

**Help-Seeking in Women Living with HIV who have Experienced Intimate  
Partner Violence**

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## Contents

Lay Summary .....	8
Help-Seeking in Women Living with HIV who have Experienced Intimate Partner Violence .....	13
Abstract .....	13
Introduction.....	15
Setting the Context for Women Living With HIV.....	17
Women Living with HIV and Intimate Partner Violence – the Crucial Role of Intersectionality .....	18
Models of Help-Seeking and Barriers to Healthcare.....	21
How Far Have UK Health Services Come?.....	23
The Rationale for the Current Study.....	25
Research Objectives.....	26
Methods.....	26
Design .....	26
Sample.....	27
Study Procedure.....	29
Analysis.....	38
Quality Appraisal.....	39
Results.....	40
HIV is a Life-Altering Diagnosis .....	40

The Abuser Uses Various Strategies to Exert Power and Control.....	48
Surviving the Abusive Relationship .....	54
Coping with the Lasting Damage of IPV.....	57
Unreliable Personal Networks.....	61
Support Services Perpetuate Patterns of Abuse.....	63
Service Provision Has Changed Over Time.....	67
For WLHA, Support Services Are Not a Place for Care .....	68
The Role of Systemic Issues in Disadvantaging Women .....	69
The Impact of Positive Support Service Experiences.....	71
Moving on From the Trauma .....	73
Discussion .....	77
The Impact of Being Diagnosed with HIV .....	78
The Role of HIV in Forming Relationships.....	78
Healthcare .....	80
Peer support.....	82
Strengths and Limitations .....	83
Implications.....	85
Suggestions for Future Research .....	87
The Barriers and Facilitators of Health-Care Help-Seeking in Women Who Have Experienced Intimate Partner Violence: A Systematic Review.....	89
Abstract .....	89

Introduction .....	91
Definition .....	91
IPV in Context.....	91
The Impact of IPV on the Victims/Survivors.....	92
IPV and Healthcare.....	94
Gaps in the Literature .....	96
Aim of the Review.....	97
Methods (Element 1 - Developing a Theory).....	98
Eligibility Criteria.....	98
Sources of Information .....	99
Search Strategy.....	99
Data Collection.....	102
Data Extraction.....	104
Quality Assessment.....	104
Data Synthesis .....	107
Results (Element 2 - Developing a Preliminary Synthesis).....	107
Selection Process .....	107
Quality Assessment of the Included Studies .....	108
Element 3 – Exploring the Relationship within and Between Studies .....	112
Discussion (Element 4 – Assessment of Robustness of Synthesis).....	148
Limitations .....	153

Implications.....	155
Chapter 4.....	157
Integration, Impact, and Dissemination.....	157
Integration .....	157
Research Ethics and Service Engagement Process.....	158
The Interview Process.....	159
Navigating Expectations .....	162
Impact and Dissemination.....	163
References .....	171
Appendix A .....	205
Appendix B .....	208
Appendix C .....	209
Appendix D.....	212
Appendix E.....	215
Appendix F.....	222
Appendix G .....	231
Appendix H.....	234
Appendix I.....	237
Appendix J .....	242
Appendix K.....	245
Appendix L.....	246

### **List of Tables**

Table 1.....	30
Table 2 .....	34
Table 3 .....	41
Table 4.....	104
Table 5.....	108
Table 6.....	114

### **List of Figures**

Figure 1 .....	39
Figure 2.....	103
Figure 3.....	159

## **Lay Summary**

### **Background**

Intimate partner violence (IPV) refers to physical, sexual, emotional, or financial abuse by an intimate partner (National Institute for Health and Care Excellence, 2016), and is common among women living with HIV/AIDS (WLHA). WLHA who have experienced intimate partner violence (WLHA/IPV) face unique challenges that can profoundly impact their health and well-being (UNAIDS, 2021). The combination of HIV status and IPV creates a complex and often dangerous situation for this population. By gaining insight into the specific barriers women face when seeking help, healthcare providers, policymakers, and support organisations can tailor their services to meet their needs better.

### **Empirical Research**

Studies have shown that WLHA are one and a half times more likely to experience IPV than those without HIV (UNAIDS, 2021). In the UK, it has been reported that as many as 52% of WLHA experience IPV (Dhairyawar et al., 2013). These women face multiple challenges, including the stigma associated with HIV, physical and mental health needs, financial difficulties, and social barriers, alongside the effects of IPV. Unfortunately, WLHA continue to be disproportionately affected by abuse in healthcare settings (Terrence Higgins Trust [THT], 2018). Stigma, fear of disclosure, and lack of support contribute to their difficulties accessing healthcare (UNAIDS, 2022a). These challenges can lead to problems sticking to their treatment plans.

While we know there is a connection between WLHA and IPV, most research on this topic has been conducted in countries other than the UK. Therefore, UK-based



research was needed to fill the gaps in our knowledge (THT, 2018). This research aimed to better understand the experiences of WLHA/IPV and their efforts to seek help. By conducting this research, we hoped to contribute to a better understanding of their experiences and possibly improve the services available to WLHA/HIV.

Six participants were recruited from HIV charities and two HIV clinics. Participants self-identified as cis-gendered (identified with the sex they were given at birth) females who had been subject to IPV and were living with HIV. A qualitative method called Interpretative Phenomenological Analysis was used to guide the interviews and to analyse the transcripts. From the analysis, twelve group themes were formed. Some, but not all, of the key themes related to:

- 1) The impact of receiving an HIV diagnosis and how it affected their view of themselves,
- 2) The abuser using strategies to control the women and using HIV as a method of abuse,
- 3) Support services recreating their experiences of the abuser through delivering stigmatised care or through a lack of understanding of the challenges they experienced,
- 4) The lasting impact of IPV on health and well-being,
- 5) The importance of peer support within the participants' recovery journey.

The findings indicated the importance of healthcare professionals (HCPs) and professionals in other support services being well-trained and skilled to support WLHA/IPV. Future research could further explore the impact of positive experiences of services in their journeys.

## **Systematic Review**

Unfortunately, IPV is one of the most common forms of violence against women. Shocking data from 2020 estimated that out of the 81,000 women and girls who lost their lives globally, 58% did so because of intimate partner or family violence (United Nations Office on Drugs and Crime, 2021). IPV can affect anyone, regardless of their social status, where they live, or their cultural background. However, studies have shown that certain groups are more likely to experience IPV (Miller & McCaw, 2019). These include individuals who identify with sexualities other than heterosexual, people with disabilities, those between the ages of 20-24 and 55-59 (Office of National Statistics, 2022), individuals with mental health difficulties (Breiding & Armour, 2015), and those from racially and ethnically minoritised groups (Smith et al., 2017). Even though we have gained a better understanding of the complexities of IPV, victims/survivors of such violence often go unnoticed in healthcare settings, despite frequently seeking medical help. To help HCPs respond more effectively, it is crucial to learn more about the experiences of IPV victims/survivors and what can help them feel comfortable and safe enough to disclose their experiences in healthcare settings. Therefore, the systematic review aimed to identify the factors that impact healthcare help-seeking in victims/survivors of IPV.

The 14 studies in the review involved diverse populations from different parts of the world and were varied in their aims and methods. When the researchers looked at all the information from these studies, they found that the barriers and facilitators to seeking healthcare for those experiencing IPV could be grouped into five categories, and these were factors related to:

- IPV (e.g., severity or type),

- Health (e.g., mental or physical health),
- Demographics (e.g., age, ethnicity, employment status),
- Psychosocial (e.g., social support),
- Health-service (e.g., availability of health service).

Overall, the results of the studies were varied, but there was consistent evidence that sexual violence and threats of physical violence, and cohabitation with the abuser acted as barriers to seeking healthcare. Factors like mental health difficulties, having access to income, and health insurance was found to be facilitators of healthcare help-seeking.

In future systematic reviews that include articles from around the world, it would be helpful to be more culturally sensitive and consider the different ages at which people get married. This is important because cultural norms and practices around marriage can influence experiences of IPV. Additionally, it would benefit future research to consider including articles from different disciplines. This could include sociology, criminology, law, and family studies articles. By including these diverse sources, researchers could gain a more comprehensive understanding of the factors that affect the disclosure of IPV in healthcare settings. Taking these steps would contribute to a more accurate representation of the various factors that impact whether individuals disclose IPV when seeking healthcare.

### **Impact and Dissemination**

WLHA/IPV, services which support them, and policy makers could benefit from hearing about the systematic review results and empirical research. Most importantly, the research could contribute towards ensuring that WLHA in the UK receive the support and care they deserve. The research also raised awareness of the

need for health care and other services to work towards creating a safer and more supportive environment for WLHA/IPV. The research will aim to be shared in various ways to ensure the research reaches this population, support services, and policymakers. For example, the researchers will aim to share a report with the following:

- participants of the study,
- services which supported recruitment and other services which may benefit from hearing about the results of the empirical research (e.g., sexual health/HIV NHS services, charities such as 4MentorMothers, Sophia Forum, SWIFT, Positively UK, Terrence Higgins Trust),
- All-Party Parliamentary Group for HIV/AIDS.

The empirical research will aim to be submitted to an academic journal and presented at an HIV/AIDS conference.

## **Help-Seeking in Women Living with HIV who have Experienced Intimate Partner Violence**

### **Abstract**

Women living with HIV/AIDS who have experienced intimate partner violence (WLHA/IPV) face unique health, safety, and overall well-being difficulties. The intersection of HIV status and IPV often exacerbates the already present challenges. Research has highlighted the complex dynamics and barriers these women encounter when seeking help, highlighting the need for further investigation to inform interventions and tailor services to their needs. This qualitative research study, therefore, aimed to explore the help-seeking experiences of WLHA/IPV using interpretative phenomenological analysis (IPA). IPA was used to understand the lived experiences and subjective interpretations of help-seeking for six WLHA/IPV. The sample included WLHA/IPV ranging between 42 and 62 years from varied racial and ethnic backgrounds. Semi-structured interviews were conducted, allowing rich and detailed narratives to emerge. The study revealed several key group experiential themes related to help-seeking among WLHA/IPV. These included: (1) HIV as a life-altering diagnosis, (2) the abusers use various strategies to exert power and control, (3) the lasting impact of IPV, (4) support services perpetuate experiences of abuse, and (5) moving on from the trauma. The participants' experiences highlighted the complex interplay between HIV status, IPV, and help-seeking, shedding light on the unique challenges faced by this vulnerable population. Additionally, the findings

underscore the importance of addressing the intersecting issues of HIV and IPV to develop more effective interventions and support services for this population. The limitations of this study include the small sample size, which may limit the generalisability of the findings, as well as potential biases inherently present in qualitative research. Nevertheless, this research provides valuable insights into the subjective experiences of WLHA/IPV and can serve as a foundation for further research and the development of targeted interventions for this population.

## Introduction

Intimate partner violence (IPV) refers to any behaviour committed within an intimate relationship which might cause physical, psychological, or sexual harm (World Health Organization [WHO], 2012). Although IPV happens across all genders (Miller & McCaw, 2019), women are at an increased risk. For example, in the UK, it is estimated that 70% of the victims of IPV are women (Office of National Statistics [ONS], 2022). Globally, the lifetime prevalence of IPV towards women is 26-28% for those between the ages of 20-49 (WHO, 2021). The empirical research and systematic review will focus on cis-gendered women's experiences of IPV only.

The social, psychological, and physical consequences of IPV have short- and long-term adverse health effects on victims/survivors (V/Ss; Bonomi et al., 2009). On top of the direct harm caused by violence, IPV is associated with worsening menopausal symptoms, increased risk of developing chronic diseases, risk-taking behaviours, and can have significant effects on CD4+ cell count (i.e., white blood cells related to the immune system; Stubbs & Szoeki, 2002). IPV can also lead to complications related to sexual health, such as unwanted pregnancies, miscarriages, and unattended antenatal care (Garcia-Moreno et al., 2013). Due to the widespread impact of IPV, increasing attention has been paid to the mental health implications. Research has indicated that V/Ss of IPV are more likely to suffer from depression, anxiety (Bacchus et al., 2018), post-traumatic stress, sleep, and eating disorders, as well as being more likely to suffer from negative interpersonal relationships (Anderton, 2022).

Qualitative research has been conducted globally to explore the experiences of IPV from the perspective of V/Ss who are women. Such research has provided

important insights into various aspects of IPV and its effects across different cultural and socio-economic contexts. For example, Dhunna et al. (2021) explored the experiences of young Māori mothers facing IPV. In this research, IPV was perceived as a direct challenge to the women's cultural identity. As a result, women experienced emotional distress, disrupted cultural connections, and complex decision-making processes regarding safety and well-being. Research with Ghanaian female head-load carriers also highlighted IPV as being detrimental to physical health, well-being, and economic stability (Adomako and Darkwa Baffour, 2021). Other qualitative research focussing solely on sexual IPV identified the impact which it has on a woman's sense of self and identity. Sexual IPV significantly impacted women's self-concept, sexuality, and overall well-being in a negative way (Tarzia, 2021).

Women experiencing IPV have shared the necessity to develop coping strategies to survive the relationship (López-Fuentes & Calvete, 2015). Using a range of resourceful tactics, such as seeking support from informal networks, using religious faith, and engaging in self-empowerment activities, highlighting their resilience and agency in navigating challenging circumstances has been described (St Vil et al., 2017). V/Ss have also shared the process of reconstructing their identities and establishing support networks as integral for the resilience needed to cope with the aftermath of IPV (López-Fuentes & Calvete, 2015).

Lastly, the complex interplay between health and healthcare access for women who have experienced IPV has been highlighted (Larsen et al., 2014). Women across cultures and countries have reported facing significant barriers to accessing healthcare due to shame, fear, and a lack of understanding among healthcare professionals (Larsen et al., 2014; López-Fuentes & Calvete, 2015). Importantly, research has



highlighted increasing links between HIV and IPV. Globally, women living with HIV/AIDS (WLHA) are one and a half times more likely to experience IPV than their HIV-negative counterparts (Campbell et al., 2008; UNAIDS, 2021). The rates of lifetime IPV in this population is exemplified in UK statistics, with rates reported to be as high as 52% (Dhairyan et al., 2013). The already unmet needs which V/Ss of IPV suffer are further compounded by the pre-existing challenges of living with HIV. These include HIV stigma, physical and mental health needs, and financial and social challenges. WLHA are also disproportionately affected by violence in the home and healthcare settings (Terrence Higgins Trust [THT], 2018). The impact of HIV stigma, fear of HIV disclosure, lack of support (WHO, 2017), and barriers to accessing care can lead to HIV treatment non-adherence (UNAIDS, 2022a). In this circumstance, the resulting risk of onward transmission makes it a public health issue.

### **Setting the Context for Women Living With HIV**

There are 30,000 WLHA in the UK, equivalent to 30% of the UK HIV population (All-Party Parliamentary Group [APPG], 2022). Over time, the demographics of this population have shifted from gay and bisexual men being mostly diagnosed to people who are heterosexual (APPG, 2022). Nonetheless, women are a minority within the UK HIV population and consequently face disadvantages in obtaining the care they need (Department of Health [DoH], 2022). Due to its history, research, clinical trials, policies, education, and service designs have often been developed through a male lens, leading to gender-biased recommendations being implemented (DoH, 2022). As a result, the experiences of WLHA continue to be overlooked and underrepresented in research, policy, and service development.

Global qualitative research has highlighted the intersectionality of the experiences of WLHA. For example, research has been conducted exploring the intersection between aging, well-being, and being a WLHA. Results indicated that WLHA over 50 experience a range of emotional, physical, and social dimensions influencing their well-being (Conway & Evangelini, in press). Additionally, cultural values, gender roles, familial responsibility, support networks, and personal agency were described as helping Black West African women cope with the challenges and demands of undergoing antiretroviral treatment (ART; Spiers et al., 2016). Other research has focused on the role of in WLHA (Logie et al., 2011). Results highlighted a complex interplay of gender, race, sexual orientation, and sex work in shaping stigma.

Healthcare-related stigma has also been researched (Colombini et al., 2014; Logie et al., 2011). The experience of discriminatory attitudes within healthcare settings was shared as a factor which hindered WLHA's access to crucial services. Such results indicate the need for stigma-reduction intervention to ensure equitable healthcare access for WLHA.

### **Women Living with HIV and Intimate Partner Violence – the Crucial Role of Intersectionality**

Building more understanding of the intersectionality of the experiences of *WLHA who have experienced IPV* (WLHA/IPV), rather than attempting to understand them as different experiences, is vital. Although this population is grossly under-researched in the UK (THT, 2018), global research has started building an evidence base to better understand the intersectionality between HIV, gender, and violence. One example is from UNAIDS (2021), who proposed four pathways of intersectionality –

gender inequality, violence as an indirect pathway to increased risk of HIV-related outcomes, direct transmission through sexual violence, and violence because of HIV status disclosure and stigma.

In many cultures, women continue to experience gender-based inequalities. Gender norms, cultural expectations (Heise, 2011; Shannon et al., 2012), and inadequately implemented policies perpetuate women's disadvantages (Heise, 2011; UNWomen, 2010). On an individual level, women suffer from unequal power within relationships. Coercive control (Jewkes et al., 2010), having a history of childhood abuse, witnessing parental violence (Richter et al., 2014), and being introduced to sex at an early age (Stockl et al., 2013), have all been found to be predictors of increased risk of HIV and IPV. Furthermore, power differentials in relationships, such as women not having financial control or decision-making powers, can compound the challenges of women negotiating within or leaving an abusive relationship (UNAIDS, 2021).

In this context, research has highlighted that women who have experienced childhood abuse are more likely to engage in risk-taking behaviours, putting them at an increased risk of HIV (Olsson et al., 2000). For example, they may be at a higher risk of engaging in transactional and unprotected sex, substance use, or partnering with older men (Dunkle et al., 2007; Jewkes et al., 2010). In addition, women in abusive relationships may have more difficulty negotiating condom use (Wingood & DiClemente, 1997), possibly due to psychological trauma, distress, or as a safety mechanism to protect themselves from violence (Johnson et al., 2003; Wingood & DiClemente, 1998). Other indirect factors, such as fear of rejection and abandonment, and IPV itself have consistently been reported as barriers to HIV testing, disclosure,

and treatment uptake and adherence (Maman et al., 2007; Obermeyer & Osborn, 2007; Turan et al., 2011).

The gender inequalities women experience reinforces power differentials between men and women, placing women at greater risk of sexual violence (Women's Aid, 2022). As well as the increased risk resulting from genital injury, penetration by multiple perpetrators, or anal penetration (Campbell et al., 2008; Watts et al., 2010), the risk of HIV transmission is elevated through repeated forced sex (Campbell et al., 2008). In many cultures, women who experience sexual violence are often stigmatised by their communities, workplaces, and healthcare institutions (WHO, 2007), thus acting as a barrier to help-seeking. V/Ss may hesitate to seek HIV-related support (Schafer et al., 2012). For example, abusers who use coercive control techniques may prevent WLHA from accessing healthcare or create barriers to HIV treatment. Not adhering to HIV treatment may lower CD4+ cell count and increase a viral load, possibly resulting in further negative health consequences (Jain et al., 2022; Mugavero et al., 2009).

HIV-related stigma has continued to be a barrier to prevention and treatment efforts. Several studies have reported that women who have disclosed their HIV status to their partners have experienced adverse reactions, such as anger, blame, ending of the relationship (Gari et al., 2010), and were three times more likely to experience physical and emotional violence (Iliyasu et al., 2011). IPV related to HIV status disclosure has been proposed as a continuum, ranging from experiencing blame, ostracisation, refusal to touch or eat food they have prepared, and verbal abuse, to physical and sexual violence (Salamander Trust, 2012). These experiences thus can contribute to and perpetuate WLHAs' challenges when seeking help.

## **Models of Help-Seeking and Barriers to Healthcare**

### ***The Role of the Individual***

Despite efforts to better identify and support V/Ss of IPV, help-seeking behaviour is a complex and multifaceted process involving individual, social, cultural, and environmental factors. The *Health Utilisation Model* (Anderson, 1995) proposes help-seeking as dependent on the interplay of the individual's predisposing factors (e.g., ethnicity, age, and health-related beliefs, such as believing services can support), enabling factors (e.g., family support, health insurance, and cultural beliefs), and the perceived, or actual need for healthcare. The various variables in this model have been tested with HIV and IPV populations. For example, research from Canada (Campbell et al., 2018) and the USA (Rao et al., 2012) demonstrated that WLHA/IPV experience multiple barriers to help-seeking, which include social stigma (stigma related to interpersonal relationships), fear of HIV disclosure or retaliation, and lack of social support. Another study by Rohn et al. (2022), based in Ghana, reported that women were more likely to seek help from services when the abuse increased, feared for their lives, or had been encouraged by family members. Barriers were related to fears of divorce, stigma, lack of trust in support services, and sociocultural norms which emphasise gender role expectations.

The role of stigma as a barrier to accessing help has been highlighted, so much so that the *HIV Stigma Framework* (Earnshaw & Chaudoir, 2009) was developed. In this framework, stigma is conceptualised as a social process which allows groups of people to separate and place themselves in a relative position of power based on the presence or absence of a socially devalued characteristic (in this case, HIV). As a response, individuals who do not have HIV exhibit psychological response

mechanisms (e.g., prejudice, stereotyping, or discrimination) towards those who are living with HIV and may pose a threat to their social standing. Reciprocatively, those living with HIV develop reactive mechanisms to having the devalued mark, such as enacted (i.e., the degree to which the person believes they have experienced stigma and discrimination), anticipated, or internalised stigma. As a result, those with HIV may experience worse HIV outcomes due to shame, difficulties with disclosure and help-seeking, or internalised stigma. For example, Paudel and Baral (2015) reported that the blame which WLHA experience has led them to live a life in fear of being discriminated against. In turn, HIV stigma has led to difficulties with HIV disclosure, trusting services, internalising HIV stigma, or being treated differently by health professionals and social networks.

### ***The Role of Healthcare Professionals***

Healthcare responses to HIV and IPV have been identified as barriers to accessing help for WLHA and women who have experienced IPV. Clouse et al. (2018) reported that women who had experienced IPV were less likely to disclose their status and IPV experiences to healthcare professionals (HCPs) and were less likely to seek help from HCPs than those without these experiences. Despite the Domestic Violence Project (2013b) developing the *Medical Power and Control Wheel*, which highlights the different damaging responses to disclosure that HCPs can have, women who have experienced IPV continue to face behaviours outlined in the wheel. These include normalising victimisation, violating confidentiality, trivialising the abuse, blaming the V/S, not respecting the V/Ss' autonomy, and ignoring their need for safety, which can all perpetuate stigma. Adding to these challenges, WLHA/IPV may face double discrimination (British HIV Association [BHIVA], 2018), limiting their access to care

(Turan et al., 2019). A recent survey conducted in the UK reported that 58% of WLHA reported having experienced some form of abuse in healthcare settings, with only one in five women accessing the sources of support they needed (THT, 2018). Abusive experiences included: non-consensual disclosure of HIV status; the refusal to provide information about services; coercion into abortion; non-consensual HIV testing; and denial of hospital treatment.

## **How Far Have UK Health Services Come?**

### ***Healthcare Services as Gatekeepers***

Considering the physical and mental health impact of IPV on women, treatment and adherence, health services are well placed to support WLHA/IPV (Heskin et al., 2022). Women experiencing IPV are more likely to be in regular contact with HCPs than any other professionals, thus providing unique opportunities for identification and support (DoH, 2017). WLHA may seek help from health services for safety, protection, and health and well-being concerns (Loutfy et al., 2017). SafeLives (2020) indicated that 80% of women in violent relationships seek help from health services, and as many as 20% of women in contact with mental health services are likely to be experiencing IPV. Moreover, the DoH (2017) have reported that the NHS spend more time dealing with the impact of IPV on women than other agencies do. The UK has had IPV on its agenda in recent years and has made attempts at improving the accessibility of healthcare for IPV V/Ss. For example, following recommendations that all clinical settings in NHS Trusts work towards training practitioners to identify potential V/Ss through sensitive enquiry, the *Pathfinder* project located specialist IPV services and Independent Domestic Violence Advocates (IDVAs) within health settings to do so. IDVAs also reviewed NHS

domestic violence policies and introduced the *Domestic Abuse Champion Network* (MacDonald, 2021).

### ***Healthcare-Related Barriers***

British HIV Association (BHIVA; 2018) highlighted the need for HCPs to be sensitive to the experiences of people living with HIV (e.g., HIV stigma, social exclusion and IPV). However, HCPs in the UK have been found to lack education and training on IPV, thus limiting their confidence in screening patients (MacDonald, 2021). Although the *Standards of Care for People Living with HIV* (BHIVA, 2018) recommend that health services have robust referral pathways and support for women experiencing IPV, including routine baseline IPV inquiry and risk assessment at the point of diagnosis, clinicians have remained unclear about the referral pathway. Therefore, they are reportedly unsure how to engage in conversations about IPV (MacDonald, 2021). Other barriers, such as lacking time, privacy, clear guidelines, policies, and employer support, were among the most frequent barriers to screening for IPV in healthcare settings (Kirk & Bezzant, 2020). A stepped-care approach for psychological services, including the need for routine and repeated formal screenings of IPV and targeted interventions, has also been recommended (BHIVA, 2011). However, HIV support services are not widely available outside cities, leaving many people with limited access to appropriate care (National Aids Trust [NAT], 2021). The public health budget cuts, and lack of straightforward commissioning for HIV services, have meant that over the years many services have been decommissioned. Only 40% of HIV services have access to mental health professionals and must otherwise refer to *Talking Therapies* (i.e., primary care psychological support), where clinicians are not routinely trained in challenges related to living with HIV (NAT,



2021). The lack of specialism in these services and fears of healthcare-related HIV stigma has deterred access for many individuals (NAT, 2021).

