

**Exploring the Experiences of People Living with HIV who have Shared their
Status Openly**

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1. Lay Summary

Systematic Review

Background:

People living with infectious diseases that can be passed from person to person (i.e., communicable diseases), can experience rejection or judgement from others (i.e., stigma). This review aimed to understand the experiences of people who openly tell others (i.e., status share) that they have a communicable disease. The research question was ‘What are the experiences of those living with a communicable disease who share their status openly?’.

Method:

A systematic review aims to critically summarise previous research that relates to a particular question, in this case, the question above. The previous research that was reviewed was related to people’s experiences (i.e., qualitative methodology), as it was hoped it would provide a more detailed summary compared to looking at statistical data. The studies included were only studies where participants were aged 18 and over and had a diagnosis of a communicable disease, such as human immunodeficiency virus (HIV), tuberculosis or leprosy. Articles were searched for on two databases and overall, 1300 papers were found. The articles were assessed for whether they were relevant to the question. Thirteen articles were thought to be relevant and have been included in this review. The findings from the articles were grouped together, (i.e., synthesised), to make overall categories or themes relating to the experiences of openly sharing.

Findings:

Findings showed the experiences of people could be grouped into three main themes: before sharing openly; the process of sharing openly; and the outcomes of sharing openly. Themes linked to before sharing included concerns about being rejected or experiencing judgement from others. Reasons why people wanted to share included wanting to share knowledge with others, wanting to get support, and not wanting to lie. Things that helped people with sharing were having information about HIV and being able to come to terms with their diagnosis. The process of sharing included sharing strategies changing over time. Benefits of sharing included getting support, supporting others, sharing knowledge with others and relationships becoming closer.

Conclusion:

Findings showed that reasons for sharing were both for the individual and for others around them. Additionally, the way people share is different for everyone and people thought there were more positive outcomes to sharing than negatives. These findings will help both people living with communicable diseases and professionals working with them to be able to support them.

Empirical Study***Background:***

People living with HIV experience difficulties linked to their physical and mental health. These include difficulties taking medication regularly, feeling alone, anxious, or depressed, and experiencing rejection and judgement from others. People who share their HIV status with others have found that they get more support from others and find it easier to regularly take medication. However, people have also experienced rejection

or judgement. This study aimed to explore the experiences of people living with HIV who openly share their status. The research question was ‘What are the experiences of adults with HIV who are open about their HIV status?’.

Method:

This study was also a qualitative study design as it was hoped this would be the best way to get detailed accounts of people’s experiences. Participants needed to be over 18, with HIV that they contracted later in life, not at birth (i.e., behaviourally acquired HIV), be ‘open’ about their status, and having received their HIV diagnosis at least six months ago. Being ‘open’ was defined as their GP, most of their friends and family and their last three sexual partners since diagnosis being told or knowing. I interviewed eight people living with HIV. Questions for my interview were written with the help of two other people living with HIV. NHS and University ethics committees reviewed the study to make sure it was safe to carry out. The interviews were studied, and themes were grouped together.

Findings:

Five main themes were created from the analysis:

- (1) Emotional reaction at diagnosis – this included sadness, shame and acceptance linked to their HIV diagnosis.
- (2) Decisions to share – reasons why people shared their status included wanting to be honest, wanting to educate and being accepting of their diagnosis. Having information about HIV and having support helped people to share.

- (3) Strategies for sharing – people had different strategies for sharing and when they started sharing. Some people were more influenced by their first experience of sharing than others.
- (4) Outcomes of sharing – positive outcomes of sharing included raising awareness about HIV, not having to lie, and getting support. Negatives included rejection, and concern from others.
- (5) Comparative experiences of sharing – there were mixed thoughts about whether people thought sharing their HIV status was better or worse than sharing other information about themselves, such as sexuality and mental health difficulties.

The main findings indicated that acceptance is an important factor linked to openly sharing, decisions to share were linked to seeing positives for yourself or someone else, sharing openly was an individual process and that participants mainly experienced positive outcomes following openly sharing.

Conclusion:

These findings hope to inform people living with HIV and professionals to understand the options that are available to people about sharing and things that might make it easier to share. They also showed the importance of accepting one's HIV diagnosis as being helpful for openly sharing and helping people to know they do not need to rush into sharing their status. Findings could also increase knowledge for people not living with HIV and charities about the process of individuals openly sharing their HIV status.

Next Steps

The systematic review and empirical study found some similarities and some differences in the themes relating to experiences of openly sharing. They found that openly sharing is an individual process and there are both positives and negative outcomes of sharing. Additionally, factors such as having knowledge and having support make it easier to share.

It is hoped that the findings will not only be able to help people living with HIV and professionals, but also charities, the HIV negative population and the academic community. The findings of the studies will be sent to HIV clinics, participants, and charities, and are going to be submitted to journals for publication.

2. A Systematic Review Exploring the Experiences of Openly Sharing Communicable Disease Status

Abstract

Research suggests that people living with communicable diseases experience stigma in relation to their illness. Some communicable diseases are associated with greater levels of stigma than others, which can be detrimental to someone's mental and physical health. Status sharing has been found to be associated with social support, however, there have been mixed outcomes found. This review looked at the experiences of people who share their communicable disease status openly, rather than selectively. The objective of this review was to critically analyse and synthesise themes associated with experiences of openly sharing of communicable disease status. Searches were run on PubMed and PsycInfo for peer-reviewed journals. Qualitative and mixed method articles were included with only qualitative data analysed. Other criteria included participants who were over 18 years old and with a diagnosis of a communicable disease. Titles and abstracts were screened and assessed for eligibility by the primary researcher and a secondary reviewer, followed by full text screening. Any disagreements were resolved by a third rater with expertise in the field. Out of 1300 articles, 13 were included in the review. Participants ranged in age, gender and sexuality and articles were from a range of locations. Studies were quality assessed for four criteria 'credibility', 'confirmability', 'transferability' and 'dependability'. Thematic synthesis identified six analytical themes: 'fears for sharing openly'; 'assists with sharing openly'; 'reasons for sharing openly'; 'methods for sharing openly'; 'benefits for sharing openly'; and 'negatives of sharing openly'. Findings suggested that reasons for sharing openly had both personal and social factors, methods of openly sharing were

variable and there were many more positive outcomes than negative outcomes. Findings will help both clinicians and people living with these illnesses to understand the different elements of status sharing and what might help individuals as well as some of the possible consequences.

Introduction

Communicable Diseases

Communicable diseases are diseases caused by microorganisms that are spread from one person to another, directly or indirectly. They are treated depending on the type of disease that they are. For example, bacterial diseases are treated with antibiotics and viral infections can be treated with antiviral medication. Some communicable diseases can be treated with medication, and cured, if the treatment is successful. For example, people with leprosy can receive a multidrug therapy which can completely cure leprosy (World Health Organisation, 2020b), similar to the treatment of tuberculosis (World Health Organisation, 2010), whilst others can be managed long term with medication but cannot be cured, as is the case for HIV. The management of these diseases will not only improve someone's physical health, but also has benefits such as improving quality of life and reducing the risk of onward transmission.

Communicable Diseases and Stigma

Whilst the management and treatment of many communicable diseases has progressed greatly, leading to better physical health and quality of life, many people with these diseases still experience a great deal of stigma in relation to their illness (Williams, Gonzalez-Medina, & Vu Le, 2011). Stigma is defined as a "negative social attitude" associated with a mental, physical or social characteristic of someone (APA, 2020). Some communicable diseases are associated with a greater level of stigma than others, and some are not stigmatised. It is possible that there might be certain features of illnesses that are associated with stigma more than others. These features might include judgement about the behaviour leading to someone contracting an illness, the

possible outcomes following contracting it or the fear of infection (Courtwright & Turner, 2010; Des Jarlais et al., 2006). For example, tuberculosis has commonly been associated with the HIV/AIDS pandemic in Southern Africa (Zolowere et al., 2008). Individuals living with these conditions experience discrimination from their family and community, including people with the same condition (Zolowere et al., 2008).

Research on HIV has found that there are different types of stigma: anticipated; internalised and enacted. Anticipated stigma is the discrimination that someone believes will be directed towards them (Earnshaw et al., 2013), whilst internalised stigma is where someone starts to believe the negative views about them or their condition (Berger et al., 2001), and enacted is the discrimination, negative attitudes, or avoidance of people living with communicable diseases (Earnshaw & Chaudoir, 2009).

All types of stigma can be detrimental to someone's mental health, as well as impacting their physical health. Stigma associated with communicable diseases impacts the likelihood of someone accessing services to be diagnosed, as has been found with people with leprosy (Nicholls et al., 2005). Moreover, it has been found that people living with HIV who experience stigma are less likely to access treatment (Chesney & Smith, 1999; Earnshaw et al., 2013; Venable et al., 2012). The stigma and prejudices, defined as a predetermined opinion that is not based on thought or experience, associated with these illnesses have a further consequence of being an obstacle for eradicating many communicable diseases, as has been found with diseases such as leprosy (Kay et al., 2010) and sexually transmitted diseases (Montgomery et al., 2008). This is due to people being less likely to seek medical treatment and hiding their status from others, which might lead to onward transmission (Des Jarlais et al., 2006).

Communicable Diseases, Stigma and Status Sharing

Stigma can have an impact on someone's physical and mental health, with people being less likely to seek medical intervention. Stigma might also lead individuals to be less likely to share their illness status with others. Patients with tuberculosis were found to fear the discrimination they might experience following sharing their status (Zolowere et al., 2008), whilst fearing social exclusion from families and communities was thought to be a barrier to sharing of individuals with leprosy (Sermittirong & Van Brakel, 2014). In particular, women were found to actively try to hide their status due to these fears (Ramasamy et al., 2020).

Factors which affect sharing in people living with HIV include 'disclosure self-efficacy' (Abler et al., 2015; Nöstlinger et al., 2015; Semple et al., 1999), sharing anxiety (Greene et al., 2013), anticipated responses in others (Greenhalgh et al., 2016; Kaushansky et al., 2017; Semple et al., 1999) sexuality (Elford et al., 2008), and age (Latkin et al., 2012). Similar findings have been found in research looking at leprosy status sharing (Thilakavathi et al., 2015) and tuberculosis (Zolowere et al., 2008). Status sharing has also been associated with feelings of trust, safety and an obligation to keep others safe (Zolowere et al., 2008).

Both benefits and negative outcomes have been found following status sharing of communicable diseases. Findings following a meta-analysis show a positive correlation between sharing HIV status and social support, and a negative correlation between stigma and sharing (Smith, Rossetto, & Peterson, 2008). Sharing of tuberculosis status has been associated with feelings of encouragement and empowerment (Zolowere et al., 2008). However, not all research looking into sharing

status has found positive outcomes. One study found that non-disclosure of HIV status was not associated with a higher prevalence of adverse health difficulties (Daskalopoulou et al., 2017). Additionally, some individuals with tuberculosis felt stigmatised following sharing their status (Zolowere et al., 2008). Given the mixed findings around status sharing and communicable diseases, it is of interest to understand more about this process.

Open Status Sharing

Open sharing is sharing some information about yourself openly with people from different domains of your life. For example, open HIV status sharing is sharing your HIV status with many people across different domains of your life (Hult, Wrubel, Bränström, Acree, & Moskowitz, 2012). Open status sharing is thought to be driven by personal and social factors but there has not been much research looking into it. Within other areas, open status sharing, for example openly sharing mental health difficulties has been associated with enhancing self-esteem and empowerment (Corrigan et al., 2013), whilst openly “coming out”, defined as publicly sharing ones sexual orientation, as homosexual has also been found to increase acceptance, support and happiness (Corrigan & Wassel, 2008).

Systematic Review Rationale

Research suggests that sharing someone’s communicable disease status may help individuals to feel more supported and possibly strengthens relationships, which in turn could help with adherence to treatment, both improving someone’s physical and mental health. Additionally, research focussed on the transmission of infectious

diseases found that to prevent further onward transmission, people need to share their disease status, which was particularly important in relation to sexually transmitted diseases and is thought to be similar for other diseases (Montgomery et al., 2008). Therefore understanding this process in more detail would be beneficial.

It is of interest psychologically to understand the open sharing process of individuals with communicable diseases, particularly stigmatised conditions, to understand their experience of sharing their status. This includes what helped them, and whether they have experienced any benefits or negative outcomes following sharing. As discussed, stigmatised conditions are often, but not always, associated more with person-to-person communicable diseases, therefore only these diseases will be included in the study.

This review is looking particularly at the experiences of people who share openly, not selectively, therefore not hiding their illness purposely from others. Only open sharing will be looked at within this review as it is thought that the experiences, across the domains mentioned above, of being open about someone's condition might be different to someone who selectively shares their diagnosis with others. Therefore, this review looks to extract themes from within studies exploring the experience of individuals with communicable diseases who openly share their status to others, which to the author's knowledge, has not been done before.

Systematic Review Objectives

The aim of the systematic review is to critically analyse and synthesise themes associated with experiences of open sharing of communicable disease status. Given the

objective is to look at the experiences of people with communicable diseases, it was thought that qualitative studies would provide much more detailed accounts than quantitative studies and therefore only qualitative data will be reviewed.

Method

Study Eligibility

The inclusion criteria were as follows:

- Empirical studies
- Using qualitative and mixed method methodologies, where it was possible to extract the qualitative data
- With participants who were over 18 years of age
- With participants with a diagnosis of a communicable disease who were open about their communicable disease status

Sources of Information

Literature searches were run on both PubMed and PsycInfo databases. Only research published in a peer-reviewed journal in English were included and there was no restriction on publication date. The reference section of eligible studies and review articles generated through the search were read to identify any other potentially relevant studies.

Search Strategy

Eligible studies needed to include the following constructs:

Open Status Sharing:

Status sharing was defined as the act of making a condition known or a fact that is made known. Open sharing was being defined as someone who will share the status

of their condition to most other people in their life. Search terms will be based on the definition of open sharing.

Communicable Physical Health Conditions:

The most common communicable diseases based on the World Health Organisation are tuberculosis, leprosy, Ebola, COVID-19, influenza, measles, pneumonia, strep throat and sexually transmitted infections (World Health Organisation, 2020a). Sexually transmitted infections included have been based on both The Terence Higgins Trust and The Well Project (The Well Project, 2020; The Terence Higgins Trust, 2020). The diseases chosen were all person-to-person communicable diseases. Not all person-to-person communicable diseases are stigmatised however these ones are thought to be associated with more stigma given the perception from others about how people might contract the illness, some of the long-term effects and the fear associated with them.

Based on these constructs and developed further following a literature review of terms, the following search terms were searched for in the title and abstract of research studies in both PubMed and PsycInfo:

- Open Disclosure: open* disclos*” OR “public* disclos” OR “open* share” OR “public* share” OR disclosure* OR disclos* OR “self-disclosure*” OR “self disclosure*” OR “open status” OR “public status”
- Communicable Diseases: tuberculosis OR TB OR leprosy OR ebola OR covid-19 OR coronavirus OR “sexually transmitted infection*” OR STI OR STD OR “sexually transmitted disease*” OR HIV OR “human immunodeficiency virus” OR chlamydia OR “genital wart*” OR HPV OR “human papilloma virus” OR

gonorrhoea OR hepatitis OR “hepatitis A” OR “hepatitis B” OR “hepatitis C”
OR HAV OR HBV OR HCV OR herpes OR LGV OR “lymphogranuloma
venereum” OR “mycoplasma genitalium” OR Mgen OR molluscum OR NSU
OR “non-specific urethritis” OR “pubic lice” OR shigella OR syphilis OR
chancroid OR trichomoniasis OR influenza OR measles OR pneumonia OR
“strep throat”

- Mixed methods and Qualitative: Qualitative OR “grounded theory” OR
“thematic analysis” OR IPA OR “interpretive phenomenological analysis” OR
“narrative analysis” OR “narrative model” OR “phenomenological model” OR
“content analysis” OR “ethnography” OR “ethnographic model” OR “case
study” OR “case study model” OR “historical model” OR “mixed methods”

Data Collection

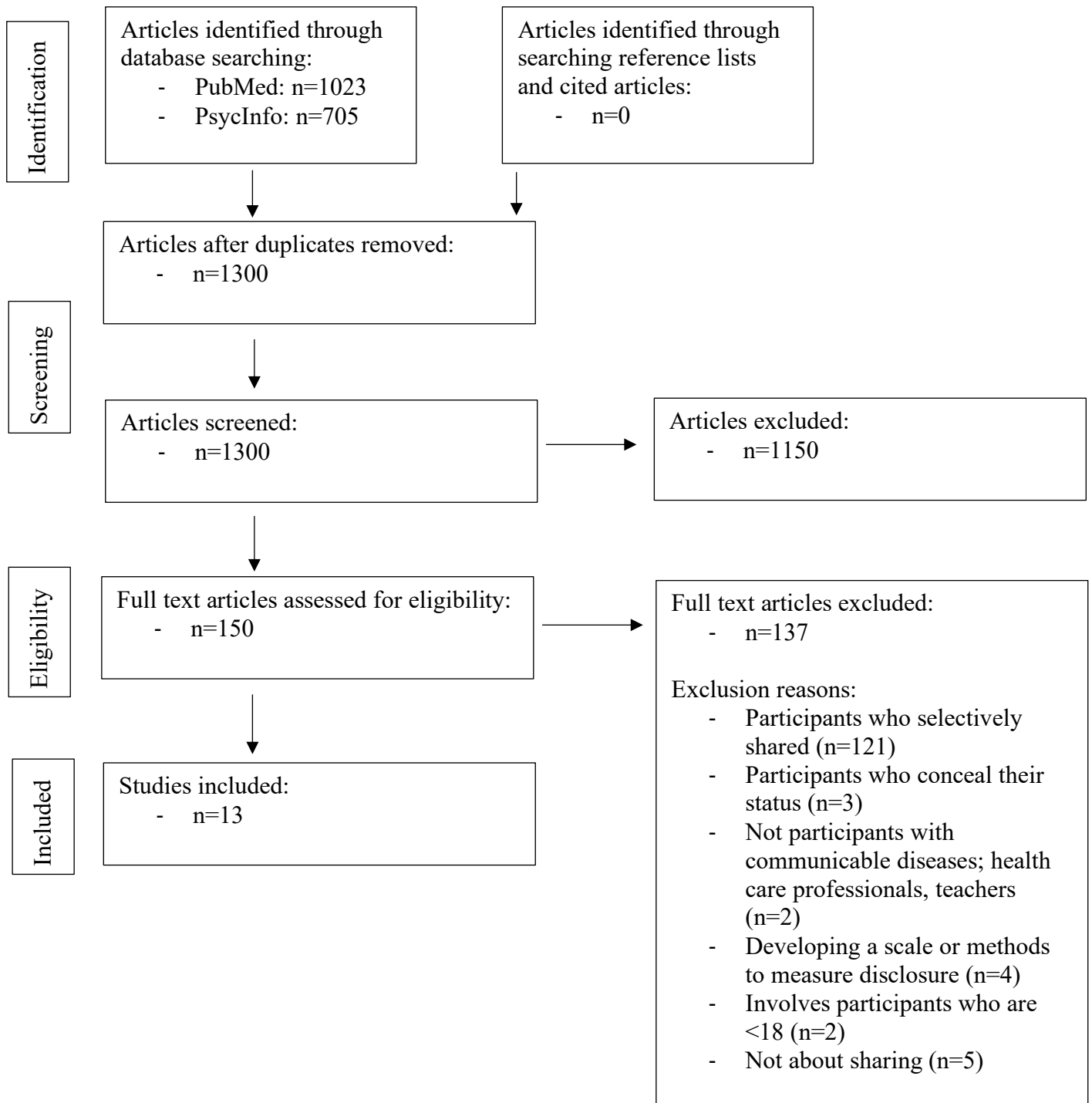
Using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines, the articles were identified, screened and quality assessed (Moher et al., 2009). The database searches were completed on 28th September 2020 and the articles meeting the criteria were identified. Duplicate articles were removed by the primary researcher.

The first step of eligibility screening involved the primary researcher and a second reviewer (a third-year psychology undergraduate student) independently screening the titles and abstracts of all the articles. At this stage, any articles considered to be eligible by either reviewer were included in the next stage of the eligibility process.

The full texts were independently screened, again by the primary researcher and the second reviewer. Reasons for excluding articles at this stage were documented. Inter-rater agreement was calculated using Cohen's Kappa (0.46) indicating a moderate reliability of inter-rater agreement (McHugh, 2012)(Appendix A). Any disagreements between the primary researcher and the second rater were reviewed by a third rater with expertise in the field. There were 46 disagreements at the title and abstract screening stage and 14 disagreements at the full text screening stage. The main reasons for disagreement were predominantly regarding whether the participants were using an open sharing strategy or a selective strategy.

Figure 1

PRISMA Diagram (Moher et al., 2009)



Data Extraction

The following information was extracted from the studies that were included: author, publication date, study design, study location, sample characteristics, qualitative methodology used, interview questions or focus of the study and themes regarding experiences of open sharing. Themes included factors linked to helping or inhibiting sharing and perceived benefits or negative experiences following sharing that might influence onward sharing.

The review looked to understand the themes linked to open sharing of communicable disease status. These themes included the experiences of sharing. Thoughts or concerns pre-sharing were looked for and included anticipated stigma or hopes for sharing. Other themes included the outcome of sharing, both personally in terms of internalised stigma and any benefits to their physical health condition, and within their relationships, for example the support they might or might not receive and any impact on the closeness of their relationship. Finally, further themes included whether their experiences of sharing have impacted further decisions to share.

Quality Assessment

The quality assessment tool used was adapted from the Cochrane Critical Appraisal of Qualitative Research (Hannes, 2011). The adapted version of this tool was adapted by and used in Evangeli, Pady and Wroe's systematic review (2016). The tool assesses four areas of quality within a study. These areas are 'Credibility', 'Transferability', 'Dependability' and 'Confirmability'. To meet each of these criteria, it was decided that each study would need to meet at least two of the sub-categories within each area. This was how the tool was used in Evangeli et al.'s (2016) review.

Quality assessment was completed by the primary researcher and second reviewer independently. Ratings for each sub-category within one of the four domains were compared by the primary researcher and any disagreements were reviewed by a third rater with expertise in the field who determined the outcome. Specific areas disagreed on included what constituted a 'thick description of sending and receiving context', 'greater than or equal to 80% response rate', 'peer review', 'audit trails' and 'reflexivity'.

Table 1

Quality Assessment Tool adapted by Evangelini et al., (2016). Tool adapted from Hannes, (2011)

Credibility	
1. Do the findings hold true?	<ul style="list-style-type: none"> At least 2 of the following used: member checks, outside auditors, attention to negative cases, independent analysis by more than one researcher, verbatim quotes, sufficient data presented to support the findings, consideration of data saturation.
Transferability	
2. Are the findings transferable to other settings?	<ul style="list-style-type: none"> At least 2 of the following used: rich detail of study participants including contextual background information and demographics, thick description of sending and receiving context, statement of sampling strategy that shows that convenience sampling was not used, $\geq 80\%$ response rate.
Dependability	
3. Is the research logical, traceable, and clearly documented?	<ul style="list-style-type: none"> At least 2 of the following used: peer review, debriefing, audit trails, self-critical reflexivity, inter-rater agreements, detailed description of analysis process including explanation of how data presented was selected from original sample.
Confirmability	
4. Is the analysis grounded in the data?	<ul style="list-style-type: none"> At least 2 of the following used: assessing the effects of the researcher during all steps of the research process, reflexivity, background information presented on researcher's background, education, and school of thought.

