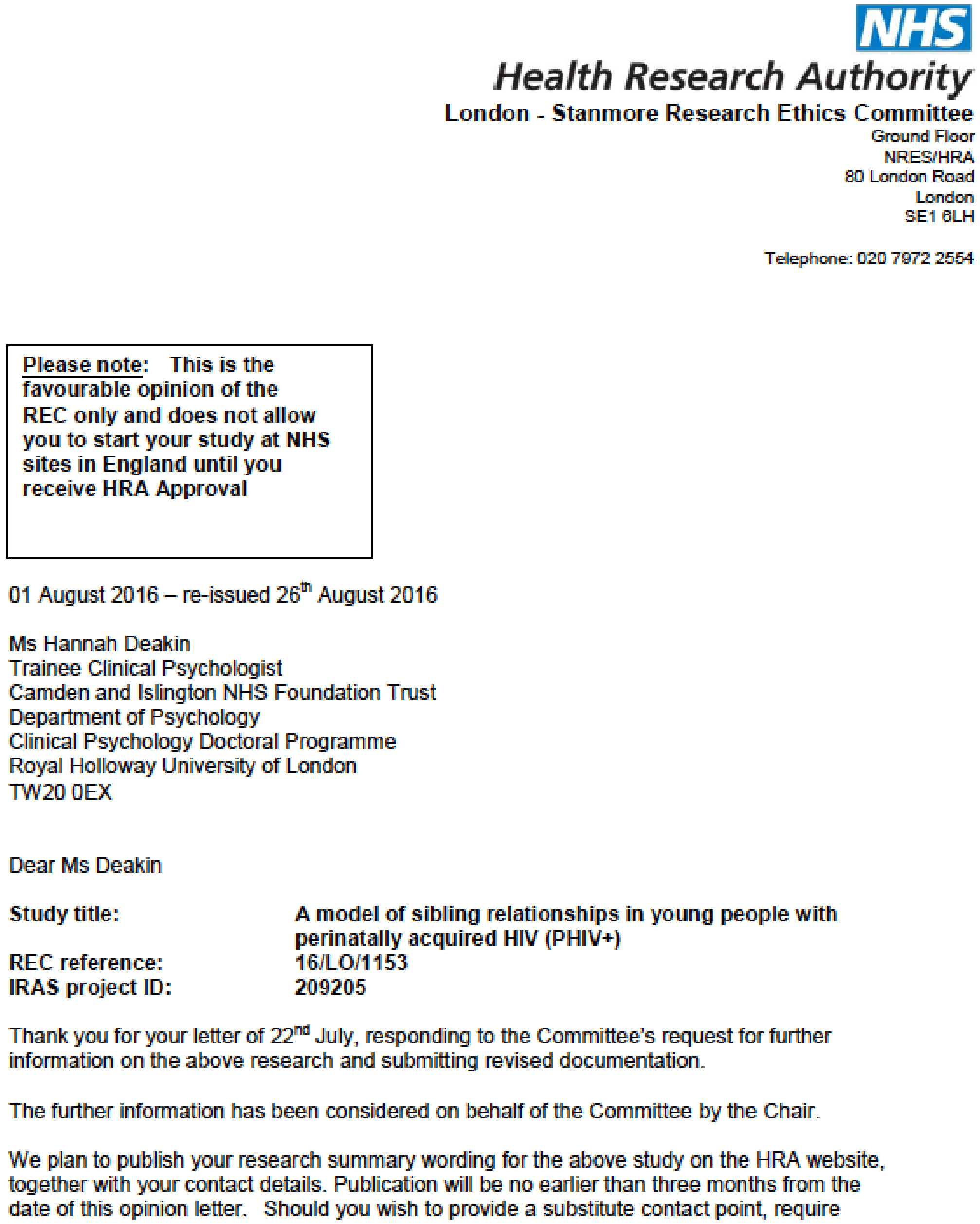
APPENDICES

Appendix 1: NHS ethics approval



NHS
Health Research Authority
London - Stanmore Research Ethics Committee
Ground Floor
NRES/HRA
80 London Road
London
SE1 6LH

Telephone: 020 7972 2554

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 August 2016 – re-issued 26th August 2016

Ms Hannah Deakin
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Department of Psychology
Clinical Psychology Doctoral Programme
Royal Holloway University of London
TW20 0EX

Dear Ms Deakin

Study title:	**A model of sibling relationships in young people with perinatally acquired HIV (PHIV+)**
REC reference:	**16/LO/1153**
IRAS project ID:	**209205**

Thank you for your letter of 22nd July, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Ms Julie Kidd, nrescommittee.london-stanmore@nhs.net .

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make 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.

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk 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 management permissions 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 within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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 contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

Non-NHS sites

Approved documents

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

Document	*Version*	*Date*
Covering letter on headed paper [Letter of Study Changes]	1	29 May 2016
Covering letter on headed paper [Letter of Study Changes]	1	22 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RHUL Indemnity Letter]	1	03 August 2015
Interview schedules or topic guides for participants [Draft Interview Guide]	2	23 May 2016
IRAS Application Form [IRAS_Form_06062016]		06 June 2016
IRAS Checklist XML [Checklist_22072016]		22 July 2016
Other [REC Unfavourable Opinion Letter]	1	24 May 2016
Other [RHUL Research Sub Committee Approval]	1	12 February 2016
Other [RHUL Research Sub Committee Feedback and Responses]	1	15 January 2016
Other [RHUL Original Project Proposal]	1	01 December 2015
Other [RHUL RSC Table of Study Changes]	1	23 May 2016
Other [RHUL RSC Revised Study Approval Email]	1	31 May 2016
Participant Health Information Sheet	1	24 April 216
Other [Participant Demographic Information]	3	22 July 2016
Other [Clinician Telephone Information Sheet]	1	22 July 2016
Participant consent form [Participant Consent Form]	4	22 July 2016
Participant information sheet (PIS) [Participant Information Sheet]	4	22 July 2016

Research protocol or project proposal [Research Protocol]	4	23 May 2016
Summary CV for Chief Investigator (CI) [Hannah Deakin CV]	1	20 January 2016
Summary CV for supervisor (student research) [Academic Supervisor CV]	2	13 January 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Recruitment Flowchart]	2	24 May 2016
Validated questionnaire [ASRQ-S Revised]	1	14 March 2016
Validated questionnaire [HADS Questionnaire]	1	14 March 2016

Statement of compliance

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

After ethical review

Reporting requirements

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

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

The 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

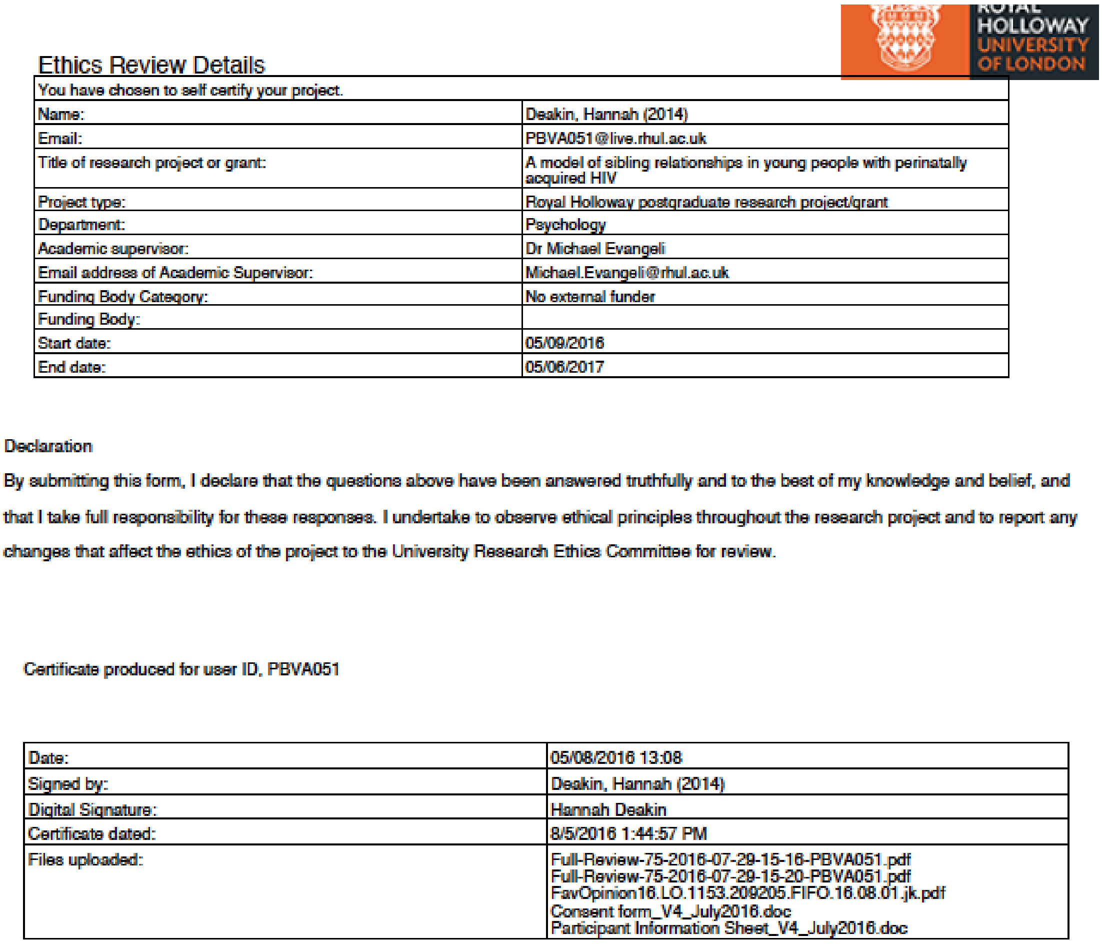
We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