In summary, WLHA/IPV face unique challenges in accessing support. Women in this population often encounter barriers related to the intersecting stigmas associated with HIV and IPV. These include fear of disclosure, concerns about confidentiality, and the potential for further victimisation. Additionally, the power dynamics within abusive relationships can make it difficult for women to seek help or leave the abusive situation. The literature emphasises the importance of providing comprehensive and tailored support services that address this population's specific needs and challenges, including integrated HIV and IPV interventions and a multidisciplinary approach involving healthcare providers, social workers, and community organisations.

### **The Rationale for the Current Study**

Although the link between IPV and WLHA has been acknowledged, most research has been conducted in Kenya, Uganda, South Africa, India, and the USA. The culture-specific contextualisation of HIV, IPV and how health services are delivered limits the generalisability of studies conducted in different countries. Consequently, a call for research to be conducted in the UK to address the gaps in knowledge of the links between violence, gender, and HIV has been made (THT, 2018). There is also a lack of research addressing the experiences of help-seeking for WLHA who have experienced IPV, globally, and in the UK. Therefore, this research aimed to do so by starting to provide a foundation to better understand the experiences of help-seeking for WLHA/IPV. From a public health perspective, such research

aimed to start addressing gaps in service provision and improve much-needed accessibility and suitability of services.

### **Research Objectives**

This research used semi-structured qualitative interviewing and interpretative phenomenological analysis (IPA; Smith, 1996) to better understand help-seeking experiences in WLHA/IPV, through exploring and making sense of their lived experience.

## **Methods**

### **Design**

A cross-sectional qualitative approach was used to explore the personal and collective experiences of help-seeking in WLHA/IPV. Semi-structured interviews were conducted to allow for reliable and comparable data collection across participants (Patton, 2015). The interviews were analysed using IPA, which aims to explore experiences through the lens of the participant. Within IPA, the participant attempts to make sense of their own experiences, while the researcher also attempts to do so (Smith et al., 2021). It also promotes change through raising awareness (Taylor, 2013) by allowing individuals to recount their stories. Such a method is essential for a population often subject to assumptions, stereotypes, and stigma, such as WLHA/IPV. In line with the philosophy of IPA, the ontological positioning of the research lay in the belief that reality is socially constructed and subjective. Within this positioning, the experiences of participants, and their meaning, are shaped by social and cultural contexts. It, therefore, focussed on understanding the lived experiences of women and the complexity of their interactions with the world whilst recognising that help-

seeking behaviours are influenced by various social, economic, and cultural factors (Smith & Davis, 2018).

Epistemologically, this qualitative research is aligned with interpretivism, whereby the researcher sought to interpret and understand the participants' experiences from their perspectives, recognising the importance of subjectivity in constructing knowledge. The emphasis is on uncovering the multiple realities of WLHA who have experienced IPV rather than seeking universal truths (Johnson et al., 2017).

Additionally, holding a feminist positioning played a crucial role in shaping the lens through which this research was conducted. Inherently, the research explored power dynamics, gender roles, and patriarchal structures, which influence women's experiences of HIV and IPV. The research area is sensitive to the intersectionality of women's identities by considering how race, class, sexual orientation, and other social categories interact with their experiences. A feminist approach consequently sought to amplify women's voices, address gender-based disparities in help-seeking, and advocate for social change to improve support systems and services for this vulnerable population (Brown & Williams, 2018).

## **Sample**

### ***Inclusion and Exclusion Criteria***

WLHA/IPV, aged 18 and over, were recruited. Although the legal age of consent for sexual activity is 16 years in the UK (Sexual Offences Act 2003), the age of majority is 18 years (Law Reform Act 1969), meaning that anyone under 18 years is still considered a child. A child's experience of HIV and IPV might differ based on legalities and power dynamics at play. The minimum age was therefore set to 18 years

to promote homogeneity in experiences by only interviewing those legally defined as adults. No upper age limit was set to promote the inclusivity of WLHA/IPV. The research also aimed to recruit cisgender women of all sexual orientations. The inclusion of transgender women was discussed in depth whilst creating the inclusion criteria. Transwomen navigate intersecting stigmas associated with HIV, IPV, and transgender identity (Bockting et al., 2013) and may face additional transgender specific challenges (Grant et al., 2011). In this context, it was felt that the experiences of transgender WLHA/IPV might warrant individual attention (Messinger & Guadalupe-Diaz, 2020). Additionally, it is likely that including both cis- and transgender women would not allow for either group of women's experiences to be appropriately heard. Participants also had to be proficient enough in English to interview.

### ***Participants***

Ten women expressed initial interest and consented to be contacted about the research. However, the final sample comprised six WLHA/IPV. The other four women either stopped replying to communications with the researcher, felt it was not the right time to participate in the interview, or did not feel they met the inclusion criteria. Although there have always been debates on the recommended sample size for qualitative research, 4-10 is advised for professional doctorates (Clarke, 2010). As IPA is committed to producing a detailed interpretive account of experiences, Smith (2004) argues for depth over breadth, if the sample size can be justified based on the studied population and whether rich data has been produced from the interviews (Smith & Osborn, 2007). The final sample of women varied in age, ethnicity, religion, relationship status, employment, time, and place of diagnosis). One participant only

partly completed the *Participant Information Questionnaire* (Appendix A), leaving out one socio-demographic question and all HIV-related questions (Table 1).

## **Study Procedure**

### ***Consultation From Women with Lived Experience***

Before recruitment and ethical approval of the study, two women with lived experience provided feedback on the study documents. The field supervisor referred the two women with lived experience. One of the women reviewed drafts of the *Recruitment Poster* (Appendix B), *Consent Form* (Appendix C), and *Interview Guide* (Appendix D), whilst the other reviewed drafts of the *Participant Information Questionnaire* and *Participant Information Sheet* (Appendix E). The women were consulted on the appropriateness, sensitivity, accessibility, and language of the materials created. They also commented on the draft questions of the interview schedule, which offered a chance for amendment and addition of any other questions relevant to the research area. Some suggestions included making travel compensation, remuneration, and researcher contact details more visible on the poster. Some amendments were made to the *Participant Information Questionnaire*, such as adding ‘no recourse to public funds’, ‘I am a carer’ and ‘no right to work’ under the employment/income question, the country of HIV diagnosis, and the setting in which they were diagnosed. The women with lived experience also advised to remove questions about HIV medication, viral load, as they felt the research question did not pertain to these sensitive questions. The language around remuneration and engagement benefits was also amended to be more sensitive in the *Participant Information Sheet*.

**Table 1***Participant Demographic Characteristics*

	Participant					
	1	2	3	4	5	6
Demographics						
Age (years)	42	55	62	47	50	55
Birth Region	Eastern Europe	UK	UK	Southern Africa	East Africa	UK
Ethnicity	White European	White European	White European	Black African	Black British	White European
Religion	Catholic	Catholic	Catholic	Catholic	Catholic	Atheist
Education	Vocational Qualification	GCSE	Undergraduate	Undergraduate	A Levels	Undergraduate
Employment /Income	Receiving Benefits	Full-time	No access to public funds	Not currently employed	Part-time	Part-time student/employment/receiving benefits

	Participant					
	1	2	3	4	5	6
Sexuality	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Pansexual
Relationship	Single	Single	Divorced	In a relationship	Single	Divorced
Children	Yes	– <sup>a</sup>	Yes	No	Yes	Yes
HIV						
Year of diagnosis	2000/2001	–	2014	2006	1998	2012
Country of diagnosis	Eastern Europe	–	UK	UK	UK	UK
Current Psychosocial support	Domestic Violence Service	–	HIV counselling	Groups	No	Psychotherapy; Peer mentoring; HIV support group

*Note.* UK – United Kingdom. <sup>a</sup>– denotes missing data for Participant 2 due to the last page of the questionnaire not being returned.

The experts were each offered £25 as a token of appreciation. One of the experts donated theirs towards a £25 prize draw for the participants, as they felt the sample would likely consist of vulnerable women, and the opportunity of an Amazon voucher could make a difference in their lives.

### ***Recruitment***

A voluntary response sampling method was used, whereby the researcher publishes a request for members of a population to participate and individuals choose whether they are interested on their own accord. Initially, recruitment was to be from two NHS HIV and sexual health clinics in London and one in southeast England to encourage a more diverse and representative sample. However, the NHS site in southeast England could not support recruitment, as the service's Research and Development (R&D) protocol dictated that research needed to be adopted by the NIHR (National Institute for Health and Care Research) CRN (Clinical Research Network) Portfolio. Consequently, two London-based NHS recruitment sites supported the study. As one of the clinics was linked to several other sites, it provided a wider catchment area. After the research received ethical and local approval from R&D (see *Ethical Considerations*), a poster promoting the research was circulated across services and made available within clinics. NHS professionals could also direct known patients towards the poster, which contained the researcher's contact details to express interest in participation.

Participants were also recruited from charities aimed at supporting WLHA. Recruiting from both NHS and charities widened access to potential participants. One of the charities used a peer-led approach to train WLHA to provide psychosocial support for pregnant WLHA and mothers. The other charity promoted and advocated



for the rights, health, and welfare of WLHA through research, policymaking, and raising awareness. Recruiting from charities may have helped to promote a sense of safety by viewing the researchers as independent from healthcare settings, and therefore inviting participants to be more open about their experiences in a safe and containing environment.

Due to challenges with recruitment, an NHS Research Ethics Committee (REC) substantial amendment was submitted for expanding the research advertisement through the organisation's social media platforms (e.g., Twitter, Facebook). This received approval on 22<sup>nd</sup> February 2023 (see *Ethical Considerations*). Although the poster was advertised on their website, one of the charities did not want to promote the research further through their social media platforms, as they did not feel the remuneration for participants was appropriate.

Once a prospective participant contacted the researcher via telephone or email, they were sent the *Participant Information Sheet* and invited to meet the researcher to ask questions before signing the *Consent Form*, completing the *Participant Information Questionnaire*, and setting a date and time for the interview. Participants were asked about their preference for receiving hard or electronic copies of the materials.

Five participants chose virtual interviews, which were held via *MS Teams*. One participant chose an in-person interview at a Royal Holloway, University of London campus. A maximum of £10 travel reimbursement was offered for the face-to-face interview. All participants were offered £10 as a gesture of appreciation and were also offered to enter a prize draw for a £25 Amazon voucher.

### ***Measures***

**Table 2**

*HARK screening questionnaire (Sohal et al., 2007)*

<u>H</u> umiliation	Within the last year, have you been humiliated or emotionally abused in other ways by your partner or your ex-partner?
<u>A</u> fraid	Within the last year, have you been afraid of your partner or ex-partner?
<u>R</u> ape	Within the last year, have you been raped or forced to have any kind of sexual activity by your partner or ex-partner?
<u>K</u> ick	Within the last year, have you been kicked, hit, slapped, or otherwise physically hurt by your partner or ex-partner?

*Note.* An individual scoring  $\geq 2$  (i.e., a score of 2, 3, or 4) would be identified as positive for IPV.

The *Humiliation, Afraid, Rape and Kick* (HARK) screening questionnaire for IPV (Sohal et al., 2007) was used to screen whether women had experienced IPV. The HARK questionnaire poses four questions based on four domains typical of IPV (Table 2) and has been assessed as an accurate measure for identifying women who

may have experienced IPV in the last year (Sohal et al., 2007). The HARK screening questionnaire also aligns with the NICE (2016) definition of IPV, which is as follows.

“Any incident or pattern of incidents of controlling behaviour, coercive behaviour or threatening behaviour, violence, or abuse between those aged 16 or over who are family members or who are, or have been, intimate partners”.

Although the HARK questionnaire has been validated (sensitivity of cut-off score  $\geq 1$  at 81%, 95% CI [confidence interval] 69-90%, and specificity 95%, CI 91-98%) as an effective screening tool for women who have been abused in the last 12 months (Sohal et al., 2007), there is no validated screening measure for lifetime experience of IPV. The questions were therefore amended to longer specify ‘in the past year?’ and changed to ‘ever’ (e.g., “Have you ever been humiliated or emotionally abused in other ways by your partner or ex-partner?”).

Socio-demographic information was collected before the interview. Collecting this allows for gathering information on the sample and placing the results within a socio-demographic context, situating the sample’s diversity and representativeness. The *Participant Information Questionnaire* collected age, place of birth, ethnicity, and education based on the UK Census questions (ONS, 2021). The *Participant Information Questionnaire* also asked HIV-related questions, such as the year of diagnosis and where they were diagnosed, which was, in the end, removed.

### ***Interview Schedule Development***

The researcher developed a semi-structured interview schedule guided by the research question. The schedule encouraged the researcher to be guided by the

interview rather than the interview being pre-determined. The questions were developed using Smith et al.'s (2021) guidance on conducting semi-structured IPA interviews, which highlights the importance of establishing rapport with the participant whilst allowing for flexible exploration of any interesting areas that may arise. IPA interviews view the respondent as the experiential expert and are encouraged to tell their story. IPA interviews typically start with the broadest question (e.g., "can you tell me a little bit about yourself?") to ease the participant into talking about the subject and proceed to use a *funnelling* technique to address more specific concerns (e.g., "I am interested in any possible relationship between your HIV and violence you have experienced from a partner"; "So that we can better understand essential factors, it would be helpful if you could start by telling me briefly about your HIV diagnosis"). Such a structure allows the respondent to share their personal experiences before the researcher focusses on more specific areas of exploration.

As previously mentioned, the interview guide was shared with women with lived experiences, reviewed by academic and field supervisors, and approved by NHS REC and the Health and Research Authority (HRA). Before recruitment, the researcher and the academic supervisor engaged in a practice interview where feedback was provided on style and structure. Feedback was also given on an interview transcript, primarily focusing on style, responses, and processes. Following this, a different transcript with the researcher's initial comments was given to an academic supervisor for feedback before going to the following stages of analysis (see Analysis section).

### ***Ethical Considerations***

The research received NHS REC and HRA (Appendix F) approval on 10<sup>th</sup> August 2022. Further approval was received on 26<sup>th</sup> October 2022 (Appendix G) following a substantial amendment related to local NHS R&D requirements, such as being identified as Participant Identification Centre or clarifying the site's CRN. Local R&D approval was received for each respective NHS site on 21<sup>st</sup> September and 7<sup>th</sup> November 2022. Another substantial amendment was submitted due to recruitment difficulties. The amendment was to obtain NHS REC and HRA approval for the sites to advertise the research poster on their social media website. Approval was received on 22<sup>nd</sup> February 2023 (Appendix H). Self-certification was submitted with Royal Holloway, University of London REC (Appendix I).

*A safety and distress protocol* was also created (Appendix J), which aimed to outline processes to keep participants safe throughout their participation in the research. For example, the researcher had a point of contact for each service participants were recruited from, which they could contact if any risk to themselves or others was identified. Furthermore, when signing the consent form, participants also consented to the researcher contacting emergency services should they feel an imminent risk is present. The lead researcher also had regular access to supervision throughout the interview and recruitment process.

Participants were informed of confidentiality and its limits, their right to withdraw and data storage. Any identifiable information was removed from the point of transcription to ensure anonymity. Due to the sensitive nature of this research topic, participants were reassured that they did not have to answer any questions they did not feel comfortable answering and could stop or pause the interview at any point. The researcher used clinical skills to monitor distress and discomfort throughout the

interviews. Participants were also debriefed following the interviews, and information about relevant HIV and IPV services was given. Participants also had the choice of opting in for their GP to be made aware of their participation in the research. Five participants consented to inform their GP of their participation, and two expressed interest in researcher-clinician liaison to access further psychological services.

## **Analysis**

### ***Interpretive Phenomenological Analysis***

Verbatim transcription was ensured by proofreading the primary transcripts. At this stage, one of the academic supervisors reviewed the transcript and offered feedback on the form of questions used, the appropriateness of interviewer responses, and provided advice on managing the practitioner-researcher role within an emotive interview. Following Smith et al. (2021) recommendations, the researcher listened to the interview and repeatedly read transcripts before writing any initial comments to immerse themselves in the data. Once immersed in the tone, narrative, and interview experience, the researcher read through the transcript line-by-line and made initial notes while exploring semantic content. Before moving on to the next step, the initial notes of one transcript were reviewed by another academic supervisor, who offered feedback on possible emerging themes that were missed and areas of focus and helped to ensure the notes were relevant to the research question. Once feedback was given, the researcher developed emergent themes, 'Personal Experiential Themes' (PETs), by focusing on chunks of the transcripts and analysing the notes made. Next, the researcher searched for connections across PETs and integrated them more succinctly. These steps were then repeated for each interview, considering the initial PETs whilst looking for new or contrasting ones. Once each interview was analysed and PETs

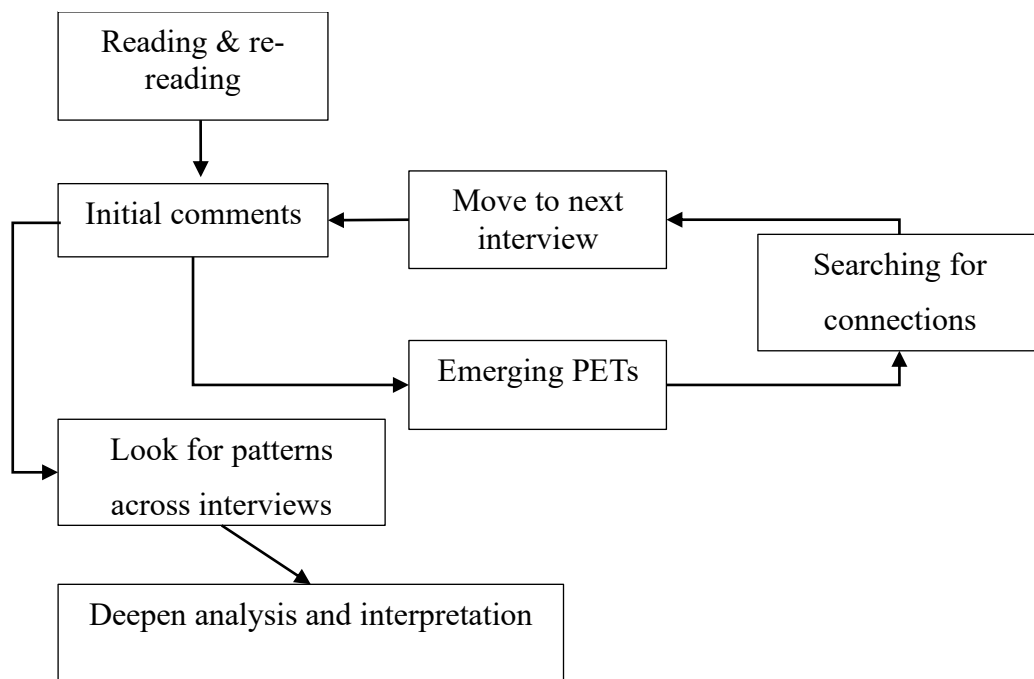
noted, the researcher looked for patterns across cases. Finally, the researcher attempted to interpret existing PETs and interviews on a deeper level, focusing on metaphors and the relation between tense used, language, and content of what is being said. This process resulted in the researcher creating Group Experiential Themes (GETs) with sub-ordinate themes. See Figure 1 for steps of IPA.

### Quality Appraisal

The research adhered to the widely used qualitative research quality criteria outlined by Guba et al. (1994). The criteria for quality assessment consider whether the research methods and analysis maintain credibility, dependability, confirmability, and transferability. The consolidated criteria for reporting qualitative research (COREQ; Booth et al., 2014) was also followed to maintain quality whilst reporting on the study. Reflective notes were also kept during the data collection stages.

**Figure 1**

*Process of Interpretive Phenomenological Analysis (Smith et al., 2021)*



Specific quality standards related to IPA were adhered to during the data collection, analysis, and reporting stages (Smith, 2021). These entailed taking into consideration the analytic span of the research, allowing space to elaborate on each PET and GET, ensuring the data is of high quality, demonstrating rigour, detailing the complexity of the analysis, demonstrating analytic depth rather than being descriptive, and being attentive to writing style.

Lastly, aspects of social and personal identity, such as race, gender, religion, and age (i.e., social GRRRAAACCEEESSS; Burnham, 2012), were considered throughout the research process. The social GRRAAACCEEESSS model allows us to reflect and consider differences individuals hold concerning beliefs, power, lifestyle, social positioning, visible and invisible, and voiced and unvoiced differences, and how these may shape our interactions and reactions (refer to *Chapter 4 – Integration, Impact and Dissemination* for in-depth reflections using the model).

## **Results**

Six semi-structured interviews were conducted, exploring help-seeking experiences in WLHA/IPV. The interviews were, on average, 112 minutes (range = 72–143mins). Eleven GETs were developed through the process of IPA, each with associated sub-themes (Table 3).

### **HIV is a Life-Altering Diagnosis**

All the participants reflected on the significant impact receiving an HIV-positive diagnosis had on their lives. The participants' journey of adjusting and processing the diagnosis was shared in four different ways: the impact of the HIV-related beliefs which they held; the emotions shared and experienced whilst retelling indicated the diagnosis being stored as a trauma memory; the isolation they



**Table 3***Group Experiential Themes and Sub-Themes*

Group Experiential Theme	Sub-Theme	Presence of Sub-Theme in Interviews					
		1	2	3	4	5	6
HIV is a life-altering diagnosis	Beliefs about HIV impacted the reaction to the diagnosis	✓	✓	✓	✓	✓	✓
	HIV diagnosis is stored as a trauma memory	✓	✓	✓	✓	✓	✓
	HIV is an isolating illness	✓	✓	✓	✓	✓	✓
	HIV status and identity become intrinsically linked	✓	✓	×	×	×	×
The abuser uses various strategies to exert power and control	Weaponising HIV	✓	✓	✓	✓	✓	✓
	The invalidation of experiences affects self-esteem and instils greater power differentials	✓	×	✓	✓	×	✓
	Pre-existing vulnerabilities act as a risk factor for getting into an abusive relationship	✓	✓	✓	✓	✓	✓

Group Experiential Theme	Sub-Theme	Presence of Sub-Theme in Interviews					
		1	2	3	4	5	6
	Exerting control through isolation	✓	✓	✓	✓	✓	✓
	Giving a false sense of freedom and control	✓	×	✓	×	×	×
	Violence is used as a way of inducing fear and control	✓	✓	✓	✓	×	✓
Surviving the abusive relationship	Denial brought a sense of safety	✓	×	✓	×	×	✓
	Making survival-based choices to cope with the abuse	×	×	✓	✓	×	✓
	Finding other ways to feel in control	✓	×	✓	✓	×	×
	Making sense of the abuser's behaviour	✓	×	✓	✓	✓	×
Coping with the lasting damage of IPV	Long-term effects of intimate partner violence on mental health and well-being	✓	✓	✓	✓	✓	✓
	Difficulties forming new intimate relationships	✓	✓	✓	✓	✓	✓

Group Experiential Theme	Sub-Theme	Presence of Sub-Theme in Interviews					
		1	2	3	4	5	6
Unreliable personal networks	Familial rejection	✓	✓	✓	✓	×	×
	The betrayal from social networks further isolated and ostracised them	✓	×	✓	✓	✓	✓
Support services perpetuate patterns of abuse	Prejudicial support services	✓	✓	✓	✓	✓	×
	The abuse of power	✓	×	✓	×	×	×
	Support services are unsafe	✓	✓	✓	✓	×	✓
	Health services are unreliable and unavailable	✓	✓	✓	×	✓	✓
	Health services make decisions about patient care based on prejudicial assumptions	✓	✓	✓	✓	✓	✓
Service provision has changed over time	Geographical inequalities in the provision of care	×	✓	✓	×	×	✓
	Services have become impersonal	✓	✓	✓	×	✓	✓
	Feeling let down and untrusting of support services	✓	✓	×	✓	×	✓

Group Experiential Theme	Sub-Theme	Presence of Sub-Theme in Interviews					
		1	2	3	4	5	6
For WLHA, support services are not a place for care	Educating services	×	✓	✓	✓	×	×
The role of systemic issues in disadvantaging women	Women as a forgotten group	×	✓	✓	×	×	✓
	Women are disadvantaged in a patriarchal society	✓	✓	✓	×	×	×
The impact of positive support service experiences	Person-centred care	✓	✓	✓	✓	✓	×
	Care which is consistent and reliable	✓	✓	✓	×	×	✓
	Receiving boundaried support	✓	✓	×	×	×	×
	Being validated and heard by health professionals	✓	✓	✓	✓	×	✓
Moving on from the trauma	Connecting with others	✓	✓	✓	✓	✓	✓
	Processing the trauma	✓	✓	✓	×	✓	✓
	Taking back control	✓	✓	×	×	✓	✓
	Self-compassion and care	✓	✓	✓	×	×	✓

experienced following the diagnosis; and how it impacted their identity and sense of self.

### ***Beliefs About HIV Impacted the Reaction to the Diagnosis***

All participants reflected on perceived HIV-related societal beliefs as having impacted their response to receiving the HIV diagnosis, particularly those associated with the images of HIV/AIDS portrayed in the media.

“Trainspotting, where the person had HIV had something spray painted on their doors... there’s so much stigma attached. So, it’s devastating really.” (P6)

“In the 80s and 90s, I knew a little bit about HIV... I was of the generation of the tombstone thing.” (P3)

Beliefs were triggered around HIV being a fatal prognosis, feelings of grief, and fears related to parenting.

“I just thought I was going have to surrender this death, and my children and my grandchildren were going to have a mum that, you know...” (P2)

Participants also reflected on the shock of receiving the diagnosis. They described their generation’s sexual health education and the media as perpetuating stereotypes of HIV.