Data Synthesis

Data synthesis was carried out using a thematic synthesis approach as found in a paper by Snilstveit, Oliver, & Vojtkova (2012). The steps were developed by Thomas & Harden (2008) and involve three steps. Firstly, coding the text, then developing descriptive themes and finally generating analytical themes. Coding involves line by line coding of the findings in each included study. Secondly, similar codes are clustered together and a new overarching code, known as a descriptive theme, is developed. Finally, analytical themes are generated by the researcher interpreting the descriptive themes relevant to the review question.

Results

Overall Study Characteristics

Thirteen studies were included in the systematic review. Twelve studies were qualitative studies, and one was mixed methods. Studies were published between 2002 and 2020. Research took place in Canada, Denmark, Kenya, Uganda, one study took place across five African Countries (Lesotho, Swaziland, South Africa, Malawi and Tanzania) and eight studies took place in the United States of America (USA). The sample size ranged from 8 to 225 (median: n=30). Seven studies included male and female participants, whilst five were female only studies, and one study was male only. Twelve of the studies inclusion criteria was PLWH, whilst the other study was specifically for participants with Hepatitis C, and HIV was one of the exclusion criteria. Two studies' inclusion criteria included either men who have sex with men (MSM) or homosexual and bisexual females. All the other studies either included heterosexual, homosexual or bisexual participants, or did not state the sexuality of participants.

For the majority of studies, data was collected using semi-structured interviews (n=9). One study conducted focus groups before undertaking semi-structured interviews, whilst another study conducted semi-structured interviews in groups and then individual semi-structured interviews. One study purely used focus groups to gather data and the final study wrote field notes alongside an intervention.

Different qualitative methods were used to analyse the data. These included Thematic Analysis, Grounded Theory, Content Analysis and an "Iterative Coding Process". Further details of the studies, including themes associated with sharing openly, can be found in Table 2.

Table 2*Summary of Included Studies Table*

Reference	Study Design	Location	Sample	Qualitative Methodology	Interview Questions or Focus of Study	Experiences of Sharing Openly
Black & Miles (2002)	Qualitative, descriptive, intervention with field notes Part of a larger RCT	USA	N=48, Women, African American, PLWH (7 were HIV positive grandmothers but primary carers) Age=22-65 (Mean=37, SD 9.2) 38% (n=18) married or living with a partner Length of time since diagnosis = 5.5. (2-11, SD 2.6)	Intervention with field notes made of each visit Content analysis and constant comparison (Lincoln & Guba, 1985)	Assessed disclosure goals	<u>Factors Pre-Sharing:</u> - Not wanting to lie - Hoping to get support - Wanting to educate others - Raising awareness or protecting others - Blame or “getting even” <u>Process for Sharing:</u> - Open within all adult relationships <u>Outcomes Post-Sharing:</u> - Educating others
Carnes, Carey,	Qualitative, semi	USA	N=84; Men, ≥18, PLWH, Black and/or	Thematic analysis	Exploring participants’	<u>Factors Pre-Sharing:</u> - Help with treatment adherence

Gelaude, Denson, & Bessler (2020)	structured interviews		<p>Latino, MSM, spoke English or Spanish</p> <p>15% (n=13) 20-29; 20% (n=17) 30-30, 33.8% (n=28) 40-49; 31.3% (n=26) 50-59</p> <p>59.5% (n=50) Black African/American, 36.9% (n=31) Hispanic/Latino, 3.6% (n=3) Black/Hispanic Latino</p> <p>69% (n=58) Gay/homosexual, 20.2% (n=17) bisexual, 10.7% (n=9) something else or other</p>		<p>degree of care engagement and HIV disclosure and social support</p> <p>Analysed response frequencies for select thematic codes (1) the number of person roles the participant reported disclosing to (2) time since diagnosis and first disclosure (3) disclosure for support in managing their care</p>	<p>- Hoping to get support</p> <p><u>Process for Sharing:</u></p> <p>- Telling all friends and family</p>
Emlet (2008)	Qualitative; semi structured	USA	<p>N=25</p> <p>Criteria: ≥ 50 years PLWH</p>	Development of conceptual model Open coding (Strauss & Corbin,	<p>“Tell me about a time you felt discriminated against or</p>	<p><u>Factors Pre-Sharing:</u></p> <p>- Not wanting to lie</p> <p>- Wanting to speak up</p> <p>- Age helping with sharing</p>

	interviews, cross sectional		<p>Aged 50-72 (m=56.1, SD=5.75),</p> <p>68% (n=17) male, 32% (n=8) female 60% (n=15) white, 36% (n=9) African American, 4% (n=1) Non-White Hispanic</p> <p>Route of HIV transmission: 36% (n=9) exposed through MSM, 36% (n=9) exposed through heterosexual sex and 16% (n=4) through injection drug use, 4% (n=1) through contaminated blood and 8% (n=2) unknown</p>	1998), Grounded Theory (Strauss & Corbin, 1998)	mistreated because of being older and having HIV disease” and “What do you think society should know about being older and having HIV disease?”	<p>- Wanting to educate others</p> <p>- Wanting to raise awareness and reduce further spreading of HIV</p> <p><u>Process for Sharing:</u></p> <p>- Process of ‘coming out’, where once decision to share was made it was then public information</p> <p><u>Outcomes Post-Sharing:</u></p> <p>- Catharsis</p>
Gillett & Parr (2010)	Qualitative; semi structured	Kenya	N=21; Women, PLWH	Thematic analysis/approach	“Why do women living with HIV	<p><u>Factors Pre-Sharing:</u></p> <p>- Seeing others sharing</p> <p>- Hoping to get support</p>

	<p>interviews</p> <p>Focus groups and then semi-structured interviews with three support group members and two support group leaders</p>		<p>62% (n=13) 40-53, 38% (n=8) 20-39</p> <p>All Christian</p> <p>33% (n=7) married, 9% (n=2) boyfriends, 33% (n=7) widowed (5 tested positive for HIV after husband died from AIDS)</p> <p>Time since diagnosis: 3 months - 7 years (majority over 3 years)</p> <p>Support group members between 4 months and 4 years</p>	(Miles & Huberman, 1994)	<p>choose to disclose their status?"</p> <p>"Why do women living with HIV choose to withhold their status?"</p> <p>"What are your experiences of HIV status disclosure and/or what are the experiences of people you know?"</p> <p>"What are your opinions about the support groups, did the support groups influence your decision to disclose your HIV status?"</p>	<ul style="list-style-type: none"> - Fears of rejection - Acceptance - Wanting to help others living with HIV - Fears of stigma - Help with treatment adherence - Raising awareness of HIV - Having support - Wanting to educate others - Feeling obliged to share <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Does not mind who they share with
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Greeff et al., (2008)	Qualitative, descriptive, focus groups	5 African countries; Lesotho, Swaziland, South Africa, Malawi & Tanzania	<p>N=225 (39 focus groups), 49.3% (n=111) PLWH of those: 46.8% (n=52) men, 53.2% (n=59) women</p> <p>Mean age 36.8</p> <p>Of focus groups 53.8% (n=121) urban settings and 46.2% (n=103) rural</p>	Tesch Open coding technique (Cresswell, 1994)	<p>Focus groups discussions: Aimed to understand an “emic view” of PLWH of stigma and discrimination.</p>	<p><u>Factors Pre-Sharing:</u></p> <ul style="list-style-type: none"> - Faith - Having support - Seeing others sharing - Hoping to get support - Health deterioration - Wanting to protect family or children - Having information - Economic factors - Raising awareness or protecting others - Acceptance <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Sharing with everyone they have relationships with - Speaking publicly at events <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Educating others - Wanting to speak up - Not being believed about HIV status
Hatala et al., (2018)	Qualitative; Two rounds of semi structured	Canada	N=21; PLWH, 55% (n=12) male, 45% (n=9) female, all Indigenous	Constructivist grounded theory approach for data generation and	First round: more generally about health	<p><u>Factors Pre-Sharing:</u></p> <ul style="list-style-type: none"> - Fears of stigma - Positive outcomes outweighing negative outcomes

	interviews		No further demographics	analysis (Charmaz, 2006; 2011)	Second round: more specifically on HIV treatment and care as well as experiences of illness disclosure	<ul style="list-style-type: none"> - Not wanting to lie to others - Others being knowledgeable about HIV - Positive previous experiences of sharing - Raising awareness of HIV and preventing further spread - Confidence to challenge stigma - Increased self-esteem or sense of self - Hoping to get support - Fear of rejection - Wanting to educate others - Difficulties with mental health - Acceptance - Helping others living with HIV <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Increased sense of purpose - Helping others living with HIV - Having a sense of belonging to something - Self-acceptance - Getting support - Trying to help with wider systemic difficulties - Strengthening relationships
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						- Educating others
Hult et al., (2012)	Mixed methods; Longitudinal cohort study	USA	<p>N=75 (but data of first 50 analysed); 92% (n=69) male, 8% (n=6) female</p> <p>Criteria: HIV diagnosis within 8 weeks (Range 1-14), English speaking, ≥ 18, be able to consent</p> <p>63% (n=47) Caucasian, 19% (n=14) African American, 12% (n=9) Latino, 6% (n=5) Asian</p> <p>78% (n=59) gay, 8% (n=6) heterosexual, 14% (n=10) bisexual/other</p> <p>Sharing patterns: 32% (n=16) stigma concerns, 16% (n=8)</p>	Thematic analysis; developed case summaries	Experiences of disclosure experience, including who, when, why, how, what the response was and how they felt	<p><u>Factors Pre-Sharing:</u></p> <ul style="list-style-type: none"> - Hoping to get support - Positive outcomes outweighing negatives - Having support - Self-acceptance - Feeling obliged to share - Others having knowledge of HIV - Not wanting to lie to others <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Initially sharing with close friends, family or partner - Sharing with a small number of people initially and a wider group within 3-9 months post diagnosis - Negative reactions not deterring future sharing <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Getting support - Receiving some mixed reactions

			social isolation, 30% (n=15) strategic disclosure, 22% (n=11) universal disclosure			
Machtiger et al., (2015)	Qualitative; semi structured interviews	USA	<p>N=8, Women, PLWH</p> <p>Aged between 23-65 mean=48, SD=14</p> <p>N=5 African American, n=1 Caucasian, n=1 Cherokee, n=1 more than one ethnicity (other)</p> <p>n=1 bisexual, n=7 heterosexual</p> <p>Length of time since diagnosis: mean = 13, range= 1-24 years</p> <p>All taking ART</p>	Thematic analysis (Braun & Clarke, 2006)	Public disclosure experiences and possible impact on interactions and relationships with others	<p><u>Factors Pre-Sharing:</u></p> <ul style="list-style-type: none"> - Educating others - Feelings of safety - Acceptance - Confidence to challenge stigma <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Sharing with smaller groups before publicly sharing <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Sisterhood - Catharsis - Self-acceptance - Safer and healthier relationships - Educating others - Increased sense of purpose - Health outcomes - Not having to lie - Acceptance from others - Sense of belonging

						<ul style="list-style-type: none"> - Helping with other difficult experiences - Negative experience for child of participant
Medley, Kennedy, Lunyolo, & Sweat (2009)	Qualitative; semi structured interviews	Uganda	<p>N = 30</p> <p>Criteria: Women, 18-49 years old, diagnosed with HIV for at least 1 month, currently pregnant or given birth in the previous year</p> <p>18 - 39 years old, median=28</p> <p>Length of time since diagnosis 1 month - 15 years (median = 12 months)</p> <p>20% (n=6) post-test support groups, 47% (n=14) urban clinics, 33% (n=10) rural clinics</p>	Iterative coding process (Bernard, 2000)	Experiences of finding out HIV positive, disclosure of HIV status, barriers to disclosure, stigma and discrimination	<p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Acceptance from others - Experiencing discrimination - Not having to lie - Educating others - Not being believed - Experiencing rejection - Getting support
Ortiz, (2005)	Qualitative, cross sectional	USA	N=19, ≥18, PLWH, Latina's (women),	Content analysis	Experiences of living with	<u>Factors Pre-Sharing:</u>

	descriptive study; semi structured interviews		<p>85% (n=16) Mexican American, 5% (n=1) Nicaraguan, 5% (n=1) Puerto Rican, 5% (n=1) Salvadorian</p> <p>50% 30-39 and mean age 37.6</p> <p>12 single; 9 never been married, 3 divorced. 5 were married, 2 were widows</p>		<p>HIV/AIDS in San Francisco Bay Area and links between social context and disclosing HIV status</p>	<ul style="list-style-type: none"> - Positive previous experiences of sharing - Not wanting to lie to people - Raising awareness and reducing the onward spread of HIV - Deterioration in physical health - Felt obliged to tell people - Wanting to educate others - Testing relationships with people - Hoping to get support <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Telling close friends and family initially - Telling everyone they see - The more people they told, the easier it became to share <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Building stronger relationships - Self-acceptance
Rodkjaer, Sodemann, Ostergaard, & Lomborg (2011)	Qualitative; semi structured interviews, cross sectional	Denmark	<p>N=16, 25% (n=4) women, 75% (n=12) men, PLWH</p> <p>Aged: 22-66</p>	Glaserian Grounded theory (Glaser, 1978; Glaser & Strauss, 1967; Lomborg & Kirkevold, 2003)	Experiences of living with HIV including facilitators and barriers and coping strategies	<p><u>Factors Pre-Sharing:</u></p> <ul style="list-style-type: none"> - Prepared to face prejudice - Having information about HIV - Not wanting to lie to others - Having support - Prepared to manage others' reactions

			<p>50% (n=8) homosexual, 50% (n=8) heterosexual</p> <p>50% (n=8) diagnosed before 1996</p>			<ul style="list-style-type: none"> - Does not mind who knows - Positive anticipated outcomes outweighing negatives - Acceptance <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Thought of as an individual process - Most people adopting a no sharing or limited sharing strategy initially before becoming more open - Would often get to know people before sharing their status <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Self-acceptance - Not having to lie to others - Experiencing rejection
Suarez (2019)	Qualitative; semi structured interviews	USA	<p>N=53; 55% (n=29) men and 45% (n=24) women</p> <p>People living with Hepatitis C</p> <p>4% (n=2) 20-30, 13% (n=7) 31-40, 40% (n=21) 41-50, 36%</p>	<p>Initial coding (Charmaz, 2002)</p> <p>Analysis approach: between technical approach vs emergent intuitive approach due to specific research questions in mind</p>	Experiences of people living with hepatitis C, including knowledge of the disease, experiences with stigma and discrimination, disclosure	<p><u>Factors Pre-Sharing:</u></p> <ul style="list-style-type: none"> - Wanting to speak up - Health deterioration - Having support - Help with treatment adherence - Faith - Privilege - Feeling obliged to share - Wanting to protect others - Wanting to support others

			<p>(n=19) 51-60, 7% (n=4) 61-70</p> <p>64% (n=34) Caucasian, 30% (n=16) African American, 6% (n=3) Asian</p> <p>Mode of transmission: 55% (n=29) drug related, 24% (n=13) transfusion/surgery, 9% (n=5) unknown mode, 6% (n=3) sex/household contact, 4% (n=2) tattoo, 2% (n=1) occupational needle stick</p> <p>People co-infected with HIV were excluded</p> <p>Disclosure Patterns: Activist: 9% (n=5)</p>	<p>e.g. strategies of disclosure) (Marshall & Rossman, 1999).</p>	<p>practices and coping techniques</p>	<ul style="list-style-type: none"> - Wanting to reduce stigma - Hoping to get support - Wanting to educate others <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Activists sharing to educate public, support others and reduce stigma - Open disclosure sharing as they saw it as the right thing to do and for support - Sharing patterns are not static but change over time and thoughts around sharing can change <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> -Self-acceptance - Experiencing discrimination
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			<p>(middle class); Open: 38% (n=20); Limited: 38% (n=20), Reluctant: 15% (n= 8)</p> <p>1 (6%) of African Americans embraced open disclosure, while all others engaged in limited and reluctant disclosure</p>			
Teti, Hayes, Farnan, Shaffer, & Gerkovich (2018)	Qualitative; Semi structured interviews in groups - 3 meetings then the exhibit and then a 1:1 interview	USA	<p>N=38, ≥18, PLWH willing to be able to take, discuss and exhibit photographs, MSM or bisexual</p> <p>21% (n=8) men and 79% (n=30) women</p>	<p>Photographs, individual interviews and groups interviews</p> <p>Theme (Charmaz, 2006) and Narrative (Riessman, 1993) analyses to analyse and to organise the data</p>	<p>Explore how the process helped them to express their experiences of HIV e.g., “what did you learn about yourself, what story did your pictures tell about your life with HIV?”</p>	<p><u>Factors Pre-Sharing:</u></p> <ul style="list-style-type: none"> - Not minding who knows - Educating others <p><u>Process for Sharing:</u></p> <ul style="list-style-type: none"> - Interviews in local papers and radio stations <p><u>Outcomes Post-Sharing:</u></p> <ul style="list-style-type: none"> - Not having to lie - Rejection - Helping others living with HIV - Sense of belonging - Catharsis - Self-acceptance

Synthesis of Study Findings

The findings from each study were synthesised using a thematic synthesis approach (Snilstveit et al., 2012). Only qualitative data was synthesised. Additionally, only findings related to the systematic review question were synthesised, namely experiences of sharing openly. Overarching descriptive codes were developed based on clustering together similar initial codes. Analytical themes were generated by interpreting the descriptive themes (Thomas & Harden, 2008). Six analytical themes were identified: 'Fears for Sharing Openly', 'Assists with Sharing Openly', 'Reasons for Sharing Openly', 'Methods of Sharing Openly', 'Benefits of Sharing Openly' and 'Negatives of Sharing Openly'. The analytical themes were divided into three categories 'Factors Pre-Sharing Openly', 'Process for Sharing Openly', 'Outcomes of Sharing Openly'. Quotes linked to each descriptive code can be found in Table 3, demonstrating how the codes were developed from the data.

Factors Pre-Sharing Openly

Fears for Sharing Openly

Only two studies (15%) indicated that participants had fears for openly sharing. These fears were linked to either rejection (Hatala et al., 2018) or enacted stigma, such as discrimination (Gillett & Parr, 2010).

Assists with Sharing Openly

Nearly all studies (n=10) reported factors that helped participants with sharing. Seven descriptive codes were developed across the studies. The most common factor mentioned was acceptance about their illness. This was a factor spoken about in seven studies, whether this was accepting their condition or coming to terms with their illness

(Gillett & Parr, 2010) and having the confidence to challenge the stigma associated with it (Hatala et al., 2018). Another key factor linked to helping people share openly was having support of others. This was a theme in six studies, whether that was support groups (Suarez, 2019), support from family (Rodkjaer et al., 2011) or counselling (Greeff et al., 2008) as well as having support leading to feelings of safety which have helped people to share (Machtinger et al., 2015). Other factors thought to help with openly sharing were having faith and being informed. Factors such as age (Emlet, 2008), being prepared to manage others' reactions, including possible prejudice (Rodkjaer et al., 2011), and privilege (Suarez, 2019) were only mentioned in one study each.

Reasons for Sharing Openly

Twelve of the 13 studies (92%) included reasons for openly sharing the status of their communicable disease, with 12 descriptive codes developed. These factors could be further subdivided into personal and social reasons for sharing. Personal reasons were economic factors, health deterioration, hoping to get support, not wanting to lie, positive outcomes outweighing negative outcomes, positive previous experiences, and relationships. Social factors were blame or 'getting even', educating others, others having knowledge, seeing others share and supporting others. Personal factors that were repeatedly mentioned in studies were around support and not wanting to lie (n=8). Other factors such as economic factors, health deterioration, positive outcomes outweighing negatives, positive previous experiences and relationships were included in between one and four studies, possibly showing the more important factors were people hoping to get support and not wanting to lie within their relationships. In terms of the social factors, themes that were repeatedly mentioned included educating

others (n=9) and supporting others (n=8). Educating others was in the context of trying to raise awareness of the communicable diseases to prevent them from spreading (Black & Miles, 2002) as well as reducing stigma (Suarez, 2019).

Process for Sharing Openly

Methods of Sharing Openly

The majority of studies (n=11) noted themes that were related to how people might openly share their status, and how they reach the point where they choose to share openly. There were six descriptive codes developed from this. These were typically only mentioned in one study with one exception where three studies found that people would initially share with close friends and family before choosing who else to share with (Carnes, Carey, Gelaude, Denson, & Bessler, 2020; Hult et al., 2012; Ortiz, 2005). They demonstrated that choosing to share openly is a process over time (Hult et al., 2012) and that all patterns for sharing change over time (Suarez, 2019). Other studies found that some people will share with people when they see them (Ortiz, 2005), whilst others would want to wait to get to know people before sharing or might not actively tell everyone but would not lie if asked (Rodkjaer et al., 2011).

Outcomes of Sharing Openly

Benefits of Sharing Openly

69% (n=9) studies included the benefits of sharing. There were nine descriptive codes identified as being benefits of sharing. The most commonly reported benefits (n=6) were getting support and acceptance of condition. Acceptance was sub-divided into self-acceptance (n=5) and acceptance from others (n=2). The next most recounted factor was educating others (n=4) and catharsis (n=3). The remaining factors were all

reported in one or two studies. As with the reasons for sharing, the benefits could be seen as personal and social benefits.

Negatives of Sharing Openly

Negative outcomes following openly sharing were reported by participants in 54% of studies (n=7). There were three descriptive codes developed from the initial coding with rejection being an outcome for participants in three studies. Participants in two studies reported experiencing discrimination following openly sharing, whilst in one study participants reported not being believed (Medley et al., 2009).