16/LO/1153	**Please quote this number on all correspondence**

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

Yours sincerely

Appendix 2: Royal Holloway University ethics approval



Ethics Review Details

You have chosen to self certify your project.	
Name:	Deakin, Hannah (2014)
Email:	PBVA051@live.rhul.ac.uk
Title of research project or grant:	A model of sibling relationships in young people with perinatally acquired HIV
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Dr Michael Evangeli
Email address of Academic Supervisor:	Michael.Evangeli@rhul.ac.uk
Funding Body Category:	No external funder
Funding Body:	
Start date:	05/09/2016
End date:	05/06/2017

Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, PBVA051

Date:	05/08/2016 13:08
Signed by:	Deakin, Hannah (2014)
Digital Signature:	Hannah Deakin
Certificate dated:	8/5/2016 1:44:57 PM
Files uploaded:	Full-Review-75-2016-07-29-15-16-PBVA051.pdf Full-Review-75-2016-07-29-15-20-PBVA051.pdf FavOpinion16.LO.1153.209205.FIFO.16.08.01.jk.pdf Consent form_V4_July2016.doc Participant Information Sheet_V4_July2016.doc

Appendix 3: HRA Approval

NHS
Health Research Authority

Ms Hannah Deakin
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Department of Psychology
Clinical Psychology Doctoral Programme
Royal Holloway University of London
TW20 0EX

Email: hra.approval@nhs.net

23 August 2016

Dear Ms Deakin

Letter of HRA Approval

Study title:	**A model of sibling relationships in young people with perinatally acquired HIV (PHIV+)**
IRAS project ID:	**209205**
REC reference:	**16/LO/1153**
Sponsor	**Doctorate in Clinical Psychology, Royal Holloway University of London**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

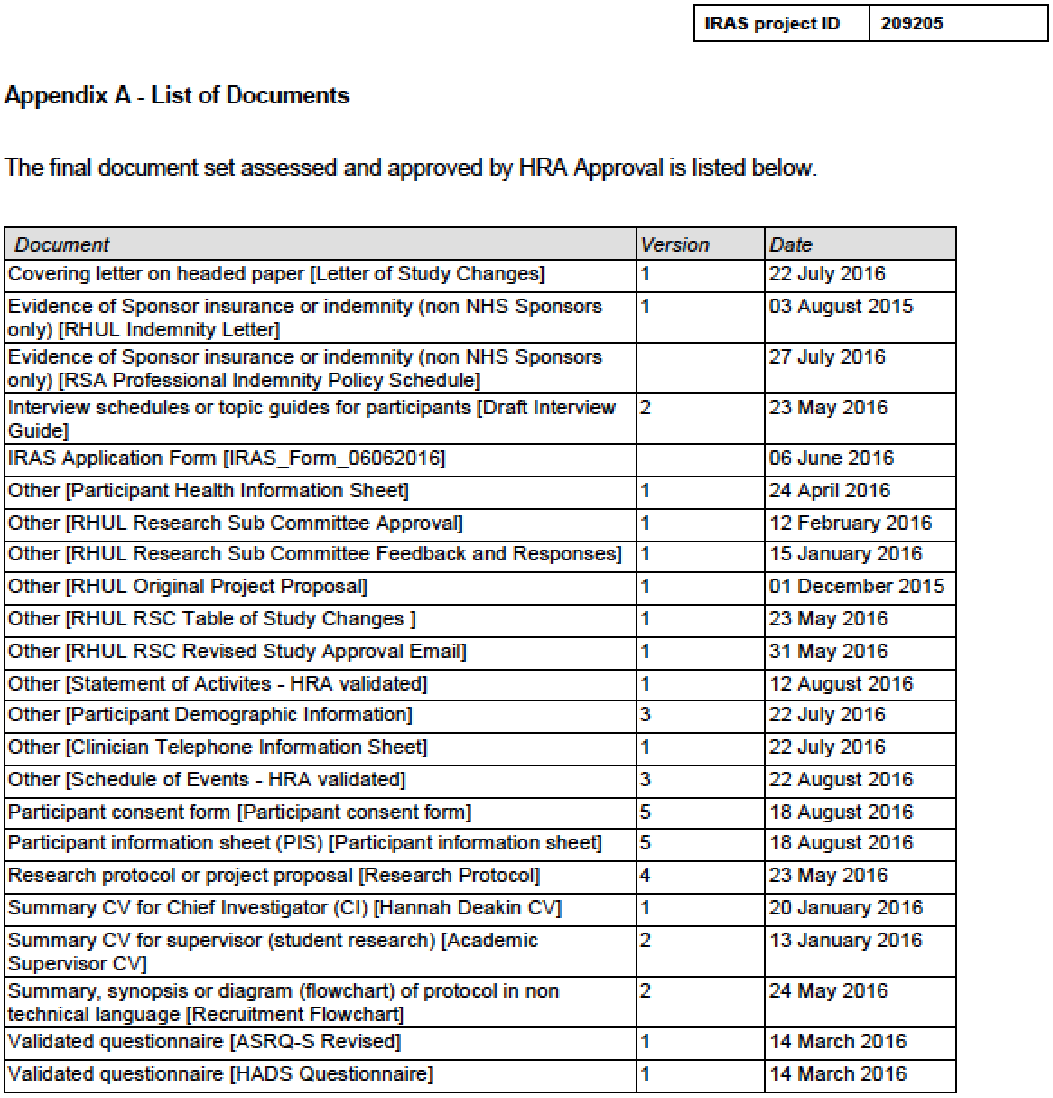
Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.



IRAS project ID	**209205**

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Covering letter on headed paper [Letter of Study Changes]	1	22 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RHUL Indemnity Letter]	1	03 August 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RSA Professional Indemnity Policy Schedule]		27 July 2016
Interview schedules or topic guides for participants [Draft Interview Guide]	2	23 May 2016
IRAS Application Form [IRAS_Form_06062016]		06 June 2016
Other [Participant Health Information Sheet]	1	24 April 2016
Other [RHUL Research Sub Committee Approval]	1	12 February 2016
Other [RHUL Research Sub Committee Feedback and Responses]	1	15 January 2016
Other [RHUL Original Project Proposal]	1	01 December 2015
Other [RHUL RSC Table of Study Changes]	1	23 May 2016
Other [RHUL RSC Revised Study Approval Email]	1	31 May 2016
Other [Statement of Activites - HRA validated]	1	12 August 2016
Other [Participant Demographic Information]	3	22 July 2016
Other [Clinician Telephone Information Sheet]	1	22 July 2016
Other [Schedule of Events - HRA validated]	3	22 August 2016
Participant consent form [Participant consent form]	5	18 August 2016
Participant information sheet (PIS) [Participant information sheet]	5	18 August 2016
Research protocol or project proposal [Research Protocol]	4	23 May 2016
Summary CV for Chief Investigator (CI) [Hannah Deakin CV]	1	20 January 2016
Summary CV for supervisor (student research) [Academic Supervisor CV]	2	13 January 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Recruitment Flowchart]	2	24 May 2016
Validated questionnaire [ASRQ-S Revised]	1	14 March 2016
Validated questionnaire [HADS Questionnaire]	1	14 March 2016