“I was just as ignorant as most people, because we just believed that it was gay men or perhaps black African women.” (P6)

### ***HIV Diagnosis is Stored as a Trauma Memory***

Recounting the time of their diagnosis elicited strong emotional responses of shock and trauma in participants.

“It was so shocking... wow, this is kind of difficult for me to tell.” (P4)

“On this end of winter coming onto spring sort of days, nice sunny day... I remember what was around me and her telling me, ‘You’re HIV positive.’” (P2)

Furthermore, the emotional and cognitive numbness possibly described survival mechanisms being triggered. The various survival mechanisms illustrated were being in denial, in a high state of arousal, or becoming consumed by the news of the diagnosis.

“I just went blank. My body just went cold all around...” (P3)

“I was functioning just enough to survive to be at home.” (P2)

### ***HIV is an Isolating Illness***

All participants referred to HIV isolating them by limiting their choice of potential romantic partners and their likelihood of acceptance. Participants shared fear or experiences of rejection/abuse based on their status.

“I don’t want to be in any relationship... because in my mind, it’s like a whole... How do I tell somebody? Maybe because of my experience with my kids’ father...” (P5)

“There’s a fear of rejection. And I know that’s quite common for people with HIV” (P6)

“Beggars can’t be choosers. So when somebody chooses you... you better stay put. And it affects your confidence... do you have that much of a voice or that much of a right?” (P1)

The women’s perception of societal stigma related to HIV and self-stigmatisation further accentuating the isolating nature of HIV. One participant spoke of the fears associated with the permanence of having HIV (“I have been fearful of the cast-iron of HIV” (P3)), leaving them to cope with difficult emotions on their own.

“... His family never knew, so when I was struggling with my emotions, it would be really hard for people to understand. And you can’t open up.” (P1)

“You’re shunned from the public.” (P4)

### ***HIV Status and Identity Become Intrinsically Linked***

Whilst reflecting on experiences of support services, the women shared being seen through an ‘HIV positive’ label rather than as a person. Some participants felt that, although the label of being ‘HIV positive’ was always present, it did not always affect the professionalism with which they were treated.

“Everybody knew because it came with my name attached. I felt no stigma from my solicitor.” (P1)

However, for others, the label of being ‘HIV positive’ took precedence over being seen as a patient.

“Sometimes I just want to be a patient. I don’t want to have to give you an HIV lesson or introduce myself as ‘[name] with HIV with an undetectable viral load’ to see the look on their face.” (P2)

This participant described not only feeling like she must adopt and accept the label she ascribed but also having to put her needs aside to contain clinicians' fears.

Although the look she was referring to is unclear in this passage, her experience reflects her anticipation of clinicians reacting negatively to hearing she was a person living with HIV and consequently needing to prepare for such a reaction.

### **The Abuser Uses Various Strategies to Exert Power and Control**

All participants shared their experiences of IPV within their relationships and reflected on how these experiences contributed to and maintained the relational dynamics of power and control. The strategies and factors shared were the weaponisation of HIV; the invalidation of experiences, thus affecting self-esteem and instilling greater power differentials; being isolated by and through their partner; giving a false sense of freedom and control; and using physical violence to induce fear in the women. The role of pre-existing vulnerabilities was also highlighted and shared as a perceived risk factor for being in an abusive relationship.

#### ***Weaponising HIV***

The abusers used HIV to intimidate, shame and stigmatise their victims, confirming existing internalised HIV stigma-related beliefs held by the participants. Weaponising HIV, in combination with other abusive strategies, affected self-worth and fears of rejection.

“He did throw it in my face once. He said, ‘Who’s going to have you with your HIV?’” (P1)

In their experience, shaming the participants through their HIV status also permitted the abuser to shift blame onto them, breaking down their self-worth.



“It just became a thing in the house whereby I was put to blame... he stopped eating the food from me... like, ‘oh, you put blood in your food, so I’m not going to eat.’” (P4)

For others, HIV was used to exert control and fear in women.

“‘I’m going to criminalise you’. He took my whole status and was using it to fight me through and through.” (P5)

For one participant, her abuser transmitting HIV to her was experienced as another way of controlling her, not only through the betrayal of their marriage it represented but also by leaving her with a permanent mark.

“[When we found out we had HIV] I was thinking he was very quiet... I wanted to say he was fearful, but he was also smug.” (P3)

One participant shared experiences of HIV being indirectly weaponised by her abuser.

“He used to bathe all the time... I started to realise that he really despised himself for being HIV positive...scraped himself in the bath and used scourers.” (P2)

His harmful behaviour, rooted in self-disgust, was not directed at her but towards himself. However, his actions may have contributed to internalised feelings of HIV stigma, mainly as he first did so after the only time they engaged in sexual intercourse.

***The Invalidation of Experiences Affects Self-Esteem and Instils Greater Power Differentials***

The abusers used techniques of emotional abuse whilst exhibiting incongruent behaviours. Invalidating the women's everyday experiences not only discredited them but also silenced them. For some, the abuser attempted to control every aspect of their lives. Others experienced the abuser as pretending they had not been abusive, consequently trivialising their emotional states.

“It's this drip, drip, drip, and each thing it's tiny and justifiable or not worth arguing about.” (P3)

“There's already a huge sense of shame that you've allowed yourself to take responsibility... like gaslighting and denying things that they've said or things that they've done.” (P6)

### ***Pre-Existing Vulnerabilities Act as a Risk Factor for an Abusive Relationship***

Most participants mentioned the impact of youth and inexperience as a factor contributing to the power imbalance in the relationship, with male partners having more life experience, power, and control over them.

“We had a 15-year difference. So, I was 20, he was 35... looking back, he never guided me.” (P1)

“My first serious relationship was from the age of 14 to 25... and all the abusive ways you can think of, and it was for a long time.” (P2)

Experiencing abuse from such a young age was seen to have contributed to the women's confidence in entering future relationships. It also meant they entered the relationship feeling more vulnerable, whereby their well-being and self-worth had already been affected.

“Over the years, it just got worse and worse because he could just see that I was losing confidence, so his control was getting bigger, and I was getting smaller, whether we were together or not.” (P1)

For many women, the abuser was experienced as exerting control by capitalising on situational factors such as finance, immigration and parenthood.

“I didn’t have any money on my own at all. He would pay for everything; he would never give me money... because I needed a visa to stay a bit longer...” (P1)

“I had some immigration issues... My partner was, “Oh, I’m going to deport you. I’m going to take the kids”. It was part and parcel of their abuse.” (P5)

The women reflected on the perceived impact of having experienced childhood abuse, their vulnerability to being targeted, and entering an abusive relationship, and how such experiences reduced their ability to recognise early signs of abuse.

“I’ve gone through violence since I was a young child. So, I think that opened up doors for what became a burner.” (P5)

Contrasting this, some women shared that family and traditional partnership values also made them vulnerable to remaining in an abusive relationship. The participants’ reflections on the impact of relationship and marriage values evoked feelings of loss and regret.

“I was always trying to find my team player... My mum could kill someone, my dad would bury the body and never tell a soul... That’s their team.” (P2)

“I was of a background and generation that saw marriage as a commitment... There're other people I could have married... I didn't go into marriage lightly.”

(P3)

### ***Exerting Control Through Isolation***

One of the strategies used by the abuser was to isolate the women from support networks, therefore creating dependence on them. Having a strained relationship with family enabled the abuser to isolate them further. For other participants, the longstanding experiences of emotional invalidation, blame, and coercive control made the women feel that the abuser would be the only person who could accept them for who they were.

“I was clinging onto him. “Well, at least this person knows me for X amount of years... He understands me. He was the only person close to me because I didn't have a close relationship with any of my family at the time.” (P1)

“It's very complex. It's not a case of just leaving... your self-esteem and your belief that you can function by yourself is in tatters.” (P6)

One participant shared that her husband could alter his personality and manipulate clinicians into believing their marriage had no problems. In her experience, doing so covertly displayed the power she held over her and isolated her from seeking help and trusting health services.

“We went to marriage guidance...but I was quite concerned... the bus stop was about 10 minutes' walk, and at that point, his personality changed.” (P3)

Several participants shared experiences of the abuser using intimidation techniques and showing jealousy to isolate them from friends and vital social networks.

“I was on a three-way call with my friends... ‘Oh, I know you want to leave me. And you want to go and see this guy.’” (P4)

### ***Giving a False Sense of Freedom and Control***

One abuse technique employed was to give the women a false sense of power throughout the relationship.

“His attitude was as if he was doing everything to please me, that it was for my benefit.” (P3)

The incongruence in the behaviour, such as allowing freedom to control other aspects of their lives, impacted the women’s ability to realise the extent of control.

“He would never stop me working. But a lot of the times he would want to come with me to castings... and it’s only looking back now that he wanted to be around women.” (P1)

### ***Violence is Used as a Way of Inducing Fear and Control***

The use of violence to induce fear and further control in the relationships was experienced as particularly effective when combined with the breaking down of self-esteem. These techniques made the women feel unlovable yet dependent on the abuser.

“When I come home, there’s a woman in the house... I’ll sleep outside. I’ll hear everything they’re doing... so I would try to be apologetic. He would just come and beat me up.” (P4)

For some, the abuser capitalised on their vulnerability to further disempower them.

“He started assaulting me more often... And don’t forget I’m looking out for a newborn...I was on maternity leave.” (P1)

For others, violence was felt to be used when the abuser felt a shift in the power and control in the relationship.

“There was just atmosphere straight away... he said ‘where have you been? You’re lying, you’re a s\*\*\*, and it’s a lie’. Next thing I know you’re trying to kill me. Zero to full.” (P2)

The participant’s switching tenses may indicate her ongoing trauma and possible reliving of the incident whilst recounting her story.

### **Surviving the Abusive Relationship**

Five of the six women who participated in the interviews shared reflections on the coping strategies they used to survive the abusive relationship and the purpose they served until they escaped. The strategies shared were denial of IPV, thus allowing to hold a false sense of safety; having to make choices related to what they were willing to accept to keep themselves and their families safe; attempting to find control in other ways in their lives; trying to make sense of the abuser’s behaviour to cope with the abuse.

#### ***Denial Brought a Sense of Safety***

To survive, the participants referred to being in denial of the abuse they were suffering. The participants not only hid their suffering from the outside world but also did so to maintain their own mental health and well-being.

“The dust under my carpet is as big as a mountain, but in the front, it is ‘I’m fine.’”  
(P1)

The moment they realised they were being abused, and the severity of their situation was associated with strong emotions, such as shock.

“She gave me a list of support groups and women’s refuge... I was horrified at thinking, ‘I’m this person!’” (P3)

### ***Making Survival-Based Choices to Cope with the Abuse***

The women also spoke of using several strategies to survive the abuse. For one participant, compartmentalising, drawing strength from her skills and knowledge of her abuser, and protecting her children allowed her to devise strategies to keep herself and her children safe.

“But I remember thinking, ‘What’s most important now is dealing with my baby’.  
So, I ring-fenced, ‘That’s a problem that I have to deal with later.’” (P3)

However, some reflected that their vulnerability and need to protect their children meant they had to be more tolerant of the abusers’ behaviour.

“I think I was just so vulnerable at being alone with the children and just more accepting of this rubbish.” (P6)

The safety survival instinct meant that several women limited their freedom to placate the abuser and reduce the likelihood of harm.

“I said, ‘Well, you’ve said this thing over and over, so I don’t want another quarrel, so I’ll just put them in a suitcase.” (P4)

### ***Finding Other Ways to Feel in Control***

The participants shared finding other ways to feel in control throughout the abusive relationship, no matter how small. For some, taking care of their health helped them cope, whereas others did so by setting challenges for themselves within the limits the abuser set. Retaliation and naming of the abuse helped demonstrate that they remained in control despite the abuser’s attempt to invalidate them.

“I’ve only got that amount of money, but I can produce something quite good, so I’d give myself a challenge... I wasn’t in control of big things. I would find a way of being in control of something smaller.” (P3)

“... I’m like, ‘no, because this is abuse. I didn’t hit you; I didn’t say anything. So why are you trying to attack me?’ Because already, emotional abuse is very bad. But now physical?” (P4)

### ***Making Sense of the Abuser’s Behaviour***

All the women reflected on the importance of labelling the abuser as part of making sense of their experiences.

“[My therapist] just commented, ‘these narcissistic people’... it just was just tremendous.” (P3)

Two participants reflected that seeing the abuser as weak or troubled helped them cope and make sense of his behaviour. Doing so allowed them to create distance



between the person they chose to be in a relationship with and the abuse they suffered at their hands. It also permitted them to justify continuing to care for them.

“He was insecure. And I was the person who he could be himself with... that’s what I believed.” (P3)

### **Coping with the Lasting Damage of IPV**

All the participants shared experiences of continuing to be affected by their experiences of IPV, despite having left the relationship. All the women shared having experienced difficulties with their mental and physical health, as well as difficulties forming new relationships in their personal lives.

### ***Long-Term Effects of IPV on Mental Health and Well-Being***

All the women shared that IPV impacted their mental health, particularly related to accepting they had experienced abuse. Although minimising the extent of the abuse helped them survive the relationship, coming to terms with it also meant allowing trauma-based memories and emotions to become more accessible.

“I was so emotionally illiterate and whole hell broke loose because I realised that I was severely abused as a child, which I didn’t have much memory of because my brain shut out that part.” (P1)

Whereas for others, they experienced a significant decline in their mental health.

“I remember feeling I was wading through. It was as if I was in a blizzard, and I would put in all my energy to put the next foot, and I couldn’t see anything in front of me.” (P3)

“I remember I tried to commit suicide. Because the abuse was so much, the abuse was too much.” (P4)

Most women reflected on needing strategies to manage being flooded by strong emotions and trauma memories.

“I’m a busy person... There’s a need to be busy. So, my head isn’t full of other traumas... but sometimes it’s also avoidance. It’s a difficult balance.” (P3)

“Sitting still, mindfulness doesn’t work for me... it just makes me cry.” (P2)

Participants reflected on challenges related to rebuilding a sense of self and identity and their trust in themselves. Some reflected on experiencing intense self-stigma and feelings that abuse was deserved.

“I just thought, ‘It’s me. It’s my problem. Something’s wrong with me’... And then shame, blame and everything on me...” (P1)

One participant reflected on her internalised self-stigma as an HIV-positive woman and felt she might be stuck within her views of herself. She reflected on feelings of being left behind or different to others.

“The self-stigma. The way I see women going out there, they’re really on Twitter everywhere. I still have that self-stigma. It’s like I didn’t jump.” (P5)

Participants shared experiences of continued long-term mental health difficulties. Despite portraying strength and resilience externally, the women described daily internal mental health struggles, which for some, were still being experienced at the time of the interview.

“Despite everything I was doing, I was still suffering from my anxiety, could not sleep at night, and I said, ‘This is taking a toll on me.’” (P5)

“What I have is post-traumatic stress.” (P3)

Participants all reflected on difficulties coping with isolation and loneliness rooted in feeling misunderstood and holding stigmatised beliefs of their experiences. The added layer of fears of disclosure and rejection further exacerbated this.

“If I’m lonely in a crowd, it’s because I can’t talk about what’s frightening me.”

(P3)

“I just wanted to be safe. I don’t want people to know... Maybe I put myself through that person, how I felt then, and how people saw me. I feel that’s still how people might perceive me.” (P5)

Longer-term abuse from childhood or IPV resulted in some participants having chronically active survival instincts. Some women shared that, as a result, they have been unable to let their guard down throughout their adult life, contributing to feelings of isolation.

“I’m tired of being strong... Because you cope... people don’t realise that you’re struggling. Or maybe I don’t even admit to myself I’m struggling.” (P3)

“I was ready to fight anybody, [mimics punching]. I had that mentality of like “I’m going to take on anything that comes my way.”” (P5)

Despite having left their abuser, three women shared fears of meeting their abuser in public. This resulted in them being hyper-vigilant, impacting their quality of life, and ability to engage in certain activities, such as being in crowds.

“If I was in the crowd, I’m not sure, if ever saw me, he’d kill me. It was almost like a book, like, ‘Oh my God’, waiting for what happens next.” (P2)

Three of the women used a book analogy to describe their experiences. Such an analogy possibly represents the feeling that their stories have been written by someone else without their having control. It may also be a defensive strategy – a way of creating distance between their wellbeing and their experiences. However, two participants referred to the end of their relationships as closing a chapter, symbolising the ability to move on to a different part of their life narrative.

“So at least that that chapter has closed now.” (P1)

Two participants shared that the coercive control they experienced impacted their identity. For example, they reflected that they found it hard to return to their previous fashion style due to the abuser having dictated what they were allowed to wear.

“He didn’t like my hair extensions... and low tops, and shoulder showing, stuff like that. It’s really hard then to come back... I still find it quite difficult to wear open cleavage tops.” (P2)

Other women were trying to rediscover a sense of self aside from the HIV label they have been ascribed to or the abuse they have experienced.

“I don’t want to be known as ‘HIV [name]’. I’ve got other things; I’ve got lots of interest.” (P3)

### ***Difficulties Forming New Intimate Relationships***

Several women shared that they did not wish to return to a relationship after escaping abuse, mainly due to difficulties trusting and feeling unsafe with men. However, this increased their feelings of isolation and loneliness. Some women gave up their hope of finding a life partner and starting a family due to past experiences.

“I said to myself that I’m not going to go into another relationship because that left me feeling vulnerable to men. I lost trust in them because I felt like the things I went through, maybe another person would do it to me.” (P4)

Others described having to sit with difficult feelings of loneliness and finding ways to combat these feelings.

“New Year this year felt even sadder. I felt a bit sorry for myself... but then I thought, ‘Oh sod it!’. Me and my daughter have been going swimming...”

“I haven’t got a team player like my mum and dad... I have a smelly bulldog, and I’ve got two tortoises...” (P2)

Some participants did so by building connections with their children or fostering pets, who are less likely to abandon or reject them.

### **Unreliable Personal Networks**

One of the group experiential themes related to social networks' impact on their experiences of IPV and seeking help. All the women either shared experiences of feeling rejected by their family in a time of need, or social networks perpetuating aspects of blame, shame, and ostracisation, thus contributing to the difficulties they experienced in seeking help.

### ***Familial Rejection***

For many participants, challenging family dynamics acted as a factor contributing towards remaining in abusive relationships. Being let down by their families meant they could not rely on them in times of need.

“I left in my pyjamas, and went to my mum’s with the kids... She told us I’d made my bed. Go lie in it now.” (P2)

Being unable to rely on family further isolated them and may have confirmed the inescapability of the relationships. Furthermore, generational marital and gender expectations also influenced the threshold of what they would tolerate and accept within their relationship.

“He was of a generation, of more my father’s, in his attitudes to women... we both had a similar level of careers... but he was the breadwinner.” (P3)

Her abuser’s gender expectations and her values towards marriage placed her abuser in a position of power, and her in a disadvantaged position. Her reflections on their marriage values and expectations relate to feelings that her threshold for tolerance of power imbalances in marriage then was higher than it would be for her now.

### ***The Betrayal from Social Networks Further Isolated and Ostracised Them***

Social networks were described as an essential factor in the ostracisation, shame, and stigma the participants experienced. The women described being othered by their social groups due to preconceived ideas of an abused woman, thus limiting their access to help.

“My social group of friends, who talk about the women who need help... They are ‘other’ women, not their friends...so that hit me.” (P3)

Related to being othered, some participants experienced abuse or HIV-related stigma, not only invalidating the trauma they have experienced,

“I became a laughingstock... like it was my fault... When I had my lip cut, I sent a picture to one of my friends... she shared that thing on WhatsApp groups.” (P4)

“I told two friends. One of them kind of had that micro expression of disgust. So that immediately made me feel terrible.” (P6)

but also further isolating them. Two participants described social networks refusing to help due to fears of becoming involved in marital affairs, thus further compounding the isolation they were subject to.

“Most people changed, moved away, including family. ‘That’s your husband. No, no, no, he’s too much.’” (P5)

### **Support Services Perpetuate Patterns of Abuse**

Whilst exploring experiences of help-seeking, the women all shared their perception of services perpetuating the patterns they experienced within their abusive relationships. The service-related, systemic patterns of abuse were through prejudiced experiences in support services; experiences of clinicians taking advantage of patient-clinician power differentials; feeling unsafe in health and care services; experiences of health and care services as being unreliable and untrustworthy; and clinicians making decisions about their care based on prejudiced assumptions.

### ***Prejudiced Support Services***

Most participants shared experiences of services exhibiting discriminatory behaviour towards their HIV or IPV. At their most vulnerable, the participants

described being discriminated against by support services based on outdated views of HIV or preconceptions of IPV.

“Consultants have written down in black and white, ‘I can’t put my surgical team at risk. We’d all have to double glove and double gown.’” (P2)

“I don’t naturally fit in into what is perceived as an abused person... In many respects if I acted the part, it was fine. But they didn’t see me, the person.” (P3)

Some participants felt clinicians were not appropriately trained to support and understand the complex dynamics underlying IPV. As a result, they described clinicians being led by presumptions rather than hearing the patient’s voice.

“I was seeing a psychologist... but she didn’t pick anything up. If anything, she kept on asking me to fill out the questionnaire for post-natal depression.” (P1)

### ***The Abuse of Power***

The participants referred to HCPs as taking advantage of their power, leading to inadequate care. Participants experienced clinicians rejecting them from services or avoiding difficult conversations.

“I was trying to explain to her how I feel... she just stood up and said, ‘Just leave.’” (P4)

“I did say to her ‘he makes me have sex when I don’t want to’... and she ignored it.” (P1)

Such experiences left the participants feeling unwanted, unseen, and unimportant in the eyes of healthcare services.

### ***Support Services are Unsafe***



Support services were experienced as unsafe by most of the participants. Due to burnout, HCPs were experienced as unable to tolerate hearing about their traumas or having unprocessed trauma themselves.

“You have to be careful because people need you... then they feel like the tree that you lean on is not stable... And then they end up blaming you [for not engaging].”

(P1)

This led to perpetuated abuse and feelings of blame for non-engagement or invalidation, thus reaffirming mistrust in support services.

“Maybe it’s me. But ever since I’ve been with this GP, they’ve never been good to me at all. I don’t think I can trust them.” (P4)

Services perpetuated V/S and HIV shaming by advising one of the women to take the blame for HIV when seeking advice on disclosing to her children—doing so made services unsafe to her and perpetuated a culture of entrenched patriarchy.

“They said, ‘Well, lie then. Say you got HIV before. It wasn’t the dad that passed it on...’ I said, ‘There have been so many lies told! That’s not the answer.’” (P3)

### ***Health Services are Unreliable and Unavailable***

All participants found health services to be unreliable or unavailable. Due to long waiting lists, strict inclusion criteria, or strained services, women could not access talking therapies. Some women described talking therapy services as not meeting their needs due to only providing short-term, surface-level interventions.

“Paying for private therapy again... because the local doctors can only offer you six or 12 sessions. That’s no good.” (P6)

The participants shared disappointment and frustration regarding being placed on waitlists for months, told they were inappropriate for the service and referred elsewhere.

“They didn’t even say goodbye, and the new person thought I was not eligible for DBT.” (P1)

They also shared experiences of being provided with unhelpful advice due to the lack of availability of appropriate services. The inaccessibility of emergency services also left them in unsafe situations.

“... and there were times when I when I called Samaritans and, unfortunately, I rang them three times in a row, nobody answered.” (P1)

HCPs within support services were perceived as incapable of understanding the challenges they experienced, perpetuating self-blame, isolation, and disempowerment.

“... And sometimes people don’t understand, even professionals... So that stops me from having the support... I feel like I’m in a glass box. It’s like people see me talking, but they can’t hear me.” (P1)

### ***Health Services Make Decisions About Patient Care Based on Prejudicial Assumptions***

One participant shared experiences of clinicians making decisions about her care based on prejudicial assumptions, preventing her from accessing crucial support groups. Doing so isolated her and perpetuated feelings of invalidation and powerlessness, which she had experienced in her relationships.

“My consultant said, ‘We don’t have many women who you would be able to relate to. They come from a different background’. I just wanted to talk to someone else!” (P3)

### **Service Provision Has Changed Over Time**

Five out of the six participants shared that their experience of health and care services had changed over time, contributing to difficulties in seeking and accessing healthcare. Two main sub-themes were noted—the first relates to the quality and accessibility of services significantly impacted by geographical location. The second relates to the loss of personal and holistic support overtime, with services experienced as impersonal.

### ***Geographical Inequalities in the Provision of Care***

A difference in experiences of service provision between rural UK towns and urban cities was noted—the challenges highlighted by living in rural towns were related to a lack of anonymity. Participants in rural towns shared being unable to separate their medical and personal lives (e.g., “I live in a village, one of the GPs is someone I go swimming with.” (P3)). For others, the lack of specialist HIV services made them feel alone in their battles.

“I just felt unsafe for a very long time... There weren’t services here anyway.” (P6)

For others, this resulted further in processing their HIV diagnosis within a stigma-ridden framework when compared to urban settings.

“Women from London are sassy. They are ‘yes I have it! Do you have a problem with it?’ instead of being shame-based.” (P6)

### ***Services Have Become Impersonal***

The women spoke of specialist HIV services becoming disjointed (e.g., “my GP... was incorporated with sexual health. And then they took that service.” (P1)) or closing due to lack of funding. The complex combination of HIV and IPV has left women in rural settings feeling like they are without support.

Participants reflected on the changes in the quality and person-centricity of services. Some commented on services increasingly providing superficial care.

“Services were much better than now. As you know, services are getting less... you knew that your needs were holistically and psychologically... like having counselling or support group. They would come and pick me up and drop me off.” (P5)

### **For WLHA, Support Services Are Not a Place for Care**

Most participants described difficult help-seeking experiences based explicitly on healthcare providers' responses to their HIV status. The shared experiences surrounding feeling let down and untrusting that services will care for and protect them in time of need and having to educate services about life living with HIV.