Table 3*Synthesis of Studies Table*

Category	Analytical Theme	Descriptive Code	Quote Example
Factors Pre-Sharing Openly	Fears for Sharing Openly	Rejection	"There is a time when you're scared to tell people, because you're scared of the reaction you're going to get. When I first got sick, I was scared to tell my family because I was scared they would push me away. But I did tell them anyway. I don't think anybody should hide it" (Hatala et al., 2018, p.7)
		Stigma or Discrimination	Fear of slander and abandonment. A major barrier to disclosure was fear of slander within the community, with the women reporting that HIV infection is associated with promiscuity and witchcraft (Gillett & Parr, 2010, p. 340)
	Helps with Sharing Openly	Acceptance	"Once you want to disclose, first you have to accept yourself, accept your status and accept the way you are...meeting others who are like me has helped."(Gillett & Parr, 2010, p.341)
		Age	"That's probably part of why I'm so open about disclosing and [doing] speaking engagements, because there's a lot of people younger than me who don't go out and speak because they don't want anyone to know. I think that's partly an age factor. After years of holding all that in and not wanting to disclose, it's like opening up the dam. It's like I don't care who knows, everybody can know.'" (Emlet, 2008, p.715)
		Being Informed	"Counseling, information, education, and advice were seen as facilitating actions in this study." (Greeff et al., 2008, p.320)
		Faith	"It is important to note that disclosure patterns are not static. For example, religiosity was a catalyst for a shift to more open disclosure for one participant. Catherine, the only African American in this group, began to disclose more

			openly over time. She coped with her health and illness through her faith and felt that she should be more open as a testament to her God" (Suarez, 2019, p.1652)
		Having Support	"All five persons were involved in support groups, which may help explain their desire to share information with others although it is unclear which came first." (Suarez, 2019, p.1651)
		Prepared to Manage Others Reactions	"The HIV-positive person had to be prepared to face stigmas and prejudices, and to support the persons to whom he or she had disclosed." (Rodkjaer et al., 2011, p.1253)
		Privilege	"All respondents except Connie, a middle-class Asian woman, were White and middle class. Only one participant reported drug use as a mode of acquisition though his other privileged positions (e.g. White, middle-class male) may have minimized fear of discrimination. Thus, this disclosure pattern was mostly limited to middle-class White participants, who have more structural and cultural privileges to balance the potential stigma from disclosure. African American participants, however, did not engage in activist disclosure." (Suarez, 2019, p.1652)
	Reasons for Sharing Openly	Blame or 'Getting Even'	"She had told them for a number of reasons, which she had carefully evaluated. One reason was a desire to get even with the man who gave her the infection. "I do think my friend had AIDS. I couldn't believe it when he told me I needed to get checked. I know I told some people to get back at him."" (Black et al., 2002, p.694)
		Economic Factors	"Economic factors, such as lack of money to access medical services, made them disclose to health professionals. Because poverty is a big problem in Africa, this aspect is different to what is stated in the literature: "Since I had no money I had to tell the doctor the truth, that I am HIV positive."" (Greeff et al., 2008, p.319)
		Educating Others	"Community education 'We do health education in schools, churches and even in the marketplace. Education shows people it's a disease that you can get without being immoral' (support group leader, age 41). 'Yes, and let them [the

			community] all be educated, because they are still holding onto the old myths that if you are cut you will be infected, if you share a cup you will get infected; yes, they are still holding onto the old teachings, let them be changed and told' (farmer, age 42). " (Gillett & Parr, 2010, p.341)
		Health Deterioration	"Ability to care for oneself. There were perceptions of risks among the women when timing their disclosures. The women would find it necessary to disclose their diagnosis if the women perceived a change in health status or when there was a noticeable physical change that would affect their everyday functioning or care-taking ability. 9: I really worry that if I do really get sick [I will have to tell my mother]. 7: [If I become ill] then I will have to tell. Because they [brother and sister] will notice [I am ill], but I see no reason [to tell them now because] the last ten years I've been healthy." (Ortiz, 2005, p.213)
		Hoping to Get Support	"If support could be gained by disclosure, like prayer, the people living with AIDS seemed more open to disclosure. This once again confirms the literature: "I wrote to my parents and all my relatives who cared for me, asking them to pray for me."" (Greeff et al., 2008, p.319)
		Not Wanting to Lie	"I didn't put a lot of thought into telling my close friends. Because I feel like any kind of secrecy I have around it and not wanting to tell people I really trust and love, I feel like it might be really unhealthy to store that inside right now, any kind of guilt or shame, because it's not how I feel about it." (Hult et al., 2012, p.186)
		Others Having Knowledge	"In all of the cases where participants decided to disclose their HIV status to a family member, they suggested a key reason was that they had faith that their family had a good understanding of the condition and would respond accordingly." (Hatala et al., 2018, p.7)

		Positive Outcomes Outweighing Negatives	"In all of these descriptions, participants noted fears of rejection and stigma from within the family, yet they made decisions to risk this potential social harm to get support and care from family members" (Hatala et al., 2018, p.7)
		Positive Previous Experiences	"The Latinas expanded their disclosing to other friends and even strangers after initial disclosing to their family members. Disclosing to the important people in their lives lessened their fears of telling other people about their seropositive status." (Ortiz, 2005, p.213)
		Relationships	"Latinas disclosed to people with whom they wanted to establish a relationship. They disclosed to a potential friend to allow the person to assess the situation to see if he or she wanted to continue or end the relationship. This process helped the women decrease the risk of rejection. 11: If I'm going to make a friend and I need somebody to talk to them, I will tell them [my diagnosis]. I tell these people [potential friends] straight out first. They can accept me or they can just go about their business. . . . That way ...I am not going to get hurt very much; still it's going to hurt me to be rejected. 9: Let me tell you so you can leave and get out of my way....I think a lot of that rejection [when] telling somebody. I [have] gotten to the point where I feel I am not going to put up with their BS and dance around a little square for them and not tell them.No, I [would] rather tell them so they can leave if they are going to leave." (Ortiz, 2005, p.213)
		Seeing Others Share	"Interaction in a group of other infected people or when another infected person disclosed his or her status tended to give people living with AIDS more courage to disclose their status than when alone in this situation." (Greeff et al., 2008, p.320)
		Supporting Others	"Activist disclosure refers to those who widely disclosed to family, friends, coworkers, and, importantly, the general public. While these participants disclosed for a variety of reasons, they specifically discussed their disclosure

			practices in terms of educating the public, supporting other persons with hepatitis C, and to reduce stigma" (Suarez, 2019, p.1649)
Process for Sharing Openly	Methods of Sharing Openly	Process Over Time	"The participants in this group disclosed their HIV status to many different people in their social network. They typically disclosed to an initial group of people right after getting diagnosed, and then told an increasing number as well as a wider circle of people by 3 and 9 months after diagnosis." (Hult et al., 2012, p.186)
		Strategies Changing Over Time	"It is important to note that disclosure patterns are not static." (Suarez, 2019, p.1652)
		Tells Everyone	"Everybody I see, out of my family, everyone knows. Whenever I see a friend, I let them know. They say how are you doing? and I say I have the virus. I am HIV positive. I always tell people because I might be on a poster or something. ...I am real open, I don't have a problem [about telling people]. Now [that] my family knows, I don't care about the rest." (Ortiz, 2005, p.213)
		What Might Change Strategy	"In contrast to the Stigma Concerns group, receiving negative reactions from others did not deter the Universal Disclosure participants from continuing to disclose. However, over time, 3 participants in this group did become more selective in their disclosure. I have a friend of mine who told me, unless it is important for the basis of your relationship to continue, nobody really needs to know! [Male, African American, age 43]" (Hult et al., 2012, p.186)
		Who People Share With	"Of those who did disclose to family, the mother was the most common person disclosed to, with fathers and other siblings disclosed to less frequently. Other relationship domains in which participants disclosed included past sex partners, housemates, support groups, co-workers, and acquaintances. Most participants recounted disclosing to sex partners either just previous to engaging in sexual activity or by seeking out sex partners with the same HIV status in advance (serosorting)." (Hult et al., 2012, p.183)

		When People Would Share	"Choosing the open strategy did not mean disclosure to everyone the participants met, but if people asked them they would disclose their status. Unintentional disclosure and concerns about others finding out about their HIV in an inadvertent way was the reason for choosing this strategy. The participants who chose the open strategy wanted people to get to know them a bit before they told them about their HIV status, especially people they were or wanted to be close to. This approach was chosen so as to be seen as the person they were without interference from other people's opinions and prejudices about HIV." (Rodkjaer et al., 2011, p.1253)
Outcomes of Sharing Openly	Benefits of Sharing Openly	Acceptance	"Being open helped the HIV-positive persons accept their new identity by balancing their integrity with their HIV status" (Rodkjaer et al., 2011, p.1253)
		Catharsis	"Because having that secret for so long and now I don't have that, it – like a big old load had been lifted and I don't have to feel ashamed no more" (Machtinger et al., 2015, p.192)
		Educating Others	"A societal benefit of disclosing for several participants was that of helping others understand the importance of preventing HIV" (Black & Miles, 2002, p.692)
		Health Outcomes	"The impact of Medea is consistent with, and adds to, an emerging literature describing the positive impacts of disclosure (of HIV and other stigmatizing experiences) and ET on the health and emotional outcomes of WLHIV" (Machtinger et al., 2015, p.194)
		Help with Other Difficulties	"While HIV disclosure was a focus of Medea, storytelling included the disclosure and processing of other stigmatizing and traumatic experiences with the support of a diverse group of women" (Machtinger et al., 2015, p.194)
		Helping Others	"Thus, being a helper is fundamentally an identity of moral empowerment and is focused around a notion of giving or offering one's voice, to speak about one's truth, and experience in such a way as to be a source of social benefit and good for others" (Hatala et al., 2018, p.9)

		Increased Sense of Purpose	"Participants described improved self efficacy in many ways, including an increased sense of purpose, accomplishment, and motivation" (Machtinger et al., 2015, p.194)
		Relationships	"So it was very healing, personally going through a process of navigating being newly diagnosed. And it was fun. You know, there was always laughing, always funny stories, always whatever. There was – I mean it did feel like a very close bond with folks. You spend so much time. You reveal some of your deepest secrets that you can't reveal to anybody else" (Machtinger et al., 2015, p.192)
		Support	"A few participants had shared their HIV status with their entire communities. Women who had disclosed to their communities often expressed relief at not having to keep their diagnosis a secret, and they reported that the community was generally supportive of them." (Medley et al., 2009, p.1750)
	Negatives of Sharing Openly	Not Being Believed	"Other women said that at first, their family members did not believe they were serious: I told my sister but she doesn't believe me at all. She often tells me that being a last born, I like making up stories in order to attract attention; she has refused to accept that I tested positive for HIV. The reason she gives is that I look too fat to have the virus in me. The perception that women looked too healthy to have HIV was relatively common among family members who disbelieved the results." (Medley et al., 2009, p. 1751)
		Rejection	"Not everyone in the HIV-positive persons' network accepted their status, and some of their network might therefore disappear during the disclosure process" (Rodkjaer et al., 2011, p.1252)
		Stigma or Discrimination	"Among women who had disclosed their HIV status to other family or community members, 2 said that their family members reacted with pity toward them. A few reported that they had been gossiped about or stigmatized by neighbors." (Medley et al., 2009, p.1751)

Quality Assessment

All studies met the criteria for ‘Credibility’ with all studies paying attention to negative cases, including verbatim quotes and with sufficient data presented to support findings. Three studies included member checks, seven studies included independent analysis by more than one researcher and four included consideration of data saturation. No studies reported the use of outside auditors.

Only 23% of studies (n=3) met criteria for ‘Transferability’. These studies were Suarez (2019), Hatala et al., (2018) and Machtinger et al., (2015). Suarez (2019) included rich detail of study participants and provided a statement of sampling strategy showing that convenience sampling was not used. Hatala et al., (2018) and Machtinger et al., (2015) provided a thick description of sending and receiving context (i.e. demographic information about the researcher) and provided a statement of sampling strategy. Machtinger et al., (2015) also had a response rate of $\geq 80\%$. Some other studies included information about the sampling strategy but no further information within this criterion.

77% of studies (n=10) met criteria for ‘Dependability’. All studies included a detailed description of the analysis process and then one of peer review, debriefing, audit trails, self-critical reflexivity and inter-rater agreements. Only one study provided information about peer review (Hatala et al., 2018) and self-critical reflexivity (Rodkjaer et al., 2011).

8% of studies (n=1) met criteria for ‘Confirmability’. This study provided information regarding assessing the effects of the researcher during all steps of the

process and reflexivity (Rodkjaer et al., 2011). Other studies provided some information on the effects of the research, reflexivity or background information about the researcher's background, education and school of thought, however, did not provide sufficient information to meet two criteria.

Table 4*Quality Assessment Table*

Study	Criterion 1: Credibility	Criterion 2: Transferability	Criterion 3: Dependability	Criterion 4: Confirmability
Suarez, 2019	✓	✓	✗	✗
Carnes et al., 2020	✓	✗	✓	✗
Hatala et al., 2018	✓	✓	✓	✗
Teti et al., 2016	✓	✗	✓	✗
Machtinger et al., 2015	✓	✓	✓	✗
Hult et al., 2012	✓	✗	✓	✗
Gillett & Parr, 2010	✓	✗	✓	✗
Medley et al., 2009	✓	✗	✓	✗
Rodkjaer et al., 2011	✓	✗	✓	✓
Emlet, 2008	✓	✗	✗	✗
Ortiz, 2005	✓	✗	✗	✗
Greeff et al., 2008	✓	✗	✓	✗
Black & Miles, 2002	✓	✗	✓	✗

Discussion

Summary

The systematic review aimed to address the research question regarding ‘the experiences of people openly sharing their communicable disease status’, with the objective of critically analysing and synthesising themes associated with these experiences. Thirteen studies were reviewed, with 12 of them related to HIV and the final study about participants with Hepatitis C. Overall, experiences of openly sharing communicable disease status were found to fit into six themes, focussed on experiences before, during and after openly sharing.

Key Findings

The most spoken about analytical theme across the studies was the reason for openly sharing. There were many different reasons that participants spoke about, and the reasons had both personal and social motivators. The main descriptive themes were not wanting to lie, a personal motivator, educating others and supporting others, both social motivators, and getting support, both a personal and social motivator. There were no differences across the papers in terms of age, gender or cultural background for these themes. Not wanting to lie or feeling obliged to share might possibly be due to a moral dilemma, which has been shown to influence PLWH status sharing practices (O’Leary & Wolitski, 2009). Most research has found getting or giving support as well as educating others as being what individuals find to be a benefit of HIV status sharing rather than a motivator as found in these studies. Social support and sharing has been found to be associated previously (Smith et al., 2008). Additionally, it is important to consider that some of these studies were done in the context of support groups.

Therefore, people reporting that they were either hoping to get support or hoping to support others might be due to why they have attended the group rather than necessarily why they are sharing their status openly.

The findings regarding the methods of openly sharing were inconsistent. Eleven of the 13 studies reported when or to whom people choose to openly share and there was some agreement on it being a process that changes or develops over time. However, some participants appear to have adopted a strategy where they tell everyone whilst others might base it more on the closeness of that relationship, who might need to know or wait to get to know people before they share their status. Waiting to get to know people and sharing with more serious partners has been found in other research of PLWH (Obermeyer et al., 2011). One of the studies found that people who adopted a ‘universal disclosure’ strategy, were less likely to be deterred from sharing if they received a negative reaction (Hult et al., 2012). However, this needs to be interpreted with caution as over a quarter of those who did initially identify as ‘universal disclosure’ did become more selective with their sharing pattern due to negative experiences. The inconsistency in these findings overall possibly indicates that the process of openly sharing communicable disease status is an individual process that is changeable over time and that there are different factors, including all the other themes linked to pre and post sharing that help to inform the process.

Factors that were thought to assist with openly sharing their communicable disease status were reported in 10 studies. Of those 10, seven studies identified acceptance of their illness as being one of the factors that might help people to share their status. Literature looking at sexuality has focussed somewhat on identity or sense

of self and how that might help with someone openly sharing (Corrigan & Wassel, 2008). This has some level of similarity to what has been found with openly sharing communicable disease status. Included within this theme were individuals wanting to challenge the stigma around their illness. This is similar to findings around ‘coming out’ (Corrigan et al., 2013) but has not been found in more selective sharing of HIV status. Whilst acceptance was a common theme across most studies, there were other themes that varied study to study, such as being informed, having faith, and having support but these were not commonly reported themes.

Although benefits of sharing were mentioned in nine studies, there were no consistent findings with regards to what these benefits were. Nine main themes were found, with getting support and help with acceptance of condition being the most frequently reported. Getting support has previously been found to be a benefit in research looking at the ‘coming out process’ (Corrigan et al., 2009) and more selective HIV status sharing (Smith et al., 2008). However, given the inconsistency across these findings, it is hard to draw conclusions that can be transferred to other populations. There were some findings that seem to be reported in other research with regards to more selective HIV sharing which are congruent with the findings of the review, such as health outcomes, medication and treatment adherence and reducing onward transmission (King et al., 2008; Klitzman et al., 2004), however, this was only found in one study. Previous findings have found a link between sharing and treatment adherence, but it would be interesting to understand whether there is a difference in adherence between open and selective sharing strategies.

As has been found in literature looking at both more selective HIV status sharing and ‘coming out’, there are both positives and negatives linked to sharing (Corrigan et al., 2009; Daskalopoulou et al., 2017). Only seven studies reported negative outcomes following sharing, which were rejection, discrimination and people not being believed. For those who were not believed about their status, these were both women in African countries. Both of these were due to the way the individual looked, possibly indicating how some illnesses are perceived by the public and indicating there is a need for further education and awareness around communicable diseases. Both fear of rejection and discrimination were themes found to be fears pre-sharing. These were only themes generated from two studies. In both cases, rejection and discrimination are consistent with literature, whether that be HIV, sexuality or mental health.

One important finding is that the negative themes, either fears or outcomes, were not mentioned nearly as frequently as the more positive elements of sharing. This could be that people have not experienced negative thoughts or outcomes as much. Another possibility is social desirability bias (Paulhus, 1991), and participants not wanting to appear weak or be judged by the researcher or not wanting others to view openly sharing as a negative thing. Therefore, it is difficult to be certain about how often people have negative experiences of openly sharing their communicable disease status.

Finally, with some findings, in both the ‘assists with sharing’ and the ‘benefits of sharing’, it is difficult to know what the cause of those themes are. For example, acceptance and support are themes that appear in two distinct categories, however there is no way to know what the role of sharing, acceptance and support are on each other

and how much they impact each other. Therefore, they need to be interpreted with caution.

Strengths and Limitations of Included Studies

In terms of the quality assessment of the studies, a strength of the studies is that they all met criteria for ‘credibility’ meaning that the findings are likely to be a fair depiction of what the participants reported and experienced. Additionally, 10 of the 13 studies (77%) met criteria for ‘dependability’. This indicates that there is clear and transparent evidence of what each study did. However, only three studies met criteria for ‘transferability’, meaning that the findings are not transferable to other settings for the majority of studies. Transferability involves providing demographic information about both participants and the researchers, as well as using a sampling method that was not convenience sampling, and finally having a $\geq 80\%$ response rate. Only one study met the criteria for ‘confirmability’ (Rodkjaer et al., 2011). This indicates that there was not sufficient evidence provided within the studies to show whether the analysis was grounded in the data or not. The criteria for ‘confirmability’ were looking for evidence of reflexivity, not only about the research but also about the impact of the researcher’s theoretical orientation on the study. This is an important element of research, taking into account any possible assumptions or biases that might be made during the research, as well as reflections on the research as a whole. It might be that some of these studies did do these things however did not report them in the write up. Therefore, it would be beneficial if future studies report elements such as reflexivity clearly. Finally, only one study was non-HIV related. Therefore, it is difficult for the studies to be transferable to other person-to-person communicable diseases other than

HIV. This is possibly inferring the importance of further research into open sharing of other communicable diseases, not just HIV.

Strengths and Limitations of Systematic Review

Strengths of the systematic review include a clear protocol being developed which was then able to be followed by the primary researcher and second reviewer, as well as a third rater with expertise in the field. Additionally, both the screening and eligibility process were completed by both the primary researcher and the second reviewer, with any disagreements resolved by the third rater. This made these steps of the process more reliable. Kappa was found to be moderate in terms of inter-rater reliability (McHugh, 2012). This might have been improved by a clearer understanding from the primary researcher and the second reviewer on what ‘open sharing’ was, as well as how experiences were being defined.

Additionally, there were a diverse range of studies included, looking at age, gender, cultural context, and location of the studies, which will hopefully demonstrate experiences of open sharing of communicable diseases across the world, and not looking at one specific demographic. Finally, both peer-reviewed literature and reference sections of eligible studies were read to identify any other potentially relevant articles. This ensured that there was a thorough search completed, and all relevant and eligible studies were included.

Despite the strengths of the review, there were also some limitations. With regards to the search terms and inclusion of communicable diseases, it was difficult to define ‘open sharing’ and therefore it is possible that some studies might not have been

located during the searches and there was some difference of opinion when studies were initially being screened and reviewed by the primary researcher and second reviewer. Another limitation of the study was which communicable diseases to include. It was decided that person-to-person communicable disease would be included and only ones that are considered to be more stigmatising. This again, was a slightly subjective choice, which was informed by looking at the WHO guidance (2020), The Terence Higgins Trust (2020) and The Well Project (2020) and reviewed by the primary researcher's academic supervisor.

Another limitation was that search terms were only searched for in the title and abstract and therefore some eligible studies might have been missed. This is also the case with only two databases being used for the literature search. By searching more databases, it might have been possible to broaden the search and find additional eligible studies. By limiting the papers to peer-reviewed journals and not including grey literature, this might have had a similar effect. Finally, the experiences of people openly sharing their communicable disease status was assessed and synthesised by including qualitative only data. However, it would be interesting to look at experimental studies to be able to understand some causal links between possible factors and sharing as using qualitative only data does not allow for any causal links to be drawn.

Research and Clinical Implications

Despite there being many findings, and in some case findings that were not consistent across all studies, the themes that emerged could help clinicians working with people from these populations to understand what helps people to share their illness statuses, particularly these stigmatised illnesses, what factors might be

encouraging or discouraging people to share, and what the perceived benefits and negative experiences were which might influence further sharing. The emphasis on support and acceptance across the categories demonstrates the importance of encouraging psychological support for individuals with communicable diseases as a way of accessing support and possibly aiding with acceptance of their condition. This might then be able to help people to think about the idea of sharing and with whom they might want to share with. This review shows that research is emerging in this area, namely open sharing of diseases particularly HIV. However, it has also highlighted some gaps in the literature, around open sharing of communicable diseases other than HIV. There have been some similarities and differences to findings looking at selective sharing, with one difference being those who are open wanting to challenge the stigma associated with their illness. This possibly highlights one difference between why individuals adopt an open sharing strategy as opposed to a selective strategy.

Although there was not a great deal of emphasis on the negatives of sharing, whether that be fears or outcomes, it is important for clinicians to understand that sharing does not always lead to positive outcomes and that openly sharing with everyone might not be the best for all individuals. This research has shown that both positives and negatives are associated with openly sharing, and the importance of being able to discuss this with individuals so they have a better understanding of sharing and can make decisions about it accordingly.

Finally, given the theme of being educated or informed in both categories of assisting with sharing and benefits of sharing, it has highlighted the ongoing need for further awareness about communicable diseases to be shared, which could help to

reduce the stigma associated with them and the ongoing discrimination that people living with these conditions experience.

Conclusions

Overall, this review has found the experiences of people openly sharing their communicable disease status can be understood looking at factors pre-sharing, outcomes post sharing, and the process of sharing. Findings have suggested that everyone's experiences have to some extent differed, but the predominant findings indicated many factors that assist with sharing as well as benefits from sharing. However, there are also fears linked to sharing and negative outcomes and therefore it is important to focus on these too and try to understand these in greater detail. Clinical implications include the importance of support and helping someone come to terms with their illness as these were significant factors that help with openly sharing.