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

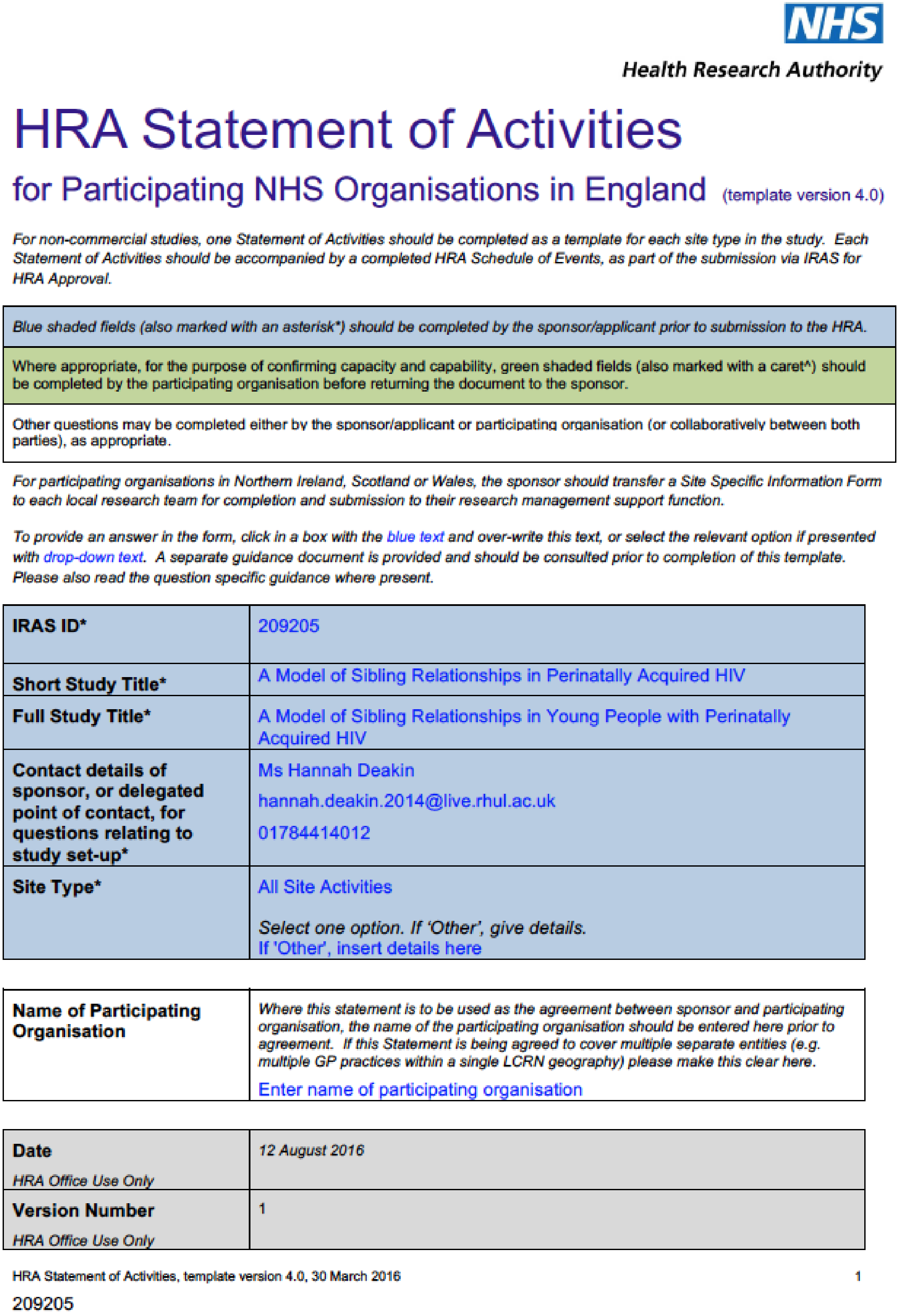
Ms Lucy Caton (01784 414317, Lucy.Caton@rhul.ac.uk)

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	Following REC favourable opinion the Participant Information Sheet and Informed Consent form have had a minor amendment to bring them in line with HRA standards. The current versions are approved as part of the HRA approval. No further approvals are required.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities will be used as the agreement between the Sponsor and participating sites.

Section	HRA Assessment Criteria	Compliant with Standards	Comments
4.2	Insurance/indemnity arrangements assessed	Yes	An updated insurance certificate has been provided by the applicant. Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No funding will be provided to participating sites.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	A revised favourable opinion letter has been requested to include the participant health information sheet.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Appendix 4: R&D ethics approval – primary research site



NHS
Health Research Authority

HRA Statement of Activities

for Participating NHS Organisations in England (template version 4.0)

For non-commercial studies, one Statement of Activities should be completed as a template for each site type in the study. Each Statement of Activities should be accompanied by a completed HRA Schedule of Events, as part of the submission via IRAS for HRA Approval.

Blue shaded fields (also marked with an asterisk) should be completed by the sponsor/applicant prior to submission to the HRA.*
Where appropriate, for the purpose of confirming capacity and capability, green shaded fields (also marked with a caret^) should be completed by the participating organisation before returning the document to the sponsor.
Other questions may be completed either by the sponsor/applicant or participating organisation (or collaboratively between both parties), as appropriate.

For participating organisations in Northern Ireland, Scotland or Wales, the sponsor should transfer a Site Specific Information Form to each local research team for completion and submission to their research management support function.

To provide an answer in the form, click in a box with the blue text and over-write this text, or select the relevant option if presented with drop-down text. A separate guidance document is provided and should be consulted prior to completion of this template. Please also read the question specific guidance where present.

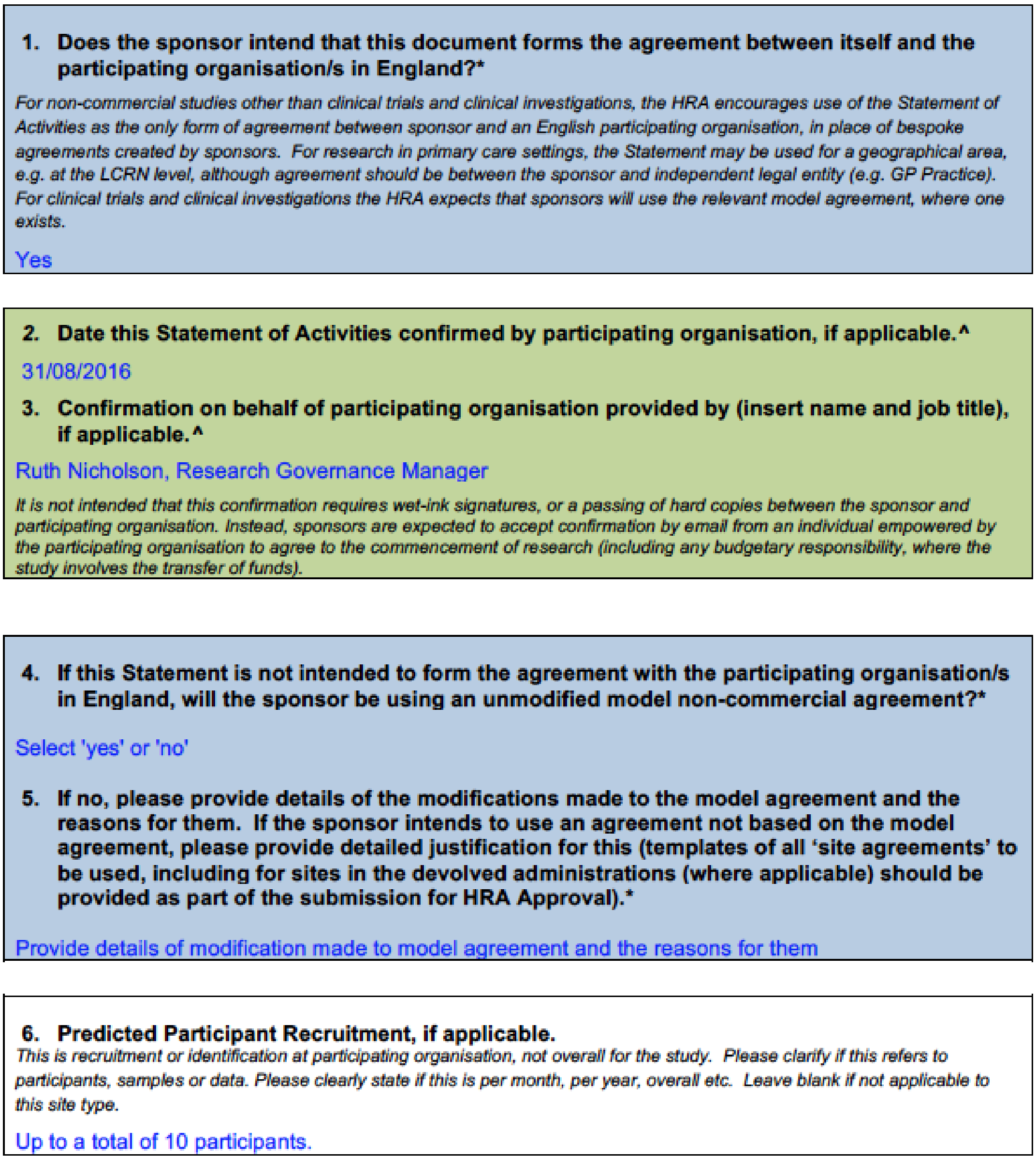
IRAS ID*	209205
Short Study Title*	A Model of Sibling Relationships in Perinatally Acquired HIV
Full Study Title*	A Model of Sibling Relationships in Young People with Perinatally Acquired HIV
Contact details of sponsor, or delegated point of contact, for questions relating to study set-up*	Ms Hannah Deakin hannah.deakin.2014@live.rhul.ac.uk 01784414012
Site Type*	All Site Activities *Select one option. If 'Other', give details.* If 'Other', insert details here

Name of Participating Organisation	*Where this statement is to be used as the agreement between sponsor and participating organisation, the name of the participating organisation should be entered here prior to agreement. If this Statement is being agreed to cover multiple separate entities (e.g. multiple GP practices within a single LCRN geography) please make this clear here.* Enter name of participating organisation

Date *HRA Office Use Only*	*12 August 2016*
Version Number *HRA Office Use Only*	1

HRA Statement of Activities, template version 4.0, 30 March 2016 1

209205



1. **Does the sponsor intend that this document forms the agreement between itself and the participating organisation/s in England?***

For non-commercial studies other than clinical trials and clinical investigations, the HRA encourages use of the Statement of Activities as the only form of agreement between sponsor and an English participating organisation, in place of bespoke agreements created by sponsors. For research in primary care settings, the Statement may be used for a geographical area, e.g. at the LCRN level, although agreement should be between the sponsor and independent legal entity (e.g. GP Practice). For clinical trials and clinical investigations the HRA expects that sponsors will use the relevant model agreement, where one exists.

Yes

2. **Date this Statement of Activities confirmed by participating organisation, if applicable.^**

31/08/2016

3. **Confirmation on behalf of participating organisation provided by (insert name and job title), if applicable.^**

Ruth Nicholson, Research Governance Manager

It is not intended that this confirmation requires wet-ink signatures, or a passing of hard copies between the sponsor and participating organisation. Instead, sponsors are expected to accept confirmation by email from an individual empowered by the participating organisation to agree to the commencement of research (including any budgetary responsibility, where the study involves the transfer of funds).