### ***Feeling Let Down and Untrusting of Support Services***

The unreliability of health and social care services in keeping them safe, as well as the uncertainty of non-discriminatory care (e.g., “I don't tell people, and I have minimal interaction with the doctor's surgery... I feel very protective and vulnerable with that information.” (P6)) resulted in the women losing trust in services. They preferred self-reliance to ensure their care and safety.

“I'm still very much living a lockdown style life now, for both reasons, for everything that's going on with NHS and fear of not getting much support.” (P1)

“I think the fear of not being somewhere safe. I didn’t feel that I would be safe in the hospital, so it didn’t feel like a viable option.” (P2)

One participant shared powerful feelings of being let down by UK support services when most vulnerable, leaving her feeling worn down and cynical of services advocating for her in the future.

“I’m just tired of seeking help, to be honest... I feel like the country has failed me.” (P4)

### ***Educating Services***

Participants reflected on regularly having to educate clinicians about HIV. They described feeling like they must be their advocate and use their experiences of discriminatory and stigmatised care to inform and improve services.

“A lot of medical staff in my health clinic now have been on courses about HIV. And my view was, ‘You need to treat people who are HIV positive differently.’” (P3)

### **The Role of Systemic Issues in Disadvantaging Women**

One of the GETs related explicitly to the experience of women. Half of the participants spoke of the impact of women’s positioning in society and how this affected accessibility to care. Notably, one of the experiences participants reflected on was the feeling that WLHA is a forgotten group in HIV care. The other theme was related to gendered systemic issues which WLHA who have experienced IPV face.

### ***Women as a Forgotten Group***

Three women reflected on specific challenges of WLHA. A narrative surrounding the disparity in the progress made for women, compared to that of WLHA, was shared. WLHA were described as overlooked throughout HIV history and further pushed aside in a world where other minority groups are given increased attention. A woman's multiple gender roles have exacerbated the lack of understanding of the experiences of WLHA.

“We are supposed to be mothers, wives, daughters, friends, lovers, and now we have the complexities of gender identity... Instead of women really feeling like they are really getting somewhere, we need to shout even louder.” (P2)

“I asked for support as a WLHA, and she said there wasn't really any. And within the same week, she's giving him [the abuser] information on transgender issues...” (P3)

One participant reflected on White women being an unrecognised and forgotten minority within the HIV community (e.g., “There's equality and diversity, and it's to support people minorities. Within HIV, and my background, I'm a minority, I should be supported.” (P3)). The lack of support and community isolated WLHA, perpetuating HIV-related shame.

“Gay people, they've built a strong community, and I think that is so key because it's the acceptance from other people which helps lead to self-acceptance.” (P6)

### ***Women are Disadvantaged in a Patriarchal Society***

The impact of women being disempowered in a patriarchal society was shared. For some, the historical power of men in marriages, notably financial, promoted ongoing power imbalances.

“He said, ‘Well, you could be the second person on my credit card’. But it also meant that I never could get a credit card without him knowing.” (P3)

Another participant commented on the androcentrism of police services, rooted in misogynistic attitudes, as contributing to her abuser successfully discrediting her.

“My ex is blaming my hormones. The male police officers said, ‘Well, maybe it is your hormones’ which completely broke me down.” (P1)

These experiences compounded the inequalities the participants experienced in their intimate relationships.

### **The Impact of Positive Support Service Experiences**

All participants shared experiences of positive and helpful support and reflected on the impact this had on their journey. Participants shared their views around person-centred care, the importance of accessing care which is consistent and reliable, receiving support from care providers which remained within the boundaries of their role, and feeling valued and heard by health professionals.

#### ***Person-Centred Care***

Most participants commented on the importance of person-centred care in giving disempowered women the feeling of being seen and safe enough to trust health services.

“She was giving me the power to where I sit, and I thought, ‘You know I don’t have power in other things.’” (P3)

“The HIV clinic... every time when I go there, I feel at home.” (P4)

Other participants reflected that the expectation of receiving person-centred care is unrealistic or has become an overused keyword employed by services to meet performance indicators.

“Person-centred care becomes a box... for me, it should be ‘individual person-centred care’. Each person may need to be approached differently.” (P2)

### ***Care which is Consistent and Reliable***

The importance of continuity of care and consistency in their approach helped the women feel safe and supported. Being under the care of health services with clinicians who have followed them through their journey played a significant role in feeling supported to leave abusive relationships. Participants reflected on feeling seen by HCPs.

“They care. I had a relationship with my doctor for ten years, so she knew me. She knew something was off...” (P1)

For one participant, the experience of a compassionate and caring clinician left a mark and allowed her to feel safe with them. The participant was left astonished. Her remark also reflects the impact of being in an abusive relationship, whereby their needs may rarely be thought about, thus resulting in a memorable moment when an HCP showed compassion towards her.

“She was just incredible. I was thinking, ‘they do actually care’, which they did! (laughs)...” (P3)

### ***Receiving Boundaried Support***



Two women commented on the impact of a professional conducting themselves within the limits of their skills and remit as a positive and safe experience.

“The solicitor, she wasn’t as good emotionally, but she was very good at her job.”

(P1)

### ***Being Validated and Heard by Health Professionals***

All participants reflected on the importance of being heard and validated by HCPs in their journey towards leaving abusive relationships. Clinicians clearly stating and naming the danger of their situation allowed them to feel acknowledged, heard and supported.

“He said, ‘You should not be living in the same house.’ I’m thinking, ‘You believe I’m actually in danger!’ It was just amazing to have someone who believed what I was saying...” (P3)

Another participant shared her views on the importance of clinicians being aware of the precariousness and vulnerability WLHA exposed to IPV may experience when first seeking help. Specifically, a need for HCPs to be gentle, compassionate, and caring could make women feel safer disclosing IPV.

“It’s just that way of beginning a conversation... Non-judgmental... creating a space... because by the point that a woman is beginning, or even thinking about reaching out, she’s down.” (P6)

### **Moving on From the Trauma**

All participants shared different ways in which they could move on from the trauma of being in an abusive relationship, as well as processing their HIV status. All women reflected on the importance of connecting with others, removing themselves

from the isolation which they previously experienced. Others shared finding ways of processing the trauma they had experienced. Several of the women shared the perceived importance of taking back control within their own lives and engaging in self-compassion and care.

### ***Connecting With Others***

For some women, accessing peer support was marked as the start of recovery. It was vital in allowing them to feel part of a community, connect, and feel understood by others, thus removing the shame, isolation, and rejection previously experienced.

“The beginning of my journey started when I went to a support group and met some other WLHA. We just grew up together and said, ‘No, we are not alone. And better, we can look good, we can be happy.’” (P5)

“Being part of the community and seeing how others live was empowering. And that’s made the biggest difference... And you don’t have to internalise all this stigma or this shame.” (P6)

Peer support groups also played a crucial part in feeling empowered to share their stories and support others by becoming peer mentors.

“I’ve got a lot of friendship. And I think a lot more confidence in talking about HIV. Because I was very fearful of who I told about HIV.” (P3)

Although the COVID-19 pandemic initially helped women access online support groups, one participant reflected on groups returning to in-person rather than virtual, resulting in feelings of loss, isolation, and feeling left behind.

“It’d be great if everyone could have peer support... why can’t they support me online?” (P3)

Some participants expressed gratitude and shared the importance of connecting and having a relationship with their children, despite the hardships they have gone through.

“[My experiences] did not affect my ability to love and to parent my children... I’ve been very fortunate there because I know for a lot of women it shuts that down.” (P6)

### ***Processing the Trauma***

Processing trauma was compared to a grieving process, whereby memories and emotions may be unexpectedly triggering.

“It’s like a grieving process. It can be very raw. Sometimes you think you’re coping, and you just get to the face [emotions]...” (P3)

An essential part of overcoming the trauma was accepting past experiences and letting go of self-punishing views and beliefs. Leaving past experiences behind was likened to a rebirth, allowing for personal growth and moving on.

“It’s like part of you dies, but you have this new part of you that hopefully comes out like a phoenix, out of the fire, and you’ve become this new person.” (P2)

Despite difficult experiences in healthcare, engaging in talking therapies was an essential part of processing the trauma for some women. Talking therapies provided them with a safe space to explore their experiences, be heard, and be validated.

“I said, “I’m returning to the therapy I did not take five years ago. Let me engage. I’m ready now.” Everybody needs to find their time...” (P5)

The participants shared that engaging in the interview was also part of moving on from the trauma. It allowed some women to discover how they felt about sharing their narratives with another. For others, sharing their stories in a research context felt essential to promote change in the challenges of WLHA/IPV.

“The difference between advocates and voices – There will always be people with positive experiences and people with both... It’s about how we contribute to research and validate and extend people’s knowledge.” (P2)

“I’m in that phase of my life now that I’m clearing my cupboards. So, talking to you, it’s helping to clear that stuff... find out how I feel about it. I seem to feel OK; you know?” (P1)

### ***Taking Back Control***

The women described finding ways of regaining control and feeling empowered, such as assigning a more compassionate label to themselves, representing their journey. Others described the importance of leading a support group to provide others with the support they did not have or focussing on their needs to compensate for a lifetime of invalidation.

“I called myself a survivor.” (P5)

“I’ve given more than 30 years of my life to look after other people... It’s my time to be who I want to be.” (P3)

### ***Self-Compassion and Care***

Part of the participants' journey to recovery was through engaging in self-care. A narrative around self-discovery and taking on new interests as part of their journey to living a life free from their abuser was shared.

“I've started all these things late in life. So now I kind of want to get going. And I do have the opportunity and the self-belief as well.” (P6)

## **Discussion**

The research aimed to better understand the help-seeking experiences of WLHA/IPV. The GETs and subthemes constructed through IPA explored the intersection between the experiences of WLHA and how it played a role in abusive relationships. Throughout the women's narratives, IPV and HIV were sometimes spoken about separately. However, at other times their experiences intersected. Although contracting HIV was not always related to being in an abusive relationship, and the abuse they suffered was not always related to their partner's views of HIV, there were clear examples of HIV being used as a weapon by their abuser. The relationship dynamics and how they described their self-view and view of the future were seemingly rooted in their beliefs and views of themselves as WLHA. For others, transmitting HIV to their partner was used as a last resort use of power against them, whilst for some, their abusive partners used the societal stigma against HIV against them to isolate and keep them trapped in the abusive relationship.

The themes also articulated participants' experiences of help-seeking and the impact of the barriers they faced. The GETs and subthemes illustrated the interaction between the impact of HIV on aspects of the self, stigma, and the way abusive strategies and HIV reinforced control and power in the relationship. The participants' conveyed a narrative of isolation, loneliness, and misunderstanding, which health

services perpetuated. This research thus provides insight into the complex and interconnected psychological, interpersonal, and societal challenges the participants confront when seeking help.

### **The Impact of Being Diagnosed with HIV**

All women shared the sub-themes related to the shock of receiving an HIV diagnosis and its impact on their sense of self and well-being. The effects of receiving an HIV diagnosis for women have been well documented in the literature. Similar to the participants' experiences, a range of emotional reactions have been reported – devastation and shock in the immediate term, and in the longer-term, depression, feeling submerged by the diagnosis, shame, and suicidality (Stevens & Hildebrand, 2006). The *Theoretical Model of Adjustment to Long-Term Conditions* (TMA-LTC; Carroll et al., 2022) alongside the HIV Stigma Framework (Earnshaw & Chaudoir, 2009) can help make sense of this. The TMA-LTC proposes that being diagnosed with a long-term condition and possible ongoing health difficulties can disrupt a person's emotional equilibrium. Adjusting to a long-term condition depends on cognitive and behavioural factors related to the inter- and intrapersonal, environmental, and illness-specific contexts. Such a diagnosis can disrupt an individual's core beliefs and assumptions about themselves and the world and can be experienced as a traumatic event (Tedeschi & Calhoun, 2004), as portrayed in the participants' narrative.

### **The Role of HIV in Forming Relationships**

*Self-determination theory* (Deci & Ryan, 1985) posits that personality, development, and situational factors influence an individual's psychological well-being. Central to this theory is the understanding that to achieve wellbeing, an individual has the autonomy and agency to make decisions not guided by internal or

external expectations (LaGuardia & Patrick, 2008). Self-determination theory's description of the causes of positive wellbeing starkly contrasts the widely acknowledged processes underlying IPV (i.e., coercion, intimidation, emotional abuse, minimisation, blame, denial, and financial abuse), contributing to the abuser having more power and control over their partner (Domestic Violence Project, 2013a). These processes were shared in the participants' narratives of the impact of the abusive strategies on their self-esteem and sense of self. Furthermore, as shared within the interviews, historical traumas and an HIV diagnosis can influence an individual's self-view.

An HIV diagnosis has been recognised in the literature as posing barriers to choosing an intimate partner, which was reflected in the participants' experiences. Starting a new relationship when living with HIV can be complicated, and the longevity of relationships may be shaped by disclosure. The literature on intimacy explains that an individual must engage in self-disclosure to develop intimacy (Reis & Patrick, 1996), and the partner's response to the disclosure will strengthen or weaken the relationship bond (Laurenceau et al., 2004). Regarding PLHA (people living with HIV/AIDS), disclosure can be more complicated. PLHA may need to negotiate disclosure (Reinius et al., 2021), such as deciding when to disclose HIV to mitigate later rejection once a closer bond has been formed (Greenhalgh et al., 2016). They may also test disclosure with different people to establish how others may react (Greenhalgh et al., 2016). Some of the participants' reflections on being limited within their choice of partnerships can be understood within this context.

When considering the risk of HIV-related IPV, the *Risk Regulation Model* articulates how individuals attempt to balance the desire to be intimate with partners

with the inherent risk of being close (Murray et al., 2006). Rejections in romantic relationships are particularly painful, activating a cognitive, affective, and behavioural system to resolve relationship conflicts (Knee et al., 2013). Therefore, when rejection seems possible, the individual may alter their behaviour to mitigate the risk. The HIV stigma the participants may have experienced in and outside the relationship and the abuse they have suffered throughout their lives may have made it feel safer to remain in a relationship than to leave and be rejected again.

Aside from the clear weaponising of HIV within IPV, the fundamental role of HIV in remaining in an abusive relationship can be understood through relational theories. Attachment, a key factor for understanding dynamics within relationships, relates to the ability and extent to which an individual can feel secure with another (Bowlby, 1969). Within attachment theory, an individual's past relational experiences, particularly those from birth, are internalised and guide future relationships. Therefore, an individual's internal working models, based on their caregiving experiences, provide expectations for themselves and others carried forward within future relationships. Caregiving experiences reflect the extent to which an individual may feel worthy of love and the extent to which they feel others will relate, respond, and support them (Henderson et al., 2005), possibly placing individuals at risk of IPV. The stigma associated with HIV and the challenges associated with a partnership for WLHA may have contributed to remaining within abusive relationships.

### **Healthcare**

The interview results indicated overwhelmingly negative, stigmatising, and discriminatory experiences of care and support. On top of this, services were experienced as unavailable or unskilled in supporting WLHA/IPV. As highlighted in



the interviews, IPV had short- and long-term physical and mental health consequences on the participants. The health outcomes of IPV often last beyond the violent relationship, which means women are more likely to seek healthcare (WHO, 2013). Typically, HCPs are the gatekeepers to dealing with the disclosure of IPV and, consequently, should be the professionals WLHA/IPV are most likely to trust and disclose IPV (Tarzia et al., 2020). A well-trained and empathetic HCP can validate women's experiences and help them access their needed support (Garcia-Moreno, 2014). However, the same healthcare barriers to disclosure highlighted in the literature (e.g., blaming the V/S, unskilled at identifying and supporting, and their own experiences of violence; Aksan, 2007) were reflected in the interviews.

Furthermore, research has highlighted the panoply of stigmatising behaviour PLHA experiences in health settings. Behaviours included neglectfulness, differential treatment, denial of care, testing, disclosing status without consent, unwarranted use of personal protective equipment, labelling files, or verbal abuse (Lazuardi et al., 2019) and were all shared in interviews. Experiencing these, or fear of experiencing them, can prevent PLHA from seeking or distrusting help from health services (Waluyo et al., 2015). Chambers et al. (2015) propose that there are three institutional or individual drivers of enacted stigma in healthcare settings which participants in this study experienced. These are risk management (i.e., separating seropositive individuals from others), fear management (i.e., behaviours related to the nervousness of virus transmission), and moral management (i.e., judgments linked to societal narratives surrounding HIV).

HCPs are often community role models who support others in their health challenges or concerns. However, as with the general population, their roles and

attitudes are shaped by their life experiences. Nonetheless, HCPs are responsible for ensuring they do not perpetuate negative attitudes towards groups of people (Paudel & Baral, 2015) and are best placed to do so. They can shape how community members treat others suffering from health difficulties by challenging stereotypes and discriminatory attitudes and modelling inclusive care (Paudel & Baral, 2015). The impact of HCPs not doing so confirms the rejection and stigma which the participants experienced.

### **Peer support**

All participants recognised the role of peer support in their journey to recovery. WLHA are often faced with rejection and discrimination from those close to them (Sandelowski et al., 2004). Peer support has, therefore, been widely recognised as one of the best sources of strength and acceptance for WLHA (APPG, 2022). Research has demonstrated that involvement with a support group can help to reduce apprehension, depression, isolation, and loneliness (Lennon-Dearing, 2008). Connecting with people with lived experience offers a safe environment for women to express and share experiences whilst also receiving validation and understanding from others (Lennon-Dearing, 2008). Not only this, but they provide a reliable social network. Furthermore, support groups can help women to feel more comfortable disclosing their status (Lennon-Dearing, 2008). Lastly, support groups have been noted to help women value themselves, and their lives, moving towards a journey of recovery (Gray, 1999). As reflected by the participants, the women felt their journey to recovery started with peer support groups rather than with their experiences with care.

In summary, several key themes were highlighted from the interviews. These were related to the shock of receiving an HIV-positive diagnosis and its impact on self-esteem and well-being, the impact of the strategies which the abuser uses, as well as the role of HIV within the abusive relationship. Lastly, themes related to healthcare and support services perpetuating trauma experienced in abusive relationships and the role of peer support in overcoming adversity were shared. The complexity and intersectionality of HIV and IPV can be understood with several theories and models which relate to navigating relationships, adjusting to a long-term health condition, the role of stigma, navigating the risk of being romantically rejected, and the role of early life experiences on dynamics at play within a relationship.

### **Strengths and Limitations**

This research had many strengths but also had its limitations. Firstly, it has given insight into the experiences of help-seeking for WLHA/IPV in the UK. Furthermore, the sample was diverse in ethnicity. However, the diversity was not representative of the UK population of WLHA, whereby it is estimated that two-thirds of the female HIV population are Black African women (Public Health England, 2017), comparing to one third of the sample in the research. The diversity in the sample nonetheless allowed for various experiences to be explored. Furthermore, 75% of UK WLHA are between 35 and 54. (Public Health England, 2017). The age of the sample of women was, therefore, representative of the population.

Using a voluntary response sampling method was beneficial for this study. Due to the sensitive nature of the research topic and their experiences, participants needed agency and anonymity to engage. However, voluntary response sampling is highly susceptible to bias due to the lack of control over sample composition. As

highlighted by the participants, their readiness to engage in the interview may have been dictated by the stage of their recovery journey. The recruitment difficulties experienced, and the ambivalence from some of those who expressed interest, raised questions about the differences between women who chose to engage compared to those who did not. For example, some women may not have felt able to recount their stories, may have still been experiencing abuse, or may have worried about a breach of confidentiality and feared the repercussions this would have on their lives.

Despite the difficulties encountered with recruitment sites' ability to support the research, the variety of sites could be retained. Therefore, the experiences of women recruited from NHS services or charities were represented in this research. The final sample also included participants from across the UK and represented different groups of women (i.e., women from different ethnic groups, geographical areas, and the context in which they acquired HIV).

Like most qualitative research, the sample size was small, thus limiting the transferability of the results. However, in line with the ethos of IPA, an in-depth analysis of the interviews was necessary to make sense of the participants' experiences (Smith, 2021). The sample size was adequate for the requirements of IPA, which promotes depth over breadth. Equally, due to the length and richness of each interview, not all results could be reported in as much depth.

IPA bases itself on the researcher making sense of the participants' experiences whilst they make sense of their experiences themselves (Smith, 2021). However, due to the emotivity and sensitivity of the subject, the researcher needed to be conscious of when it felt appropriate to explore emotional reactions within the interview. The researcher was mindful of the risk of re-traumatising the participants through reliving

experiences and relied on the devised *Safety and Distress Protocol*. The researcher was, therefore, conscious of allowing participants to have agency over the level of depth they wanted to share in the interview. However, as a result, a deeper level of emotional content was possibly lost. Furthermore, processes of countertransference (Laplanche & Pontalis, 1973) were possibly present throughout the interviews. The researcher's empathy and protectiveness towards the participant and their distress throughout the interview may have possibly inhibited opportunities for full exploration of the emotional impact of their experiences. Furthermore, the vicarious trauma faced by the researcher throughout the interviews (Moran & Asquith, 2020) may have limited the amount of in-depth exploration they felt able to conduct. As many interviews were conducted online, the researcher had to be mindful of the risk of exploring traumatic events while also managing their emotional reactions to the shared narrative (refer to *Integration, Impact, and Dissemination* section).

Lastly, due to time constraints and difficulties with recruitment, the analysis results could not be shared with the participants before they were submitted. The research is, therefore, missing a crucial perspective from those with lived experience, thus limiting the confirmability of the results.

## **Implications**

The results help build on the existing literature on the intersectionality of IPV, HIV, and help-seeking for women in the UK. Furthermore, this research provides crucial information on the weaknesses within services intended to support these vulnerable women. Despite its limitations, the result has implications for several stakeholders. Firstly, the results have implications for WLHA/IPV. Awareness of peers' experiences can help validate and empower the women in this population and

make them feel less alone in their experiences. The results can also help better inform services that may encounter WLHA/IPV. Not only is there a need for HCPs to have a better understanding of the complex processes underlying IPV, but also of the intersection and challenges that WLHA face in accessing help. Whether charities, health and social care, or judicial services, frontline service staff would benefit from specific training to better understand the challenges WLHA/IPV face. Training could also support HCPs to feel skilled in noticing signs of IPV, enquire, and supporting them appropriately. Heskin et al. (2022) mentioned the need for health and sexual health services to implement routine and safe enquiry into IPV, mainly as consultations are increasingly being held online.

The research had specific implications for talking therapists. In some ways, talking therapists are best positioned to support WLHA/IPV by providing them with a safe place to disclose their experiences. Therefore, they must be mindful of their presumptions and how they may impact those trying to access care. Talking therapists, including clinical psychologists, would also benefit from becoming better skilled at noticing the signs of IPV. For example, therapists may benefit from being trained on the definition of IPV, such as consensual sex within a relationship, how emotional abuse may present itself or make an individual feel, or the role of financial abuse. Like frontline staff, there is a need for a framework related to IPV to be developed and implemented to support them in acquiring skills in enquiring about IPV, supporting them psychologically, and advocating for them. This framework could include training on recognising signs of IPV, assessing and exploring possible IPV, and working psychologically with women who have experienced IPV. This may

include complex trauma, relational theories, and the impact of IPV on health and mental health.

### **Suggestions for Future Research**

Some participants reflected on the experience of White women as a minority group who have been forgotten in research and the public health response to HIV. It would therefore be beneficial for further research to be conducted to better understand the unique challenges that White WLHA face as a minority group within an already existing minority. Additionally, research focusing on the experiences of help-seeking in other groups, such as transgender PLHIV or men living with HIV who have experienced IPV, may be beneficial to understand their experiences better. Doing so would allow services to be appropriately tailored to the needs of the service-users.

Further research exploring therapists' experiences in supporting WLHA/IPV could help inform better practice and guidelines. Research on the experiences of HCPs in working with WLHA/IPV could help inform gaps in training, skills, and confidence in supporting this population. Doing so could contribute to informing a comprehensive evidence base on which better policies could be developed. For example, although there are robust *Standards of Care for PLHA* (BHIVA, 2018) and *Standards of Psychological support for PLHA* (BHIVA, 2011), which outline a stepped model of care, the only recommendation related to violence is to ensure a repeated screening is conducted (BHIVA, 2011). Furthermore, the national guidance for supporting individuals who have experienced IPV only outlines the need for HCPs to engage in multiagency working and with specific advice on routine screening (MacDonald, 2021). Therefore, the guidelines for supporting people subject to IPV do not represent the complexity of this population, not that of WLHA.

Considering the high rate of IPV in WLHA, developing specific guidelines for clinicians working in sexual health clinics specifically targeting IPV is needed. For example, guidelines could highlight the sensitive and complex nature of disclosing IPV, advise on how to inquire about IPV sensitively and highlight the HIV-specific processes that impact WLHA/IPV. The outcomes of this research also support the need for gendered issues related to IPV and HIV to become more prominent on the public health agenda and for these women to have more of a voice in their lives.