3. Exploring the Experiences of People Living with HIV who have Shared their Status Openly

Abstract

HIV can cause difficulties linked with physical and mental health as well as stigma. HIV status sharing has been associated with increased medication adherence, psychological benefits such as social support, and the reduction of onward transmission. However, negative consequences such as rejection and discrimination have also been found. This study aimed to address the gap in the literature and explore the process of openly sharing one's HIV status, with the main research question being 'What are the experiences of adults with HIV who are open about their HIV status?' It also investigated whether the first experience of sharing impacted future decisions to share, and which factors were perceived to influence the decision to adopt an open sharing strategy. Semi structured interviews were conducted with eight PLWH. Participants were all male, identified as homosexual and had undetectable viral loads. They ranged in age, ethnicity, and time since diagnosis. Interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA). Five master themes were identified: 'emotional reaction at diagnosis'; 'decisions to share'; 'strategies for sharing'; 'outcomes of sharing'; and 'comparative experience of sharing'. Findings indicated that open sharing was an individual process in terms of when they shared, how they shared, why they shared, what helped them to share and the outcomes of sharing. Important factors included being educated and wanting to educate others, to help to reduce stigma. Acceptance of one's HIV status helped with sharing and particularly sharing openly. Findings could be helpful for PLWH and clinicians to understand the different options as well as the role of acceptance and approaching

sharing with caution until someone is ready to share. Findings around increasing knowledge and the process of open sharing will also be beneficial to charities, the HIV negative population and the academic community.

Introduction

HIV

Human Immunodeficiency Virus (HIV) targets the immune system leading to an increased likelihood of contracting other infections and illnesses. If left untreated, HIV can develop into Acquired Immunodeficiency Syndrome (AIDS) (World Health Organisation, 2019).

Approximately 38 million people were living with HIV (PLWH) worldwide in 2019 (World Health Organisation, 2019). Of those, an estimated 105,200 people were living with HIV in the UK and a total of 98,522 were accessing treatment (The National Aids Trust, 2021). In 2019 in the UK, just over two thirds of individuals accessing treatment for HIV were male (68,088) and over half were white (54,621) and just over a quarter were Black African (28,525). Over 90% acquired HIV through sexual transmission (91,216) and of those, the proportion was very similar through heterosexual sex and men who have sex with men (MSM). Overall, new HIV infections have been reduced by 20% since 2010 (World Health Organisation, 2019).

HIV and Challenges

The physical health difficulties associated with HIV can be managed by taking lifelong medication: anti-retroviral treatment (ART). ART does not cure HIV but suppresses someone's viral load and allows their immune system to become stronger and therefore have the ability to fight infections. By taking ART medication, it is possible to suppress someone's viral load to the point where it is 'undetectable', with more recent findings indicating that those with an undetectable viral load are unable to

transmit the virus to others. This is known as ‘Undetectable = Untransmittable’ (U=U) (Rodger et al., 2019). In addition to using medication to manage the illness of the individual, it is possible to give others preventative medication, pre-exposure prophylaxis (PrEP), which protects people who are HIV-negative from contracting HIV (World Health Organisation, 2019). However, there are challenges to taking medication which might impact adherence to it. These include side effects, difficulty taking the medication, treatment fatigue and not wanting to be reminded every day that you are living with HIV (CDC, 2021).

There are other challenges associated with HIV. Firstly, HIV stigma, which can be experienced in different ways, whether it is internalised (i.e. having a negative view of yourself linked to HIV), enacted (i.e. discrimination from others towards PLWH) or anticipated (i.e. the belief that discrimination will be directed towards PLWH) (Earnshaw & Chaudoir, 2009). Secondly, mental health difficulties are over-represented in PLWH compared to the general population (Owe-Larsson et al., 2009). Some of the most common mental health difficulties PLWH experience are depression and anxiety (Remien et al., 2019). Mental health difficulties can lead to negative health outcomes among PLWH (Adams et al., 2016). Challenges have also been found in the development of meaningful relationships, including feared or enacted rejection (Driskell et al., 2008; Rutledge, 2007) and feelings of loneliness due to difficulties accessing social support (Vance, 2006).

HIV and Status Sharing

HIV status sharing has been associated with positive outcomes. Although in some areas, the evidence is variable, there is strong evidence that status sharing can

result in psychological benefits, such as increased social support (Smith et al., 2008), increased self-esteem (Quinn & Chaudoir, 2009; Vyavaharkar et al., 2011) and reduced anxiety levels (King et al., 2008). There is, however, some variable evidence, with some studies not finding positive outcomes linked to status sharing and adverse health difficulties (Daskalopoulou et al., 2017; Kittner et al., 2014). There is good evidence that status sharing can reduce ongoing transmission of HIV by individuals using condoms during sex (Hightow-Weidman et al., 2013; King et al., 2008; Pinkerton & Galletly, 2007), increased numbers of people taking PrEP and encouraging others to be tested (King et al., 2008). In terms of physical health, status sharing has been found to improve engagement in treatment more generally compared to those who do not share their status (King et al., 2008; Klitzman et al., 2004; Spangler et al., 2014). It has also been found that there are higher levels of individuals starting and adhering to ART treatment (Ekama et al., 2012) due to accessing support and less need to conceal medication (Calabrese et al., 2012). Due to this evidence, it is valuable to investigate the relationship between status sharing and HIV further. By understanding more about status sharing in HIV, it might be possible to help individuals across many domains in their life.

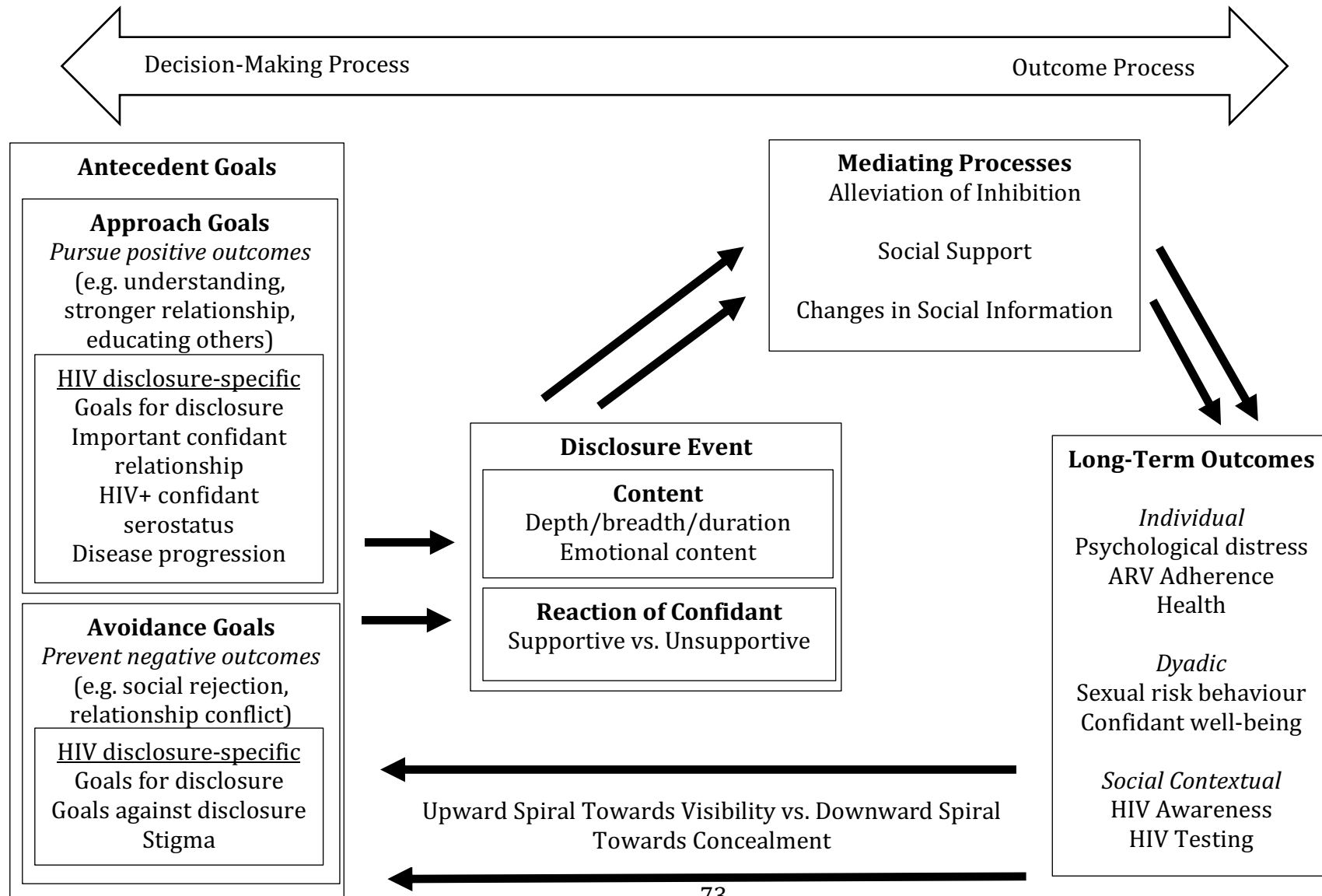
Disclosure Processes Model

The Disclosure Processes Model (Chaudoir & Fisher, 2010), adapted for an HIV population, outlines a possible process that occurs when individuals share their HIV status. ‘Antecedent Goals’ are split into ‘Approach Goals’ and ‘Avoidance Goals’. Approach goals relate to pursuing positive outcomes whilst avoidance goals are linked to preventing negative outcomes. The next part focuses on the ‘disclosure event’: the content of the event and the reaction of the recipient. The next stage is the mediating

processes, and three processes are highlighted: alleviation of inhibition, social support and changes in social information. These processes impact the ‘Long Term Outcomes’ on an individual, dyadic and social contextual level. Finally, these ‘feedback loops’ might result in people being more open or trying to hide their status.

Figure 2

Disclosure Processes Model adapted for HIV disclosure (Chaudoir & Fisher, 2010)



Patterns of Sharing

Status sharing can be selective or open. Often individuals might ‘selectively’, also known as ‘strategically’, share their status. Selective sharing is sharing with people within their social network, but within that it will still be strategic, meaning they are dependent on the personal characteristics of that person. Patterns of selective sharing have shown that in the nine months following diagnosis, people might start to selectively share (Hult et al., 2012). This is thought to be to get support (Maman et al., 2014) or to reduce onward transmission (Anglewicz & Chintsanya, 2011).

Open HIV status sharing is sharing your status with many people across different domains of your life (Hult et al., 2012). A few HIV studies have looked at open sharing within a subset of their sample and found benefits of openly sharing their status, both at an individual and population level. This includes additional support, building a positive identity, greater acceptance and increased wellbeing (Hatala et al., 2018). One study looked at disclosure and non-disclosure in HIV with a sample with mixed sharing patterns (Hult et al., 2012). A subset of the sample openly shared, and it was found sharing can be influenced by stigma experienced and need for social support.

Status sharing has also been associated with negative outcomes. Selective status sharing to partners has been found to lead to arguments, rejection and feelings of distress from partners (Damian et al., 2019) whilst open status has been associated with outcomes such as rejection and discrimination (Medley et al., 2009).

No studies have looked solely at individuals who openly share their HIV status. It is unclear why some people choose to share openly and some more selectively, as

well as the process taking someone from selective sharing to open sharing. Additionally, it is unclear whether the motivators to share are different depending on whether you are sharing selectively or openly.

One possibility is whether open sharing is something to do with identity and acceptance of one's HIV diagnosis. It is thought to be unlikely that individuals will be open about sharing their status unless they have accepted it. Jaspal & Breakwell (2012) found that we develop an identity which is made up of content and value dimensions. Two processes, the 'assimilation-accommodation' process, and the 'evaluation' process regulate our identity. Assimilation-accommodation involves us taking in and adjusting to new information whilst evaluation communicates meaning and value on what makes up one's identity. Four principles guide this process: 'continuity', across both time and situations, 'distinctiveness', 'self-efficacy' and 'self-esteem' (Jaspal & Breakwell, 2012). Other principles have been added, including 'belonging' and 'meaning' (Breakwell et al., 2002; Vignoles et al., 2006) and 'psychological coherence principle' (Jaspal & Cinnirella, 2012). Identity process theory suggests that some people's identities might be more resilient and can incorporate new information without it being problematic whilst others will find it more challenging and will need to use coping strategies to aid them.

Whilst another possibility is what motivates someone to share, and more specifically, to share openly rather than selectively. Self-determination theory views behaviours as being on a continuum which ranges in the extent that someone is motivated to complete a behaviour and what the motivation is (Deci & Ryan, 1985, 2008). On the more controlled end of the continuum is 'external regulation' which is

the behaviour that is motivated by external factors that might be controlled by others. 'Introjected regulation' is controlled by occurrences that are internalised, and individuals might feel shame if they do not complete behaviours but approval if they do. 'Identified regulation' is more led by the individual and involves 'conscious acceptance' of the behaviour and the outcome might outweigh other difficulties associated with the behaviour. Finally, the other end of the continuum is 'integrated regulation'. This form of motivation involves an individual not only identifying with the behaviour, but it is also integrated into their belief system. It might be that if someone is sharing due to their identity, for example wanting to be open and honest, then there is possibly a deeper motivation, whilst extrinsic motivation might be less deeply motivated but also have benefits.

Current Project

This project, informed by theory such as the Disclosure Processes Model (Chaudoir & Fisher, 2010), aims to address the gap in the literature and explore the process of open sharing in HIV. This includes the link between acceptance and adjustment, as well as motivation for open sharing, mediating factors of sharing, including acceptance and adjustment, and consequences of sharing. This is clinically relevant as it will aid professionals' understanding of how people might come to terms with their HIV diagnosis, what has made it possible to share their status and the effects of sharing. This could help with functional strategies to manage stigma of having an HIV diagnosis and how to adjust to life living with HIV. Additionally, factors such as U=U will be explored in this project, to understand whether these findings impact on someone's decision to share their status.

Study Objectives

This project aims to understand the experiences of individuals who are open about their status. It aims to understand emotional reactions at diagnosis, reasons why individuals openly share their status, whether recent findings of U=U and access to PrEP, impact the decision to, and consequences of sharing. Also, perceptions of how others responded to HIV sharing are explored with the hope of gaining insights into what might help with HIV stigma reduction, given a lack of knowledge has been linked to increased stigma (Lifson et al., 2012).

Questions were guided by the Chaudoir and Fisher model (2010). The primary research question is ‘What are the experiences of adults with HIV who are open about their HIV status?’ This includes reasons why people choose to share their status and the experiences of sharing. Secondary research questions include whether the first experience of sharing has impacted future decisions and which factors were perceived to influence the decision to adopt an open sharing strategy.

Method

Design

A cross-sectional, qualitative approach was used. As this was an exploratory study looking at the experiences of PLWH openly sharing their status, qualitative analysis was chosen over quantitative, with the aim of understanding individuals' experiences of sharing openly, its consequences and factors that might help someone to develop an open sharing strategy. A qualitative approach is helpful in understanding an individual's perspective, feelings, understanding of their experiences and behaviour (Rahman, 2016). Interpretative phenomenological analysis (IPA) was used to analyse the data (Smith, Flowers, & Larkin, 2009).

IPA was chosen over other models, such as Grounded Theory (Charmaz, 2014), as the aim for this project was to understand individuals' experiences and personal factors rather than generate a model. IPA allowed for the participants to tell their own experiences in their own words which allowed for experiences to be gathered in the individual's own terms and not according to pre-determined themes. The researcher then attempted to interpret the individual's understanding.

Participants

The inclusion criteria included: adults (≥ 18 years), of any gender or sexuality, who are HIV positive, having acquired HIV behaviourally and who are "open about their HIV status". Behaviourally acquired HIV is when someone is not born with HIV or contracts it during birth, rather contracts it later in life. Open about their status was operationalised as the following people being told or knowing: their GP, most of their

friends and family and their last three sexual partners since diagnosis. This was based on previous research (Daskalopoulou et al., 2017), however it was also acknowledged that there is no recognised way to operationalise this. The criteria were based on acknowledging that people will categorise open in different ways, but it was thought that proportion was important. Exclusion criteria included those who are at risk of harm to themselves or others, at the point of initial recruitment or interview stages, and individuals who had been diagnosed with HIV within the last 6 months. This was due to ensuring that individuals have had some time to process their diagnosis and the chance to share their status.

Participants (n=8) were recruited from HIV clinics. All participants identified as male and homosexual. Participants ranged in age (range: 25 – 63 years old, median: 45 years old), ethnicity, religion, relationship status and other self-identified health conditions, as can be shown in Table 5.

All participants consented to basic clinical information to be provided by clinicians. Participants ranged in length of time since diagnosis (Range: 2 – 18 years, median: 14 years). All participants were on ART, with undetectable viral loads and CD4 counts ranging between 175 and 616 cells/mm³, with a median of 440 cells/mm³. Viral load is the term used to describe the amount of HIV in your blood and is considered to be undetectable when the number is <50 copies. A CD4 count is the measure of white blood cells an individual has, which are important for your immune system. The ‘normal’ range for CD4 is between 500 and 1200 cells/mm³.

Table 5*Participant Demographic Data*

Participant Number	Age	Time Since Diagnosis	Ethnicity	Religion	Relationship Status	Self-Identified Health Conditions	Viral Load	CD4 Count
1	37	12 years	Hispanic	Christian	Married	Anxiety	<40	475
2	25	2 years	Black Caribbean	No Religion	In a relationship	N/A	<20	374
3	45	16 years	Black African	No Religion	Married	N/A	<20	487
4	45	18 years	White British	Christian	Married	N/A	<40	616
5	26	8 years	White British	Christian	In a relationship	N/A	<20	405
6	45	16 years	White British	No Religion	Single	Borderline Personality Disorder, Dysthymia, Eating Disorder, Anxiety and Panic Disorder	47	574
7	57	12 years	White British	Christian	Single	Borderline Personality Disorder, Depression and Anxiety	<20	330
8	63	16 years	White British	No Religion	Married	Eczema and Asthma	<20	175

Sampling

Convenience sampling was used. It was ensured that the research problem was relevant and personally significant to all of the participants as in needed in IPA (Pietkiewicz & Smith, 2014). When calculating sample size, data saturation was taken into account as it is often a measure of validity for a qualitative research project. Data saturation occurs when no new information is being found by further interviews (Chamberlain, 1999). For IPA, the focus is on ensuring full and rich accounts are obtained and both similarities and differences in experiences are explored across the sample (Hale et al., 2008). Secondly, the specificity of the research question impacts the sample size, and although the HIV population is large, those who are open about their status is small. Therefore, based on the guidance (Smith, 2004), and taking into account the points above and the information found in the interviews, it was thought that eight participants was plausible to achieve the aims of the study and ensure in depth data was gathered and similarities and differences in experiences were understood but the amount of data is not too great to be analysed (Turpin et al., 1997).

Recruitment

Participants were recruited from two HIV clinics within central London. Clinicians from within these clinics identified potential participants and approached them with the study details. If they were interested in taking part and consented to their details being passed on to the researcher, they were referred. The researcher provided potential participants with the participant information sheet (Appendix B), detailing the purpose of the study and what it involved. Participants had the opportunity to ask questions before consenting to take part (Appendix C). Due to the ongoing coronavirus

pandemic, the interviews took place remotely, either over the telephone or over skype and were audio recorded using a dictaphone. Six of the participants were recruited from an outpatient HIV clinic which has 1094 patients, Site A. The other two participants were recruited from a service that has 3100 patients, Site B.

Overall, 38 potential participants were approached by clinicians to take part in the study. Eight declined, 20 did not meet criteria, as they had not shared with most of their friends and family. Of the 10 who were approached by the researcher and met the criteria, eight participants agreed to take part and two did not respond.

Questionnaires

Participants completed the Hospital Anxiety and Depression Scale (HADS) (See Appendix D) (Zigmond & Snaith, 1983a). The HADS is a 14-item valid tool within hospital settings as well as valid in community and primary care settings (Zigmond & Snaith, 1983a). This tool was not used as a diagnostic tool for the study. This scale has been found to be a useful screening tool for depression in HIV populations (Savard et al., 1998). Results showed that overall, there was a higher anxiety scores than depression within the sample, and that one participant had a high depression score. See Table 6 for full results.

Participants also completed the Living with HIV Cognition Questionnaire (See Appendix E). This questionnaire was adapted for PLWH from the original questionnaire, the Illness Cognition Questionnaire (Evers et al., 2001) which is validated in chronic illness samples. This questionnaire has been used in HIV studies previously (Earnshaw et al., 2013). It is an 18-item questionnaire which looks at

individuals' cognitions around helplessness, acceptance, and perceived benefits in people with HIV. Overall, the 'acceptance' scores were high whilst there was a variation on the 'perceived benefits' scores. There was one high score on 'helplessness' however the other scores were low. See Table 7 for full results.

Participants completed a demographic questionnaire to help situate the sample. See Appendix F for the demographic questionnaire. Participants also consented for clinicians to complete a clinical questionnaire. See Appendix G for the clinical questionnaire.

Table 6*HADS Scores (Zigmond & Snaith, 1983)*

Participant Number	Anxiety Score (/21)	Depression Score (/21)
1	14	1
2	1	0
3	4	1
4	5	2
5	2	1
6	19	15
7	2	5
8	13	7
Subscale Median:	4.5	1.5

Table 7*Living with HIV Cognition Questionnaire Scores (Adapted from Evers et al., 2001)*

Participant Number	Helplessness Subscale (/24)	Acceptance Subscale (/24)	Perceived Benefits (/24)
1	6	24	19
2	6	23	19
3	6	23	24
4	6	23	17
5	7	23	23
6	18	22	12
7	6	24	20
8	8	17	12
Subscale Median	6	23	19

Interview Schedule Development

Draft interview questions were initially generated by the researcher, guided by the Chaudoir and Fisher model (2010). These questions were reviewed by the academic and field supervisors. The researcher also discussed the interview questions with two PLWH, who did not meet the study criteria as they were not open about their status, for any insight into the language used and to ensure the relevant areas were covered. The interview schedule was amended based on feedback (see Appendix H for feedback and changes made).

The researcher and academic supervisor role-played the interview schedule before the first interview. The academic supervisor also reviewed the first unannotated interview transcript and commented on interview style. Both the role-play and the transcript provided helpful feedback which focussed on using clinical skills such as asking for further information and summarising on more occasions throughout the interview.

Procedure

Semi-structured interviews, with 11 open-ended questions, were conducted. Each question had further follow-ups and prompts (see Appendix I for the Interview Schedule). Questions focussed on experiences of sharing, specifically the first experience of sharing and whether this impacted future decisions to share, what factors made it easier for people to share, with one possibility being U=U, strategies for sharing and consequences of sharing. Interviews lasted between 45 and 93 minutes. Participants and service users, who reviewed the interview schedule, were offered a £10 Amazon voucher as a token of appreciation.

IPA

Interviews were recorded and transcribed verbatim. Analysis of the data was done using IPA which allowed for the individual's experiences to be understood. Following the steps outlined by (Smith et al., 2009), the transcripts were read and re-read until the researcher was familiar with the data. The next step was initial coding, which involved coding the data across three categories: descriptive, linguistic and conceptual. From this, emergent themes were then generated and connections across the themes were explored. Once this was completed with one transcript, the process was repeated with the next. See Appendix J for an extract of a coded transcript. Finally, patterns across the transcripts were identified. The academic supervisor reviewed two coded transcripts and provided feedback on these as well as commenting on a draft table of themes.