4. **If this Statement is not intended to form the agreement with the participating organisation/s in England, will the sponsor be using an unmodified model non-commercial agreement?***

Select 'yes' or 'no'

5. **If no, please provide details of the modifications made to the model agreement and the reasons for them. If the sponsor intends to use an agreement not based on the model agreement, please provide detailed justification for this (templates of all 'site agreements' to be used, including for sites in the devolved administrations (where applicable) should be provided as part of the submission for HRA Approval).***

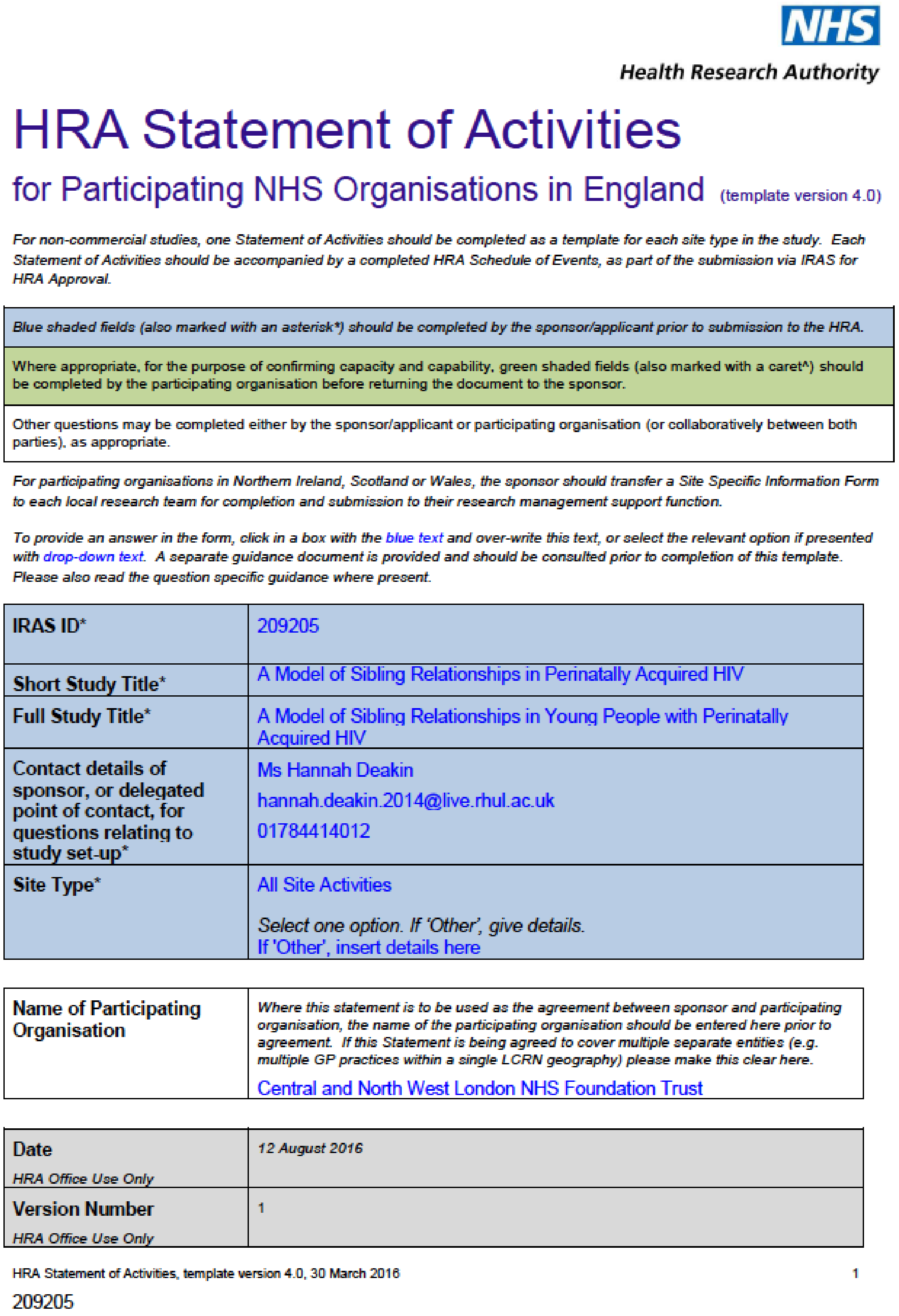
Provide details of modification made to model agreement and the reasons for them

6. **Predicted Participant Recruitment, if applicable.**

This is recruitment or identification at participating organisation, not overall for the study. Please clarify if this refers to participants, samples or data. Please clearly state if this is per month, per year, overall etc. Leave blank if not applicable to this site type.

Up to a total of 10 participants.

Appendix 5: R&D ethics approval – secondary research site



Health Research Authority

HRA Statement of Activities

for Participating NHS Organisations in England (template version 4.0)

For non-commercial studies, one Statement of Activities should be completed as a template for each site type in the study. Each Statement of Activities should be accompanied by a completed HRA Schedule of Events, as part of the submission via IRAS for HRA Approval.

Blue shaded fields (also marked with an asterisk) should be completed by the sponsor/applicant prior to submission to the HRA.*

Where appropriate, for the purpose of confirming capacity and capability, green shaded fields (also marked with a caret^) should be completed by the participating organisation before returning the document to the sponsor.

Other questions may be completed either by the sponsor/applicant or participating organisation (or collaboratively between both parties), as appropriate.

For participating organisations in Northern Ireland, Scotland or Wales, the sponsor should transfer a Site Specific Information Form to each local research team for completion and submission to their research management support function.

To provide an answer in the form, click in a box with the blue text and over-write this text, or select the relevant option if presented with drop-down text. A separate guidance document is provided and should be consulted prior to completion of this template. Please also read the question specific guidance where present.

IRAS ID*	209205
Short Study Title*	A Model of Sibling Relationships in Perinatally Acquired HIV
Full Study Title*	A Model of Sibling Relationships in Young People with Perinatally Acquired HIV
Contact details of sponsor, or delegated point of contact, for questions relating to study set-up*	Ms Hannah Deakin hannah.deakin.2014@live.rhul.ac.uk 01784414012
Site Type*	All Site Activities *Select one option. If 'Other', give details.* If 'Other', insert details here

Name of Participating Organisation	*Where this statement is to be used as the agreement between sponsor and participating organisation, the name of the participating organisation should be entered here prior to agreement. If this Statement is being agreed to cover multiple separate entities (e.g. multiple GP practices within a single LCRN geography) please make this clear here.* Central and North West London NHS Foundation Trust

Date *HRA Office Use Only*	*12 August 2016*
Version Number *HRA Office Use Only*	1

HRA Statement of Activities, template version 4.0, 30 March 2016 1

209205

1. **Does the sponsor intend that this document forms the agreement between itself and the participating organisation/s in England?***

For non-commercial studies other than clinical trials and clinical investigations, the HRA encourages use of the Statement of Activities as the only form of agreement between sponsor and an English participating organisation, in place of bespoke agreements created by sponsors. For research in primary care settings, the Statement may be used for a geographical area, e.g. at the LCRN level, although agreement should be between the sponsor and independent legal entity (e.g. GP Practice). For clinical trials and clinical investigations the HRA expects that sponsors will use the relevant model agreement, where one exists.

Yes

2. **Date this Statement of Activities confirmed by participating organisation, if applicable.^**

30 August 2016

3. **Confirmation on behalf of participating organisation provided by (insert name and job title), if applicable.^**

Lynis Lewis, Service Director (Noclor Research Support)

It is not intended that this confirmation requires wet-ink signatures, or a passing of hard copies between the sponsor and participating organisation. Instead, sponsors are expected to accept confirmation by email from an individual empowered by the participating organisation to agree to the commencement of research (including any budgetary responsibility, where the study involves the transfer of funds).

4. **If this Statement is not intended to form the agreement with the participating organisation/s in England, will the sponsor be using an unmodified model non-commercial agreement?***

Select 'yes' or 'no'

5. **If no, please provide details of the modifications made to the model agreement and the reasons for them. If the sponsor intends to use an agreement not based on the model agreement, please provide detailed justification for this (templates of all 'site agreements' to be used, including for sites in the devolved administrations (where applicable) should be provided as part of the submission for HRA Approval).***

Provide details of modification made to model agreement and the reasons for them

6. **Predicted Participant Recruitment, if applicable.**

This is recruitment or identification at participating organisation, not overall for the study. Please clarify if this refers to participants, samples or data. Please clearly state if this is per month, per year, overall etc. Leave blank if not applicable to this site type.

Up to a total of 10 participants.

Appendix 6: Participant Information Sheet

(insert site logo)

PARTICIPANT INFORMATION SHEET

August 2016, Version 5

Project title: A model of sibling relationships in young people with perinatally acquired HIV

We are carrying out a study exploring the sibling (brother or sister) relationships in young people where one sibling has perinatally acquired HIV (PHIV). We would like to invite you to be interviewed by Hannah Deakin, a Trainee Clinical Psychologist at Royal Holloway, University of London (RHUL). The interview will last approximately 45 minutes.

Before you decide if you want to take part, it's important that you understand why this study is being carried out and what will happen if you take part. Please read this sheet carefully. If you want to discuss the study with a member of clinic staff or someone close to you before making a decision about taking part, please feel free to do so. You can also ask Hannah any questions you might have about the study.

Why are we doing this study?