## **The Barriers and Facilitators of Health-Care Help-Seeking in Women Who Have Experienced Intimate Partner Violence: A Systematic Review**

### **Abstract**

Intimate partner violence (IPV) is a pervasive public health issue with significant physical, emotional, and social consequences. This systematic review aimed to understand the barriers and facilitators that impact health-care help-seeking among women who experience IPV. Records were systematically searched across electronic databases, including PubMed and PsycINFO, from January 2012 to July 2022. Studies published in peer-reviewed journals, in English, with quantitative research methods, were eligible for inclusion. A narrative synthesis approach was employed to analyse and integrate the findings, focusing on the barriers and facilitators to health-care help-seeking for women who have experienced IPV. The initial search yielded 5732 articles, 14 of which met the inclusion criteria. The studies encompassed diverse populations from different geographical regions and thus were highly heterogenous. The identified barriers and facilitators across studies were synthesised in five groups: (1) IPV-specific, (2) health, (3) demographic, (4) psychosocial, and (5) health-service-related factors. Generally, the results were heterogenous. However, there was consistent evidence that experiencing sexual violence and threats of physical violence alone, and cohabitation with their abusers were barriers to seeking healthcare. Mental health difficulties, access to income, and health insurance were consistently found to be facilitators of healthcare help-seeking across studies. This systematic review highlights the multifaceted barriers and facilitators associated with health-care help-

seeking among women who have experienced IPV. However, the heterogeneity within the included articles and the findings emphasises the need for a more specific systematic review to address these issues. Furthermore, the results highlight the need for a multidimensional approach to address these barriers and enhance support systems for women who have experienced IPV.

## **Introduction**

### **Definition**

The *empirical research introduction* outlines the definition of intimate Partner violence (IPV). The conceptualisation and terms used to describe IPV have changed over time (e.g., ‘wife battering’ or ‘family violence’; Van Parys et al., 2014).

Historically, research has mainly focused on physical violence and its consequences (Avant et al., 2011). However, the changes in attitudes and its conceptualisation contributed towards providing better support for victims/survivors (V/Ss) of IPV.

From a public health perspective, developing knowledge of IPV has broadened the understanding of the complex interactions underpinning these relationships (Lagdon et al., 2014). However, that same understanding has not always reached V/Ss. For example, the *Crime Survey of England and Wales (CSEW) 2020* reported that the general population has less understanding of coercive control than other forms of domestic abuse, and respondents who were V/Ss did not recognise their experiences as abuse (ONS, 2022).

### **IPV in Context**

IPV is one of the most common forms of violence against women. Recent data has estimated that out of the 81,000 women and girls killed globally in 2020, 58% died because of intimate partner or family violence (United Nations Office on Drugs and Crime, 2021). Miller and McCaw (2019) highlighted that IPV is not specific to social strata, geographical location, or cultural background. However, other data has indicated that certain groups of people have a higher prevalence of victimisation. These are women who identify with sexualities other than heterosexual (Messinger, 2011), are disabled, between the age of 20-24 and 55-59 years (ONS, 2022), have

comorbid mental health difficulties (Breiding & Armour, 2015), and are from a racial and ethnically minoritised group (Smith et al., 2017).

Although IPV is not a new phenomenon, COVID-19 brought new attention to IPV, raising it as a public health priority (WHO, 2021) and a ‘shadow pandemic’ (UNWomen, 2022). The measures taken to protect the medically vulnerable, such as lockdown and social distancing rules, did not consider the impact on those in abusive relationships. Data from this period indicated a worldwide increase in reported IPV to support services (WHO, 2021), with some countries reporting a five-fold increase (UNWomen, 2022). A survey conducted by *Women’s Aid* (Davidge et al., 2020) indicated that 78% of V/Ss reported that COVID-19 made it harder to leave the relationship. For example, much of the usual support switched to telecommunications, which exacerbated barriers to accessing help for those who lack privacy and access to technology due to being subject to controlling behaviours in the relationship.

### **The Impact of IPV on the Victims/Survivors**

IPV has a widespread and significant impact on V/Ss’ health. Women suffer from direct physical injuries and longer-term consequences such as functional chronic health problems derived from chronic stress (Anderton, 2022). Furthermore, V/Ss’ potential inability to negotiate contraception and forced sexual intercourse can lead to sexual and reproductive health problems, such as unintended pregnancies, sexually transmitted infections, and other reproductive health difficulties (Campbell, 2002; Miller & McCaw, 2019). Compared to women who have not experienced IPV, women who have experienced IPV are more likely to suffer psychological harm, which in turn, is associated with poorer physical health (Anderton, 2022).

Being in a violent intimate relationship can result in severe psychological trauma. Generally, both romantic partners should act as attachment figures for each other, providing caregiving in times of stress (Feeney, 2008). However, in the context of IPV, the V/Ss' closest relationship becomes a source of fear and pain (MacLaren, 2021), resulting in psychological and relational wounds. Such dissonance between the expected security and comfort in a relationship and the violent experiences can result in post-traumatic stress disorder ([PTSD]; Janoff-Bulman, 1992; Taft et al., 2011). For example, a V/S's daily routine can become concentrated on attempts to manage and reduce the likelihood of abuse, leading to a constant state of anxiety. V/Ss may also start to alter their behaviour to appease the perpetrator. On top of the emotional abuse experienced, the development of such patterns can further lead V/Ss to believe they are to blame for the abuse (Anderton, 2022).

With this in mind, the most prevalent mental health problem for women who experience IPV is depression, with over one-third of V/Ss experiencing depressive symptoms (Nixon et al., 2004). Not only does depression impact the individual's sense of self, but it also affects the person's relationship with others. Compounding these difficulties, perpetrators often attempt to disrupt the social networks of V/Ss, thus maintaining psychological distress (Joiner & Timmons, 2010) and isolation. For example, the CSEW (2021) reported that 49.8% of IPV V/Ss aged 16-59 reported emotional problems, around 25% had stopped trusting people, and experienced difficulties in other relationships. Psychological abuse also significantly impacts emotional, psychological, and mental well-being. V/Ss may be subject to feelings of worthlessness, and dependency on the perpetrator, leading to depression, anxiety, PTSD, sleeping and eating disorders, and substance abuse (Anderton, 2022).

IPV has often been seen as an issue that remains in the privacy of people's homes and, consequently, can be assumed to be beyond service providers' reach (WHO, 2021). However, women who experience IPV have complex, multisectoral needs (i.e., health, social care, and legal). On top of the health impact of V/Ss, IPV has a broader impact on women's children, starting from low-birth weight to paediatric developmental and health problems (Hill et al., 2016), as well as leading to a higher likelihood of intergenerational perpetration of violence (Cannon et al., 2009; Miller & McCaw, 2019). In this context, IPV is recognised as a transgression of societal values related to freedom and equality, having devastating impacts through the loss and destruction of lives. IPV is an acknowledged risk factor for suicide ideation and attempts (Anderton, 2022; Taft et al., 2011). Furthermore, the social and economic costs of treating physical and emotional harm, difficulties maintaining and achieving successful education, employment, and sustained income due to being absent from work are estimated to be £66 billion in the UK (MacLaren, 2021). Additional complexities associated with abuse-related financial dependence also contribute to these costs (Lagdon et al., 2014).

### **IPV and Healthcare**

IPV is common, costly, and associated with increased morbidity and mortality. The widespread impact of IPV on V/Ss' health and mental health outcomes and the intergenerational effects places healthcare systems in a central and unique position for prevention, identification, intervention, and recovery (Miller & McCaw, 2019). Despite women who have experienced IPV being more likely to seek healthcare for illness (WHO, 2017), health services have not always been effective in identifying and supporting V/Ss of IPV (Campbell et al., 2002; Feder et al., 2006). In a recent UK

national survey calling for evidence on violence against women, 77% of V/Ss of IPV report insufficient support in healthcare services. There appears to be a lack of understanding about the complexity of the experiences of women who have experienced IPV from support services. Furthermore, the survey's respondents perceived services as geared towards supporting men and engaging in 'victim-blaming' (MacLaren, 2021) when HCPs could be the V/Ss' most trusted source of support (WHO, 2017).

The *Health Utilisation Model* (Anderson, 1995), referred to in the Introduction of the empirical research, provides an explanation of an individual's decision to seek help from healthcare. The direct impact of trauma and coercive control can leave V/Ss with feelings of shame and worthlessness, and they are to blame for their situation. On top of the psychological impacts, V/Ss may also fear repercussions of disclosing IPV, as they may be financially dependent on the abuser, their immigration status may rely on their partner (Anderton, 2022), they may be fearful of having their children taken away, escalation of harm, or fear that they may be blamed (WHO, 2012). Cultural barriers, such as gender role expectations, may also create additional challenges to disclosing IPV (Anderton, 2022). Strategies such as routine enquiry about IPV by HCPs can promote disclosure of abusive behaviour and provide a new lens through which deterioration in health could be understood. It can also improve the management of chronic conditions, connect V/Ss to support services, and prevent further harm to women and children (Miller & McCaw, 2019). HCPs have generally not felt comfortable, capable, and sufficiently trained or have limited access to resources, privacy, or time to enquire about IPV in consultations (Beynon et al., 2012; Taylor et al., 2013).

Given the lack of expertise from HCPs, WHO (2017) developed a manual for health managers, highlighting the need for a multisectoral response to IPV involving identification, facilitating access to other services, integrating health education, documenting, and advocating for the prevention of IPV. In line with this, specific policies have been introduced to improve response to the disclosure of IPV, such as recommending direct questioning (Howard et al., 2010) and employing a survivor-centric approach. The approach includes non-judgemental enquiry, first-line psychological support (i.e., psychological interventions such as guided self-help, cognitive behavioural therapy, or counselling for common mental health problems), treatment for underlying conditions, and short- and long-term mental health support (WHO, 2021). The UK, for example, has implemented a new relationship, health, and sex education curriculum in schools, increased awareness-raising campaigns to address the stigma that can be felt about being in an abusive relationship and increased the provision of IPV training in health settings. Notably, the UK has recently changed aspects of the judicial system by including all forms of IPV in the definition of IPV in the *Domestic Abuse Act 2021* introduces more V/S-centric proceedings (Home Office, 2022).

### **Gaps in the Literature**

Despite these recent changes, gaps in the understanding, assessment, and support for IPV remain. For example, although the definition of IPV has expanded, there continue to be wide variations in the conceptualisation and understanding of IPV, particularly regarding coercive control, emotional abuse, and financial abuse. Consequently, there remains a lack of standardised measures to identify IPV (WHO, 2021). Despite the growing understanding of the complexities of IPV, V/Ss remain



unidentified in health settings, despite seeking frequent healthcare throughout their lives. To improve HCPs' responses, it is essential to better understand V/Ss' experiences and what can support and prevent disclosure of IPV in healthcare settings.

Robinson and Spilsbury (2008) conducted a systematic qualitative review on disclosing IPV to HCPs and found that V/Ss wanted the topic of abuse to be routinely raised by HCPs but had concerns about the consultation time not being enough to build a trusting relationship. Heron and Eisma (2020) conducted an updated qualitative systematic review investigating the experiences and perceptions of people who experience IPV on disclosure in healthcare settings. In this review, results suggested that having a positive relationship with HCPs, direct questioning of abuse, and ensuring the environment is safe and confidential promoted disclosure. These reviews focused on the role of the HCP in aiding disclosure. Therefore, a systematic review identifying factors related to the individual that impact healthcare help-seeking in women who have experienced IPV was needed.

### **Aim of the Review**

Robinson and Spilsbury (2008), and Heron and Eisma (2020), provided an essential foundation for building evidence based on the factors impacting the disclosure of IPV in healthcare settings. However, identifying factors associated with a disclosure from a quantitative standpoint is still needed, and quantitative data can be more conducive to generalising results due to larger samples, standardised measures, and statistical analysis. Therefore, this review aimed to address the following question:

- 1) What are the factors associated with women disclosing IPV to healthcare services?

A quantitative systematic review was conducted using the narrative synthesis approach. Narrative synthesis guides the review and synthesis of findings from multiple studies by relying primarily on words and text. Popay et al. (2006) devised a guide to make the process more systematic and minimise bias. This approach uses four interactive elements:

- 1) developing a theory of why predictors might impact outcomes;
- 2) developing a preliminary synthesis of the findings;
- 3) exploring the relationships within the data;
- 4) assessing the robustness of the synthesis.

### **Methods (Element 1 - Developing a Theory)**

#### **Eligibility Criteria**

The inclusion criteria for studies were as follows:

- Empirical;
- Quantitative methodologies;
- Participants were 18 years of age and over. Studies that included participants under 18 years were included where it was possible to extract relevant data;
- Participants were cis-gendered females. Studies with males were included where relevant data could be extracted;
- Participants who had experienced IPV.

The exclusion criteria for the studies were as follows:

- Qualitative methodologies;
- Opinion articles, literature reviews,
- Other systematic reviews or meta-analyses;
- Participants aged below 18 years. Studies which included participants under the age of 18 were included if the relevant data could be extracted;
- Trans-gender people, or cis-gender men. Studies which included trans-gender people, and cis-gender men, were included if the relevant data could be extracted;
- Participants who have not experienced IPV.

### **Sources of Information**

Literature searches were run on PubMed and PsychINFO databases, and only research published in peer-reviewed journals and written in English were included. A ten-year restriction was placed on the publication date (January 2012- July 2022). Historically, IPV research focused solely on physical violence and its consequences (Avant et al., 2011), in line with its conceptual understanding of the time. By implementing a time restriction, it was hoped that the final sample of articles would be inclusive of the modern understanding of IPV (i.e., as including financial abuse, psychological abuse, and emotional coercion), thus improving construct validity. Therefore, this period was chosen to reflect up-to-date research based on the developments in understanding IPV.

### **Search Strategy**

Eligible studies needed to include the following constructs:

#### ***Help-Seeking***

The construct of help-seeking was operationalised as any use of healthcare support and resources by V/Ss concerning their experience of IPV. Disclosure of IPV to healthcare professionals and services was also included within this construct.

### ***Intimate Partner Violence***

The construct of IPV has changed over time and is conceptualised differently in different cultures and countries. Although the time restrictions may have promoted homogeneity in the concept of IPV, it can also be a culture-specific term and construct. For example, some research might use the term ‘domestic violence’, including violence from other family members (Van Parys et al., 2014). Other research encompasses other forms of violence against women, such as dating violence, violence against women because of sex work, or non-partner rape (Anderton, 2022). Due to the different nature of these acts of violence against women, studies were included when their definition of IPV co-aligned with the WHO (2012) definition of IPV – “any behaviour within an intimate relationship that causes physical, psychological, or sexual harm to those in the relationship”.

### ***Healthcare***

The construct of healthcare was operationalised as any health system in place to support individuals’ physical or mental health needs through illness and disease prevention, diagnosis, treatment, rehabilitation, and amelioration (<https://www.who.int>). These include primary, secondary, tertiary, and emergency care systems. These systems have a well-trained workforce, base their decisions and policies on reliable information, and deliver quality medicine and technologies.

### ***Female***

The term ‘female’ was operationalised as a human born of the sex that produces eggs and can biologically bear offspring (Merriam-Webster, 2022a). Cisgender defines a person whose gender identity corresponds to the sex assigned at birth (Merriam-Webster, 2022b). Therefore, the term ‘cis-gendered female’ was operationalised as a person of the female sex who identifies as a female.

### *Quantitative*

Quantitative research methods were descriptive, correlational, causal, comparative, quasi-experimental, and experimental (Bhandari, 2022).

Based on these constructs, using Boolean operators, the following search terms were used to screen titles and abstracts for relevant studies:

- *Female*: woman OR women OR female\* OR wife OR wives OR girlfriend\* OR spouse\*
- *IPV*: “domestic violence” OR “intimate partner violence” OR “partner violence” OR “intimate partner abuse” OR “domestic abuse” OR “partner abuse\*” OR “battered wom\*” OR IPV OR “spouse abuse” OR coercion OR abus\* OR “sexual abuse” OR “physical abuse” OR “financial abuse” OR “psychological abuse” OR “verbal abuse” OR “gender based violence” OR “gender-based violence”
- *Help-seeking*: disclos\* OR non-disclos\* OR “non disclos\*” OR “self disclos\*” OR self-disclos\* OR help-seeking OR “help seeking” OR report\*
- *Healthcare*: “Health care service\*” OR “Health care professional\*” OR “Health Care Clinician\*” OR “Health setting\*” OR “Health Care Provider\*” OR nurse\* OR doctor\* OR “primary care setting\*” OR

“mental health service\*” OR healthcare OR “health care” OR “health service” OR “emergency care.”

- *Research method*: NOT qualitative

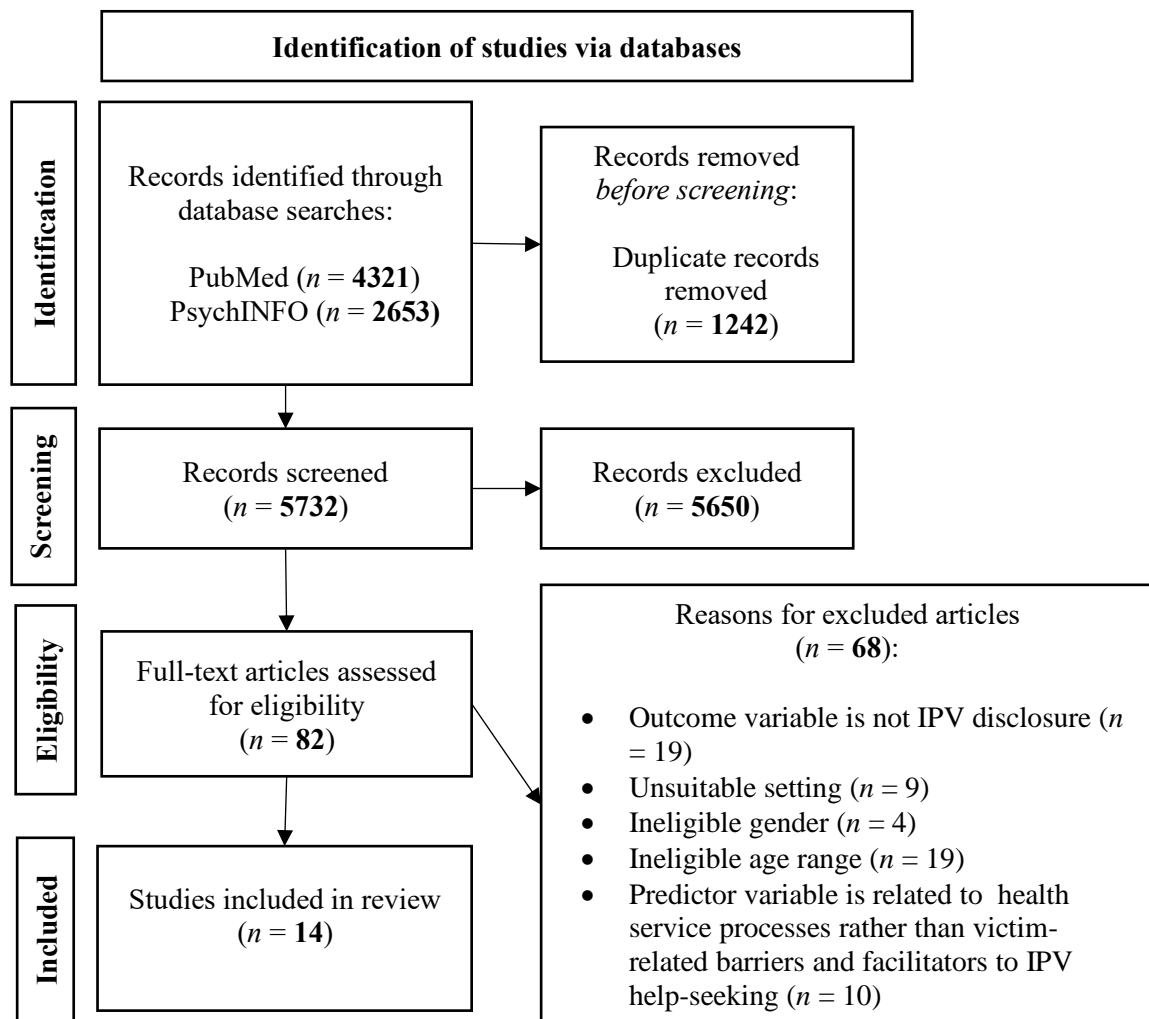
Filters were applied for each database. Those applied for PubMed searches were *in the last ten years, humans, English, female, 19+, 19-24 years, 19-44 years, 45+ years, 45-64 years, 65+ years, and 80+ years* were applied. For PsychINFO searches, the filters were *2012-2022, Peer reviewed, peer-reviewed journal, English, adulthood (18 years and older), young adulthood (18-29years), thirties (30-39years), middle age (40-64years), aged (65years & older), very old (85years & older), human, female, journal article, empirical study, follow-up study, longitudinal study, prospective study, retrospective study, field study, interview, systematic review, quantitative study* were applied.

### **Data Collection**

The data collection followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram tool to support a structured approach to data collection (Page et al., 2021). The database search was conducted on 23<sup>rd</sup> August 2022. All records captured were exported to *Rayyan*, a free web tool which supports researchers working on systematic reviews. All duplicates were removed (see Figure 2).

The first step of eligibility screening involved the primary (first author) and second reviewers (a BSc Psychology student) working independently to screen all titles and abstracts of the remaining articles. Articles that did not meet the inclusion criteria were excluded. Those considered eligible by either reviewer were included in the next stage of the process, which involved reviewing full texts.

**Figure 2**  
*Search procedure PRISMA flow diagram (Page et al., 2020)*



The full texts were also independently screened for eligibility by the primary and second reviewers, with reasons for exclusion noted down (Figure 2). Inter-rater agreement was calculated using Cohen’s Kappa ( $\kappa = .344$ ; Appendix K), indicating a ‘fair’ level of agreement between raters (McHugh, 2012). Disagreements were discussed with a third reviewer (Professor and academic supervisor), and decisions on inclusion were made. Although the kappa value is below the expected level of agreement, several factors have impacted the result. For example, the secondary

reviewer included papers they could not access as a precautionary measure. However, upon reading the article, it was clear they did not meet the age inclusion criteria. Other forms of disagreement were based on whether certain healthcare-related factors would meet the inclusion criteria, such as screening methods or clinician experience and training effect on disclosure. Most importantly, there were disagreements on what classifies 'disclosure'. Due to the limited number of papers which specifically mentioned disclosure, articles expressly referring to IPV-related healthcare seeking were included in this systematic review. In total, there were 19 disagreements at the full-text screening stage.

### **Data Extraction**

The following information was extracted from the included studies: author, year of publication, research questions, study design, study location, sample characteristics, study aim, predictors, outcomes, and findings.

### **Quality Assessment**

Quality assessment of included articles was completed following data extraction using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). This assessment tool appraises the methodological quality of five different designs of studies: qualitative research, randomised controlled trials, non-randomised studies, quantitative descriptive, and mixed methods studies. The MMAT requires reviewers to choose the appropriate study category to appraise and rate the criteria (i.e., 'yes', 'no' or 'cannot tell') of the chosen category (Table 4). This systematic review primarily included quantitative descriptive studies but also one non-randomised study. These two categories were therefore used for quality assessment.



**Table 4***Appraisal criteria from Mixed Methods Assessment Tool (Hong et al., 2018)*

Screening Questions	S1. Are there clear research aims? S2. Do the collected data allow us to address the aim of the research?
Non-Randomised Studies	3.1. Are the participants representative of the target population? 3.2. Are the measurements appropriate regarding the outcome and intervention (or exposure)? 3.3. Are there complete outcome data? 3.4. Are the confounders accounted for in the design and analysis 3.5. Was the intervention administered (or exposure occurred) as intended during the study period?
Quantitative Descriptive Studies	4.1. Is the sampling strategy relevant to address the research questions? 4.2. Is the sample representative of the target population? 4.3. Are the measurements appropriate? 4.4. Is the risk of nonresponse bias low? 4.5. Is the statistical analysis appropriate to answer the research question?

Inter-rater agreement for the MMAT (Hong et al., 2018) criterion decisions was also calculated using Cohen's Kappa ( $\kappa = .823$ , Appendix L). The inter-rater reliability for the MMAT critical appraisal tool indicated a 'strong' level of agreement between raters (McHugh, 2012). Any disagreements were discussed with the third reviewer, and decisions on the presence or absence of a criterion were made.

Although the authors of the MMAT advise not to present an overall score when reporting the results, this recommendation is based on the premise that prospective readers would lose the qualitative information of the quality assessment.

However, they have provided guidance using descriptors to report results (i.e., using \* for each criterion met) as well as percentage conversions. Therefore, studies which have met all five criteria could be described as ‘100% quality criteria met’ or ‘\*\*\*\*\*’ (Hong et al., 2018).

The primary and secondary reviewers independently completed the quality assessment. Ratings for each criterion were compared, and the third reviewer settled any disagreements. Specific areas of disagreement for quantitative descriptive studies were:

- Is the sampling strategy relevant to address the research question?
  - Referring to Wadsworth (2018) as an example, the primary reviewer rated this criterion as ‘no’ as the convenience sampling strategy did not appropriately address the research question. In contrast, the secondary reviewer rated it as ‘cannot tell’.
- Is the sample representative of the target population?
  - E.g., in Dougherty et al. (2018), the primary reviewer said ‘yes’ as the sampling strategy was random. In contrast, the secondary reviewer rated this question as ‘cannot tell’ as the inclusion/exclusion criteria were not specified.
- Is the risk of non-response bias low?
  - E.g., in Dias et al. (2020), the primary reviewer rated this criterion ‘yes’ as the rate of non-response was above 70% (Prince, 2012), and no imputation of missing data was conducted. In contrast, the secondary reviewer rated it as ‘cannot tell’ as the amount of missing data was not reported.

- Are the measures appropriate?
  - E.g., the primary reviewer in Carmona-Torres et al. (2019) rated this criterion as ‘no’ because the internal consistency of the questionnaire used is 0.4. In contrast, the second reviewer rated it as ‘yes’, as all other measures had internal consistencies above 0.8.