Maintaining Quality

To maintain quality standards, the analysis adhered to seven qualitative research standards (Elliott et al., 1999). This involved 'owning one's perspective' including describing theoretical, methodological and personal orientations linked to the study. The researcher kept memos which captured her thoughts, interpretations and decision making. The researcher continued to use supervision and feedback from the participants to reflect on their own contribution to the process (Charmaz, 2014). The researcher always considered her predeterminations linked to her position as a heterosexual, 27-year-old, white British, HIV negative female and how this might have impacted on the conducting the research. This might have included her interactions with participants and interpretation of data. Other research standards adhered to were 'situating the sample' by providing demographic data, 'grounding in examples' by providing

examples for each theme, 'coherence' using a table to summarise the analysis and show relationships between the themes, 'accomplishing general compared to specific research tasks' by ensuring the conclusions drawn are from the participants involved and 'resonating with the readers' by presenting the findings in a way that will improve the reader's understanding of experiences of PLWH who have shared their status openly. The final standard of 'credibility checks' involved the researcher's academic supervisor reviewing data analysis and 'member checks' being completed by participants. These involved participants reviewing the overall themes concluded from the data. This ensured respondent validation (i.e., that it was a fair reflection of the transcriptions and the experiences of the participants). All participants agreed to being contacted for member checks, however, only one participant responded.

Ethical Considerations

This project received full NHS REC and HRA approval from the Camden and Kings Cross REC on 13th and 14th July 2020 respectively (Appendix K and Appendix L). Self-certification from the Royal Holloway, University of London REC was completed on 14th August 2020 (Appendix M). The study received approval from the Site A Research and Development (R&D) committee on 9th October 2020 (Appendix 0) and Site B R&D committee on 29th October 2020 (Appendix N).

As the focus of the interview was sensitive in nature, time since diagnosis was considered when recruiting to ensure that individuals had the opportunity to adjust to the positive HIV test result. Additionally, the researcher monitored participants' reactions and affect throughout their interaction and could stop the interview at any time due if there were any concerns. Participants were also reminded they could choose

not to answer any questions during the interview. Confidentiality was fully explained to participants and the limits of confidentiality both in writing and verbally. For one participant a full risk assessment was completed, and no immediate concerns emerged. The clinical team were informed of this and followed up with the participant. Support services were also discussed with the participant. Participants were also aware they could withdraw from the study up until the end of February 2021.

Results

Based on the emergent themes, five master themes were found. Within these master themes, there were further subordinate themes. See Table 8 for an overview of the master themes and subordinate themes.

Table 8

Master and Subordinate Themes

Master Themes	Subordinate Themes
Emotional Reaction at Diagnosis	Negative Other
Decisions to Share	Reasons why people share their status What made it easier to share
Strategies for Sharing	Who they share with When they share How they share Future sharing
Outcomes of Sharing	Benefits Negatives
Comparative Experiences of Sharing	Sharing mental health difficulties or sexuality worse than HIV Sharing HIV worse than other things Conflict of professional and personal life

Each master theme is discussed, with reference to the subordinate themes. To demonstrate each theme and ground the themes in the participants' narratives,

quotations will be included and reference to some of the emergent themes to show how the subordinate and master themes were synthesised from the transcripts. The themes discussed are linked to the research questions. Other themes that were found, but were unrelated to the research questions, were not included.

Theme 1 – Emotional Reaction at Diagnosis

All participants spoke about their emotional reaction to receiving an HIV positive diagnosis. Some of these reactions might have been linked to whether or not they had symptoms of HIV or whether it was a regular sexual health check-up.

Negative

All eight participants described some negative reactions to their diagnosis. There were a couple of thoughts that were repeatedly spoken about. Firstly, three participants described being confused when they received their HIV positive diagnosis. The confusion appeared to be around how they contracted HIV:

“I was kind of, I couldn’t necessarily pinpoint how or when” (P5).

In addition to being confused about receiving an HIV positive diagnosis, one participant also showed an element of feeling that it was unfair or unjust:

“I’m a bit confused still, because he was undetectable, so I’m not 100% sure how I got it...I questioned a bit, not why that had happened, but how that had happened” (P2).

Feelings of sadness, devastation and shame also featured. Five participants expressed feeling sad or unsettled when they received their HIV diagnosis:

“Um and then I found out and I was diagnosed so it was kind of a shock, it wasn’t like I was expecting that result. Um, I was just being safe rather than sorry” (P5).

The other three participants expressed feelings of devastation upon receiving their diagnosis:

“It was quite devastating for me. Despite the fact that there was a part of me that knew that I might be positive, there was also um, a part of me that never wanted that to happen so when it happened it was quite devastating” (P3).

Finally, two participants spoke about feelings of shame when they received their HIV positive diagnosis:

“Um, I think there was a little bit of shame attached to it in so much that I should have known better” (P7).

Other

Whilst participants expressed feelings of sadness and devastation, four of the participants also spoke about being accepting of their HIV positive diagnosis at the time they received it:

“It wasn’t a relief that I was HIV positive, but it was a relief that all the horrible symptoms of the last month were that and weren’t something else that was going on that I didn’t know about...I don’t think I realised that I was anxious about not getting HIV until I suddenly didn’t feel anxious once I had it, it was kind of weird” (P4).

“I actually said to the nurse that was sat across me at the Hospital I actually said “Is it going to be this time?” and she said “mm yes” um it was, I was quite like ok then” (P1).

Theme 2 – Decisions to Share

Reasons why people share their status openly

All participants discussed reasons that led them to share their status openly. An overarching theme for openly sharing was participants being able to see a benefit for themselves or others. Seven participants spoke about the desire to be honest with people. For some participants it was so they did not have to be so secretive:

“But as soon as I left work I only saw the people I like after that anyway... So there’s no point in being so secretive” (P8).

Whilst for others there was possibly an additional element of feeling empowered when they shared openly with people:

“That it is very empowering, that is one less secret that you have to carry around” (P3).

Six participants discussed wanting to share openly to educate people. Educating people was not only about dispelling possible myths or increasing people's knowledge, but also to try to reduce the spread of HIV:

"Um, I think the biggest thing now is for me to be an educator...because I think, again it's you know you, you very much in the past year about how to defeat a virus, it is together, so education is the biggest thing for me" (P5).

Another reason for sharing openly was being able to support others who have received an HIV positive diagnosis. Six participants spoke about this, with three of the participants working in the HIV field:

"I wanted to give back, I have done peer support and all that" (P6).

Three participants described sharing openly due to their acceptance of their diagnosis and how it was a part of them, and they wanted people to be aware of it:

"I think maybe in the beginning I might have been a bit nervous to, especially when I hadn't told many people, but nowadays it is one of those things where, if people don't take you for who you are then they don't need to be in your life, in a way" (P5).

In contrast to reasons why participants would share, something they all acknowledged was that they did not want to be reduced to their diagnosis and maintained it was a part of them but there was more to them than just being HIV positive:

“I mean there's more to me than just my diagnosis... In fact it is one of the smallest parts” (P8).

What made it easier to share

There were eight themes linked to factors that made it easier for people to share their status. The most common theme that arose was having knowledge or being informed. Participants spoke about how this helped, particularly in being able to respond when people asked questions:

“And I guess, always have the knowledge behind you as well because I think that helps quite a lot because if and when you do get asked questions or people coming back to you, you kind of know most of the answers and that gives them an understanding and makes it helpful for them as well to understand a bit more about what HIV is, what it means, how it is transmitted and kind of all the information that goes with that” (P2).

In addition to this, being informed helped to give people confidence while they were sharing:

“But I think overall it is it's being informed, um thinking about the way you tell people and just I suppose oozing confidence is not the right word but it is really about being confident about it rather than having that like oh I have got something to tell you and it is not very nice or you know, it is being right ok, I have got something to say, you know, I'm living with HIV, everything's fine, I'm on treatments, I'm undetectable, and explain what that is and you know I'm very comfortable with this” (P7).

Possibly linked with people having knowledge, some participants (n=4) thought sharing with someone who was HIV positive made it easier to share. This was possibly due to feeling a sense of belonging as well as those individuals knowing how you might feel about it:

“I lived in [Spanish city] for about four years and um in a way I was looking forward to going back and telling two or three of them that I’ve joined the club kind of thing... Because that they were really really supportive...Because they knew, they knew what I was going to feel” (P8).

Together with gaining knowledge, medical advancements, and most notably U=U, were mentioned by six participants as a factor helping them to share their status:

“Erm, yeah, I would say U=U is probably the biggest thing that you know, it should make it easier because it shouldn’t allow people to think something crazy like you sneeze on someone and they are going to get HIV or something” (P2).

“I just personally think that it is one of the many advancements that we are going to see in the area of HIV that we need to talk about and we need to educate people more about it” (P3).

Relationships and support were also thought to be involved in making it easier to share. Most participants (n=6) spoke about how the nature of their relationship with

others helped them to share, particularly helping with trust. This factor was most commonly spoken about when referring to sharing initially:

“How close I am to someone” (P2).

Some participants felt that trust was particularly important as they felt more control over who knew and knowing that others would not be told:

“And then he would never have shared that information with anyone until I, I did” (P8).

Five participants described different elements of feeling supported as helping with sharing, this was in relation to feeling supported by friends or family:

“Ah so I could you know, I was listened to, there was no judgments, you know there was no sadness either you know, in fact we probably ended up chatting for quite some time and having a bit of a laugh and yeah” (P7).

As well as being supported by professionals:

“Yeah, he was saying how, that I had fallen into a trap of “my name is X and I have got this” but I had fallen into the trap of “I am this, but my name is X”” (P6).

Other emergent themes, separate from knowledge and support were common amongst the transcripts. Six participants talked about not having expectations of how people will react helping them with sharing:

“So just accept the circumstances and what is about to happen... And don’t be afraid of whatever reaction comes” (P5).

Four participants spoke about how accepting your diagnosis can make sharing easier, but they also stated the importance of not sharing with too many people too quickly:

“You have to recreate your own confidence again... I think you need, well I needed a real time of reflection” (P8).

“The hardest thing is, and I still say this now to people that newly positive is, it is better to not tell too many people too quickly because you end up supporting their emotional reaction rather than dealing with your own reaction” (P4).

Finally, the age or stage in someone’s life helped three participants with sharing:

“Um, I think it is really neither here nor there, so at this stage of my life it really is neither here nor there so as long as I have my medication with me, I am fine” (P1).

Theme 3 – Strategies for Sharing Openly

All participants discussed their strategies for sharing openly, which was synthesised into four subordinate themes: who they share with; when they shared; how they share; and future sharing.

Who they share with

Five participants spoke about telling people on a need-to-know basis:

“So going forward, if people needed to know... I would tell them” (P1).

Three of these five spoke about the importance of their ‘gut feeling’ about who they should tell and how it was often right:

“Um, because I think, like I say, I do regret not telling my family sooner, however they kind of proved me right because they over worried, like I know the reasons why I didn’t want to tell them were right however since telling them, well since them knowing shall I say, it has made a lot of things more easier for me” (P5).

The other three participants described themselves as advocates, where they have publicly told people across social media or newspaper articles:

“I encourage people to test, I support people who reach out to me who have just been diagnosed, I share my life’s story so much so that people can know that HIV is not a death sentence, it is not, um, it is not you know yeah, it is what it is, you can live with it and you can manage it effectively” (P3).

“So I was quite quite outspoken but I would say now much more of an advocate, much more of wanting to educate people so I've moved away from that kind of in your face kind of you know you're wrong kind of thing, you know this is the science, you know get up to speed with things to more kind of like well okay so you've got some worries about this, let's talk through them. So more of an advocate, so yeah just want to try and educate people” (P7).

When they shared

All participants described gradually telling more people over time and not acknowledging a particular point when they felt like they were “open” about their HIV status. They described:

“Once you have passed the 5 or 10 mark, these things tend to err [laughs]...rapidly escalate” (P4).

In addition to gradually telling more people, six participants described the experience getting easier the more people they shared with:

“So the more, I kind of opened up myself to other people about it, the easier it became” (P1).

In terms of when people first shared, four participants described sharing their status immediately after receiving the diagnosis:

“Essentially just told them all straight away” (P2).

Whilst other participants (n=3) were more cautious initially:

“I was cautious about sharing, just because of what I have said before which is I had seen people go out and tell 20 people in what, 2 days, and then spend 6 months managing those 20 people who wanted to come round, cook for you, look after you, make sure you are ok and I was like I really don’t want any of that” (P4).

This included some participants initially not sharing for months or possibly years:

“Like I said I never said anything about it, so this was maybe 3 or 4 years after” (P3).

How they share

The main point that participants spoke about in terms of how they share was the importance of sharing in a natural way, possibly due to not wanting to place too much emphasis on it. Seven participants mentioned this:

“You can't just knock on the door and say put the kettle on you know, it needs to be organic” (P8).

“Over time and it was only when I felt like it was appropriate I didn’t want to just like splurt it out and just make a thing of it, it was only like if a situation arose or

like, so you know what I mean, if it came into, if that sort of topic came up, I might have mentioned it” (P5).

“It’s not something that I will blurt out, it is normally going along that conversation and so seems a bit more natural” (P2).

Other strategies of how participants shared were less commonly mentioned across the participants but included using humour (n=2):

“Er, it is just um, I think it is just casually, um, you know, if we are, I am with a group of people in a bar and we are discussing you know PrEP or anything then I will often say, you know, that ship has sailed I am now on meds, [laughs], er I think it is just, um, I think people are fine with the way I say it, people are happy with it” (P1).

And using mixed media (n=3):

“Um so that was World Aids Day campaign, well it was a couple of days before world aids day that year, so that was like when I kind of told the world really, or readers of the the [newspaper] and then I started doing some, well I then joined some community forums for people living with HIV and I was very open about it there, you know, I had my photo taken for my profile, so yeah I would say it was a couple of years down the line, maybe three years down the line after” (P7).

Whilst other participants would normalise HIV (n=4) at the same time as sharing their status:

“And I explained to her the advance in medicine and that taking one tablet a day was going to mean that I was going to live a, you know, a normal life, so yeah” (P1).

Although the language used was only mentioned by one participant, this participant placed a great deal of emphasis on it throughout:

“Yeah absolutely yeah I’ve kind of moved from perhaps saying I’m HIV positive which I used to say, or to then moving to saying I’m living with HIV to now sort of saying well I’m on treatment and undetectable” (P7).

Some thought was also given to what to do once you have shared with someone. This included giving people time to process what you have said or allowing them time to get information (n=2):

“Want you to go, go off and ask a doctor, a friend and read about it, by yourself and find your own sources, and I said make sure the source of information you go after is um is a good source of information” (P1).

And finally, not making assumptions about reactions (n=1):

“And in the same way I think with the telling people your status, and this goes, this is true for sexuality as well, you know people assume it is their special thing, it is their special time, and they forget that other people might, you can have your own

prejudices about the person you are telling and don't be surprised if they come out with something that surprises you [laughs]" (P4).

Future sharing

Participants spoke about future sharing and how previous experiences might or might not have influenced sharing going forward. Three participants reported being impacted by their first sharing experience:

"After seeing their reaction because they were first, I guess that kind of set for me hopefully what everyone's reaction would kind of be like. Um, and it pretty much fit into that, there wasn't anyone who I was shocked about their reaction" (P2).

In addition to the first experience impacting future sharing, some participants (n=4) said they have learnt from both positive and negative experiences:

"So maybe that was the start of my kind of advocacy of my kind of you know, after that I thought there is no way that I am having somebody be like that" (P7).

In contrast to this, two participants reported their sharing practices have not been influenced by previous sharing experiences:

"No, I mean people talk about how they tell people and people don't react to them very well, it doesn't stop me from telling other people" (P3).

Theme 4 – Outcomes of Sharing

The outcomes of sharing have been synthesised into two subordinate categories: benefits and negative outcomes.

Benefits

Seven participants described sharing strengthening their relationships with those they shared with:

“It actually made it [our relationship] closer” (P8).

“Again, I think really only positively” (P4).

Linked with strengthening relationships, three participants said they viewed a benefit of sharing as getting support from others:

“And if you do have a strong rapport with family or friends then definitely do speak to them and never be afraid to speak to friends/family/clinicians if you are feeling really upset, feeling down” (P2).

As well as receiving support from others, two participants spoke about the benefit of being able to help others by sharing:

“And there are times therefore where it makes it very relevant to talk about personal experience, I think” (P4).

Participants (n=7) also acknowledged the benefit of not having to lie to people, particularly about attending appointments or taking medication:

“However, since telling them, well since them knowing shall I say, it has made a lot of things more easier for me...Um, not having to lie about doctor’s appointment, not having to hide my medication in drawers, stuff like that” (P5).

Finally, being able to educate others, either to raise awareness of reduce stigma was a benefit that almost all participants (n=7) spoke about:

“I think it is judiciously used and I think it is important for people to see that a diverse range of people are living with HIV and that it is not an impairment to succeeding and working in various fields and various specialities and various different areas” (P4).

Negatives

There were three negative outcome themes that arose. The most commonly spoken about was concern from others. This was only mentioned by three participants:

“Um and one was a very old school friend, who reacted quite negatively, but um, only because she was upset” (P4).

Only two participants spoke about experiencing rejection following sharing their status:

“And he said no no not at all he said I can't possibly go out with you, [laughs] and this was over lunch so that was a bit I remember feeling quite annoyed by that, and thinking for goodness sake, you know you've met me, you have come to sort of have lunch with me and we were getting really really well but just because I told you that information then all of a sudden he's like no I can't possibly see you again. It's almost like guilty by association you know you're gonna get HIV by associating with somebody so I remember the few times when I was quite angry with some people's reactions” (P7).

Finally, one participant spoke about their status being shared without their permission:

“Then that person then went on to tell a lot of other people in a very spiteful manner and um, because that person was hoping that I had had sex with someone, unprotected, without telling them” (P1).

Theme 5 – Comparative Experiences of Sharing

The final master theme that arose was the comparative experiences of sharing. This was divided into three subordinate themes.

Sharing mental health difficulties or sexuality worse than HIV

Four participants described sharing their HIV status as being easier than sharing either their mental health difficulties:

“And both my the last two guys I was seeing I told them about my HIV status long before talking about my mental health problems. Um I am still a little bit reticent around that um so it's obviously some kind of internalised stigma around that maybe, about mental health” (P7).

Or their sexuality:

“I guess in a way it is sort of similar to coming out as gay in a way...I think actually that was probably harder than having to tell people about my diagnosis to be fair. But then having said that, I say that, but then everyone’s reactions were very similar” (P2).

Sharing HIV worse than other things

One participant described sharing their HIV status as more difficult than other things, for example their sexuality:

“Um yeah it is different, I mean I was more comfortable coming out than telling people about my status for a long time, it took me quite a long time to be able to tell people about my status but I was very comfortable coming out to talk about my sexuality, so yeah I was very comfortable talking about my struggle with mental health than I was to talk about my struggle with HIV so yeah it is different to how I talk about certain things” (P3).

Conflict of professional and personal life

Finally, one participant spoke about how there is sometimes a conflict for them with regards to their professional and personal life and that it can be helpful but also occasionally unhelpful:

“but sometimes it takes some audience members down completely the wrong sort of track, because then they start asking you questions that are not relevant to the topic [laughs]...So it can a distracting, a distractor, as well as a positive thing” (P4).

Discussion

This study aimed to understand the experiences of individuals who are open about their HIV status. This included their emotional reaction at diagnosis, reasons why they chose to share their status and the experiences of sharing. Secondary research questions included whether the first experience of sharing has impacted future decisions and which factors were perceived to influence the decision to adopt an open sharing strategy. Interest in perceptions of how others responded was explored with the hope of gaining insights into how HIV stigma can be reduced.

IPA was used to analyse eight interviews with men who are open about their HIV status. The findings indicate that openly sharing one's HIV status is an individual process that is different for everyone. Other findings suggest that acceptance of HIV status and having knowledge influence openly sharing one's HIV status and the benefits of sharing outweigh the negative outcomes.

Overview of Study Findings

The results will be discussed in relation to the research questions as well as the Disclosure Processes Model (Chaudoir & Fisher, 2010), previous research and theory. Similarities, differences, and new findings will be highlighted.

Experiences of People Sharing

Reasons to Status Share

Reasons that individuals chose to share had an overarching theme of being able to see the benefits for either themselves or those they were sharing with. This ties in

with self-determination theory (Deci & Ryan, 1985, 2008). Self-determination theory views behaviours as being on a continuum which ranges in the extent that someone is motivated to complete a behaviour and what the motivation is (Deci & Ryan, 1985, 2008). It is possible that people who share their HIV status openly have ‘identified regulation’ and have a conscious acceptance of wanting to share to achieve their valued outcomes, such as educating others or being honest. Conversely, people who have more selective sharing strategies might feel more external regulators to their behaviour or it might not align with their values.

The finding of being honest also ties in with previous research identifying a moral element to status sharing (O’Leary & Wolitski, 2009). Furthermore, participants also reported feeling empowered being open about their HIV status as found in other research and this might have encouraged them to share further (Hatala et al., 2018).

Additionally, when comparing the reasons to share from this study to the Disclosure Processes Model (Chaudoir & Fisher, 2010), the findings indicate that participants’ decision-making process was more focussed on ‘approach goals’ rather than ‘avoidance goals’. This might have been due to the nature of the participants being open about their status and therefore being less focussed on times when they do not share but also could be in line with self-determination theory and what their motivation is.

Outcomes

Many benefits were described following sharing with few negative outcomes spoken about. The negative outcomes discussed were similar to what has been found in

previous research about HIV status sharing outcomes (Medley et al., 2009). It is possible that participants did not want to report the negative experiences and were potentially concerned that it might dissuade others from considering sharing. Additionally, it is possible that the benefits outweighed the negatives and therefore might not be thought about as much or paid as much attention given the sample were individuals who were willing to discuss sharing their status.

In terms of benefits, the individual long-term outcomes in the Disclosure Processes Model, and previous research, such as psychological distress, adherence to ART and health outcomes were not common themes found in this study (Chaudoir & Fisher, 2010; Machtinger et al., 2015). On an individual level, getting support was a benefit that was spoken about by most participants. This has also been found in other research looking at those openly sharing their HIV status (Hult et al., 2012; Medley et al., 2009).

In terms of ‘dyadic long-term outcomes’, participants spoke about relationships being strengthened and not having to lie to others. Relationships being strengthened has been an outcome found in previous research (Machtinger et al., 2015), whilst not wanting to lie is more often a reason to share in other studies (Hult et al., 2012). Participants did talk about others being concerned for them; however this was not a theme shared by all participants.

As with previous research, the ‘social contextual long-term outcomes’ of raising awareness and testing were outcomes for participants as well (Black & Miles, 2002).

However, it is difficult to draw a conclusion of this being an outcome rather than the ability to educate others about HIV and testing given the qualitative nature of this study.