We would like to find out more about sibling relationships where one young person has perinatally acquired HIV. We are particularly interested in your experiences of sibling relationships both before and after you knew about your diagnosis, whether you talk to your siblings about HIV and how your sibling relationships might provide support with managing HIV.

Why are you asking me to take part?

We are inviting you to take part in this study because you are a young person with perinatally acquired HIV and you attend this clinic where the study is taking place.

What will happen in the interview?

The interview will take place in a quiet and private room. To allow you to be able to speak freely, we ask that you attend the interview alone. Hannah will go through a consent form with you which confirms that you are agreeing to take part in the study. You can ask any questions you have at this point, before the interview starts. You will also be asked to fill out some short questionnaires about yourself and your sibling relationship. The interview will then take place, beginning with some general questions about your relationship with your sibling(s), before asking more about the impact that HIV might have on these relationships. The consent form also asks your permission for Hannah to collect some basic information about your HIV (for example your blood counts) on the Participant Health Information sheet, via your clinician after the interview. 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 at a location that is convenient to you. This could be at this clinic, at RHUL offices in Central London, or at your home.

Do I have to take part?

No, you don't. The study will not affect your care at this clinic 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 choose not to take part anymore in the study, your care will not be affected. You can let Hannah know if you want your data to be withdrawn from the study as well.

Will the interview be confidential?

What you talk about with Hannah Deakin 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, Hannah 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 this clinic. The transcription of 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?

Hannah Deakin will use the information to write a thesis as part of a professional qualification to become a Clinical Psychologist. The Academic Supervisor for this thesis is Dr Michael Evangeli (Clinical Psychologist and Senior Lecturer) at Royal Holloway University of London. 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 Hannah Deakin (using the details below) **anytime between 20th- 31st March, 2017.** 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. Anonymous quotations from the interviews may be used in the reports for this study. All identifying information will be removed.

Are there any disadvantages or risks of taking part?

Some people might find talking about their diagnosis of HIV and their relationship with their sibling difficult, sensitive or in some cases upsetting. You will be given the opportunity to reflect on your experience of the interview immediately afterwards with Hannah. If you feel that you need to speak to someone else 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 siblings in young people with perinatally acquired HIV. This knowledge could help to develop better services for people in your situation and their families in the future.

Will I get anything personally for taking part?

We will reimburse your time for taking part in the study to the value of £10 (in high street vouchers). If you decide to attend an interview on a different day to your routine clinic appointment, you will also be reimbursed for travel expenses.

Who has reviewed the study?

Studies being conducted in the NHS are looked at by an independent group called a Research Ethics Committee. This study has been reviewed and given favourable opinion by London-Stanmore NHS Research Ethics Committee (IRAS ref: 209205). It has also been approved by Royal Holloway, University of London 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.

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

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 *(insert site name)* who will be happy to listen to you and will help you make a formal complaint if you wish. Their number is *(insert)*.

What happens next?

If you are interested in taking part, you will be given the opportunity to meet with Hannah 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 for you. If Hannah 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.

For further information, please contact:
Hannah Deakin
(Insert researcher and recruitment site collaborator contact details)

Appendix 7: Clinician research summary sheet

Clinician (telephone) research summary sheet

Project title: A model of sibling relationships in young people with perinatally acquired HIV

Please contact suitable participants via telephone up to one week prior to their routine clinic appointment to let them know about the study. Please check suitability for the study according to the following inclusion/exclusion criteria:

Who is suitable?

- Young people aged 16-25 *(at the time of interview)*
- The young person must have at least one sibling that shares the same biological mother and that they have lived with in the same household for at least 5 years in their lifetime (but may be living apart at present).
- Diagnosis of Perinatally Acquired HIV
- Diagnosis of HIV known by the young person 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 who have emotional problems to a degree that might impact their ability to engage in the interview
- Young people at 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 on the telephone…

Hannah, a Trainee Clinical Psychologist, is conducting a research project looking at relationships with brothers and sisters in young people with Perinatally Acquired HIV. If you are interested in taking part, it would involve filling out some short questionnaires and being interviewed by Hannah for around 45 minutes about what your sibling relationships are like. You would receive £10 for your time (in high street vouchers) and any additional travel expenses if you are interviewed outside of your usual clinic visit.

If you are interested and would like to find out more about the study before your clinic appointment, I can provide you with a contact telephone number for Hannah. Hannah will also be at the clinic after your appointment on (*date)*, if you would like to find out more about the study or ask any questions. You will also have the option of taking part in the research after your clinic appointment, if it is convenient for you.

Appendix 8: Participant Consent Form

(insert site logo)

PARTICIPANT CONSENT FORM

Title of the Study: A model of sibling relationships in young people with perinatally acquired HIV

Name of Researcher: Hannah Deakin
Ethics Committee Reference number: 16/LO/1153
IRAS Reference: 209205

1. I confirm that I have read and understood the information sheet dated………. (version……) for the above study and have had the opportunity to ask questions which have been answered satisfactorily ☐
2. I understand that my participation is voluntary and I can withdraw from the study at any time, without giving any reason, and without my medical care and legal rights being affected ☐
3. I agree to have my interviews with Hannah Deakin, Trainee Clinical Psychologist, audio recorded ☐
4. I understand that information will be stored confidentially according to the NHS code of ethics ☐
5. I agree to having my anonymous quotations used in the reports for this study ☐
6. I agree to the clinical information identified on the "Participant Health Information" sheet being recorded via a member of my clinical team, for the purposes of this research ☐
7. I understand that if Hannah Deakin believes there is a serious risk of harm to either myself or someone else, she may need to speak to my clinical team about this ☐
8. I agree to take part in the above study ☐

Name of participant	Date	Signature
Name of researcher	Date	Signature

Appendix 9: Draft interview guide

DRAFT Interview Guide

1) **Can you describe to me who is in your family?** ***(Genogram?)***

2) **Can you tell me about when you first became aware you were HIV positive?**
- How did you find out?
- How old were you?
- Who told you?
- What was that like for you? How did you feel?
- Who else in your family has the same condition?

3) **How does having HIV affect your life now?**
- In what ways has your life changed since your diagnosis?
- In what ways is your life the same?
- How has it affected your life in the past?

4) **How well would you say you manage your illness/ HIV?**
- What helps you manage living with HIV?
- What doesn't help or makes it harder?

5) **Tell me about your siblings/ brother or sister?**

Let's talk now about the sibling that you chose to fill in the questionnaire about…

6) **What made you choose this sibling?**
- If you have more than one sibling, why did you not choose them?

7) **How would you describe this sibling?**
- What kind of person are they?
- What kind of things do you do together?

8) **What was your relationship like with this sibling when you were younger (before you knew you had HIV)?**

9) **Does this sibling know that you are HIV positive?**

If yes, go to question 10. If no, go to question 13.

10) **When did your sibling become aware that you were HIV positive?**
- How did they find out/ who told them?
- How old were you when they found out?
- How did they respond? And how did you respond?
- How many people know about your HIV status?
- Do all your siblings know about your HIV status?
- How did your other sibling(s) find out?
- How did they respond?

11) Do you know if your sibling has told anyone else about your HIV status?

- Who did they tell?
- How did you feel about this?
- Did they talk to you about this first?

12) How has your relationship been with your sibling since they found out?

- How would you like your relationship with your sibling to be?

Continue to question 14

13) What influenced your decision not to tell this sibling about your HIV status?

- How many people know about your HIV status?
- Do any of your siblings know?
- If yes, how did they find out?
- How did they respond?
- How would you describe your relationship with a sibling that knows about your HIV status?

14) What is your relationship like now with your sibling?

- How would you like your relationship with your sibling to be?

15) How, if at all, does HIV affect your relationship with your sibling?

- How, if at all, has HIV affected any other of your family relationships (e.g. Mum/ Dad/ other siblings)?
- How, if at all, do you think HIV affects your sibling's life?

16) How, if at all, does your sibling try and support you (*with your illness*)?

- What does your sibling do that you appreciate/ helps you?
- How does support from your brother/sister compare to support from other people (e.g. friends/ family/ partner)?
- Do they do anything that is unhelpful?
- Has there been a time when they offered you more support?

17) How, if at all, do you feel you offer support your sibling?

- What times do you offer them more/less support?
- What type of support do you give them? (practical vs. emotional)

18) How much do you talk to your sibling about HIV?

- What kind of things do you talk about with them?
- How does talking to your sibling about HIV make you feel?
- Who do you talk to most about your illness?
- How much do they know about your HIV status/ management?

19) How important is your relationship with this sibling compared to other relationships in your life (e.g. friends/ family/ partner)?

Appendix 10: Service user feedback guidance sheet

Service user feedback guidance sheet

Summary of the project

Hannah Deakin (a Trainee Clinical Psychologist at Royal Holloway, University of London) is carrying out a research project looking at relationships with siblings (brothers and sisters) in young people with Perinatally Acquired HIV (PHIV). Hannah aims to interview 10 young people, aged 16-25, with PHIV about their experiences of sibling relationships before and after they knew about their diagnosis, how much they talk to their siblings about HIV and how their sibling relationships might provide support with managing HIV.

Hannah 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 PHIV and their families in the future.

How can you help?

Before conducting the interviews, it would be helpful to discuss the interview questions with young people living with HIV. The interview is semi-structured. This means that the interview questions are 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 needed. The order the questions are asked will be guided by the interviewees' responses.

Please consider the following when looking at the interview guide:

- 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?