The criterion of disagreement for quantitative non-randomised studies was:

- Are there complete outcome data?
  - In Gartland et al. (2022), the primary reviewer rated this criterion as ‘yes’ as most of the original cohort (63.2%) participated in the ten-year follow-up. In contrast, the secondary reviewer rated it as ‘cannot tell’.

### **Data Synthesis**

The most appropriate approach to data synthesis for this systematic review was a ‘narrative synthesis’. Although a meta-analysis would be standard for quantitative systematic reviews, the research question should be conducive to a homogenous group of studies (Haidich, 2010). A narrative synthesis was more appropriate as this systematic review has broader inclusion criteria, such as looking at any factors related to IPV disclosure in healthcare, and includes heterogeneous study designs (Popay et al., 2006). The results of this narrative synthesis will be presented in grouping or clusters according to predictor variables.

## **Results (Element 2 - Developing a Preliminary Synthesis)**

### **Selection Process**

A final sample of fourteen articles (13 cross-sectional studies, three of which used secondary data and one prospective cohort study) met the inclusion criteria.

**Table 5***MMAT quality assessment results (n = 14)*

Author (Year)	Quality Assessment
<b>Quantitative Randomised</b>	
Gartland et al. (2022)	*** (60%)
<b>Quantitative Descriptive</b>	
Carmona-Torres et al. (2019)	*** (60%)
Cheng & Lo (2015)	**** (80%)
Cho et al. (2021)	**** (80%)
Dias et al. (2020)	***** (100%)
Dougherty et al. (2018)	**** (80%)
Edmond et al. (2013)	** (40%)
El-Nimr et al. (2020)	***** (100%)
Kamimura et al. (2014)	**** (80%)
Leone et al. (2014)	**** (80%)
Lucea et al. (2013)	*** (60%)
Ormon et al. (2016)	**** (80%)
Sharpless et al. (2022)	**** (80%)
Wadsworth et al. (2018)	** (40%)

**Quality Assessment of the Included Studies**

The quality assessment for each study is reported in Table 5.

***Non-Randomised Studies***

Gartland et al. (2022) used a prospective cohort design and adequately reported 60% of the domains for this design method. The article reported sample representativeness, the selection and use of measures for the outcome and predictor variable and accounted for confounders within the design. Regarding the completeness of outcome data, Gartland et al. (2022) used an imputation model to

replace missing data at follow-up, resulting in higher prevalence estimates. They also reported that 63.2% of the original cohort participated in the ten-year follow-up.

The attrition rate was higher than the expected range for a follow-up of more than one year (i.e., 30%; Viswanathan & Berkman, 2012), and therefore did not meet the criteria for completeness of outcome data. Furthermore, Gartland et al. (2022) did not refer to any potential changes to the participants' exposure status (i.e., improvement in mental health) and therefore did not meet this criterion.

### ***Quantitative Descriptive Studies***

**Sample Strategy.** Thirteen studies used a sampling strategy appropriate for the research question. Most studies used random sampling methods and clearly described the selection procedure and rationale of the chosen strategy. However, Edmond et al. (2013) and Wadsworth (2018) both used purposive sampling and recruited participants from settings which were unaligned with the research question. Despite investigating health and mental health service use, respectively, Wadsworth (2018) and Edmond et al. (2013) used a *Young Woman's Christian Association* and a legal advocacy programme as recruitment sites. Doing so can increase the likelihood of volunteer and sampling bias and affect the sample's representativeness and generalisability. Other studies also used purposive sampling (Carmona-Torres et al., 2019; Dias et al., 2020; Ormon et al., 2016; Sharpless et al., 2022). Despite the sampling method being linked to the research question, purposive sampling can result in selection bias and impact generalisability.

**Sample Representativeness.** Two studies did not meet the criteria for sample representativeness (Edmond et al., 2013; Wadsworth, 2018). For example, the response rate in Edmond et al. (2013) was 12.5% and used an incentive of \$25. Using

an incentive, a low response rate, and inappropriate recruitment sites increases the chance of non-response bias, raising questions on differences between the characteristics of those who chose to participate versus those who did not. Although Lucea et al. (2013) also provided \$20 remuneration for participation, their final sample characteristics were similar to the broader population.

The 12 other studies used random sampling methods, appropriate recruitment sites for their research question (i.e., national public health system or community), were guided by sample size calculations, and reported sample characteristics. Therefore, they provide a context on which to base the sample and increase the possibility of making inferences about the wider population.

**Measures.** All studies but one (Carmona-Torres et al., 2019) provided a complete description and justification of the measures used. For standardised measures, internal consistency was stated in all papers and ranged between ‘acceptable’ and ‘excellent’ ( $\alpha = .44 - .99$ ). The measures used were appropriate and reliable for answering the research questions.

Although the studies were published in the last ten years, several studies used secondary data collected in previous years, reporting results with outdated definitions and measures of IPV. For example, Lucea et al. (2013) used the WEB ([Women’s Experience of Battering scale]; Smith et al., 1995). Although initially demonstrating high internal consistency and reliability, it would not meet the current understanding of IPV. Only Sharpless et al. (2022) and Dias et al. (2020) used the most recent version of the CTS2 ([Conflict Tactic Scale-Revised]; Straus et al., 2003), which includes experiences of physical, emotional, and sexual abuse. Other studies adapted outdated versions of various IPV scales (Leone et al., 2014) or included

unstandardised measures developed for a previous national survey (Cheng & Lo, 2015; Cho et al., 2021).

Similarly, Leone et al. (2014) used IPV concepts (e.g., intimate partner terrorism and situational couple violence) based on a typology developed by Johnson (1995). *Intimate Partner Terrorism* refers to violence embedded in a general pattern of power and coercive control over one's partner. *Situational Couple Violence* refers to violence outside the norm, emerging from a specific situation. Although the understanding of IPV is still developing and inclusive of the dynamic between power and control, it also goes beyond physical abuse and encompasses emotional, sexual, verbal, and financial abuse. Using such definitions can affect construct validity and generalisability.

Likewise, the content validity of the mental health-related measures must be considered. Leone et al. (2014) measured the consequences of IPV using the PTSD Symptom Scale-1 (Foa et al., 1993), and Edmond et al. (2013) used the Diagnostic Interview Schedule-IV (DIS; Robins et al., 2000), both of which were developed using the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> ed; American Psychiatric Association [APA], 1994). The DSM-IV has since been updated; therefore, these measures may not meet the current understanding of mental health presentations.

Two studies (Carmona-Torres et al., 2019; Ormon et al., 2016) used culturally sensitive and appropriate measures for their cultural understanding of IPV and described the development and review process of the measures. Other studies used questionnaires developed by organisations like the *Centers for Disease and Prevention* (El-Nimr et al., 2020).

**Non-response Bias.** Only three studies (Dias et al., 2020; El-Nimr et al., 2020; Lucea et al., 2013) described steps taken to minimise non-response bias. Dias et al. (2020) used country specific IPV prevalence to establish the minimum sample size, which was proportionally stratified to the age and sex distribution of each country. Sites which did not recruit the minimum number of participants were excluded from their study. El-Nimr et al. (2020) reported a response rate of 87.6%. Apart from those discussed in the *Sample Representativeness* subsection, Dias et al. (2020), El-Nimr et al. (2020), and Lucea et al. (2013), insufficient information on non-response rates or strategies to reduce non-response was provided.

**Statistical Analysis.** All but one article used statistical analyses appropriate to the research question. Although Lucea et al. (2013) used chi-square to describe associations between categorical variables and included theoretically relevant variables, they did not specify *p*-values for some variables, thus limiting the interpretation of the results. All other papers appropriately described their choice of statistical analysis, conducted rigorous analyses in line with statistical theory, and provided clear statements of results.

### **Element 3 – Exploring the Relationship within and Between Studies**

This section attempts to synthesise and explore the relationship between the studies according to categories of factors that impact disclosure and healthcare-seeking in women who have experienced IPV. The various studies aimed to identify the: (i) factors which contributed to women accessing or not accessing healthcare; (ii) frequency of healthcare use following IPV; (iii) help-seeking responses to IPV; (iv) disclosure of IPV; and (v) use of services. Due to the heterogeneity of the study aims and variables, the term ‘healthcare help-seeking’ has been used to describe the



different types of help-seeking defined in the studies. Overall, studies were published between 2013-2022. Seven were based in the USA, three in Europe, two in Africa, one in Asia, and one in Australia. A summary of the study characteristics and results is provided in Table 6.

Within the 14 articles, six categories of barriers and facilitators of seeking help from healthcare services following IPV emerged:

- 1) IPV-specific factors ( $n = 7$ );
- 2) Health factors ( $n = 5$ );
- 3) Demographic factors ( $n = 10$ )
- 4) Psychosocial factors ( $n = 6$ );
- 5) Health service-related factors ( $n = 6$ ).

### ***IPV-Specific Factors***

Several studies investigated IPV-related factors, such as type ( $n=4$ ), injury ( $n=1$ ), or severity ( $n=3$ ), on healthcare help-seeking following IPV.

The results on IPV-type and its impact on healthcare help-seeking were varied. Some of the studies investigated different forms of IPV in help-seeking. In some studies, physical IPV was not a significant factor for help-seeking (Dougherty et al., 2018), and those exposed were as likely as those who experienced emotional IPV to seek help (Gartland et al., 2022). In other studies, different forms of physical or sexual IPV and coercive controlling behaviours (Cheng & Lo, 2015) were significantly associated with increased healthcare help-seeking (Dias et al., 2020). Cheng and Lo (2015) accounted for the role of ethnicity. Physical assault and stalking remained significant in the Hispanic and White subsample, and controlling behaviour remained significant in the African American and White subsample. Healthcare help-seeking for

**Table 6***Characteristics of studies included (n=14)*

Author (year)	Country	Study Design	Gender (n of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
Carmona-Torres et al. (2019)	Spain	Cross-sectional	Female (794)	18+ (- <sup>a</sup> )	Health services	Sociodemographic questionnaire  <b>IPV:</b> VGME	IPV disclosure to a healthcare professional (HCP)	<ul style="list-style-type: none"> <li>• Married women less frequently disclosed IPV than non-married (<math>p &lt; .001</math>).</li> <li>• Women living with ex/current partners less frequently disclosed IPV than other living situations (<math>p &lt; .01</math>).</li> <li>• Women living in an urban area less frequently disclosed IPV than those in rural areas (<math>p &lt; .05</math>).</li> <li>• Women relying on combined income less frequently</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								disclosed IPV than those who were not ( $p < .001$ ). <ul style="list-style-type: none"> <li>• Nurses more frequently disclosed IPV to psychologists than to other HCPs (<math>p &lt; .05</math>).</li> <li>• Physicians more frequently disclosed IPV to a trusted other than to an HCP (<math>p &lt; .05</math>).</li> </ul>
Cheng & Lo (2015)	USA	Cross-sectional Secondary data	Female (6589)	18-64 (37.3)	Mental Health	Sociodemographic questionnaire Study-specific questionnaire ( <i>n</i> of IPV incidents, health, drug, and alcohol use)	IPV-related mental health service use	<b>Sig. positive association with mental health service use (<math>p &lt; .01</math>, unless otherwise specified):</b> <ul style="list-style-type: none"> <li>• Controlling behaviours (<math>b = 1.72</math>), physical assault (<math>b = 1.29</math>), forced sex (<math>b = 5.78</math>) &amp; stalking (<math>b = 1.19</math>).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
						<b>Health:</b> Adapted SF-36		<ul style="list-style-type: none"> <li>• Depression (<math>b = .28</math>) &amp; PTSD (<math>b = .34</math>).</li> <li>• Education level (<math>b = 2.03</math>) &amp; income (<math>b = .55</math>).</li> </ul> <p><b>Sig. negative association with mental health service use (<math>p &lt; .01</math>, unless otherwise specified):</b></p> <ul style="list-style-type: none"> <li>• Married (<math>b = -3.38</math>) &amp; age (<math>b = -.13</math>).</li> <li>• African American (<math>b = 6.59</math>, <math>p &lt; .05</math>) &amp; Hispanic <math>b = -3.02</math> ethnicity.</li> </ul> <p><b>African American (<math>p &lt; .01</math>, unless otherwise specified):</b>  <i>Sig. positive association</i></p>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>Physical assault (<math>b = .93</math>), controlling behaviours (<math>b = .75</math>) &amp; forced sex (<math>b = 32.89</math>).</li> <li>Personal income (<math>b = 1.37, p &lt; .05</math>) &amp; free health care coverage (<math>b = 8.25, p &lt; .05</math>).</li> </ul> <p><b><i>Sig. negative association</i></b></p> <ul style="list-style-type: none"> <li>Illicit drug use (<math>b = 11.69, p &lt; .05</math>) &amp; employment (<math>b = -4.69, p &lt; .05</math>).</li> </ul> <p><b>Hispanic (<math>p &lt; .01</math>, unless otherwise specified):</b></p> <p><b><i>Sig. positive association</i></b></p> <ul style="list-style-type: none"> <li>Physical assault (<math>b = 1.85</math>), stalking (<math>b = 36.32</math>), &amp; forced sex (<math>b = 14.93</math>).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>PTSD (<math>b = .44, p &lt; .01</math>) &amp; other health coverage (<math>b = 8.89, p &lt; .05</math>).</li> </ul> <p><i>Sig. negative association</i></p> <ul style="list-style-type: none"> <li>Incidents of threats (<math>b = 1.49</math>) &amp; marriage (<math>b = -5.02, p &lt; .05</math>).</li> </ul> <p><b>White (<math>p &lt; .01</math>, unless otherwise specified):</b></p> <p><i>Sig. positive association</i></p> <ul style="list-style-type: none"> <li>Controlling behaviours (<math>b = 1.72</math>), physical assault (<math>b = 1.29</math>), forced sex (<math>b = 5.78</math>) &amp; stalking (<math>b = 1.19</math>).</li> <li>Depression (<math>b = .26, p &lt; .05</math>), PTSD (<math>b = .42</math>), education level</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<p>(<math>b = .48, p &lt; .05</math>) &amp; personal income (<math>b = 2.51</math>).</p> <p><b><i>Sig. negative association</i></b></p> <ul style="list-style-type: none"> <li>Being married (<math>b = -2.98</math>) &amp; age (<math>b = -.12</math>).</li> </ul> <p><b>Other ethnicities (<math>p &lt; .01</math>, unless otherwise specified):</b></p> <p><b><i>Sig. positive association</i></b></p> <ul style="list-style-type: none"> <li>Incidents of forced sex (<math>b = 1.05</math>), incidents of physical assault (<math>b = 1.51</math>), PTSD (<math>b = .68</math>) &amp; stimulant use (<math>b = 72.48, p &lt; .05</math>).</li> </ul>
Cho et al. (2021)	USA	Cross-section	Female (474)	18-70 (33.4)	Any care Medical care	Sociodemographic questionnaire	IPV-related service use	<p><b>Violence Type (<math>p &lt; .001</math>)</b></p> <ul style="list-style-type: none"> <li>Physical violence (<math>X^2 = 15.37</math>) &amp; verbal threat (<math>X^2 = 62.64</math>)</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
		Secondary data			Legal help	Study-specific questionnaire (IPV type, consequence)		<p>were sig. associated with seeking medical care, but not sexual violence.</p> <p><b>Health (<math>p &lt; .001</math>)</b></p> <ul style="list-style-type: none"> <li>Severe psychological distress (<math>X^2 = 25.30</math>), long-term mental health problems (<math>t = 6.37</math>), and long-term physical health problems (<math>t = 5.40</math>) were sig. associated with seeking medical care.</li> </ul> <p><b>Sociocultural (<math>p &lt; .001</math>)</b></p> <ul style="list-style-type: none"> <li>Problems at work (<math>X^2 = 11.49</math>) and social relationships (<math>X^2 = 15.3</math>) were sig. associated with seeking medical care.</li> </ul>



Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>Education &amp; marital status = no sig. difference in help-seeking.</li> </ul> <p><b>Psychosocial (<math>p &lt; .05</math>)</b></p> <ul style="list-style-type: none"> <li>Victims who had severe psychological distress (<math>OR = 1.75</math>, 95% CI [.99, 3.06]) or problems in social relationships (<math>OR = 2.08</math> [1.06, 4.06]) sought sig. more medical treatment than those without.</li> </ul>
Dias et al. (2020)	Greece Hungary UK Sweden Portugal Germany	Cross-sectional Secondary data	Male (1647) Female (1849)	18-64 (-)	Primary care (PC) Emergency department (ED)	Sociodemographic questionnaire <b>IPV:</b> CTS2	IPV-related frequency of PC & ED use	<p><b>IPV-type and visits to ED, compared to non-victims.</b></p> <ul style="list-style-type: none"> <li>Sexual coercion sig. increased likelihood of visiting ED more than once yearly (4.2% vs 2.0%, <math>p &lt; .05</math>).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
						<b>Social Support:</b> MSPSS		<ul style="list-style-type: none"> <li>Physical assault sig. increased likelihood of visiting ED more than once yearly (3.9% vs 2.0%, <math>p &lt; 0.5</math>).</li> </ul> <p><b>IPV-type and visits to PC, compared to non-victims</b></p> <ul style="list-style-type: none"> <li>No statistical sig. difference.</li> </ul> <p><b>Social support and IPV-type X more than one visit to PC</b></p> <ul style="list-style-type: none"> <li>Sexual coercion and high social support = sig. decreased likelihood of visiting PC (<math>OR = 0.75</math>, 95% CI [0.51, 1.10]) compared to low social support (<math>OR = 1.05</math> [0.78, 1.42]).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>Physical assault and high social support = sig. increased likelihood of visiting PC (<i>OR</i> = 1.14 [0.86, 1.51]) compared to low social support (<i>OR</i> = 0.69 [0.45, 1.06]).</li> </ul> <p><b>Social support X IPV-type X more than one visit to ED</b></p> <ul style="list-style-type: none"> <li>Physical assault and low social support = sig. increased likelihood of visiting (<i>OR</i> = 2.01 [1.09, 3.71]), compared to high social support (<i>OR</i> = 1.13 [0.33, 3.86]).</li> <li>Sexual coercion and high social support = sig. increased</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								likelihood of visiting ED ( <i>OR</i> = 2.88 [1.16, 7.16]), compared to low social support ( <i>OR</i> = 1.82 [0.96, 3.44]).
Dougherty et al. (2018)	Botswana	Cross-sectional	Female (419)	18+ (32.7)	Local clinics	Sociodemographic questionnaire Study-specific questionnaire (health, physical, sexual violence)	Women <u>not</u> visiting a health clinic following IPV.	<p><b>Most common reasons for not visiting the clinic</b></p> <ul style="list-style-type: none"> <li>• 29% had chores to do in the house.</li> <li>• 25% did not have enough money for transportation.</li> </ul> <p><b>Factors associated with healthcare utilisation</b></p> <ul style="list-style-type: none"> <li>• Recent experience of sexual IPV was sig. more likely to not go to the clinic (<i>OR</i> = 2.79,</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<p>95% CI [1.37-5.68], <math>p &lt; .01</math>) than those who had not.</p> <ul style="list-style-type: none"> <li>• Physical IPV alone was not a significant predictor of health seeking.</li> <li>• Women with a 10–30-minute commute were sig. more likely to not attend a clinic if they have experienced physical IPV (<math>OR = 4.37 [1.24, 15.3]</math>, <math>p &lt; .05</math>) or sexual IPV (<math>OR = 4.69 [1.33, 16.5]</math>, <math>p &lt; .05</math>) than those whose commute was less than 10 minutes.</li> <li>• Women who visited clinics ‘a few times a year’ were a sig. more likely to not attend clinic</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								following physical IPV ( <i>OR</i> = 1.94 [1.05, 3.56], <i>p</i> < .05), or sexual IPV ( <i>OR</i> = 1.98 [1.07, 3.65], <i>p</i> < .05) than those who were ‘infrequent visitors’.
Edmond et al. (2013)	USA	Cross-sectional	Female (50)	18+ (35)	Health services	Sociodemographic questionnaire Access to services  <b>IPV:</b> CAS  <b>Health:</b> DIS-IV  <b>Healthcare:</b>	IPV-related frequency of service use	<ul style="list-style-type: none"> <li>Family doctor was the most frequently used medical service (82%), 95% of which found them helpful, and 29% found them difficult to access.</li> <li>50% of the sample went ED on four separate occasions, all of which found them helpful and easy to access.</li> <li>Women with PTSD &amp; depression used mental health</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
						HSU		<p>services on 25.3 (<i>SD</i> = 24.5) occasions, with sig. difference for those with PTSD/depression (<i>M</i> = 30.9) than those without (<i>M</i> = 9.2, <i>t</i> = -1.7, <i>p</i> &lt; .05).</p> <ul style="list-style-type: none"> <li>• Women with PTSD/depression used sig. more services than women without (8.6 vs. 6.6, <i>t</i> = 2.2, <i>p</i> &lt; .05).</li> <li>• Women with both PTSD and depression used sig. more service than those without (8.0 vs 6.3, <i>t</i> = -.23, <i>p</i> &lt; .05).</li> <li>• Women with only PTSD used more services than those without (8.4 vs 6.5, <i>t</i> = -2.1, <i>p</i> &lt; .05).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>• Service use for depression, helpfulness, and ease of access were all not sig. different.</li> </ul>
El-Nimr et al. (2020)	Egypt	Cross-sectional	Female (514)	18-45 (32)	Hospitals Private Clinics Pharmacies Social support	Sociodemographic questionnaire Study-specific questionnaire (violence knowledge, attitudes, exposure)	IPV-related health service use	<ul style="list-style-type: none"> <li>• 66.2% of women exposed to IPV never asked for healthcare upon exposure, 31.2% sometimes sought healthcare, and 2.6% always sought healthcare.</li> </ul> <p><b>Frequency of reasons given <u>for seeking healthcare</u></b></p> <ul style="list-style-type: none"> <li>• Inability to withstand violence (45.8%), fear for own life (27.0%), encouraged by someone (14.5%), &amp;</li> </ul>



Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								safeguarding of children (12.5%).
								<p><b>Frequency of reasons given by victims for <u>not</u> seeking healthcare.</b></p> <ul style="list-style-type: none"> <li>• Danger to themselves (41.4%), fear for their children (22.7%), the violence stopped (12.7%), fear of their husband (8.8%), fear of humiliation (8.3%), &amp; not having enough money (4.8%).</li> </ul>
Gartland et al. (2022)	Australia	Prospective cohort	Female (1507 BL <sup>b</sup> , 952 F/U <sup>c</sup> )	18+ (-)	Public hospitals	<p><b>IPV:</b></p> <p>CAS</p> <p><b>Health:</b></p>	IPV-related health service use	<p><b>GP visits x IPV x mental health within ten months of F/U</b></p> <ul style="list-style-type: none"> <li>• Women with IPV (<i>AOR</i> = 1.8, 95% CI [1.1-4.4], <i>p</i> &lt; .05), or</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
						CES-D BAI PCL-C		with both IPV & mental health sig. made five visits or more to GP ( <i>AOR</i> = 2.5 [1.4-4.4], <i>p</i> < .001) than making two visits or less.
								<p><b>Disclosure of IPV to health professionals</b></p> <ul style="list-style-type: none"> <li>• A higher proportion talked to mental health professionals about relationship issues/violence at home (27.5% vs 16.7%) than GP.</li> <li>• 73% had not talked to a mental health professional, 83.3% had not talked to GP, and 65.2%</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<p>had not talked to any health professional.</p> <ul style="list-style-type: none"> <li>• Women with physical IPV were no more likely to discuss IPV or relationship issues with GP (16.3% vs 17.3%, <i>OR</i> = 0.9 [0.4-2.5]) or mental health professional (30.6% vs 27.2%, <i>OR</i> = 1.4 [0.6-3.1]) compared to women experiencing emotional IPV alone.</li> <li>• The most used service for mental health problems and IPV was counselling (50.7% [39.8-61.5]).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
Kamimura et al. (2014)	Japan	Cross-sectional	Female (101)	18+ (48)	Any healthcare service	Sociodemographic questionnaire Study-specific questionnaire (IPV, healthcare seeking)	Initial IPV-related health service use	<p><b>Model 1 (IPV injuries, age, education)</b></p> <ul style="list-style-type: none"> <li>• Injury (<math>OR = 3.04, p &lt; .01</math>), physical IPV (<math>OR = 2.24, p &lt; .05</math>), &amp; sexual IPV (<math>OR = 1.73, p &lt; .05</math>) were sig. associated with a shorter time to initial health-seeking.</li> <li>• Older age (<math>OR = .96, p &lt; .01</math>) was sig. associated with a longer time for health-seeking.</li> </ul> <p><b>Model 2 (welfare assistance, employment, formal and informal help-seeking, childbirth, and cohabitation)</b></p>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>• Formal help-seeking sig. shortener time to initial health-seeking (<math>OR = 4.52, p &lt; .01</math>).</li> <li>• IPV-related injury sig. shortened time to health-seeking (<math>OR = 2.85, p &lt; .01</math>).</li> <li>• Physical, sexual, and age were no longer significant.</li> </ul>
Leone et al. (2014)	USA	Cross-sectional Secondary	Female (389)	18-62 (31)	Police Medical Centres Counsellors	Sociodemographic questionnaire Violence frequency, severity, injuries Injuries  <b>IPV:</b>	IPV-related help service use	<ul style="list-style-type: none"> <li>• 70.2% of intimate terrorism victims (ITV<sup>d</sup>) sought help from formal sources vs 44.4% of situational couple violence victims (SCVV<sup>e</sup>) (<math>X^2(1,389) = 24.18, p &lt; .01</math>).</li> <li>• ITV was sig. more likely to attend a medical centre (44% vs</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
						CCS PVS  <b>Health:</b> PSS-1 MOS  <b>Social support:</b> SSNS		18.5%, $X^2 = 28.97, p < .01$ ) and a counsellor (24.8% vs 14.1, $X^2 = 6.99, p < .01$ ) than SCVV.  <ul style="list-style-type: none"> <li>ITV was sig. more likely to cite ‘fear’ as the reason for not contacting a medical centre (4.8% vs 0.5%, <math>X^2 = 6.50, p &lt; .05</math>) or counsellor (11.3% vs 3.3%, <math>X^2 = 7.95, p &lt; .05</math>), than SCVV.</li> <li>ITV was sig. more likely to report ‘not needing help’ as the reason for not contacting a medical centre (62.7% vs 86.8%, <math>X^2 = 21.47, p &lt; .05</math>) or a counsellor (10.4% vs 32.4%, <math>X^2 = 18.19, p &lt; .05</math>) than SCVV.</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>• Regardless of violence type, PTSD was associated with reporting ‘fear’ as the reason for not seeking help from a counsellor (<i>OR</i> = 1.45, <i>p</i> &lt; .01).</li> <li>• Having no access to money was associated with a higher likelihood of reporting that help was not needed (<i>OR</i> = 2.40, <i>p</i> &lt; .05) from a counsellor.</li> <li>• No sig. interaction effects existed between violence type and other variables.</li> </ul>
Lucea et al. (2013)	USA	Cross-sectional	Female (543)	18-55 (-)	Primary care	Sociodemographic questionnaire	IPV support service utilisation	<ul style="list-style-type: none"> <li>• Women over the age of 34-44 years were sig. more likely to access medical resources (<i>AOR</i></li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
					Prenatal clinics	Awareness of resources	following IPV	= 2.65, 95% CI [1.19-5.89], $p < .05$ ) than 18–24-year-olds.
					Family planning clinics	<b>IPV:</b> WEB AAS SVAWS DA  <b>Health:</b> CES-D PC-PTSD		<ul style="list-style-type: none"> <li>• Women in employment were sig. less likely to use health care resources (<math>AOR = 0.3</math>, [0.16-0.56], <math>p &lt; .05</math>) than unemployed women.</li> <li>• Race, marital status, and having children under 18 were not independent correlates of health service use.</li> <li>• 66% of women were unaware that PC and ED were available to help.</li> <li>• College graduates were sig. more likely to know that PC services were available to help</li> </ul>



Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								( <i>AOR</i> = 3.83, [1.37-10.71, <i>p</i> < .05) than those with a high school education.
Ormon et al. (2016)	Sweden	Cross-sectional	Female (77)	18+ (34)	Psychiatric clinic	<b>IPV:</b> NorAQ	IPV disclosure in the clinic	<ul style="list-style-type: none"> <li>• The most common form of IPV is physical (93%), yet 55% did not tell clinic staff about their experiences (55%).</li> <li>• 90% spoke to others, then clinic staff, about their experiences.</li> <li>• 79% experienced emotional abuse, yet 67% disclosed it to psychiatric clinic staff.</li> <li>• 71% experienced sexual abuse, yet 67% disclosed clinic staff.</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
Sharpless et al. (2022)	USA	Cross-sectional Secondary Data	Female (272)	18-35 (25.7)	Sexual Health Clinic	Sociodemographic questionnaire Study-specific questionnaire (PrEP initiation)	IPV-related PrEP acceptance	<ul style="list-style-type: none"> <li>Women who experienced higher severity of psychological IPV were sig. more embarrassed to initiate PrEP discussion (<math>OR = 1.037</math>, 95% CI [1.017-1.055], <math>p &lt; .01</math>) than those with less severe psychological IPV.</li> <li>Sexual IPV and IPV-specific mistrust were sig. associated with willingness to accept PrEP recommendation by a healthcare provider (<math>B(SE) = .003 (.002)</math>, <math>p &lt; .05</math>).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
Wadsworth et al. (2018)	USA	Cross-sectional	Female (97)	18+ (32.9)	Women's shelter	Sociodemographic questionnaire. Study-specific questionnaire (health perception, unmet needs).  <b>IPV:</b> <b>HITS</b>	IPV health impact Barriers accessing healthcare	<ul style="list-style-type: none"> <li>• Transportation (29.3%) and cost (18.2%) were the two most common reasons for not accessing healthcare.</li> <li>• Mental health was the most common unmet need (40.1%), but not sig.</li> <li>• Health insurance was sig. associated with fewer unmet reproductive health needs (4.1%) compared to those without (20.8%, <math>p &lt; .05</math>).</li> <li>• Hispanic ethnicity was sig. associated with increased reports that IPV had affected their health 'a lot' (83.3% vs 29.0%, <math>p &lt; .001</math>).</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								<ul style="list-style-type: none"> <li>• Hispanic ethnicity was sig. associated with more difficulties accessing healthcare due to fear of seeing abusers (25% vs 3.9%, <math>p &lt; .05</math>) and costs (41.7% vs 14.3%, <math>p &lt; .05</math>) compared to non-Hispanic women.</li> <li>• Hispanic women were sig. less likely to disclose IPV when asked than non-Hispanic women (11.1% vs 64.8%, <math>p &lt; .01</math>).</li> <li>• More severely abused women were sig. more likely to endorse resources provided by HCPs than less severely abused</li> </ul>

Author (year)	Country	Study Design	Gender ( <i>n</i> of female)	Age Criterion (mean age)	Setting	Predictor Variables	Outcome Variable	Results
								women (79.0% vs 56.5%, $p < .05$ ). <ul style="list-style-type: none"> <li>• Women with transportation issues were sig. more likely to endorse mobile health clinics than those who did not have transportation issues (88.5% vs 66.7%, <math>p &lt; .05</math>).</li> </ul>

*Note.* VGME - Spanish Ill-Treatment of Females Scale; SF-36 – Short Form 36 Health Survey Questionnaire; CTS-2 – Conflict Tactic Scale; MSPSS – Multidimensional Scale of Perceived Social Support; CAS – Composite Abuse Scale; DIS – Diagnostic Interview Schedule IV; HSU – Health Services Use Instrument; CES-D – Centre for Epidemiologic Studies Depression Scale; BAI – Beck Anxiety Inventory; PCL-C – Posttraumatic Stress Disorder Checklist – Civilian Version; CCS – Coercive Control Scale; PVS – Physical Violence Scale; PSS-1 – PTSD Symptom Scale; MOS – Medical Outcome Study; SSNS – Social Support Network Scale; WEB – Women’s Experience of Battering Scale; AAS – Abuse Assessment Screen; SVAWS – Severity of Violence Against Women Instrument; DA – Danger Assessment; PC-PTSD – Primary Care Posttraumatic Stress Disorder Screening; Noraq – Norvold Abuse Questionnaire; SES – Sexual Experiences Survey; PMWI – Psychological Maltreatment of Women Inventory; GBMS – Group-Based Medical Mistrust Scale; HITS – Hurt Insulted Threatened with harm and Screamed instrument.

<sup>a</sup> – Denotes information which was not available. <sup>b</sup> BL = Baseline. <sup>c</sup> F/U = Follow-up. <sup>d</sup> ITV = Intimate Terrorism Victim. <sup>e</sup> SCVV = Situational Couple Violence.

sexual IPV remained significant in the African American subsample (Cheng & Lo, 2015).

Kamimura et al. (2014) investigated the time taken to seek help and found that physical and sexual IPV were significant predictors of V/Ss taking less time to seek help from healthcare than other forms of IPV. However, compared to other IPV consequences, injury remained a significant predictor of shorter time to help-seeking when sociocultural were controlled for, whilst physical and sexual IPV did not.

Some forms of IPV were associated with not seeking healthcare help, such as sexual violence (Dougherty et al., 2018) or threatening physical violence in a Hispanic subsample (Cheng & Lo, 2015).

V/Ss of *Intimate* terrorism (conceptualised as longstanding experiences of IPV), in Leone et al. (2014), sought healthcare significantly more frequently than *situational couple violence* V/Ss (those who have experienced standalone IPV in their relationship). Lastly, more severely abused V/Ss were significantly more likely to accept resources provided by HCPs than their counterparts in Wadsworth (2018).

### ***Health Factors***

Five studies investigated the impact of health-specific factors, such as mental health ( $n = 4$ ) and physical health problems ( $n = 1$ ), in healthcare help-seeking. Psychological distress and long-term mental health consequences were significantly associated with healthcare help-seeking (Cho et al., 2021). Furthermore, women with comorbid PTSD and depression, or PTSD only, were significant predictors of increased healthcare help-seeking compared to those without mental health difficulties (Cheng & Lo, 2015; Edmond et al., 2013). When accounting for ethnicity, depression

and PTSD remained a significant predictors in a White subsample, whereas only PTSD remained significant in the Hispanic subsample (Cheng & Lo, 2015). PTSD was also significantly associated with a higher likelihood of stating “fear” for not speaking to an HCP than those without PTSD (Leone et al., 2014).

Only Cho et al. (2021) looked specifically at the impact of long-term physical health problems on healthcare-seeking, with long-term physical health consequences significantly associated with increased healthcare use.

### ***Demographic Factors***

Most studies investigated the impact of demographic factors in healthcare-seeking following IPV. The factors investigated were ethnicity ( $n = 3$ ), income ( $n = 6$ ), education ( $n = 3$ ), employment ( $n = 3$ ), access to health insurance ( $n = 2$ ), geographical location ( $n = 3$ ), living situation ( $n = 3$ ), age ( $n = 4$ ), and civil status ( $n=3$ ).

Ethnicity, specifically African American and Hispanic, were significantly associated with less healthcare services use (Cheng & Lo, 2015). Furthermore, Hispanic women were significantly more likely than non-Hispanic women to report that IPV affected their health ‘a lot’ yet were significantly less likely to disclose IPV when asked by an HCP (Wadsworth, 2018). Contrarily, ethnicity was not a significant predictor of health-seeking in Lucea et al. (2013).

Income was reported as one of the top reasons for not accessing healthcare (Dougherty et al., 2018; El-Nimr et al., 2020; Wadsworth, 2018). Not having access to money was significantly associated with V/Ss saying that ‘help was not needed’ as the reason for not seeking help (Leone et al., 2014), as was relying on combined income

(Carmona-Torres et al., 2019). Furthermore, the cost of healthcare was a significant factor in not seeking help from healthcare for Hispanic women compared to non-Hispanic women (Wadsworth, 2018). Higher-income in a White and African American subsample was a significant positive predictor of healthcare help-seeking (Cheng & Lo, 2015).

Results on education as a factor contributing to healthcare seeking were inconsistent. In some studies, attaining a higher education level was a significant factor associated with increased healthcare help-seeking, and higher education significantly predicted increased mental health service use (Cheng & Lo, 2015; Lucea et al., 2013). However, one study found education as a non-significant factor (Cho et al., 2021).

Being in employment was found to be a significant predictor for increased healthcare help-seeking in an African American subsample (Cheng & Lo, 2015). Contradicting this, it was also found to be a significant predictor for less help-seeking in Lucea et al. (2013) and was non-significant in Cho et al. (2021).

Access to health insurance was associated with having significantly fewer unmet reproductive health needs than those without (Wadsworth, 2018) and was also a significant predictor of increased mental health service use in African American and Hispanic subsamples (Cheng & Lo, 2015).

Transportation barriers were also one of the most common reasons for not seeking healthcare and were significantly associated with increased use of mobile health clinics compared to those without transportation barriers (Wadsworth, 2018). Women who experienced physical and sexual IPV and had a travel time to a clinic of 10-30 minutes were significantly more likely not to attend the clinic than those who



had a commute of 10 minutes or less (Dougherty et al., 2018). Contradicting Dougherty et al. (2018), women living in urban areas significantly disclosed IPV to HCPs less than those living in rural areas (Carmona-Torres et al., 2019).

Lastly, women cohabiting with their ex or current abuser disclosed IPV significantly less to HCPs than those in different living situations (Carmona-Torres et al., 2019). However, having children under 18 did not significantly predict help-seeking (Lucea et al., 2013).

Age's role in healthcare-seeking V/Ss produced varied results across studies. V/Ss in the 34–44-year age group were significantly more likely to access medical resources than 18–24-year-olds (Lucea et al., 2013). However, other studies have contradicted these results, whereby older age was a significant factor in less healthcare help-seeking in a White sub-sample (Cheng & Lo, 2015). Furthermore, although Kamimura et al. (2014) initially found older age to be a significant predictor of taking longer to seek help, it was no longer significant after controlling for sociocultural factors, which aligns with Cho et al.'s (2021) findings.

Similar to age, findings on civil status contributing to healthcare-seeking following IPV were mixed. Cho et al. (2021) found civil status to be a non-significant predictor of help-seeking, whereas being married was significantly associated with less frequent disclosure of IPV to an HCP (Carmona-Torres et al., 2019) and healthcare help-seeking, particularly in a White and Hispanic subsample (Cheng & Lo, 2015).

### ***Psychosocial Factors***

Six studies investigated the impact of psychosocial factors in healthcare-seeking following IPV. Such factors include social support ( $n = 1$ ), drug use ( $n = 1$ ), and attitudes related to violence or help-seeking ( $n = 4$ ).

Only one study investigated the role of low social support on healthcare help-seeking. Low social support for V/Ss who have experienced physical IPV significantly increased healthcare help-seeking (Dias et al., 2020). In contrast, those exposed to sexual coercion and high social support significantly decreased healthcare help-seeking (Dias et al. 2018).

Only Cheng and Lo (2015) looked at drug use as a factor impacting healthcare help-seeking, a significant predictor of less mental health service use in an African American and ‘other ethnicities’ subsample.

Lastly, the role of attitudes and perceptions in IPV and health-seeking supported each other across papers. Fear was noted as a common emotion which significantly prevented V/Ss from accessing healthcare – fear of the abuser (Wadsworth, 2018), fear of seeing the abuser (Leone et al., 2014), fear of the danger it will cause to themselves or their children, or fear of humiliation (El-Nimr et al., 2020). Other beliefs related to the abuser, such as believing the danger has stopped (El-Nimr et al., 2020). Sharpless et al. (2022), who conducted research within a sample of women living with HIV, reported that lower levels of medical mistrust were a significant predictor of accepting HIV medication recommendations by an HCP. In contrast, high-severity psychological abuse was reported as a significant predictor of experiencing more embarrassment in discussing HIV medication with HCPs (Sharpless et al., 2022).

### ***Health-Service Factors***

Six studies reported factors explicitly related to health services, such as disclosure to specific clinicians ( $n=3$ ) and perceived helpfulness and access to services ( $n=1$ ). Seeking help from health-services services, instead of other forms of help-seeking such as social support, was significantly associated with taking less time to first time seeking help (Kamimura et al., 2014). Regarding the source of help, Cho et al. (2021) reported that V/Ss of physical violence sought more help from any source (legal, medical, or informal), followed by legal help, with the least frequent being medical help.

Several studies investigated the health professional to whom V/Ss are more likely to disclose IPV. Although a higher proportion of women experiencing IPV had talked to a mental health professional about relationship issues or violence at home than had talked to a GP, further analysis indicated that women experiencing physical IPV appeared no more likely to discuss IPV with their GP or mental health professional than women experiencing emotional IPV alone (Gartland et al., 2022). Similarly, 93% of women had experienced physical IPV, yet only 45% disclosed it to psychiatric clinic staff, whereas 79% of women experienced emotional abuse and 71% of sexual abuse, whilst 67% of each disclosed it to staff within a psychiatric clinic (Ormon et al., 2016). Counsellors/psychologists were identified as the preferred clinician to disclose IPV to in both Gartland et al. (2022) and Carmona-Torres et al. (2019). Carmona-Torres et al. (2019) reported that nurses who were V/Ss significantly disclosed IPV to a psychologist more compared to physicians, whereas physicians disclosed IPV more to a trusted other.

The helpfulness of health services was also investigated as a factor affecting help-seeking (Edmond et al., 2013). In a sample comparing women who have

experienced IPV and have PTSD or depression, they reported no significant difference in service use, perceptions of helpfulness, or difficulties accessing services between women with PTSD and depression.

#### **Discussion (Element 4 – Assessment of Robustness of Synthesis)**

This review investigated the factors associated with women seeking help in a healthcare setting following IPV. These were categorised by IPV-specific, health-related, demographic, psychosocial, and health service-related factors. Generally, the findings were heterogeneous, but some consistent relationships were identified across studies. Certain IPV-related factors, such as physical threats and sexual violence, were consistently found as barriers to accessing healthcare. Co-habitation with the abuser, a demographic factor, was also consistently found to be a barrier in accessing healthcare. Contrastingly, experiencing mental health difficulties, the victim having access to income, and health insurance, were all consistently found to be facilitating factors of healthcare help-seeking.”

There was consistent evidence that those who experienced sexual violence or threats of physical violence were associated with not seeking healthcare compared to other forms of IPV. These results are consistent with findings that V/Ss of sexual IPV may experience social stigma and fear which may act as a barrier to help-seeking (Wright et al., 2022). Furthermore, gender and cultural norms may contribute to women not seeking help following sexual violence. As this systematic review included global articles, the cultural understanding and conceptualisation of IPV may differ in each country. Different cultural conceptualisations may result in varying acceptance and recognition of abuse. These may be engrained in cultural views, gender roles and expectations, and a culturally specific understanding of physical and

mental health. These variations may have contributed to the inconsistent results related to IPV type and its impact on healthcare help-seeking. For example, whereas Western countries criminalise non-consenting sex, some highly patriarchal countries emphasise women's perceived duties to their husbands, including tending to their sexual needs, and do not criminalise IPV (Barchi et al., 2018).

The evidence of mental health difficulties associated with increased healthcare help-seeking was consistent within the review and the literature. Psychological distress, PTSD, or depression were associated with increased healthcare help-seeking following IPV compared to those who did not have PTSD or depression. Cheng and Lo's (2015) results relating differences in help-seeking patterns within different ethnic groups were consistent with Sabri et al. (2013). These differences can be explained by how different cultures' view health and illness, seek treatment, and ascribe to the Eurocentric understanding of mental health (Gopalkrishnan, 2018). For example, the literature highlights that women of ethnic minority groups who have experienced IPV tend to use avoidance patterns, such as denial and wishful thinking (Krause et al., 2008) or avoiding morbid thoughts (Leong & Lau, 2001).

Although most articles devised study-specific questionnaires and adjusted outcome measures to suit the sample being studied, it is essential to consider the cultural validity of the measures used, particularly when considering the Eurocentricity of the measures (Gone & Kirmayer, 2010). However, IPV's complex relational interactions and impact on mental health should be considered beyond depression and PTSD. A pattern of shame, embarrassment, stigmatisation (Robinson & Spilsbury, 2008), lack of recognition of the abuse taking place, self-doubt, fear of

losses, and wanting to protect the perpetrator (Petersen et al., 2005) also play a part in the decision to seek help.

Three demographic factors, cohabitation, income, and access to health insurance, were associated with increased healthcare help-seeking, which was consistent with the literature (Cattaneo & DeLoveh, 2008; Flicker et al., 2011; Fugate et al., 2005). Some literature proposes that financial strains can lead to strains in the relationship. For example, the lack of access to finances and inaccessible healthcare insurance will likely limit V/Ss' agency in seeking help in countries that require health insurance to access healthcare (Abramsky et al., 2019). The interaction between individual predisposing factors, enabling factors (e.g., social support, health insurance, and cultural beliefs), and perception of a need for healthcare contribute to help-seeking (Andersen, 1995). The review noted fear as a common emotion that significantly prevented V/Ss from accessing healthcare, and other beliefs related to the abuser or healthcare mistrust were found to impact help-seeking. Furthermore, Cho et al.'s (2021) results reported the increased help-seeking for participants with long-term physical health difficulties, which can be understood within this model.

The evidence on ethnicity contributing to healthcare help-seeking following IPV were mixed within this review. Cheng and Lo (2015) and Wadsworth (2018) found that those from ethnically minoritised groups in the USA were less likely to seek healthcare help following IPV. These results are consistent with previous research, highlighting that African American women are less likely than their White counterparts to access mental health services following IPV (Flicker et al., 2011). Research has suggested that health services, specifically those in the USA, are not culturally sensitive and overlook cultural biases that individuals of ethnic minorities

can face (Overstreet & Quinn et al., 2013). Furthermore, differences in responses to IPV in ethnic minority groups may be influenced by the social contexts in which they live (Bent-Goodley, 2007) and may also account for the contradicting results.

The findings on civil status contributing to healthcare-seeking following IPV were mixed. Cho et al. (2021) found civil status to be a non-significant predictor of help-seeking, whereas being married was significantly associated with less frequent disclosure of IPV to an HCP (Carmona-Torres et al., 2019) and healthcare help-seeking, particularly in a White and Hispanic subsample (Cheng & Lo, 2015). Generally, Asian, Latino, and African cultures hold collectivist worldviews based on a strong sense of community and family values (Brabeck & Guzman, 2008). These worldviews contrast Western individualistic ideologies (Lee & Hadeed, 2009). Collectivist cultural values within an individualist society may act as a barrier to help-seeking from traditional sources due to the expectations of upholding the family's image by not sourcing external help, solving the problem within the family to avoid shaming and embarrassing the family (Bent-Goodley, 2007; Ingram, 2007). Therefore, the first line of contact for many women of ethnically minoritised groups are likely to be within their networks rather than with HCPs (El-Khoury et al., 2004).

The results from Dias et al. (2018), a multi-country study, could also be understood in this context. Generally, IPV V/Ss tend to turn to social networks before seeking legal help (Goodman & Smyth, 2011). It is possible that a social network provides a safe place to process experiences but may also support V/Ss seeking the appropriate help (Rose et al., 2010). Dias et al. (2018) reported that V/Ss with high social support had significantly higher odds of visiting an emergency department than those with lower social support. These results may be understood through cultural

factors and the stigma associated with IPV and seeking help. It is possible that without social support, women cannot discuss their experiences, which could have otherwise helped break down the stigma and shame they may be feeling (Coker et al., 2003). In comparison, the experiences of women who have experienced IPV may be validated by their social support, which may encourage them to seek help from healthcare (Coker et al. 2003). Social support can also be instrumental and informational in help-seeking for women who have experienced IPV. For example, social support not only can be a source of practical support but also can be associated with normalising and promoting healthcare use (Sylaska & Edwards, 2014).

Education level as a factor contributing to V/Ss seeking healthcare help was consistent across the studies and the broader literature (Cheng & Lo, 2015; Lucea et al., 2013). However, one study (Cho et al., 2021) reported inconsistent results. Generally, the literature reports that V/Ss who have attained high education and are employed are more likely to seek help from formal sources (Coker et al., 2000; Kaukinen et al., 2013). Attainment of higher levels of education has generally been one of the most significant predictors of non-acceptance of IPV (Waltermaurer et al., 2013). Education has been reported to enhance liberal norms and decrease acceptance of violence (Yount et al., 2011). Again, Cho et al. (2021)'s contradicting results may be due to the cultural differences within the sample.

The results investigating the role of age healthcare help-seeking following IPV were mixed. Lucea et al. (2013) found that older women are more likely to seek help, consistent with existing literature on the impact of older age on help-seeking (Breiding et al., 2008; Felson & Pare, 2005; Fleming & Resick, 2017). After controlling for sociocultural factors, Cho et al. (2021) and Kamimura et al. (2014)



contradict these findings. Furthermore, studies which explored employment (Cheng & Lo, 2015; Cho et al., 2021; Lucea et al., 2013) and geographical location and transportation (Carmona-Torres et al., 2019; Dougherty et al., 2018) contradicted each other in their results. The heterogeneity in the sample, research question, and methods may be associated with inconsistent results. Another systematic review on non-healthcare-based help-seeking noted that help-seeking related to IPV is a complex multifactorial process which is dependent on IPV characteristics, sociodemographic factors, environmental barriers, children-related factors, social stigma, societal norms and values, psychological consequences of violence, partner relationship, and religion (LeLaurain et al., 2017). In this context, it is understandable that the results have been contradictory. For example, the cultural and societal roles surrounding gender roles, family dynamics, and help-seeking behaviour can vary widely across countries (Weziak-Bialowolska, 2015). These differences may vary regarding work-family and employment expectations for women (Weziak-Bialowolska, 2015). Gender norms and expectations may also be represented in workplace policies, legal protection, and availability of support services for survivors of IPV (González & Rodríguez-Planas, 2020) and impact V/Ss' ability to seek help for IPV.

### **Limitations**

This systematic review is the first of its kind and has several strengths. It used defined inclusion criteria, employed a rigorous search strategy, assessed quality, and was conducted through systematic analysis of the findings. However, several limitations affected the review's quality, generalisability, and implications.

This review initially aimed to investigate the factors impacting the disclosure of IPV in healthcare settings. However, throughout the screening process, it became

clear that there is limited research which explicitly investigates the disclosure of IPV in healthcare settings with women aged 18 and over. Due to researcher time constraints, the conceptual understanding of disclosure had to be broadened to IPV-related help-seeking in healthcare. Broadening the concept late may have contributed to the low inter-rater reliability score. The heterogeneity made it impossible to synthesise the results in a meaningful way. Despite the ten-year publication date restriction, some articles, including secondary data, used data collected years before the restriction was placed. The data collected consequently included outdated concepts of IPV. Furthermore, despite the aim of improving construct validity through placing a publication date restriction, several countries have different conceptual understandings of IPV, thus also affecting the construct validity of this systematic review. Additionally, not all studies looked at the same factors, had the same control variables, or used similar analyses (i.e., frequency, odds ratio, regression). The heterogeneity was mirrored in the measures used in the studies – no study used the same IPV or health measure. The range of the interrater reliability for the measures used was wide between studies, and as previously discussed, some were outdated. Notably, the quality of the studies was also varied. Therefore, the lack of specificity within this systematic review affects the extent to which generalisable conclusions can be formed.