The First Experience of Sharing

The process of sharing highlighted that it was a personal process, and all participants had a different journey to openly sharing their HIV status. When comparing to the Disclosure Processes Model (Chaudoir & Fisher, 2010), the ‘disclosure event’ and the ‘feedback loop’ were important to some participants, but less significant to others. This might be due to levels of acceptance, possibly how expectant someone is of a reaction or the reasons why they were choosing to share. Previous research has also found that individuals who ‘universally disclosed’ were not deterred from future sharing by previous reactions (Hult et al., 2012).

Factors Perceived to Influence an Open Sharing Strategy

Mediating processes, such as having support, were discussed by participants as a factor making it easier to share, but other factors such as knowledge were also central to helping them to share. This is in line with previous research looking at openly sharing Hepatitis C and HIV status and to some extent, the Disclosure Processes Model (Chaudoir & Fisher, 2010; Greeff et al., 2008; Suarez, 2019). Having knowledge about HIV was a reason for sharing as well as a factor that made it easier to share. Research has shown that stigma associated attitudes are often linked with a lack of knowledge about HIV transmission, treatment or not knowing someone living with HIV (Lifson et al., 2012).

The most agreed upon factor across participants was that sharing openly was a gradual process and there was not a moment in time when individuals decided to be ‘open’ about their HIV status. This is similar to what has been found with the coming out process, where it is thought there are five developmental stages of coming out: pre-coming out; coming out; exploration; first relationship; and identity integration (Coleman, 1982). It would be interesting to see whether this process also occurs in a heterosexual population in the same way, or whether for some people their experience of sharing an aspect of their identity previously supported their sharing process.

Acceptance was a factor across many of the master themes and could be considered another mediating process. Across the journey of openly sharing, acceptance seemed to be a factor that helped people to share initially and then to continue sharing. Although all participants described feeling negative emotions at diagnosis, half of them spoke about some element of acceptance. It is possible that acceptance, even if just a small amount, helped them with the process of sharing. This might be due to them experiencing less internalised stigma, which is a challenge associated with living with HIV (Earnshaw & Chaudoir, 2009).

These findings align with previous research looking at identity. Identity process theory suggests that some people’s identities might be more resilient and can incorporate new information without it being problematic (Jaspal & Breakwell, 2012). Conversely others will find it more challenging and will need to use coping strategies to aid them. Individuals’ perception of HIV as a threat might vary depending on factors such as when they were diagnosed, their age, their knowledge, and medical advancements, such as U=U. The perception of threat and someone’s identity resilience

together might influence the process of acceptance. Those who can assimilate and accommodate the new information about their diagnosis, might have been more able to accept their diagnosis. This is because the information might have been integrated into their identity and become part of them but not the only element of their identity. This might be the case with those who are open about their HIV status.

Strengths and Limitations

There were strengths and limitations to this research. Strengths included using IPA for data analysis. IPA provided an in-depth analysis of participants experiences and the ability for their experiences to be individually explored (Smith et al., 2009). Secondly, the interview schedule was developed by the primary researcher with input from both the academic supervisor, field supervisors and two service users who are living with HIV but did not meet criteria for the research. This ensured that relevant questions and prompts were asked as well as language being appropriate and sensitive to the population it was aimed at. The academic supervisor also reviewed two coded interview transcripts to give advice on how to improve both the interviews and the coding. The researcher ensured that all standards for maintaining study quality were adhered to (Elliott et al., 1999; Hannes, 2011) as discussed in the methods section. Finally, it was felt that the aims of the study were met and full and rich accounts were obtained, with data saturation being met (Chamberlain, 1999).

However, there were also limitations in this study. Although having a fairly homogeneous sample is a benefit of IPA, it possible that it also makes it less transferable to other populations, such as women or people who do not identify as homosexual. This might possibly be due to convenience sampling being used rather

than theoretical sampling. Secondly, it is important to take into the account the researcher's background and that findings were based on the researcher's interpretations of the data, as is the case with IPA. Although both member checks and reviews by the researcher's academic supervisor took place, others conducting the same research might have interpreted the transcripts in a slightly different way and only one participant responded to the member checks. It was noted that many benefits were discussed with participants, and very few negatives. It is possible that participants wanted to appear positive about their experiences or felt that questions were directing them to talk about positive experiences, but it would have been interesting to understand whether it was a true reflection of their experiences.

There are a few limitations linked to the way the research was set up. The definition of 'open' was challenging to operationalise. Literature was reviewed to see how previous research has defined 'open', but there was not consensus on how to operationalise open. If this study was to be repeated, it is possible that the criteria might not be fully replicated as 'most of friends and family' is relatively subjective. Secondly, due to COVID-19, the interviews took place remotely, via skype or over the telephone. Although there were no difficulties with the interviews, it is possible that smaller details, such as body language, might have been lost from not being in the room with the participant and factors like this might have added to the analysis and findings. Finally, some of the prompts in the interview schedule were possibly too leading. Although it was important to ask the same questions to participants, the researcher was aware that some questions might have been too leading and therefore some conversations might not have been naturally spoken about by participants or been an important factor for them to speak about.

Implications

This study adds further to our understanding of HIV status sharing, but particularly individuals sharing their status openly. To the authors knowledge, no research into HIV has looked at a sample who are all open about their HIV status and their journey of sharing. Many of the findings are in line with or agree with previous research on more selective status sharing but add to the literature looking at open sharing. One of the main findings was that having knowledge helps with status sharing, emphasising the need to educate people, both those living with HIV and the HIV negative population, about what HIV is, how it is transmitted and the treatment options. This is particularly important as a lack of knowledge about HIV has been associated with stigma (Lifson et al., 2012).

Secondly, it was found that sharing HIV status openly was an individual process and that participants had different strategies. When clinicians are working with individuals who have been given an HIV positive diagnosis, it might be helpful for both clinicians and PLWH to be aware that there is no right way of them doing this process but that individuals need to find the way that suits them. It might be helpful to acknowledge that acceptance was a key contributing factor to helping participants share openly and therefore emphasising that there is no time limit for people to start sharing and possibly the more they are able to accept their diagnosis and be cautious with sharing initially, the easier the process of being open about their status might be.

Additionally, this research has helped to inform about factors that people found helpful when they were considering sharing their status with others and that support was a key factor. Therefore, it would be important for clinicians working with people

who are given an HIV positive diagnosis to ensure they have some form of support, even if initially it is support from clinicians and that people do not feel isolated whilst they are coming to terms with their diagnosis. Finally, this study found that even though participants differed on their reasons for sharing, overall, the reasons were due to them either being able to see benefits for themselves or others.

Future Research

This study has highlighted some areas for future research. Firstly, acceptance was a prominent finding, which impacted individuals across the sharing process. It would be interesting to understand more about the acceptance process. Secondly, this sample was homogenous being men who identified as gay. It would be interesting to see whether the findings are similar if the demographic of the sample was more diverse. Additionally, it would be interesting to understand more about people's perceptions of HIV pre-diagnosis and how this might link to their own perception of people's reactions, and whether the reactions were concordant or discordant with their own held beliefs. Finally, when thinking about how HIV might be appraised as a threat, it would be interesting to understand differences in the threat perception from people diagnosed at different times.

Conclusion

Overall, the findings showed that the experience of sharing openly was an individual process with each participant having slightly different experiences from the other. This was in terms of when they shared for the first time, how they shared, reasons why they shared and what helped them to share and the outcomes of sharing. Most

participants spoke about the importance of both PLWH having knowledge but also the need to educate others to help to reduce the stigma around HIV. It was also found that acceptance of one's status helped with sharing and particularly sharing openly. This research adds to the current literature and also aids both clinicians working with PLWH and those with HIV to understand the process of sharing openly and how individuals can be helped in the future.

4. Integration, Impact and Dissemination Summary

Integration

Overall, the aim of the thesis was to understand the experiences of PLWH who are open about their HIV status. This was achieved through both the systematic review and the empirical study. The systematic review looked more generally at the experiences of people with a communicable disease who are open about their status, whilst the empirical study looked solely at PLWH who are open about their status.

The two studies were conducted at the same time and therefore were able to inform each other, with the systematic review providing background research that was relevant to the empirical study. This was possibly more informative than initially expected. It was hoped that the systematic review would be a review of experiences of openly sharing communicable disease status, however following the screening and eligibility searches, 12 of the 13 studies were a sample of PLWH, with the other study focussing on people with Hepatitis C. This meant that although it was not possible to critically evaluate papers regarding other communicable diseases, it was informative for the empirical study as subsets of these samples were open about their HIV status. Findings indicated what literature was available on openly sharing HIV status and informed conclusions drawn from the empirical study. Additionally, given the systematic review was solely looking at qualitative papers, the quality assessment helped inform factors that needed to be considered and included in the empirical study. However, it might have been that analysing both at the same time meant that certain themes stood out more than others during the interpretation of the empirical study, based on the findings in the systematic review.

The systematic review was initially meant to look at all stigmatised conditions, not just physical health conditions. This included stigmatised mental health conditions. However due to the volume of papers, the question was adapted and overall, it was decided the criteria would be communicable diseases. It would have been interesting to understand what sharing open experiences of other stigmatised conditions was like and draw further comparisons, not just among physical health, and mainly HIV.

Additionally, the systematic review included studies worldwide, with none of the studies being based in the UK. In contrast, the empirical study recruited participants from two HIV clinics in London. It is possible that the important factors, themes and conclusions drawn from the empirical study might be slightly different to the studies in the systematic review due to different circumstances, culture, access to healthcare, including treatment options and availability, and societal view and knowledge about HIV. This is an important factor to consider, particularly with regards to transferability of findings. Another difference to consider for the interpretation of the findings is the different demographics of the samples, as the empirical study sample ended up being a sample of all men who identified as being homosexual. Some of the experiences and interpretations drawn from their experiences could be different to those who are either female or with a different sexual orientation.

There were many similarities in the themes found across the systematic review and the empirical study. The systematic review articles had subsets of samples who were open about their HIV status, and not the whole sample, as in the empirical study. Although there were similarities found, it is difficult to draw full comparisons as the

studies in the systematic review had different aims or might have been looking at one aspect of sharing. In comparison, the empirical study tried to understand the full experience someone might have, from receiving their HIV positive diagnosis, adjusting and possibly accepting that diagnosis, making the decision to share their HIV positive status, and choosing to be open about it.

The themes that were similar included factors that made it easier to share, including having knowledge, acceptance of HIV diagnosis, having support, one's age and being prepared for any reactions. Findings from the systematic review in terms of what made it easier to share also included privilege and faith, both of these were not discussed in the empirical study but are interesting factors to hold in mind.

Similar findings on reasons why individuals shared their status were to educate others, wanting to be honest and wanting to support others. In the systematic review, other findings included blame, economic factors, health deterioration, relationships and seeing others share their status.

Both the systematic review and the empirical study highlighted that the process and strategies for sharing their status differed for all individuals, with some people being advocates and others telling people on a 'need to know' basis, as well as when people chose to start sharing their status and be more open about it. Findings from the empirical study also included how people shared their status and factors related to future sharing and whether they were impacted by previous experiences.

Benefits of sharing from both the systematic review and empirical study included strengthening relationships, support, educating others and helping others, whilst studies from the systematic review also spoke about health outcome benefits. Negative outcomes following sharing for both the systematic review and the empirical study included rejection, and experiences from the systematic review included not being believed as well as experiencing enacted stigma, whilst in the empirical study, participants spoke about concern from others and their status being shared without their permission.

Other differences in findings included the systematic review having more emphasis on fears of individuals before sharing, whilst in the empirical study, there was more emphasis on understanding participants reactions at diagnosis. Finally, in the empirical study, participants spoke about comparative experiences of sharing in relation to other personal information they might share about themselves, such as mental health difficulties, sexuality. They also spoke about difficulties when working in the HIV field and managing when is an appropriate and helpful time to share and when it might be obstructive or unhelpful to your work.

Reflections on the Research

Empirical Study Research Process

A dominating factor that impacted the empirical study research process that it is important to consider is the COVID-19 pandemic. As will be explained in more detail below, the pandemic impacted the NHS ethics and R&D approval, recruitment, and the interview process.

Carrying out the NHS ethics process was without many difficulties. It was slightly delayed due to the start of the COVID-19 pandemic, as the process was moving to a remote platform and adjustments needed to be made to the project to allow for it to all take place remotely. Submitting documents to R&D at both sites was slightly delayed due to further clarification with regards to the need to recruit remotely.

The recruitment process was carried out efficiently by the clinicians at the HIV clinics, particularly given the restrictions in place due to COVID-19 and this sample being a ‘hard to recruit’ sample. Due to the restrictions, the researcher was unable to be on site so was not able to have a presence within the service and speak with clinicians to discuss the research study. As outlined in the methods section, clinicians were the first point of contact with potential participants regarding the study. Many staff within the HIV clinics were re-deployed to other services to support during the pandemic, meaning that there was less availability for clinicians to help with recruitment and possibly some clinics and appointments were postponed. Given all of this, recruitment was efficient, and we were able to reach our target recruitment number.

PLWH who are open about their HIV status are considered a ‘hard to recruit’ population as although there are 105,200 number of people living in the UK with HIV (World Health Organisation, 2019), there are not many who are open about their status. Due to this, at times it was difficult for clinicians for find potential participants who would meet criteria or want to take part in the study. This possibly meant that recruitment was longer than if it was not a ‘hard to recruit’ population. Ethics was also approved to recruit from a psychology service at one of the sites, however, recruitment was unsuccessful there. Some potential participants were approached, however they did

not want to take part in the study. It is interesting to consider why this might be the case. One hypothesis is that during therapy, they did not feel comfortable taking part in a research study.

Empirical Study Interview Process

Interviews took place over skype (n=6) or the telephone (n=2). It is possible that some of the nuances were lost due to this, particularly during the telephone interviews. However, it might have made taking part in the study more appealing as participants could do it from their own homes and might have felt safer and able to be more open with a slight sense of detachment from the interviewer.

It was also important to reflect on, and continue to reflect during the write up, on the differences between myself and the participants. As a white, HIV negative, heterosexual female, with no experience working with people with HIV or knowing anyone who is HIV positive, there would be factors that I would not know, and it was important to reflect and be curious during the interviews. This included summarising and checking my understanding to ensure during analysis the interpretations of their experiences was as accurate as possible.

I have reflected on the need to be aware of language used and the questions I was asking, and not wanting to put participants in a position where they did not feel comfortable to answer some of the questions. Participants were very open and honest, and it compelled me to want to help them to raise further awareness and create a space for the right talking points to be spoken about with regards to HIV. All participants and service users involved in helping with the interview schedule were very helpful and

would state their hopes for making a difference to PLWH and raising awareness of HIV, whether it be testing, treatment and medical advancements.

Throughout the interview process, I was able to reflect on the interviews. Interviews would be transcribed straight after to allow for discussion during supervision with my academic supervisor. This enabled me to reflect on some of the themes of the interviews and to think about whether there were other areas or questions that I could focus on or ask.

Researcher Bias

It is also important to consider and reflect on any possible researcher bias. I was aware of my own background, both demographically and my clinical experience to date. I thought in supervision about how this might impact the way I chose to interpret the participants' experiences, particularly with the interpretative nature of IPA as an analysis method. The main model I have used throughout my clinical experience is cognitive behavioural therapy, therefore some of my questions and prompts, as well as my interpretations, might have been informed by this. Additionally, I have not worked with the HIV population before and so I have less understanding of other models that might be applicable to working with this population.

It has also been helpful to think further about how things have changed in terms of the treatment, the cultural views and the possible trauma associated with an HIV positive diagnosis. Some participants spoke about the trauma experienced previously and how that is still very much on people's minds or something they lived through. It was a factor that was really important to hold in mind throughout my research as my

initial thoughts when considering how treatment had moved on was linked primarily to the medical advancements and cultural views about HIV. Additionally, to get different perspectives, it was helpful to speak with people from different countries and of different ages working in different areas to see how this has impacted them.

Service User Involvement

Service users, who are living with HIV, were consulted for the design of the research, the analysis of results and the dissemination.

Design of the research:

Two service users reviewed the draft interview schedule in terms of the number of questions, the wording of questions and whether they suggested any additions or changes to the interview schedule. This helped to ensure the questions were relevant, the language was appropriate and sensitive and that the necessary questions were included.

Analysis of results:

Following the transcription and analysis of results, participants were asked to review the overall themes concluded from the data. This ensures respondent validation, meaning that the themes are a fair interpretation and reflection of the experiences of the participants. Only one participant responded to the member checks, and although this was very helpful, further responses might have provided more insight into whether the findings were a true reflection of their experiences.

Dissemination of findings:

Service users involved in the consulting on the interview schedule were also consulted about the best way to present these findings back to the services involved and the participants. A summary of the findings that is easily accessible to all participants and service users will be created.

Impact

Challenges of HIV

As mentioned, HIV has been associated with challenges including physical health difficulties if left untreated (World Health Organisation, 2019), mental health difficulties (Owe-Larsson et al., 2009), feelings of isolation (Vance, 2006), and enacted, internalised or anticipated stigma (Earnshaw & Chaudoir, 2009).

Potential Beneficiaries

Given previous research about HIV and status sharing, it is hoped that by having a better understanding of individual's experiences when they receive an HIV positive diagnosis and understanding factors linked to sharing their HIV status, that it might be possible to help PLWH to make decisions about whether they want to share their status and what factors consider. Additionally, it is hoped that the findings of this research will impact not only those living with HIV, but will help inform clinicians, charities, the HIV negative population and the academic community.

People Living with HIV:

Findings from the empirical study followed the process of receiving an HIV positive diagnosis and the factors and steps individuals took to openly sharing their HIV status. Overall, despite some negative outcomes and worries, participants saw the benefits of sharing openly, not only for themselves but also for others, who are living with HIV or who are HIV negative. Findings included reasons why people wanted to share, what made it easier to share, the process of sharing and strategies that people used, outcomes of sharing and comparing sharing to other experiences. There were similar findings in both the empirical study and the systematic review.

Both studies indicated there was no right way for people to share with others and acknowledged that the outcomes and reactions are not always positive and that there might be times when people might be better not to share. By increasing PLWH's knowledge about HIV, including treatment and the sharing process, it might help PLWH when they receive their HIV positive diagnosis. Knowledge about the sharing process could include what options are available and what factors have been important and helped others. This is particularly relevant given the emphasis that participants placed on being informed and having knowledge.

Acceptance was a key factor that came up across both studies and seemed to be something that was very important at the time of receiving their diagnosis and what helped with making the decision to share and made it easier to share. Firstly, by understanding the importance of acceptance linked with sharing openly, it might help PLWH to understand that there is no time limit to sharing with others and that initially being cautious with sharing and taking time to reflect on their diagnosis could be helpful. Also, by accepting one's diagnosis, it makes it easier to share as you are possibly less expectant and hopeful for a particular reaction and can adapt depending on the reaction you receive. For all participants, the time period of acceptance was different and therefore helping PLWH to understand that the acceptance and adjustment process can take time might ease pressure they might feel to be accepting of their diagnosis.

HIV Negative Population:

Increasing awareness of the findings from both the systematic review and the empirical study might help the HIV negative population in multiple ways. Initially, by increasing awareness about the most recent medical advancements regarding how HIV is or is not transmitted and treatment options might help to reduce the spread of HIV, promote testing, and promote people seeking help. Additionally, increased knowledge might help to reduce the stigma associated with HIV, which is possibly currently due to the lack of knowledge around the subject.

Clinicians:

Participants spoke about the importance of support, both professional and personal, throughout their experiences. The findings from the systematic review and the empirical study will be helpful for all clinicians working with PLWH, not just mental health clinicians working with PLWH. This might include clinicians working in areas such as A&E where someone might be given an HIV positive diagnosis. Findings can inform clinicians about the support that can be offered to PLWH, when they receive their diagnosis, when they are trying to adjust to life with it, and when they are thinking about sharing. The findings highlight reasons why participants wanted to share and what made it easier for them as well as the ways in which they chose to share and building to becoming open about their status. Clinicians might be able to share some of this information with PLWH and discuss options with them and emphasise that there are many ways for this process to happen, with no one way being the right option.

The awareness of acceptance helping with openly sharing one's status will be helpful for clinicians to know. Additionally, possibly acknowledging that this can take

time and therefore discussing with PLWH whether being cautious initially with who you want to share with until they have come to terms with it might be helpful. Being aware of this and having these discussions with PLWH might help to relieve possible pressure they feel to share but also to think about support options for them whilst they are trying to come to terms with their diagnosis. Additionally, these findings might be able to inform criteria for support to ensure that there is not a “cut off” for individuals coming to terms with their diagnosis and that people might benefit from education and support further down the line.

Findings from the empirical study also demonstrate that although participants were positive overall about their experiences, there were times when they did experience negative feedback from those they shared with. Therefore, if clinicians can speak openly with PLWH about the possibility of this happening it might help PLWH to be aware and prepared for a diverse range of reactions and be able to become informed and feel able to respond to questions people might have.

Charities:

Charities such as the Terence Higgins Trust and Positively UK are a support to those living with HIV and a resource to clinicians and the HIV negative population. The results found in this research emphasise the importance of raising awareness about HIV. By sharing the results with these charities, they might inform charities what factors people find important when they are considering sharing their status and different ways people share their status and the outcomes people have received. This information is also important for the HIV negative population to understand to improve their knowledge and support those living with HIV.

Academic Community:

This research was completed as a gap in the literature had been identified. This gap was there being little understanding as to the process PLWH go through when they receive an HIV diagnosis and the factors they consider when thinking about sharing their status openly. By sharing the findings, they can add to the current literature and inform academics and clinicians to help to integrate the findings into their work as well as identifying areas for future research. These include replicating the research with a different sample demographic or understanding more about what helped individuals to accept their diagnosis.

Dissemination

It is important to try to maximise the impact of the thesis by ensuring the findings are shared with beneficiaries. This includes sharing the findings with PLWH, clinicians, HIV negative population, charities, and the academic community as well as academic publication in relevant journals.

To disseminate to PLWH and clinicians, a summary of the systematic review and the empirical study findings will be sent to each recruitment site, including the participants, HIV charities and HIV services. The summaries will be written in language that is applicable to its audience, highlighting the key findings. Additionally, posters and leaflets will be sent to HIV services and charities that can be distributed to PLWH. The posters might be a reminder for clinicians to remember to speak to PLWH to see if they need any support or space to discuss acceptance and adjustment of HIV and options around sharing. The posters might also help PLWH to signpost they can ask for extra support around these areas. The leaflets will outline the key findings.

For clinicians, the summaries will include implications and recommendations based on the findings with the hope they can be integrated into the work done at both charities and HIV services. It also might be possible to present at team meetings to discuss the findings with clinicians, and to think together about how this research might be relevant to their services. By discussing the findings at team meetings, it might also be possible to answer any questions in relation to the findings.

For charities, a summary of findings will be sent to them, which if they are interested, it could go on their website and help to raise awareness about HIV. This

could include the different options there are for PLWH thinking about sharing their status but also provides knowledge to the HIV negative population who are interested in understanding more about HIV and the sharing process.