After the study…

Hannah would also like to feed back the results from the study to young people with HIV who might be interested in the results. If you have any ideas about where the best places might be to talk about the results of the study or who would be interested in knowing about the findings, then please let Hannah know.

Appendix 11: Interview guide post-feedback

Interview Guide

1) **Can you tell me who is in your family? *(Genogram?)***

2) **When were you first aware that you had HIV?**
- How did you find out? Who told you?
- How old were you?
- What was that like for you? How did you feel?
- Who else in your family has HIV?

3) **How does having HIV affect your life now?**
- Has your life changed in any way since you were told about your status?
- In what ways is your life the same?
- How has it affected your life in the past?

4) **How well would you say you cope with living with HIV?**
- What (or who) helps you manage living with HIV?
- What doesn't help or makes it harder?

5) **Tell me about your siblings/ brother or sister?**
- What are they like? What do they do?

Let's talk now about the sibling that you chose to fill in the questionnaire about…

6) **What made you choose this sibling?**
- If you have more than one sibling, why did you not choose them?

7) **How would you describe this sibling?**
- What kind of person are they? How would other people describe them/ how would they describe themselves? What does (s)he like doing?
- How do you spend your time together?

8) **Does this sibling know that you are HIV positive?**
- Does this sibling have HIV?

If yes to question 8, go to question 9. If no, go to question 13.

9) **When did your sibling become aware that you were HIV positive?**
- How did they find out/ who told them/ what led to them being told?
- How old were you when they found out?
- How did they respond? And how did you respond?
- How many people know about your HIV status (friends/family)?
- Do all your siblings know about your HIV status?
- How did your other sibling(s) find out? How did they respond?

10) **How do you feel your sibling reacted to knowing you're HIV positive?**
- Do you know if they have told anyone about your status?

- Did they talk to you about this first?
- How did it make you feel?

11) How has your relationship been with your sibling since they found out?

- Has your relationship with your sibling changed since they found out?

12) How much do you talk to your sibling about HIV?

- What kind of things do you talk about with them?
- How does talking to your sibling about HIV make you feel?
- Who do you talk to most about HIV (friends/family/health professionals)?
- How much do they know about your HIV status?

Continue to question 14

13) What influenced your decision not to tell this sibling about your HIV status?

- What would be the best/ worst thing about disclosing to your sibling?
- How many people know about your HIV status (friends/family)?
- Do any of your siblings know?
- If yes, how did they find out? How did they respond?
- How would you describe your relationship with a sibling that knows about your HIV status? Does this sibling have HIV?

14) What is your current relationship like with your sibling?

- Would you like anything to be different in your relationship?
- How do you think things might be in the future in your relationship?
- What was your relationship like with this sibling when you were younger (before you knew you had HIV)?

15) How, if at all, does HIV affect your relationship with your sibling?

- How, if at all, has HIV affected any other of your family relationships (e.g. Mum/ Dad/ other siblings)?
- How, if at all, do you think HIV affects your sibling's life?

16) How, if at all, does your sibling try and support you (*with HIV*)?

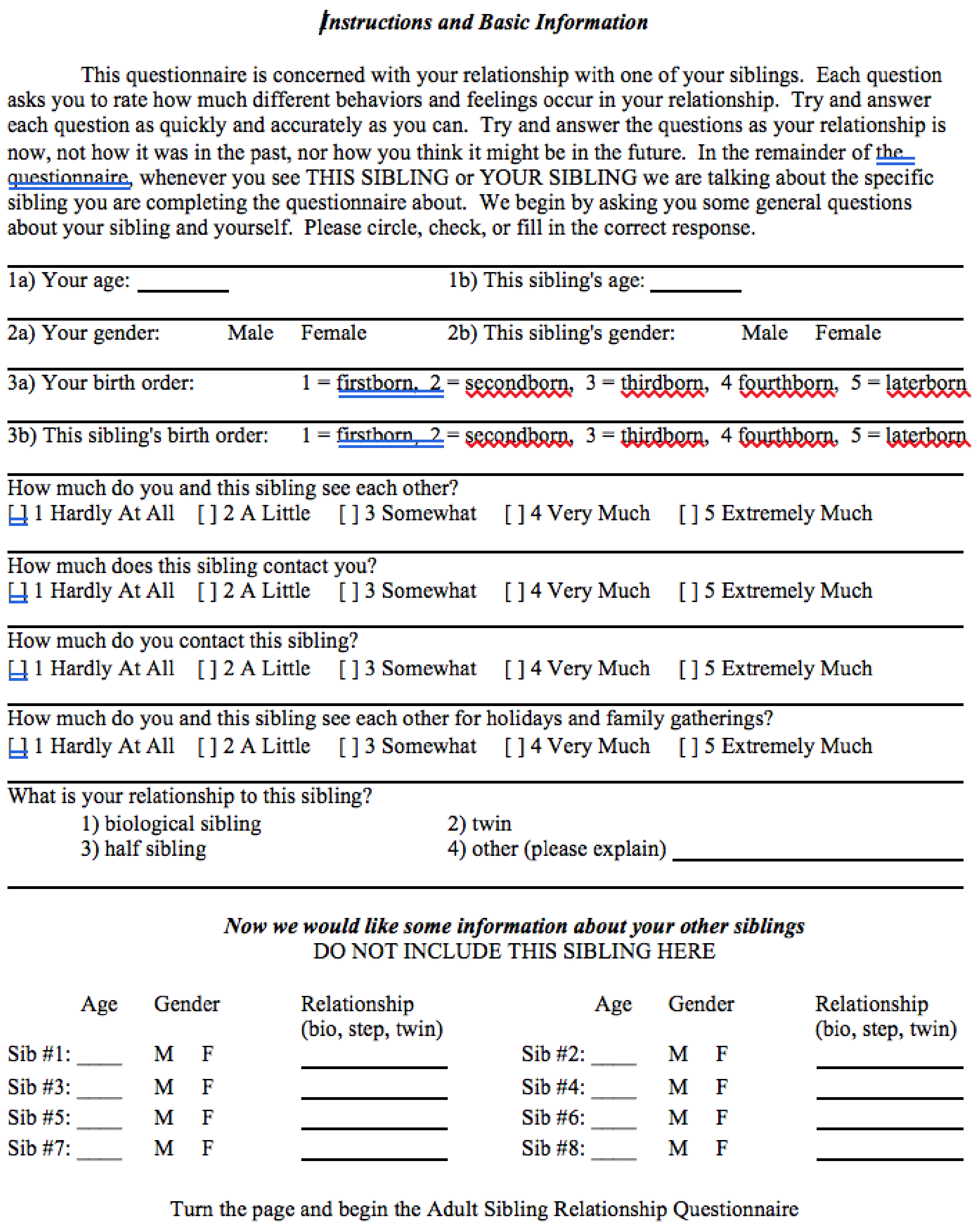
- What does your sibling do that you appreciate/ helps you?
- How does your sibling help with living with HIV?
- How does support from your brother/sister compare to support from other people (e.g. friends/ family/ partner)?
- Do they do anything that is unhelpful?
- Has there been a time when they offered you more or less support?

17) How, if at all, do you feel you offer support your sibling?

- When do you offer them more/less support?
- What type of support do you give them? (practical vs. emotional)

18) How important is your relationship with this sibling compared to other relationships in your life (e.g. friends/ family/ partner?)

Appendix 12: Adult Sibling Relationship Questionnaire-Short



Instructions and Basic Information

This questionnaire is concerned with your relationship with one of your siblings. Each question asks you to rate how much different behaviors and feelings occur in your relationship. Try and answer each question as quickly and accurately as you can. Try and answer the questions as your relationship is now, not how it was in the past, nor how you think it might be in the future. In the remainder of the questionnaire, whenever you see THIS SIBLING or YOUR SIBLING we are talking about the specific sibling you are completing the questionnaire about. We begin by asking you some general questions about your sibling and yourself. Please circle, check, or fill in the correct response.

1a) Your age: ________ 1b) This sibling's age: ________

2a) Your gender: Male Female 2b) This sibling's gender: Male Female

3a) Your birth order: 1 = firstborn, 2 = secondborn, 3 = thirdborn, 4 fourthborn, 5 = laterborn

3b) This sibling's birth order: 1 = firstborn, 2 = secondborn, 3 = thirdborn, 4 fourthborn, 5 = laterborn

How much do you and this sibling see each other?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

How much does this sibling contact you?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

How much do you contact this sibling?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

How much do you and this sibling see each other for holidays and family gatherings?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

What is your relationship to this sibling?
1) biological sibling 2) twin
3) half sibling 4) other (please explain) ____________________

Now we would like some information about your other siblings
DO NOT INCLUDE THIS SIBLING HERE

	Age	Gender	Relationship (bio, step, twin)		Age	Gender	Relationship (bio, step, twin)
Sib #1:	____	M F	____________	Sib #2:	____	M F	____________
Sib #3:	____	M F	____________	Sib #4:	____	M F	____________
Sib #5:	____	M F	____________	Sib #6:	____	M F	____________
Sib #7:	____	M F	____________	Sib #8:	____	M F	____________

Turn the page and begin the Adult Sibling Relationship Questionnaire

1) How much do you talk to this sibling about things that are important to you?
[ ] 1 Hardly Anything [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

2) How much does this sibling talk to you about things that are important to him or her?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

3) How much do you and this sibling argue with each other?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

4) How much do you irritate this sibling?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

5) How much does this sibling irritate you?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

6) How much does this sibling try to cheer you up when you are feeling down?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

7) How much do you try to cheer this sibling up when he or she is feeling down?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

8) How much do you discuss your feelings or personal issues with this sibling?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

9) How much does this sibling discuss his or her feelings or personal issues with you?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

10) How often does this sibling criticize you?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

11) How often do you criticize this sibling?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

12) How often does this sibling do things to make you mad?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

13) How often do you do things to make this sibling mad?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

14) How much can you count on this sibling to be supportive when you are feeling stressed?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

15) How much can this sibling count on you to be supportive when he or she is feeling stressed?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

16) How much do you really understand this sibling?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

17) How much does this sibling really understand you?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

18) How much does this sibling disagree with you about things?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

19) How much do you disagree with this sibling about things?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

20) How much does this sibling put you down?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

21) How much do you put this sibling down?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

22) How much do you discuss important personal decisions with this sibling?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

23) How much does this sibling discuss important personal decisions with you?
[ ] 1 Hardly At All [ ] 2 A Little [ ] 3 Somewhat [ ] 4 Very Much [ ] 5 Extremely Much

Thank you for completing this questionnaire.