For the academic community, the research has been presented to Royal Holloway, University of London trainees and academic tutors. The aim of presenting was firstly to summarise the findings and what they might add to the literature, and secondly that trainees starting their research might be able to add to these current findings and address other gaps in the literature with regards to HIV and status sharing. Media is recommended as a way of maximising the impact of results in the Economic and Social Research Journal and therefore HIV publications and sexual health journals will be contacted to see if they would want to be involved in disseminating the findings.

Academic Publication

The systematic review and empirical study will be submitted to peer-reviewed journals for publication. Journals include AIDS and Behaviour and AIDS care. These journals focus on behavioural, social, and psychological impact of living with HIV and are widely read. It is also hoped that these findings will be presented at conferences. By publishing in peer-reviewed journals and presenting at conferences, it is another way of disseminating the findings and raising awareness, among clinicians and the academic community, around the process that individuals might go through when they receive an HIV positive diagnosis and the options related to open status sharing.

Evidencing Impact

In addition to the need to disseminate the findings to all potential beneficiaries, there is a need to access feedback from potential beneficiaries to understand what impact, if any, these findings have had. This might also prompt what future research could be helpful.

For PLWH, feedback could be obtained from clinics, including the recruitment sites, as to what they think they might need help with, with regards to HIV status sharing and whether they think it is being answered or the relevant support is accessible. Feedback from clinicians would be helpful to understand what their views are of the findings and the recommendations and how likely they are, or whether they think it is possible, to incorporate it into their work. It would also be interesting to understand how to improve dissemination and whether they think the findings have influenced their work, in a positive or negative way. Charities could be asked to provide feedback as to whether the information provided is useful to their users. Finally, through presentations, conferences and publishing the findings, it might be possible to access feedback from the academic community.

Feedback could be obtained anonymously using online surveys, designed specifically for the target audience, with a variety of likert scales and free text responses so that individuals can provide as detailed feedback as they think is necessary. When team meetings are attended, feedback could also be obtained verbally.

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Appendices

Appendix A: SPSS Output for Inter-Rater Kappa Calculation

➔ Crosstabs

Case Processing Summary

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
VAR00004 * VAR00005	150	0.2%	64243	99.8%	64393	100.0%

VAR00004 * VAR00005 Crosstabulation

Count

		VAR00005		Total
		1.00	2.00	
VAR00004	1.00	7	12	19
	2.00	2	129	131
Total		9	141	150

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.456	.119	6.057	.000
N of Valid Cases		150			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Appendix B: Participant Information Sheet



PARTICIPANT INFORMATION SHEET

Project Title: Exploring the experience of people living with HIV who have shared their status openly

You have been asked to take part in a study about experiences of being open about HIV status, which is being carried out by Saskia Naylor, Trainee Clinical Psychologist, as part of her Clinical Psychology Doctorate Degree, and both [REDACTED] and [REDACTED].

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 Saskia any questions you might have about the study.

Why are we doing this study?

Living with HIV can be difficult and is associated with different challenges. If someone is able to share their status, they can get support and help to live with the challenges they experience. To date, there has been no research into understanding the experiences of people who are open about their HIV positive status. The aim of the study is to understand more about the experiences of people who are open about their HIV status. This study hopes to understand your experiences of being given an HIV positive diagnosis, the decisions to share your status, different ways of sharing, and what factors have been involved for both adjusting to your HIV positive diagnosis and sharing your status.

Who can take part in the study?

You have been asked to take part in this study because you are open about your HIV positive status. We are describing being "open" as telling the following people or them knowing; your GP, your last three sexual partners since diagnosis and most of your friends and family. You have also received an HIV positive diagnosis over 6 months ago. If you do not meet those criteria, then you will not be eligible for the study.

Do I have to take part?

Taking part in the study is completely voluntary. If you wish you withdraw, you may do so up until February 2021, without giving a reason. If you choose not to take part, or to withdraw, this will not affect the standard of your medical care in any way.

Are there any disadvantages or risks of taking part in the study?

Some people might find talking about their HIV positive diagnosis, or other factors linked to your HIV status, such as decisions to share their status with others, sensitive or in some cases upsetting. You will be given the opportunity to reflect on your experience of the interview immediately afterwards with Saskia. If you feel you need further support, the first people we suggest you should speak to are your clinician at your HIV clinic or your GP.

Are there any benefits of taking part?

You may find talking about your experiences helpful. The information you share will help to increase knowledge about how people might come to terms with their HIV diagnosis, what has made it possible to share their status and the effects of sharing. This could help to understand ways of managing the possible stigma linked with having an HIV positive diagnosis and how to adjust to life living with HIV. This knowledge could help to develop better services for both people living with HIV and those around them in the future.

05/07/2020

Version 2
IRAS ID: 280289

**Where will the study take place?**

The study will take place at in clinics associated with [REDACTED] and [REDACTED].

What will the study involve?

If you are happy to take part, Saskia will go through a consent form with you which confirms you are agreeing to take part in the study. You will also be asked to fill out some questionnaires. There are three brief questionnaires, one about mood, one about living HIV and one with background details about you, for example your age and ethnicity. The main part of the study will involve you being interviewed about your experiences of receiving an HIV positive diagnosis and then thinking more about your decisions to share your status. The consent form also asks your permission for Saskia to collect some basic medical information about your HIV (for example blood counts) via your clinician or your medical notes after your interview. With your consent the interview will be audio recorded. This is to make sure that no important information is missed for the write up of the study.

How long will it take?

The interview should take between 45-60 minutes with the whole meeting taking up to 95 minutes.

How will we use information about you?

We will need to use information from you and your medical records for this research project. This information includes your name, contact details, age, gender, sexuality, ethnicity, time since diagnosis and viral load. People will use this information to do the research or to check the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

The interview will be recorded on a Dictaphone so that it can be transcribed and analysed at a later date. The recording will be transcribed by the Saskia and the transcribed data will be stored in a password protected folder on a password-protected computer. The recording will be deleted once the interview has been transcribed.

Once we have finished the study, we will keep some of the data so we can check the results. Your consent form will be kept for two years and then destroyed. Data will be kept for five years and then destroyed. The write up will be written in a way that no-one can work out that you took part in the study.

Will I receive anything for taking part?

You will receive a £10 voucher for taking part in the study. If you decide to attend an interview on a different day to your routine clinic appointment, you will also be compensated for travel expenses, up to £12. This is funded by Royal Holloway, University of London.

What will happen with the results?

The research will be submitted as part of a Clinical Psychology Doctorate degree. We will also aim to publish its results in a peer-reviewed journal and at conferences. Any written up data will be anonymised and no participants will be identified. If you would like, we will send you a summary of the findings via this clinic.

**Who has reviewed the study?**

Studies being conducted in the NHS are looked at by an independent group called a Research Ethics Committee. These are committees who make decisions about whether it is right to carry out the study. This study has been reviewed and given favourable opinion by Camden & Islington NHS Research Ethics Committee (IRAS ref: 280289). It has also been approved by Royal Holloway, University of London Ethics Committee, the Health Regulation Authority and the Research and Development Committees at both [REDACTED] and [REDACTED]. 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.

Who should I contact if I have any questions?

This project is supervised by Dr Michael Evangelji (Reader in Clinical Psychology at Royal Holloway University London) and [REDACTED] and [REDACTED].

The main person to contact for this project is Saskia Naylor, Trainee Clinical Psychologist at the Department of Clinical Psychology, Royal Holloway University of London (RHUL). My email is: Saskia.naylor.2018@live.rhul.ac.uk

Additionally, if you would like to contact Dr Michael Evangelji, his email is michael.evangelji@rhul.ac.uk

What if I have any concerns or complaints?

If you feel unhappy with the research in any way then please contact a member of the research team, as seen on the details above. If you are still unhappy or would prefer to speak to someone outside of the research team, then please contact the Patient Advice and Liaison Services (PALS) at [REDACTED] or at [REDACTED].

GDPR

There is a possibility that the study will be audited by independent bodies, to verify that the research has been carried out in accordance with NHS Health Research Authority protocol and in line with the GDPR and Data Protection Act 2018. They may have access to the consent forms, transcripts and questionnaire data

For information about GDPR, please read the information below.

Thank you for taking the time to read the information sheet. If you are happy to participate, please complete the consent form.



Patient data and research

This leaflet explains how health research uses information from patients. If you are asked to take part in research, you can ask what will happen in the study.

What is patient data?

When you go to your GP or hospital, the doctors and others looking after you will record information about your health. This will include your health problems, and the tests and treatment you have had. They might want to know about family history, if you smoke or what work you do. All this information that is recorded about you is called patient data or patient information.

When information about your health care joins together with information that can show who you are (like your name or NHS number) it is called identifiable patient information. It's important to all of us that this identifiable patient information is kept confidential to the patient and the people who need to know relevant bits of that information to look after the patient. There are special rules to keep confidential patient information safe and secure.

What sort of patient data does health and care research use?

There are lots of different types of health and care research.

If you take part in a clinical trial, researchers will be testing a medicine or other treatment. Or you may take part in a research study where you have some health tests or answer some questions. When you have agreed to take part in the study, the research team may look at your medical history and ask you questions to see if you are suitable for the study. During the study you may have blood tests or other health checks, and you may complete questionnaires. The research team will record this data in special forms and combine it with the information from everyone else in the study. This recorded information is research data.

In other types of research, you won't need to do anything different, but the research team will be looking at some of your health records. This sort of research may use some data from your GP, hospital or central NHS records. Some research will combine these records with information from other places, like schools or social care. The information that the researcher collects from the health records is research data.

Why does health and care research use information from patients?

In clinical trials, the researchers are collecting data that will tell them whether one treatment is better or worse than other. The information they collect will show how safe a treatment is, or whether it is making a difference to your health. Different people can respond differently to a treatment. By collecting information from lots of people, researchers can use statistics to work out what effect a treatment is having.

Other types of research will collect data from lots of health records to look for patterns. It might be looking to see if any problems happen more in patients taking a medicine. Or to see if people who have screening tests are more likely to stay healthier.

Some research will use blood tests or samples along with information about the patient's health. Researchers may be looking at changes in cells or chemicals due to a disease. All research should only use the patient data that it really needs to do the research. You can ask what parts of your health records will be looked at.

How does research use patient data?

If you take part in some types of research, like clinical trials, some of the research team will need to know your name and contact details so they can contact you about your research appointments, or to send you questionnaires. Researchers must always make sure that as few people as possible can see this sort of information that can show who you are.

In lots of research, most of the research team will not need to know your name. In these cases, someone will remove your name from the research data and replace it with a code number. This is called coded data, or the technical term is pseudonymised data. For example, your blood test might be labelled with your code number instead of your name. It can be matched up with the rest of the data relating to you by the code number.

In other research, only the doctor copying the data from your health records will know your name. They will replace your name with a code number. They will also make sure that any other information that could show who you are is removed. For example, instead of using your date of birth they will give the research team your age. When there is no information that could show who you are, this is called anonymous data.

Where will my data go?

Sometimes your own doctor or care team will be involved in doing a research study. Often, they will be part of a bigger research team. This may involve other hospitals, or universities or companies developing new treatments. Sometimes parts of the research team will be in other countries. You can ask about where your data will go. You can also check whether the data they get will include information that could show who you are. Research teams in other countries must stick to the rules that the UK uses.

All the computers storing patient data must meet special security arrangements. If you want to find out more about how companies develop and sell new medicines, the Association of the British Pharmaceutical Industry has information on [its website](http://www.abpi.org.uk) at <http://www.abpi.org.uk>.

What are my choices about my patient data?

- You can stop being part of a research study at any time, without giving a reason, but the research team will keep the research data about you that they already have. You can find out what would happen with your data before you agree to take part in a study.
- In some studies, once you have finished treatment the research team will continue to collect some information from your doctor or from central NHS records over a few months or years so the research team can track your health. If you do not want this to happen, you can say you want to stop any more information being collected.
- Researchers need to manage your records in specific ways for the research to be reliable. This means that they won't be able to let you see or change the data they hold about you. Research could go wrong if data is removed or changed.

What happens to my research data after the study?

Researchers must make sure they write the reports about the study in a way that no-one can work out that you took part in the study.

Once they have finished the study, the research team will keep the research data for several years, in case they need to check it. You can ask about who will keep it, whether it includes your name, and how long they will keep it.

Usually your hospital or GP where you are taking part in the study will keep a copy of the research data along with your name. The organisation running the research will usually only keep a coded copy of your research data, without your name included. This is kept so the results can be checked.

If you agree to take part in a research study, you may get the choice to give your research data from this study for future research. Sometimes this future research may use research data that has had your name and NHS number removed. Or it may use research data that



could show who you are. You will be told what options there are. You will get details if your research data will be joined up with other information about you or your health, such as from your GP or social services.

Once your details like your name or NHS number have been removed, other researchers won't be able to contact you to ask you about future research.

Any information that could show who you are will be held safely with strict limits on who can access it.

You may also have the choice for the hospital or researchers to keep your contact details and some of your health information, so they can invite you to take part in future clinical trials or other studies. Your data will not be used to sell you anything. It will not be given to other organisations or companies except for research.

Will the use of my data meet GDPR rules?

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

Universities, NHS organisations and companies may use patient data to do research to make health and care better.

When companies do research to develop new treatments, they need to be able to prove that they need to use patient data for the research, and that they need to do the research to develop new treatments. In legal terms this means that they have a 'legitimate interest' in using patient data.

Universities and the NHS are funded from taxes and they are expected to do research as part of their job. They still need to be able to prove that they need to use patient data for the research. In legal terms this means that they use patient data as part of 'a task in the public interest'.

If they could do the research without using patient data they would not be allowed to get your data.

Researchers must show that their research takes account of the views of patients and ordinary members of the public. They must also show how they protect the privacy of the people who take part. An NHS research ethics committee checks this before the research starts.

What if I don't want my patient data used for research?

You will have a choice about taking part in a clinical trial testing a treatment. If you choose not to take part, that is fine.

In most cases you will also have a choice about your patient data being used for other types of research. There are two cases where this might not happen:

1. When the research is using anonymous information. Because it's anonymous, the research team don't know whose data it is and can't ask you.
2. When it would not be possible for the research team to ask everyone. This would usually be because of the number of people who would have to be contacted. Sometimes it will be because the research could be biased if some people chose not to agree. In this case a special NHS group will check that the reasons are valid. You can opt-out of your data being used for this sort of research. You can ask your GP



about opting-out, or you can find out more at <https://www.nhs.uk/your-nhs-data-matters/>.

Who can I contact if I have a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer. The research team can give you details of the right Data Protection Officer.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

Appendix C: Participant Consent Form



CONSENT FORM

March 2020, Version 1

Project Title: Exploring the experience of people living with HIV who have shared their status openly

Name of Researcher: Saskia Naylor

Ethics Committee Reference Number: 20/LO/0698

IRAS Reference: 280289

	Please Initial
I confirm that I have read and understood the information sheet for the above study	
I confirm that I have had the opportunity to ask questions which have been answered satisfactorily	
I understand that participation in this study is voluntary, and I can withdraw from the study up until February 2021, without giving any reason. If I chose not to take part, or withdraw from the study, I know my medical care will not be impacted in any way	
I agree to have my interviews audio recorded	
I understand that information will be stored confidentially	
I understand that if Saskia Naylor 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	
I agree to having my anonymous quotations used in the write up of this study	
I agree to information on my medical records that is relevant to this study (viral load at date of diagnosis) being accessed by Saskia Naylor for the purposes of this research	
I agree to take part in the above study	

Name of participant

Date

Signature

Name of researcher

Date

Signature

Copies for: Participant, Researcher site file, Participant Medical records

Date Created: March 2020

Version 1

Participant ID Number:

Appendix D: The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over your replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much	0		Not at all
1		Not quite so much	1		Occasionally
2		Only a little	2		Quite Often
3		Hardly at all	3		Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could	3		Very much indeed
1		Not quite so much now	2		Quite a lot
2		Definitely not so much now	1		Not very much
3		Not at all	0		Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all	3		Very often indeed
2		Not often	2		Quite often
1		Sometimes	1		Not very often
0		Most of the time	0		Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
0		Definitely	0		Often
1		Usually	1		Sometimes
2		Not Often	2		Not often
3		Not at all	3		Very seldom

Please check you have answered all the questions

Patients are asked to choose one response from the four given for each interview. They should give an immediate response and be dissuaded from thinking too long about their answers. The questions relating to anxiety are marked "A", and to depression "D". The score for each answer is given in the right column. Instruct the patient to answer how it currently describes their feelings.

Appendix E: Living with HIV Cognition Questionnaire (Evers et al., 2001)

LIVING WITH HIV COGNITION QUESTIONNAIRE

Adapted from: 1998 © A.W.M. Evers & F.W. Kraaijaat illness cognition questionnaire.

Instructions

On the next page is a list of statements by people with a long-term health condition. Please indicate the extent to which you agree with them by circling one of the answers following the statement. An example is provided below.

Example

If you agree with the statement below to a **large extent**, circle **3**:

	not at all	some- what	to a large extent	completely
I have learned to live with my HIV.	1	2	3	4

Work through the entire list of statements in this way. Do not spend too much time considering your answer. Your first impression is usually the best.

LIVING WITH HIV COGNITION QUESTIONNAIRE

To what extent do you agree with the following statements?

	not at all	some- what	to a large extent	completely
1. Because I am living with HIV I miss the things I like to do most.	1	2	3	4
2. I can handle the problems related to living with HIV.	1	2	3	4
3. I have learned to live with HIV.	1	2	3	4
4. Dealing with living with HIV has made me a stronger person.	1	2	3	4
5. Living with HIV controls my life.	1	2	3	4
6. I have learned a great deal from living with HIV.	1	2	3	4
7. Living with HIV makes me feel useless at times.	1	2	3	4
8. Living with HIV has made life more precious to me.	1	2	3	4
9. Living with HIV prevents me from doing what I would really like to do.	1	2	3	4
10. I have learned to accept the limitations imposed by living with HIV.	1	2	3	4
11. Looking back, I can see that living with HIV has also brought about some positive changes in my life.	1	2	3	4
12. Living with HIV limits me in everything that is important to me.	1	2	3	4
13. I can accept living with HIV well.	1	2	3	4
14. I think I can handle the problems related to living with HIV, even if it gets worse.	1	2	3	4
15. Living with HIV frequently makes me feel helpless.	1	2	3	4
16. Living with HIV has helped me realise what's important in life.	1	2	3	4
17. I can cope effectively with living with HIV.	1	2	3	4
18. Living with HIV has taught me to enjoy the moment more.	1	2	3	4

Scoring procedure for the HIV COGNITION QUESTIONNAIRE (ICQ)

The following items have to be added together to obtain the scale scores:

Helplessness	item 1, 5, 7, 9, 12, 15
Acceptance	item 2, 3, 10, 13, 14, 17
Perceived benefits	item 4, 6, 8, 11, 16, 18

Appendix F: Demographic Questionnaire



Participant Demographic Questionnaire

Participant ID:		Administrator initials:	
Participant Age:		Participant Gender:	
Date completed:			

<p>Religion:</p> <p><input type="checkbox"/> Christian (Catholic, Protestant, or any other denomination)</p> <p><input type="checkbox"/> Buddhist</p> <p><input type="checkbox"/> Hindu</p> <p><input type="checkbox"/> Muslim</p> <p><input type="checkbox"/> Jewish</p> <p><input type="checkbox"/> Sikh</p> <p><input type="checkbox"/> No religion</p> <p><input type="checkbox"/> Any other religion (please specify):</p> <p>_____</p>	<p>Ethnicity:</p> <p>White:</p> <p><input type="checkbox"/> British</p> <p><input type="checkbox"/> Irish</p> <p><input type="checkbox"/> Other (please specify):</p> <p>_____</p> <p>Black:</p> <p><input type="checkbox"/> Caribbean</p> <p><input type="checkbox"/> African</p> <p><input type="checkbox"/> Other (please specify):</p> <p>_____</p> <p>Asian:</p> <p><input type="checkbox"/> Indian</p> <p><input type="checkbox"/> Pakistani</p> <p><input type="checkbox"/> Bangladeshi</p> <p><input type="checkbox"/> Other (please specify):</p> <p>_____</p> <p>Mixed:</p> <p><input type="checkbox"/> White/Black Caribbean</p> <p><input type="checkbox"/> White/Black African</p> <p><input type="checkbox"/> White/Asian</p> <p><input type="checkbox"/> Other (please specify):</p> <p>_____</p> <p><input type="checkbox"/> Chinese</p> <p><input type="checkbox"/> Other ethnic group:</p> <p>_____</p>
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Relationship Status <input type="checkbox"/> Single <input type="checkbox"/> In a relationship	Sexuality <input type="checkbox"/> Heterosexual <input type="checkbox"/> Homosexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Other If 'Other' please specify _____
Health conditions _____ _____ _____ _____	

Appendix G: Clinical Questionnaire



Clinical Information:

Participant ID:		Administrator initials:	
Participant Age:		Participant Gender:	
Date completed:			

Date of diagnosis:	
Medication:	
ART	Yes/No
Last Viral Load:	
Date:	
Last CD4 Count:	
Date:	

Appendix H: Service User Interview Schedule Feedback



Draft 1: Interview Questions and Prompts	Service User Feedback:
Question 1: Tell me about your views of HIV before you were diagnosed?	Do you know any friends who are HIV+?
Question 2: Tell me about your experience of finding out you were HIV positive [What led you to take the HIV test/did you think you might be HIV positive/were you unwell? How did you feel about being tested for HIV? What was it like waiting for the confirmatory results after the reactive test?]	How did you Find out you were HIV+? Did you take a test, or did you get ill & were routinely tested? or did you get ill & the doctor suggested a test. - for some it's not a conscious decision to take a test
Question 3: How do you feel about being HIV positive? [What impact has it had on your life? (Acceptance, helplessness and benefit) What has been the impact, if any? (Future, health, identity, career, relationships – family, intimate, friends, employers, health care professionals) How do you feel about taking antiretroviral medication? How have other people responded?]	Issues with medication while abroad Have you been questioned about your medication when travelling abroad? Do you decant or hide your medication while traveling? Before and after hearing of your positive status did you receive professional counselling? What was their advice and was it helpful?

<p>Question 4: Tell me about the decision to share your status for the first time</p> <p>[How long after you were diagnosed as HIV positive, did you share your status with someone?</p> <p>What were your hopes when you shared your status (goal/aim)?</p> <p>Advocating?</p> <p>Did you have any concerns/worries? If so, what were they?</p> <p>Did anything help/support you with sharing your status?</p> <p>What was the experience like?</p> <p>How have other people responded?]</p>	<p>Were you "outed" as being HIV+</p>
<p>Question 5: Tell me what happened afterwards about sharing your status</p> <p>[Who did you share your status with?</p> <p>Were these active decisions to tell people afterwards?</p> <p>What was the <u>time period</u> in which this happened?]</p>	<p>Have you ever had casual sexual relationships and not revealed your status?</p> <p>Have you been or are you in a long-term relationship and not revealed your status?</p>

<p>Question 6: Was there a particular point where you decided to tell more people?</p> <p>[If yes, tell me what led to that decision If no, tell me more about getting from telling some people to telling everyone]</p>	
<p>Question 7: Tell me about the way you share your status?</p> <p>[Is it different for different people (partners/family members/friends)?</p> <p>In person/via text/phone/social media?</p> <p>Did you have a particular strategy or method for telling everyone/most people?</p> <p>Are there any other developments in HIV that have influenced your decision to share over the recent years? (PrEP and U=U)]</p>	
<p>Question 8: What has your experience of telling people been like?</p> <p>[Is it different if you know the status of the person you are disclosing to?</p> <p>What thoughts do you tend to have?</p>	

<p>How does it make you feel?</p> <p>What has their reaction been like? Thoughts, feelings, behaviours</p> <p>Was their reaction what you expected?</p> <p>Has this influenced you telling other people?</p> <p>Has this influenced how you tell people?</p> <p>Has this been similar or different to any other experience of telling other people about yourself (Coming out)]</p>	Great question: - it can be like coming out again & again
<p>Question 9:</p> <p>What do you know about recent findings about undetectable viral loads and transmitting HIV?</p> <p>[Are you aware of your viral load level?</p> <p>Does this have any impact on your decisions to share your status? Can you tell me more about it?]</p>	
<p>Question 10:</p> <p>Is there anything else you feel is important regarding sharing your status that we have not covered together?</p>	

Other Feedback:

When you meet someone, you are interested in dating / having sex with, at what point do you disclose your HIV+ status?

If you use online dating sites, (grinder, ~~Growlr~~ etc) do you disclose your HIV+ status? If so, how has this impacted on finding dates.

Asking your interviewee's social economic status would be helpful in later evaluation of the results

Financial – have you had issues related to borrowing money or other related business matters

Insurance related issues

Do you believe that after being on medication you have been less likely to suffer from colds and flu and that your general health has improved?

Do you have a heightened appreciation of life knowing that without your timely diagnosis and that fate allowed you to be living a relatively wealthy western country where you would have otherwise died without your lifesaving medication?

Appendix I: Interview Schedule

Version 2

IRAS ID: 280289

Interview Schedule

1. Tell me about your views of HIV before you were diagnosed?
 - a. Did you know others who were HIV positive?
2. Tell me about your experience of finding out you were HIV positive
 - a. What led you to take the HIV test/did you think you might be HIV positive/were you unwell?
 - b. How did you feel about being tested for HIV?
 - c. What was it like waiting for the confirmatory results after the reactive test?
3. How do you feel about being HIV positive?
 - a. What impact has it had on your life? (Acceptance, helplessness and benefit)
 - b. What has been the impact, if any? (Future, health, identity, career, relationships – family, intimate, friends, employers, health care professionals)
 - c. How do you feel about taking antiretroviral medication?
 - d. How have other people responded?
 - e. Have you received any support?
4. Tell me about the decision to share your status for the first time
 - a. Did you choose to share you status for the first time?
 - b. How long after you were diagnosed as HIV positive, did you share your status with someone (date)?
 - c. What were your hopes when you shared your status (goal/aim)? Advocating?
 - d. Did you have any concerns/worries? If so, what were they?
 - e. Did anything help/support you with sharing your status?
 - f. What was the experience like?
 - g. How have other people responded?
5. Tell me what happened afterwards about sharing your status
 - a. Who did you share your status with?
 - b. Were these active decisions to tell people afterwards?

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- c. What was the time period in which this happened?
- 6. Was there a particular point where you decided to tell more people?
 - a. If yes, tell me what led to that decision
 - b. If no, tell me more about getting from telling some people to telling everyone
- 7. Tell me about the way you share your status?
 - a. Is it different for different people (partners/family members/friends)?
 - b. In person/via text/phone/social media/dating apps?
 - c. Did you have a particular strategy or method for telling everyone/most people?
 - d. Are there any other developments in HIV that have influenced your decision to share over the recent years? (PrEP and U=U)
- 8. What has your experience of telling people been like?
 - a. Is it different if you know the status of the person you are disclosing to?
 - b. What thoughts do you tend to have?
 - c. How does it make you feel?
 - d. What has their reaction been like? Thoughts, feelings, behaviours
 - e. Was their reaction what you expected?
 - f. Has this influenced you telling other people?
 - g. Has this influenced how you tell people?
 - h. Has this been similar or different to any other experience of telling other people about yourself (Coming out)
- 9. What do you know about recent findings about undetectable viral loads and transmitting HIV?
 - a. Are you aware of your viral load level?
 - b. Does this have any impact on your decisions to share your status? Can you tell me more about it?
- 10. Is there anything else you feel is important regarding sharing your status that we have not covered together?

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- a. Situations where you have chosen to not share your status

11. What advice would you give others thinking about living life openly?

Debrief:

How did you find the interview?/How are you feeling after the interview?

Was there anything during the interview that you would like to discuss further? [Anything that you have concerns about?]

Do you have any questions about the interview or anything else linked to the study?

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Appendix J: Extract Coded Transcript

*Choice of words – “it wasn’t terrible”
Emphasis on it being a negative experience?*

Relief

Acceptance? Anxiety about not getting HIV “I don’t think I realised that I was anxious about not getting HIV until I suddenly didn’t feel anxious once I had it, it was kind of weird”

Perceived benefits? “you sort of start taking stock of sort of things you have been doing in your life that aren’t making you happy, behaviours that have not been making you happy um, who you are hanging out with, what things you are doing that are positive in your life, what things that are negative, um and so yeah you definitely do take stock”

Experience of disclosing – need to accept it yourself first

Focussing on own emotional reaction initially before telling others “The hardest thing is, and I still say this now to people that newly positive is, it is better to not tell too many people too quickly because you end up supporting their emotional reaction rather than dealing with your own reaction”

Perception of HIV as a death sentence?
More difficult to tell family than friends

127 R: Yep
128 P: So yeah, **it wasn’t terrible**
129 R: Ok, that’s good to hear
130 P: Yep
131 R: And how did you feel about being HIV positive?
132 P: Yeah I mean that feeling of relief did continue
133 actually, there was kind of, **I don’t think I realised**
134 **that I was anxious about not getting HIV until I**
135 **suddenly didn’t feel anxious once I had it, it was kind**
136 **of weird**, and like I say, it wasn’t that I, I tried to
137 explain this to people subsequently, it is not that you
138 want people to get HIV but there was certainly a
139 growing up, some of the questions that you asked
140 earlier in the questionnaires, **you sort of start taking**
141 **stock of sort of things you have been doing in your**
142 **life that aren’t making you happy, behaviours that**
143 **have not been making you happy um, who you are**
144 **hanging out with, what things you are doing that are**
145 **positive in your life, what things that are negative, um**
146 **and so yeah you definitely do take stock**
147 R: Mhmm
148 P: And that was not a negative experience for me. **The**
149 **hardest thing is, and I still say this now to people that**
150 **newly positive is, it is better to not tell too many**
151 **people too quickly because you end up supporting**
152 **their emotional reaction rather than dealing with**
153 **your own reaction**
154 R: Mhmm
155 P: So yeah I think the hardest thing in retrospect was
156 telling not so much friends but certainly family who
157 you know at that point, 2002, I think still had this
158 idea that you know you might live for 10 or 20 years

Acceptance or Fear of contracting HIV causing anxiety “I don’t think I realised that I was anxious about not getting HIV until I suddenly didn’t feel anxious once I had it, it was kind of weird”

Acceptance of HIV/Perceived benefits “you sort of start taking stock of sort of things you have been doing in your life that aren’t making you happy, behaviours that have not been making you happy um, who you are hanging out with, what things you are doing that are positive in your life, what things that are negative, um and so yeah you definitely do take stock”

Help with disclosing – need to accept it yourself first “The hardest thing is, and I still say this now to people that newly positive is, it is better to not tell too many people too quickly because you end up supporting their emotional reaction rather than dealing with your own reaction”

Acceptance of others – HIV a death sentence in some people’s eyes

5

Using humour as a way to tell people/coping

Acceptance?

Perceived benefits "I did, I feel like I made positive life ~~cho~~ positive life changes, um and positive health choices actually"

Difficulties separating personal and professional life

Some areas of medicine might be more difficult to talk about being HIV positive in
Stigma in some areas more than others

Sexuality vs HIV positive status "It is very difficult to tease out what is HIV and what is sexuality"

159 but it wasn't not going to be 40. In fact I think that,
160 apparently, this is terrible because I was 27,
161 apparently I told my mum that you know, it would be
162 fine I would easily live till 40, which sounded like
163 ages at the time [laughs] and now that I am 45, it
164 doesn't feel like quite so long [laughs]. So she
165 remembers that

166 R: Aw

167 P: Um but yeah um I wasn't that negative about it

168 R: Mhmm

169 P: I did, I feel like I made positive life ~~cho~~ positive
170 life changes, um and positive health choices actually

171 R: That's really good to hear, and you have already
172 moved onto this, but has there been any other
173 impacts on your life um, that you can link to being
174 HIV positive?

175 P: Um, so I avoided working in the sector for quite
176 some time and then it kept kind of calling me back in
177 a way, so I ended up working, and that, that has been
178 a kind of mixed blessing because I love my job but I
179 guess defining the boundaries can be quite difficult
180 R: Yep

181 P: Some patient groups that know about my status
182 very much want me to be talking about being HIV
183 positive a lot, whereas actually my main role is as a
184 professional who works in the field. Um, that said, it
185 is a sector of medicine that is very easy to talk about
186 HIV I am not sure it would be so easy if I was an
187 orthopaedic surgeon or a cardiologist, um, I am trying
188 to think what else it might have impacted. It is very
189 difficult to tease out what is HIV and what is sexuality
190 R: Mhmm

Acceptance "Um but yeah um I wasn't that negative about it"

Perceived benefits "I did, I feel like I made positive life ~~cho~~ positive life changes, um and positive health choices actually"

Conflict of personal vs professional life "so I avoided working in the sector for quite some time and then it kept kind of calling me back in a way, so I ended up working, and that, that has been a kind of mixed blessing because I love my job but I guess defining the boundaries can be quite difficult"

Stigma in work "Um, that said, it is a sector of medicine that is very easy to talk about HIV I am not sure it would be so easy if I was an orthopaedic surgeon or a cardiologist"

Identity: HIV vs sexuality "It is very difficult to tease out what is HIV and what is sexuality"

6

Appendix K: NHS REC Approval



London - Camden & Kings Cross Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

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

13 July 2020

Miss Saskia Naylor
Trainee Clinical Psychologist
Camden & Islington NHS Foundation Trust
Department of Psychology
Royal Holloway, University of London
Egham, Surrey
TW20 0EX

Dear Miss Naylor,

Study title:	Exploring the experience of people living with HIV who have shared their status openly
REC reference:	20/LO/0698
Protocol number:	N/A
IRAS project ID:	280289

Thank you for your submission on 07 July 2020, 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 and Lead Reviewer.

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

A Research Ethics Committee established by the Health Research Authority

the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) 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 HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>)

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

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).

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, including early termination of the study

- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) 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/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

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

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RHUL professional indemnity policy schedule]	Version 1	07 April 2020
Interview schedules or topic guides for participants [Draft Interview Schedule]	Version 1	14 April 2020
Interview schedules or topic guides for participants [Interview Schedule]	Version 2	05 July 2020
IRAS Application Form [IRAS_Form_16042020]		16 April 2020
Other [Sub Committee Provisional Approval]	Version 1	07 April 2020
Other [Provisional Approval Response]	Version 1	07 April 2020
Other [Sub Committee Provisional Approval 2]	Version 1	07 April 2020
Other [Provisional Approval 2 Response]	Version 1	07 April 2020
Other [RHUL Research Sub Committee Approval]	Version 1	07 April 2020
Other [REC Provisional Opinion Responses]	Version 1	05 July 2020
Participant consent form [Participant Consent Form]	Version 1	16 March 2020
Participant information sheet (PIS) [Participant Information Sheet]	Version 2	05 July 2020
Research protocol or project proposal [Research Proposal]	Version 1	14 November 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		07 April 2020
Summary CV for supervisor (student research) [CV Supervisor]	Version 1	07 April 2020

Statement of compliance

A Research Ethics Committee established by the Health Research Authority

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.

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 Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS project ID: 280289 Please quote this number on all correspondence
--

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

Yours sincerely,



Katie Arnold
Approvals Officer
P.P
Mrs Rosie Glazebrook
Chair

Email: CamdenandKingsCross.REC@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Miss Leisha Wickham

Appendix L: HRA Ethics Approval



Miss Saskia Naylor
Trainee Clinical Psychologist
Camden & Islington NHS Foundation Trust
Department of Psychology
Royal Holloway, University of London
Egham, Surrey
TW20 0EX

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

14 July 2020

Dear Miss Naylor

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Exploring the experience of people living with HIV who have shared their status openly
IRAS project ID:	280289
Protocol number:	N/A
REC reference:	20/LO/0698
Sponsor	Doctorate in Clinical Psychology

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **280289**. Please quote this on all correspondence.

Yours sincerely,
Christie Ord

Approvals Specialist

Email:
approvals@hra.nhs.uk

Copy to: *Miss Leisha Wickham*

List of Documents

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

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [RHUL professional indemnity policy schedule]	Version 1	07 April 2020
Interview schedules or topic guides for participants [Draft Interview Schedule]	Version 1	14 April 2020
Interview schedules or topic guides for participants [Interview Schedule]	Version 2	05 July 2020
IRAS Application Form [IRAS_Form_16042020]		16 April 2020
Organisation Information Document	2	07 May 2020
Other [REC Provisional Opinion Responses]	Version 1	05 July 2020
Other [Sub Committee Provisional Approval]	Version 1	07 April 2020
Other [Provisional Approval Response]	Version 1	07 April 2020
Other [Sub Committee Provisional Approval 2]	Version 1	07 April 2020
Other [Provisional Approval 2 Response]	Version 1	07 April 2020
Other [RHUL Research Sub Committee Approval]	Version 1	07 April 2020
Participant consent form [Participant Consent Form]	Version 1	16 March 2020
Participant information sheet (PIS) [Participant Information Sheet]	Version 2	05 July 2020
Research protocol or project proposal [Research Proposal]	Version 1	14 November 2019
Schedule of Events or SoECAT [Schedule of Events]	Version 1	07 April 2020
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		07 April 2020
Summary CV for supervisor (student research) [CV Supervisor]	Version 1	07 April 2020

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
All sites will perform the same research activities therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No study funding will be provided to sites as per the Organisation Information Document	A Local Collaborator should be appointed at study sites of this type	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix M: Royal Holloway University of London, Self-Certification Ethical Approval



Ethics Review Details

You have chosen to self certify your project.	
Name:	Naylor, Saskia (2018)
Email:	NFJTD18@live.rhul.ac.uk
Title of research project or grant:	Exploring the experience of people living with HIV who have shared their status openly
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Dr Michael Evangelini
Email address of Academic Supervisor:	michael.evangelini@rhul.ac.uk
Funding Body Category:	No external funder
Funding Body:	
Start date:	01/09/2020
End date:	30/07/2021

Research question summary:

This project aims to understand the experiences of individuals who are open about their status. Open about their status is operationalised as their GP, most of their family and friends and their last three sexual partners since diagnosis being told or knowing. The primary aim of the research is to understand the experiences of individuals who are open about their HIV positive status, to try and understand in more detail the link between adjustment or acceptance of HIV and someone sharing their status. Secondary aims include identifying what might help individuals decide to share their status, whether the first experience of sharing has impacted future disclosures and what factors made it easy to share their status. Possibilities for this include the finding that an undetectable viral load means the virus is untransmittable, and another possibility being internal factors, including emotional experiences, that have influenced decisions to share. This may provide insights into how HIV stigma can be reduced.

Research method summary:

A qualitative approach will be used and interviews will be conducted. The aim is to interview eight participants. Inclusion criteria includes adults (18 or over) who are HIV positive, having acquired HIV behaviourally. Participants can be any gender and any sexuality. Additionally, participants need to be "open about their HIV status". Participants need to have told or the following people know: their GP, most of their friends and family and their last three sexual partners since diagnosis. Inclusion criteria will be assessed by clinicians at the recruitment clinics.

Exclusion criteria includes those whom are at risk of harm to themselves or others, at the point of initial recruitment or interview stages. Individuals who have been diagnosed with HIV within the last six months will not be included. This will be needed due to ethical reasons, plus to ensure that there has been enough time for sharing to take place.

Recruitment will take place at two sites and potential participants will be approached by their clinicians. If they are interested in taking part and consent to their details being shared with the researcher, the researcher will then contact them to arrange a time to go through the participant information sheet, gain consent and conduct the interviews. Participants will also complete the Hospital Anxiety and Depression Scale, the Living with HIV Cognitions Questionnaire and a demographic questionnaire to help to situate the sample. The interviews will either take place face to face or over the telephone/via Skype.

The transcribed data will be analysed using interpretative phenomenological analysis (IPA) (Smith, 2017). IPA was chosen over other models, such as Grounded Theory as the aim for this project is to understand individuals' experiences and internal factors rather than generate a model.

Risks to participants

Does your research involve any of the below?

Children (under the age of 16),

No

Participants with cognitive or physical impairment that may render them unable to give informed consent,

No

Participants who may be vulnerable for personal, emotional, psychological or other reasons,

Yes

Participants who may become vulnerable as a result of the conduct of the study (e.g. because it raises sensitive issues) or as a result of what is revealed in the study (e.g. criminal behaviour, or behaviour which is culturally or socially questionable),

Yes

Participants in unequal power relations (e.g. groups that you teach or work with, in which participants may feel coerced or unable to withdraw),

No

Participants who are likely to suffer negative consequences if identified (e.g. professional censure, exposure to stigma or abuse, damage to professional or social standing),

Yes

Details,

Some of the interview questions may raise difficult emotions and memories. In an attempt to manage this participants can not have received their positive HIV diagnosis in the last six months. This is so they have the opportunity to adjust to the test result. The participant information sheet will identify some of the areas that the interview is likely to cover. This is to help ensure that participants are providing informed consent and are aware of the types of questions they may be asked.

The chief investigator will be sure to monitor participants' reactions and affect throughout the interview. If the chief investigator feels it is necessary to, she will stop the interview at any time if a participant appears distressed. Participants will be reminded that they do not have to answer any questions that they do not feel happy to. All participants will be given the opportunity to reflect on their experience of the interview process with the chief investigator. If deemed to require further support after the debrief, a member of the clinical team will be informed to help manage this.

Participants will be sign posted to relevant support agencies should they need it. All participants will be aware that they can withdraw from the research up until February 2021. If it is thought that an individual is likely to be at risk from participating the research they would not be eligible to take part. This will be assessed by clinicians at each HIV clinic. Additionally, should the interviews take place over the telephone or via skype, the researcher will ensure they have the phone number of the clinician linked to the participant to raise any risk concerns straight away with the clinician.

All data collected will be anonymised and therefore no one will be identified in the write up of this study.

Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time?,

No

Is there a risk that participants may be or become identifiable?,

No

Is pain or discomfort likely to result from the study?,

No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?,

Yes

Does this research require approval from the NHS?,

Yes

If so what is the NHS Approval number,

20/LQ/0698

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?,

No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project?,

No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use?,

Yes

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?,

No

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures?,

No

Details,

HRA and REC approval has already been obtained for this study. R&D is currently being obtained and therefore any use of secure information will have been consented to by both the research sites and the participants before the information is accessed.

Some of the interview questions may raise difficult emotions and memories. In an attempt to manage this participants can not have received their positive HIV diagnosis in the last six months. This is so they have the opportunity to adjust to the test result. The participant information sheet will identify some of the areas that the interview is likely to cover. This is to help ensure that participants are providing informed consent and are aware of the types of questions they may be asked.

The chief investigator will be sure to monitor participants' reactions and affect throughout the interview. If the chief investigator feels it is necessary to, she will stop the interview at any time if a participant appears distressed. Participants will be reminded that they do not have to answer any questions that they do not feel happy to. All participants will be given the opportunity to reflect on their experience of the interview process with the chief investigator. If deemed to require further support after the debrief, a member of the clinical team will be informed to help manage this.

Participants will be sign posted to relevant support agencies should they need it. All participants will be aware that they can withdraw from the research up until February 2021. If it is thought that an individual is likely to be at risk from participating the research they would not be eligible to take part. This will be assessed by clinicians at each HIV clinic. Additionally, should the interviews take place over the telephone or via skype, the researcher will ensure they have the phone number of the clinician linked to the participant to raise any risk concerns

straight away with the clinician.

Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artifacts?,

No

Will the research be undertaken on private or government property without permission?,

No

Will geological or sedimentological samples be removed without permission?,

No

Will cultural or archaeological artifacts be removed without permission?,

No

Details,

Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)?,

No

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?,

No

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?,

No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?,

No

Is there any reputational risk concerning the source of your funding?,

No

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute?,

No

Details,

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, NFJT018

Date:	14/08/2020 14:08
Signed by:	Naylor, Saskia (2018)
Digital Signature:	Saskia Naylor
Certificate dated:	14/08/2020
Files uploaded:	20-LO-0698, IRAS ID 280289 Favourable Opinion on Further Information 13 July 2020(1).pdf 280289, 20.LO.0698 Letter of HRA and HCRW Approval 14.07.20.pdf

Appendix N: Site A R&D Approval



9th October 2020

Saskia Naylor
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Department of Psychology
Royal Holloway, University of London
Egham
Surrey TW20 0EX

Dear Saskia,

RE: IRAS: 280289 - Exploring the experience of people living with HIV who have shared their status openly – [REDACTED]

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation.

Please be advised that should you require access to the Trust's premises and/or patients, you must report to your line manager within the Trust before conducting any research activities. You must bring a copy of this letter and proof of ID.

We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through [REDACTED] NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on **9th October 2020** and ends on **31st July 2021** unless terminated earlier in accordance with the clauses below. **If you require an extension to your letter of access, you must inform the Research and Development office at least one month in advance.**

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the

research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [REDACTED] you will remain accountable to your employer, **Camden and Islington NHS Foundation Trust** but you are required to follow the reasonable instructions of your nominated manager, **Dr [REDACTED]** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust [REDACTED] prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

[REDACTED] will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

A large black rectangular box redacting the signature of the Research Delivery Operations Manager.

Research Delivery Operations Manager

A black rectangular box redacting the contact information of the Research Delivery Operations Manager.

Appendix O: Site B R&D Approval

Miss Saskia Naylor

Dear Miss Naylor,

Letter of access for research

This letter should be presented to each participating organisation before you commence your research at that site [REDACTED]

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on **29 October 2020 from and ends on 28 October 2023** unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with the participating organisation(s). The organisation(s) is/are satisfied that the research activities that you will undertake in the organisation(s) are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the organisation(s). Evidence of checks should be available on request to [REDACTED]

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving the organisation(s) permission to conduct the project.

~~You are considered to be~~ a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and [REDACTED] in particular that of an employee.

While undertaking research through [REDACTED] you will remain accountable to your employer **C&I NHS Foundation Trust** but you are required to follow the reasonable instructions of your nominated manager [REDACTED] in each organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and [REDACTED] prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The ~~organisation(s)~~ will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) accept no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation(s) terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you

must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation.

Yours sincerely,

[Redacted Signature]

cc: Substantive HR: Sylvie Melson HR.Support@Candi.nhs.uk

[Redacted Email Address]