Appendix 13: Hospital Anxiety and Depression Scale

Instructions: This questionnaire is designed to help us know how you are feeling. Read each item and circle the reply which comes closest to how you have been feeling in the LAST WEEK. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':	**A**
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I still enjoy the things I used to enjoy:	**D**
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like something awful is about to happen:	**A**
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

I can laugh and see the funny side of things:	**D**
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

Worrying thoughts go through my mind:	**A**
A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

I feel cheerful:	**D**
Not at all	3
Not often	2
Sometimes	1
Most of the time	0

I can sit at ease and feel relaxed:	**A**
Definitely	0
Usually	1
Not often	2
Not at all	3

I feel as if I am slowed down:	**D**
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I get a sort of frightened feeling like 'butterflies in the stomach':	**A**
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I have lost interest in my appearance:	**D**
Definitely	3
I don't take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I feel restless as if I have to be on the move:	**A**
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

I look forward with enjoyment to things:	**D**
A much as I ever did	0
Rather less than I used to	1
Definitely less than I used to	3
Hardly at all	2

I get sudden feelings of panic:	**A**
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

I can enjoy a good book or radio or TV programme:	**D**
Often	0
Sometimes	1
Not often	2
Very seldom	3

Appendix 14: Participant demographic questionnaire

PARTICIPANT DEMOGRAPHIC INFORMATION

1) What is your ethnicity (*please circle one*)?

White
1. English/Welsh/Scottish/Northern Irish/British
2. Irish
3. Any other White background, please describe

Mixed/Multiple ethnic groups
4. White and Black Caribbean
5. White and Black African
6. White and Asian
7. Any other Mixed/Multiple ethnic background, please describe

Asian/Asian British
8. Indian
9. Pakistani
10. Bangladeshi
11. Chinese
12. Any other Asian background, please describe

Black/ African/Caribbean/Black British
13. African
14. Caribbean
15. Any other Black/African/Caribbean background, please describe

Other ethnic group
16. Any other ethnic group, please describe

2) What is your country of birth?

____

3) If your country of birth is outside the UK, what year did you come to live here?

____

4) What is your current relationship status?

   1. Single (not in a relationship)
   2. Relationship (not living with a partner)
   3. Cohabiting (living with a partner)
   4. Married/ civil partnership
   5. Other (*please state*)

5) Who currently lives with you in your household (*please list their relationship to you)*?

   - ____
   - ____
   - ____
   - ____
   - ____
   - ____
   - ____
   - ____

6) What is your current employment status?

   1. Employed (full time)
   2. Employed (part time)
   3. Self-employed
   4. Unemployed
   5. Full time student
   6. Part time student
   7. Other (*please state*)

Appendix 15: Participant health information sheet

PARTICIPANT HEALTH INFORMATION

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

Currently attending: *(please tick all that apply)*
Psychiatry ☐
Psychology ☐
Counselling ☐
Other mental health support ☐
Please describe: ___________________________

Appendix 16: Example research diary entries

Tuesday 17th January 2017

I carried out my final participant interview today and it has led me to reflect again on how humbled and extremely grateful I am to all the young people who have shared their stories and experiences with me. While I am reflecting on the impact these interviews have had on me, I am also left thinking about the impact of these interviews on my participants. I am thinking back to and reviewing some of the comments made by participants at the end of their interviews and wondering what thoughts or feelings they were left with.

I remember participant six saying that the interview felt "like a weird therapy session" and that he doesn't usually talk much about his HIV status or about his family. I wonder what he meant by "weird" and whether he found the interview had some therapeutic benefit, by providing him with a space to talk about his experiences, even if this was not the aim of the meeting. It also leaves me thinking again about participants' motivations for taking part in the study, and whether they were hoping for this confidential space to talk. Alternatively, they may have been interested in being part of a research study, might have wanted the £10 voucher, or might have agreed as a 'favour' to one of the healthcare staff who invited them to take part in the study.

Participant ten mentioned today that he was going to go home to talk to his sibling about the interview and I was wondering what he might say or what it might have given him to think about regarding his sibling relationship. For participants who have a sibling who are unaware of their HIV status; is it going to make them go away and think about telling their siblings? What is the impact of this going to be on their relationship?

Participant eight commented that it made her think more about her sisters and how HIV affects them. It also made her want to talk to them about it more and find out what they know, so that she can educate them and understand how they feel about it. I wonder if this will be a helpful thing for her to feel more able or motivated to talk to her sisters about her HIV, but am also aware that it may have left her with concerns about how her illness is affecting her siblings and family. I also wonder how her sisters and mother will react to her potentially initiating conversations about HIV at home in future.

Friday 24th February 2017

While transcribing interview eight today, I realised that this was the first participant to explicitly recognise the impact of her illness on her parent's treatment of her siblings. She talked about her mother having to spend more time with her when she is unwell or in hospital, which leaves her sisters to be cared for at home by their father. This is an example of the parental differential treatment I had read about in chronic illness literature and was expecting to hear more of in interviews than I did in practice.

I am not surprised that it was this participant who made this link, as she immediately seemed to be more reflective and open about her experiences than many of the other participants have been. I wonder whether this is because she said she has been/is in therapy and has been socialised to talking about her life experiences in a different way, or is practiced at reflecting on aspects of her life. The way she spoke about her experiences seemed to be much more open than many other participants and she was more self-reflective than I might expect for someone of her age.

This interview also felt quite different to the others as it was the only interview where the participant had met with me on a non-clinic day. This seemed to give it an additional sense of agency and importance as the participant had given up her time to travel to the clinic specifically for our meeting. I was extremely grateful to her for doing this and feel that this interview made a valuable contribution to data collection.

Wednesday 1st February 2017

Reflections following our Grounded Theory Peer Supervision meeting today:

- Another trainee was talking about paying attention to the questions that you felt uncomfortable asking or that participants were finding it difficult to answer. This can potentially tell you something useful about either the question itself or an area of difficulty for participants to talk about. I remembered that participants had found it difficult to answer my question about whether their sibling had told other people about their HIV status. I am left reflecting on why this might have been and whether this was something participants had thought about before or if it was a particular concern of theirs and therefore felt uncomfortable answering?
- First vs. third person initial codes? Check which is recommended in Grounded Theory methodology.
- Use of NVivo or not? Another trainee was considering the use of computer coding package NVivo for Grounded Theory. I had considered this and thought that on balance, the time constraint associated with this project and the risk of a coding programme forcing codes on the data is not conducive to its use in this project.

Saturday 4th February 2017

I have been thinking about two powerful quotes from the last two interviews that I have transcribed. The first was something said by participant nine:

> "*you can talk about cancer… you can't really talk about HIV*"

Having been diagnosed with both cancer and HIV around the same time (and both fairly recently – within the last 2 years), he was able to reflect on and compare his experiences of both. This quote resonated with me in the interview itself and highlighted all participant's experiences of stigma that are not experienced by people other chronic illnesses.

Participant ten also said something that stuck with me:

> “*it really doesn’t impact my well-being, it just impacts my immune system*”

I think what he was trying to communicate to me was that HIV doesn’t impact who he is as a person and that, at least a present, he doesn’t recognise a huge emotional impact of being HIV positive. He is conceptualizing it as a physical illness that affects his immune system and physical well-being, but is keeping it distanced from his emotional well-being. He is also achieving what he hopes to at this stage of his life by attending university, which may reduce the perceived impact of HIV on his life at present.

Appendix 17: Example interview transcript

Participant 8	**Initial codes**	**Focused Codes**
It was kind of like a shock to all of us… *I: That they didn't know?* Yeah, not to my mum, but it was just really random, like the way my mum just kind of told them. And, I don't know, like I felt kind of hurt by it, because she didn't tell me she was gonna tell them. And I would have like wanted to do it properly. Kind of like, explain it to them because I feel like, it was kind of unfinished, like surprise and then that's it. So, I feel like they don't really understand it. But they're just kind of like, going with it and trying not to ask too many questions. But, yeah, they, after that they were ok with it. *I: Yeah? And have they asked you any questions about it since then?* Not really, they know I've stopped taking my medication because they know I don't like it. But, yeah before my sister used to, the younger one, she used to bother me with my medication. She'd be like "*(name),* you didn't take your medication" and I used to just be like	Feeling that disclosure was a shock to them all Feeling that disclosure was random Mum telling her sisters they have HIV Disclosure from a family member to sibling Feeling hurt by the disclosure Not being prepared or consulted Wanting to disclose 'properly' Wanting to explain it to her sisters Not knowing how much her sisters understand about HIV Feeling that the disclosure was unfinished Being surprised at the disclosure Sisters trying not to ask too many questions Increased communication about HIV after disclosure Limiting questions about HIV Thinking sisters are ok with it Sisters not asking many questions since Sisters knowing she has stopped taking her medication Sisters knowing she doesn't like taking medication	Direct/ indirect sibling disclosure Times of increased sibling communication Perceptions of sibling coping Finding ways to talk about HIV

“leave me alone, don’t talk to me”. And so she stopped doing that, but other than that, no we don’t really talk about it.	Younger sister bothering her about medication Sister asking direct questions about HIV Telling her younger sister to leave her alone Not talking to her sisters about HIV	
I: No? Ok, and so, you said that they were kind of shocked to hear it, even though your older sister might have kind of guessed what’s been going on from the things that you’ve been doing, the activities. Umm, how much do you think your sisters understand about HIV?		
Not a lot, no I don’t think they have any clue what it actually is or how I got it, because I don’t know, umm, I would like for me and my mum to kind of explain it to them, I feel like my mum wouldn’t want to.	Not knowing what her sisters know about HIV Thinking her sisters don’t know about HIV or how she got it Wanting to explain it to her sisters with her mum Feeling like her mum wouldn’t want to talk to them about it	Not knowing
Because then it would involve me like talking about my dad and then that kind of thing, and I don’t think my mum likes talking about that. So, I don’t know.	Fear of exposing family secrets Concerned about having to talk about her dad with mum Thinking her mum doesn’t like talking about her dad	Keeping the secret
Maybe one day, I’ll kind of like go through it with them, but I still feel like they’re kind of young at the moment. So, it’s not really relevant to them. So yeah they just kind of know that I have it pretty much, that’s it.	Wanting to talk to them about it in future Feeling that they are still young Feeling that it’s not relevant to them Sisters knowing enough for now	Times of increased sibling communication
I: And since they’ve found out, what kind of conversations have they had with you about it? So, you said that they worry about you taking your medication and being unwell…?		
Yeah, we don’t talk about it specifically, but they’ll be like “oh, *(name)*, you’re not well, you should take medication” or they’ll like notice something and be like “oh, are you ok?” and then they’ll try and help as much as they can, but I think they know that there’s not much that they can do. And it’s kind of something that I have	Not talking about HIV specifically with her sisters Sisters encouraging her to take medication	Finding ways to talk about HIV Sources of support

to deal with. Where, they're just there, kinda like to be supportive and just kinda help out as much as they can.	Sisters asking if she is ok Sisters trying to help Sisters knowing there isn't much they can do to help Feeling it's something she has to deal with herself Sisters being there for her Sisters supporting her (emotional support) Sisters helping her out (practical support)	Sources of support
I: Hmm, so what ways do they try and help you?		
Well, my, the older one, she kinda, I don't know, takes it, tries to make it seem like light-hearted. And so, she'll be like "oh *(name)*, you're so sick, you need to go lie down or something" *(in a dramatic voice)*. Or she'll be like "oh, you're always sick you know, it's always you".	Older sister making it light-hearted Older sister making fun of her Older sister joking with her about being unwell Making a joke of HIV	Finding ways to talk about HIV
I: Like making a bit of a joke of it?		
Yeah. And, I'll like, I'll complain about something and she'll be like "ugh, again, really?" and I don't know, it's kinda like, it's kind of our thing so she makes it seem like, I don't know, not as bad as it actually is, whereas the doctors are like, "oh, you know, could do with this" and my mum's panicking. And then she's just there, just trying to make jokes out of it. And so, yeah, that kinda helps because, not having to take it seriously all the time. So, yeah.	Making a joke of HIV with her sister Helping her to cope Making it feel less serious Mum panicking Taking it less seriously with her sister	Finding ways to talk about HIV

Appendix 18: Example memos

Memo on patterns of support between siblings

I am definitely noticing a pattern of support emerging between siblings, who describe the type of support they offer one another as changing as they get older. It seems to shift from primarily being practical support between siblings when they were younger and there was more conflict in their relationship, to emotional support as they get older and there is more warmth in their relationship.

> "*when we were like children, we sort of, we'd fight quite a lot, […] and then it was when she, when she urgh, finished school, so when she was, finished her A Levels, and I was probably in year 10 or something, we got really close*" (P4)
>
> "*Yeah, we're close. Like, we, when we were younger we weren't really close […] but then, as we got older, I think she became less close with my brother and now I'm more closer*." (P5)
>
> "*we just used to clash anyway, 'cos I was like the annoying one, so I used to just annoy her all the time, so, that's why we didn't used to get along, but now it's alright.*" (P5)

I would also have expected that as young people get older and enter into romantic relationships, their source of emotional support might transfer from their sibling or friends to their partner. I was interested in the potential impact of this on the sibling relationship, however, I am finding that very few (if any) participants are currently in a romantic relationship or have ever had one. I am interested in whether this is related to being PHIV+ and concerns around disclosure of HIV status to partners, particularly in sexual relationships. I am also now thinking about the impact on the sibling relationship of not entering into romantic relationships at a time when their peers are and whether this might prolong periods of closeness between siblings. This is something for me to consider as I continue to code the data.

While transcribing interview seven today I was also considering levels of support in the sibling relationship in the context of participant's culture. I wondered about expectations from within the family for older siblings to look after their younger siblings. Is this a cultural influence of growing up with parents of black African origin or is this because their mother was unwell/ absent due to HIV-related illness? Participants do not refer explicitly to this being a cultural expectation or norm, but it seems to be important to bear it in mind. In fact the only explicit reference to culture so far has been the impact of a participant's boyfriend's African culture on this beliefs about HIV. She mentioned her partner would associate it with AIDS (and therefore death?) because he is African.

> "*he's still scared. He's still scared himself, I mean he's still trying to understand it. Because he's African himself and obviously in Africa as soon as they hear that they probably think AIDS*" (P7)

It is interesting that participants haven't referred to culture more and I wonder if this is because they (and their siblings) have all grown up in a Western culture from a young age. I also notice that no-one has mentioned religion in any of their interviews, as a source of support or coping. I had expected that this might come up based on previous research with HIV populations (Kang et al., 2011). I wonder again whether this might represent the changing face of this generation who may identify with or follow religion less than previous generations of African descent?

I am aware of a potential overlap between the initial codes of "supporting sibling" and "HIV-related sibling support". There will need to be a distinction between HIV-related support between siblings and other types of support, so the "supporting sibling" codes will need to be re-named to reflect this. They could possibly be called "Supporting sibling (practical, non-HIV related support)" and "Supporting sibling (emotional, non-HIV related support)". I will consider this distinction going forward.

Memo on gender

As recruitment continues I am increasingly considering the impact of gender on levels of support and communication in the sibling relationship, as well as the impact of gender on the perceived quality of the sibling relationship. Having recruited 6 females and one male participant(s) so far, I am concerned that I will not be capturing the potential impact of gender on aspects of the sibling relationship. I have noticed so far that participants have been choosing to talk about an 'identified sibling' who is the same gender as themselves, and wonder whether this might be reflective of them perceiving this relationship to be closer. I am reminded of literature in the general population about female siblings having higher levels of intimacy (Kim et al., 2006) and the impact of potential increased communication between female siblings or increased levels of emotional support. This may also not be the case, as the only participant to not have any siblings who are aware of their HIV status so far is female with female siblings. The only male to have been interviewed also described close, supportive relationships with both his brothers.

I think it is important to attempt to explore this aspect of sibling relationships further and will therefore discuss in supervision whether this might be an opportunity for theoretical sampling going forward.

I am also aware, however, that the six sampled participants may not have had a choice about which gender of sibling to talk about their relationship with, as two only had one sibling and three only had siblings the same gender as themselves. I need to be mindful of maintaining an open and reflective stance on this aspect of sibling relationships and not forcing a relationship to exist where it may not for these participants.

Appendix 19: Summary of focused codes across participants

Theoretical codes	**Focused codes**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1. Personal adjustment to PHIV+ diagnosis	1.1 Learning about HIV	X	X		X	X	X	X	X	X	X
	1.2 Impact of stigma	X		X	X	X	X	X		X	X
	1.3 Medication adherence	X	X	X	X	X	X	X	X	X	X
2. PHIV+ disclosure in the sibling relationship	2.1 Growing up as HIV+ siblings		X			X	X	X			
	2.2 Direct/ indirect sibling disclosure	X			X	X			X	X	X
	2.3 Guessed/ non-disclosure to sibling		X	X			X	X			
3. Patterns of communication about PHIV+ between siblings	3.1 Finding ways to talk about HIV	X	X		X	X	X		X	X	
	3.2 Times of increased sibling communication	X			X		X		X	X	X
	3.3 Keeping the secret	X	X	X	X	X	X	X	X	X	X
	3.4 Not knowing	X	X	X		X	X	X	X	X	X
4. Patterns of coping and support in the PHIV+ sibling relationship	4.1 Feeling normal	X	X	X	X	X	X	X	X	X	X
	4.2 Valuing the sibling relationship	X	X	X	X	X	X	X	X	X	X
	4.3 Perceptions of sibling coping	X		X	X	X	X	X	X	X	X
	4.4 Sources of support	X	X	X	X	X	X	X	X	X	X