Several limitations within the review process impacted the quality of this systematic review, which should be more carefully considered in future research. Although this review aimed to include research conducted globally, it was noted during screening and full-text reading that many of the Eastern, Asian, or African countries conducted relevant studies, but with females under 18, often in line with

their country's legal age of marriage. The age inclusion criterion was set at 18 years due to the different power and developmental-related perspectives these females may bring. However, in doing so, many articles which would be relevant were excluded from this review.

The databases used for this review were also a limitation. Due to the initial search drawing many papers to screen, and researcher-related time constraints, only two databases were used, which focused on psychological (PsychInfo) and medical (PubMed) journals. If a more thorough systematic review were conducted, it would have been beneficial to include a sociological database that includes sociological, criminological, and familial matters, which are core to the issue of IPV.

### **Implications**

Although this systematic review has several methodological and quality-based limitations, it has nonetheless provided a starting point to consider the factors that may impact IPV disclosure or healthcare-seeking. Although it may not be enough to inform policy or services, it can hopefully inform future research on which factors (or categories) must be considered.

Only two studies met the full criteria of the MMAT (Hong et al., 2018) quality assessment. The most common criterion not met was non-response bias ( $n=13$ ). Therefore, the limited availability of high-quality studies, combined with the unavailability of studies looking explicitly at a disclosure to healthcare, highlights the need for more research in this area. It would be beneficial for future research to ensure that up-to-date, validated, and reliable measures are used, particularly those aligned with the contemporary understanding of IPV and mental health. For example, financial abuse and coercive control were not considered in any of the studies.

Considering our current understanding of the widespread impact of IPV on health, it would be beneficial for future studies to look beyond depression and PTSD when considering mental health consequences, such as anxiety, sleep disorder, eating disorder, and self-esteem, and be more inclusive of physical health factors. However, it would also be essential to bear in mind the complexities related to experiencing IPV, which may be overlooked when collecting data with a pre-determined questionnaire, and therefore consider a mixed-methods approach in future research.

Furthermore, future systematic reviews that include global articles would benefit from being more culturally sensitive and considering the different marriage ages. Lastly, it would be beneficial for future research to capture more relevant articles published on the subject by including sociological, criminological, law, and familial journal articles. It may therefore provide a more accurate representation of factors which impact IPV disclosure in healthcare settings.

## Chapter 4

### Integration, Impact, and Dissemination

#### Integration

The rationale for conducting the systematic review and the empirical research was developed by reviewing the literature and recent reports published on the experiences of WLHA/IPV. Doing so gave me a perspective on the current evidence base and research needs. Violence against women has been on the UK Government and public health agenda for several years (Home Office, 2022) and has continued to be a worldwide issue (WHO, 2021). Furthermore, the challenges associated with leaving an IPV relationship are well understood within the academic literature (Rakovec-Felser, 2014). It, therefore, seemed necessary to start paying some much-needed attention to the experiences of women suffering daily inequalities by understanding how, as HCPs, we could better support these women.

Unfortunately, as mentioned in the systematic review *Discussion* section, several methodological challenges (e.g., time constraints, the volume of initial searches, limited use of databases, and culturally specific concepts related to the legal age of marriage) limited the conclusions that could be drawn. The challenges associated with synthesising cross-cultural research limited the certainty that this systematic review could comment on the worldwide barriers and facilitators to help-seeking for women who have experienced IPV.

Similar to the systematic review, the rationale for the empirical research was developed by conducting an in-depth review of the literature published on WLHA, focusing on the role of IPV. Doing so helped to gain perspective on the current challenges WLHA experiences, the progress made, and current recommendations by

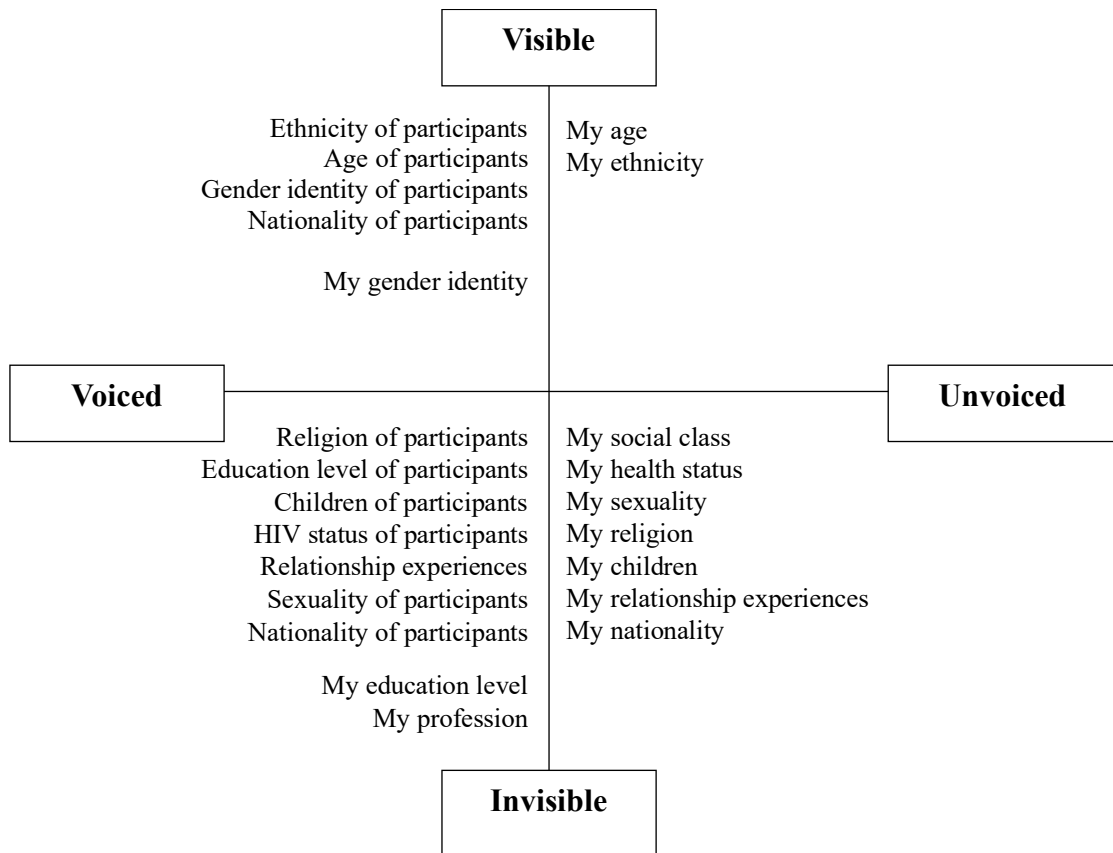
other academics, organisations, and policymakers. By doing so, it transpired that within the evidence base, a clear link between WLHA and IPV had been established, and the predictors and impact on well-being were well understood (THT, 2018; UNAIDS, 2021). However, it also became clear that most of the research was conducted in other countries. The UK seemed to be falling behind in understanding the impact and intersection of these women's challenges, particularly in seeking help from services. With the NHS under more severe pressure than ever, chronic understaffing, poor staff retention, long-wait lists, and insufficient funding (British Medical Association, 2023), it increasingly relies on external services, such as charities, for support. Considering the intersectionality of the experiences of WLHA/IPV, it felt necessary to include their experiences of support from other services to understand their views and experiences of help-seeking.

### **Research Ethics and Service Engagement Process**

Throughout the empirical research, I became increasingly frustrated by the barriers I faced in conducting it. On the one hand, I felt my research was fundamentally important. However, I also felt that the bureaucracy took precedence over the need for this research to be conducted and the impact it could have on the quality of life and well-being of the targeted population. I felt that money-related aspects (i.e., the need for NIHR CRN portfolio adoption) greatly limited its accessibility. Nonetheless, I felt incredibly grateful for the services and organisations that went above and beyond to support and facilitate my research. Despite these challenges, the women appreciated the research being open to women nationwide and allowed the participants to feel they contributed to supporting others in their community and improving services.

**Figure 3**

*Reflections on Social GRRRAACCEEESSS*



### **The Interview Process**

Burnham (2012) developed a tool to support reflexivity of the intersection and impact of different aspects of identity (also known as the social GRRRAACCEEESSS) within the research process. Using this tool (Figure 3) helped me to reflect on the inter- and intra-personal processes which may have been taking place within the interview. This model also helped me maintain a reflexive position throughout the analysis and interpretation of results and allowed me to adapt how I approached each subsequent interview. Using supervision as a place to reflect on these processes also helped to maintain methodological quality.

Throughout the interviews, I found myself being emotionally affected by the narratives which were being shared. There was an uncomfortable aspect of power differentials between me asking personal and sensitive questions and the inequity between the level of detail they shared about themselves (invisible-voiced) and me (invisible-unvoiced). Notably, one participant asked me about my motivation for conducting the research. At that moment, I felt particularly conscious of wanting to justify my position as a researcher who genuinely cares about their experiences, despite not having lived their experiences. Although the differences between the participants' experiences of relationships (voiced-invisible), and mine (unvoiced-invisible), our voiced-visible gender identity united us to an extent. Despite not having experienced IPV, I felt that my experiences of gender-based inequalities and violence as a woman, albeit to a lesser extent, allowing for an unspoken relatability of experiences with the participants. Our gender identities, cis-gendered women, both voiced-visible, supported to build rapport, safety, and understanding between us. Furthermore, although I am not a WLHA, I am a woman living with a chronic, invisible, autoimmune disease, which I felt allowed me to relate to some of the experiences they shared (e.g., the shock of diagnosis, the impact on identity and self-esteem, and adjusting to living with a life-long condition).

One of the most challenging aspects of this research was the emotivity and weight of the shared experiences. I found balancing being a researcher, therapist, and an individual with personal experiences demanding. Although therapeutic skills such as building rapport, listening, validating, and containing were extremely helpful in making the interviews safe enough to discuss traumatic experiences, I initially crossed the boundary from researcher to therapist. Using supervision and reviewing the first



transcript, we noticed I was using cognitive reframing techniques, mainly when narratives of self-blame were present in the interview. The possible transference of powerlessness and internal distress I felt through listening to their narratives and my wish not to come across as ‘using’ the participants meant I was drawn into a role of wanting to rectify and alleviate their pain. Holding on to the overwhelmingly positive feedback I received from the interview process helped me understand the importance of my research and feel more confident in my interview skills and role as a researcher-practitioner.

On reflection, I had not anticipated experiencing the level of vicarious trauma which I did. I felt emotionally exhausted following an interview and sometimes avoided the analysis. At other times, I felt anxious whilst analysing the interviews, possibly internalising their traumas. Not only this, but part of me felt guilty for experiencing such feelings, as I had not lived through what they had. On a personal level, I also noticed that I had begun to internalise the women’s experience of IPV and was becoming increasingly defensive in my relationship with my partner. Supervision, self-care, and my reflective skills as a clinical psychologist helped me through the research process.

Furthermore, I felt frustrated, upset, and disappointed with the health service and role I represented in the interviews. I found myself feeling both exasperated and defensive of my profession. The overwhelming narrative of health services having perpetuated their traumas, particularly the role of psychologists, was challenging for me to manage. In interviews, I wanted to justify my position as a ‘good psychologist’ and protect and defend others in my profession.

## **Navigating Expectations**

At times, the course expectations and requirements and my personal views of how I would have liked to conduct the research conflicted. For example, the systematic review, which had severe methodological limitations, could have been rectified with more time. However, the volume of papers to screen meant that I had to limit the databases used and could not start again when I realised that I needed to change some of the terms and inclusion criteria. The systematic review was, therefore, unable to inform and complement the empirical research as much as it could have.

The involvement and support from women with lived experience were invaluable. Not only did they support the research, but they were able to bridge the gap between the researcher's perspective and the person-centred approach. Furthermore, the consultants with lived experience raised essential questions on the reasons behind my target population, highlighting the need for research in other areas, such as men and trans people living with HIV who have experienced IPV. Both are widely under-researched, which helped provide ideas for future research.

More than that, I felt pressured by the expectations of having a minimum of six participants. Although I can reflect on how well the interviews complement each other, I also felt that I did not stay true to the ethos of IPA. By recruiting the minimum number of participants expected for a Doctoral thesis, I felt as if the premise of IPA was somewhat disregarded, as I had reached some form of data saturation by the third interview. Due to the large volume of data, some GETs, and subthemes had to be omitted. This, I found to be frustrating. Not only that, but due to the recruitment challenges, and the delays in reaching the expected six participants, I could not spend as much time on the analysis as was required. I feel that the time pressure partly

contributed to the difficult feelings I was experiencing throughout the analysis. Additionally, considering the sensitivity and importance of the subject, I would have liked to honour the participants' engagement and openness by spending more time on the analysis. This also contributed to my inability to share the results with the participants before reporting them. Nonetheless, I hope to have still been able to report their experiences meaningfully and representatively.

### **Impact and Dissemination**

HIV and IPV remain global public health issues (WHO, 2021). In recent years, violence against women and girls has been on the government agenda, with the UK Government investing over £230 million to tackle an issue that impacts 2.4 million adults yearly (MacLaren, 2021). Despite this, IPV continues to be widely misunderstood on a societal, organisational, professional, and individual level. Considering the specific challenges that WLHA face, the intersection between HIV and IPV appears to have compounded the issue. However, the unique challenges of the 30,000 WLHA in the UK, with an acknowledged higher risk of IPV, continue to be overlooked by academics, services, and policymakers. Unfortunately, the results have reflected some of the severe pressures the NHS faces and its impact on WLHA/IPV. The results indicated that women had experienced a re-traumatisation and perpetuation of stigma within services that are, in theory, supposed to care for their well-being. These results are particularly pertinent within the current NHS climate and could inform how NHS services could be improved.

### ***Academic Significance***

Although the academic significance of the systematic review is limited, it would be beneficial for another to be replicated whilst considering the mentioned

limitations. Gaining a better understanding of the individual factors impacting help-seeking could help to better target interventions and services to increase V/S confidence in seeking healthcare when experiencing IPV. Conducting such a systematic review would also allow us to make comparisons between countries, thus potentially highlighting culturally specific and global barriers to seeking help.

However, the empirical research findings can contribute to the existing knowledge on the intersection of HIV, IPV, and experiences of help-seeking behaviours. This research can potentially inform and expand theoretical frameworks related to these issues, providing a deeper understanding of the complexities involved. The intersection between the impact of receiving an HIV diagnosis, rooted within pre-existing views about living with HIV, and its role in violent relationships, can contribute to the existing knowledge of processes underlying IPV relationships. Additionally, the research contributes to the current understanding of the challenges of seeking help. It provides a unique perspective on the interplay between HIV and IPV on women on help-seeking. The results are significant for the clinical psychology and HIV, women's health, public health, and criminology (i.e., related to IPV as a criminal offence and police attitudes towards women and HIV) sectors.

Submitting the research to peer-reviewed journals in the fields of public health (e.g., *Frontiers in Public Health*), HIV/AIDS (e.g., *Journal of the Association of Nurses in AIDS Care*), or women's health (*Women & Health*) could ensure that the findings reach the academic community and contribute to the existing literature. The research could also be presented at national and international conferences, seminars, or workshops and can provide a platform for sharing the findings with a broader audience, engaging in discussions, and receiving feedback from experts in the field.

For example, a suitable conference might be the *19<sup>th</sup> European AIDS Conference*, which focuses on EU and non-EU countries' equal access to care and marginalised populations and discusses harm reduction programmes related to HIV/AIDS. This conference accepts detailed research which focuses on epidemiology, public health, and models of care, in which the results of this research would be fitting.

### ***Potential Beneficiaries and Dissemination***

Findings and recommendations from the empirical study could benefit the psychological, social, health and well-being of WLHA/IPV along with health and social care services and all other services supporting WLHA/IPV. Lastly, the results from the research could also have significant service-level implications.

**Implications for WLHA who have Experienced IPV.** It is hoped that the results from this research represent the participants' experiences. By adequately interpreting and representing their experiences, the participants may feel that the injustices they have suffered, and their stories have finally been heard. Due to my dual role as a researcher-clinician, being able to report their experiences appropriately may also restore some hope and trust in psychologists, healthcare professionals, and health services. Furthermore, the women may feel they have contributed toward raising awareness of their experiences and promoting changes in their care.

The results may also help validate the experiences of WLHA/IPV. As highlighted in previous sections, these women often face multiple forms of stigma and discrimination (Earnshaw & Chaudoir, 2009). Research highlighting their struggles and challenges could help reduce their isolation and marginalisation (Paudel & Baral, 2015).

Dissemination of research findings could empower WLHA/IPV. Research can also provide evidence that can be used to advocate for policy changes and to support the creation of support networks or organisations dedicated to addressing the needs of this population. The results will be shared with the participants through a lay summary of the findings. Doing so could empower WLHA/IPV by validating their experiences, giving them a voice and platform to share their experiences safely, and shedding light on their unique struggles. Collaborating with community organisations, support groups, or advocacy networks can help disseminate the findings among the target population, circulate knowledge, and foster dialogue between researchers, service providers, and affected communities. For example, creating a summary poster of the research findings alongside a lay summary of results and sharing these with relevant organisations, such as specialist sexual health clinics, domestic violence services (e.g., *Galop*, *Victim Support*, *Standing Together*, *SafeLives*), and HIV/AIDS charities (e.g., *4MentorMothers*, *SWIFT*, *Sophia Forum*, *Terrence Higgins Trust*, *National AIDS Trust*, or *Positively UK*) could help to widen visibility and access of the results.

**Implications for Professionals and Services that Support.** The findings can help identify and understand the barriers WLHA/IPV faces when seeking help. Understanding these barriers can help service providers develop more effective interventions that address the unique challenges of this population. For example, the results highlight a serious need for all HCPs to be trained to identify and support women who have experienced IPV. More specifically, considering the clear link between WLHA and the risk of IPV, sexual health and HIV services would greatly benefit from this training, as they are most likely to encounter women experiencing

IPV (Heskin et al., 2022). However, research and reports show that pathways to referring and supporting women experiencing IPV are still unclear. Health services may benefit from ensuring that a clear screening protocol and pathway to support are developed. Additionally, the results indicate a need for HCPs, particularly frontline staff (e.g., nurses and doctors), to receive training on contemporary life with HIV. Similar recommendations also apply to services like charities, social work, or the police. The participants reflected on the assumptions and stereotypes services hold towards WLHA and the ‘type’ of woman who experiences IPV. The results from this research can help inform the need for better awareness of the challenges of WLHA and IPV processes.

From the results, there is a need for increased training on trauma-informed care. Ensuring that service users are given a choice and provided with non-judgemental and transparent care and the need for HCPs to receive supervision and emotional support is imperative in fostering a culture of trust between the service user and service provider. Notably, the results indicate a need to ensure that service users are informed and included in decisions about their care, and doing so could help promote IPV disclosure and restore trust within NHS services.

The research could also inform service providers, such as HCPs, social workers, and psychologists, about the specific needs and barriers faced by women in this population. The findings can help tailor services and interventions to meet these women’s needs better, promoting their overall well-being and safety. The results have specific implications for psychologists. Participants experienced psychologists as avoiding or not identifying their disclosures of IPV, being limited by the therapy their services provide, prioritising the abuser’s views and positions, and not being

supportive whilst on waitlists. The participants also mentioned psychologists not supporting them to find other sources of support when they were deemed unsuitable for their service. Psychologists have the skills to enquire in a sensitive and containing way, validate and manage risk. However, despite the multi-disciplinary working model, clinical psychologists may feel hindered by the lack of specialist training in identifying and working with the unique challenges related to individuals who have experienced IPV.

Psychologists' skills mean they are particularly well-placed to support women who have experienced IPV. For example, clinical psychologists are trained in evidence-based psychological models and skilled in supporting people with complex mental health presentations, including trauma (Health & Care Professions Council, 2015). However, there are no guidelines for working psychologically with individuals who have experienced IPV, let alone WLHIV/IPV. The current NICE (2016) guidelines for supporting people who have experienced IPV highlight the need to refer to specialist services that may target their specific needs related to risk and safety. However, the role of psychological therapies is not addressed. Working psychologically with individuals who have experienced IPV suggests following a disorder-specific, evidence-based treatment (Hameed et al., 2020). However, the interview results suggest that disorder-specific treatments may not meet the needs of WLHA/IPV. Furthermore, the compounding factors of HIV within the abuse suggest a specific intervention framework for psychologists. Clinical psychologists would therefore benefit from specific training on working with WLHA/IPV and women who have experienced IPV.



**Implications for Policy Makers.** The results can inform policymakers and organisations working in HIV, IPV, and women’s health. The findings highlight this population’s unique challenges and could guide the development of evidence-based policies, guidelines, and interventions to support WLHA/IPV. The participants all referred to the changes they experienced in health services. For some, they were impacted by removing ring-fenced funding for HIV in their areas; for others, they noticed service provision becoming more superficial over time, often left on the shoulders of the service user or charities to carry. For others, they shared the total inaccessibility of psychological therapies. The link between health and mental health is widely recognised (DoH, 2014) yet often overlooked in service provision. HIV being a long-term health condition with so much associated societal and personal stigma, it is unsurprising that PLHA requires psychological support. Likewise, the impact of IPV on physical and mental health has been consistently recognised (Oliver et al., 2019). However, V/Ss continue not to be adequately supported by health and social care services.

Considering IPV’s vast economic and social costs are estimated to be £66 billion yearly (Oliver et al., 2019), equivalent to nearly 40% of the £162 billion NHS budget (BMA, 2023), the results from this study are pertinent. The UK government has started to introduce changes through education and prevention in schools and ensuring that the new sex education curriculum addresses stigma and violence in relationships remains and continues to be developed is vital to shaping future generations. Furthermore, funding for NHS trusts to better train HCPs and improve access to psychologists to reduce wait times and the pressures charities must take on to make up for the shortfalls of health services should be a priority. Lastly, the

changes made to the *Domestic Abuse Act 2021* were pivotal in supporting IPV V/Ss. It is, therefore, imperative for women's rights and health to continue being present on the government agenda, as is highlighted by the results of this project.

Developing concise summaries or reports targeted at policymakers, government agencies, and charities could effectively communicate the research findings and recommendations for policy and practice. For example, the results could be presented to the *APPG on HIV/AIDs*, which would be well placed to raise the profile and implications of the research while raising awareness of the issues mentioned. Sharing the research findings could attract attention from organisations, researchers, and funders interested in supporting further research in this area, possibly leading to significant changes in the support provided for WLHA/IPV. Furthermore, as my final placement is in Parliament, I could raise awareness of the challenges related to help-seeking for WLHA/IPV through writing articles which will be published in political magazines or proposing to table a question for debate.

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## Appendix A

### Participant Information Questionnaire

*This questionnaire will ask you some questions about yourself, as well as questions about your health. Please answer the following questions as best as you can. If you do not wish to answer a question, please leave it blank.*

**1. Please write your age (in years) below:**

.....

**2. Please tell us which country you were born in.**

.....

**3. What best describes your ethnicity?**

- A. White
- B. Black, African, Caribbean, or Black British
- C. Asian or Asian British
- D. Mixed or multiple ethnic backgrounds
- E. Latin American or Latino
- F. I prefer not to say
- G. Other (*please specify on the dotted line overleaf*)

.....

**4. What is your religion?**

- a. No religion (Atheist)
- b. Agnostic
- c. Christian (Catholic, Protestant or any other denomination)
- d. Buddhist
- e. Hindu
- f. Jewish
- g. Muslim
- h. Sikh

- i. Prefer not to say
  - j. Any other religion (*please specify on the dotted lines below*)
- .....

**5. What is the highest degree or level of education you have completed?**

- a. No formal education
  - b. GCSE
  - c. A Level/BTEC
  - d. Undergraduate Degree (e.g., BA, BSc)
  - e. Postgraduate degree (e.g., MA, MSc, PhD)
  - f. Prefer not to say
  - g. Other (*please specify on the dotted lines below*)
- .....

**6. What is your current employment status? (*please circle one or more*)**

- a. Full-time employment
- b. Part-time employment
- c. Not currently employed
- d. Full-time student
- e. Part-time student
- f. No right to work
- g. No recourse to public funds (e.g., I am a carer)
- h. Receiving benefits
- i. Prefer not to say

**7. What is your sexual orientation?**

- a. Straight/heterosexual
  - b. Gay or Lesbian
  - c. Bisexual
  - d. Prefer not to say
  - e. Other sexual orientation (*please specify on the dotted lines below*)
- .....

- 8. What is your current relationship status?**
- a. Single
  - b. In a relationship (also includes married/civil partnership)
  - c. Separated or divorced
  - d. Widowed
  - e. Prefer not to say

- 9. Do you have any children (your own or looked after)?**
- a. Yes
  - b. No
  - c. Prefer not to say

**Health-Related Questions**

- 1. How long ago were you diagnosed with HIV?**  
*(If you are unsure, please give an estimate of the year you were diagnosed)*  
 .....
- 2. Where were you living when you were first diagnosed with HIV?**
- a. UK
  - b. Overseas *(please specify where/which country on the dotted lines below)*
  - c. Prefer not to say
- .....
- 3. In what setting were you diagnosed?**
- a. Hospital
  - b. HIV clinic
  - c. Prefer not to say
  - d. Other *(please specify on the dotted lines below)*
- .....
- 4. Other than the clinic/service, are you currently accessing any other support services (i.e., peer support, groups, mental health services)? If so, please specify?**  
 .....

**Thank you for taking the time to complete the questionnaire.**

## Appendix B

### Recruitment Poster



# Study exploring support for **women** living with **HIV** who have experienced **violence** in intimate relationships

We want to hear from women living with HIV who have experienced violence in intimate relationships, to better understand their experiences in accessing support.

#### You are eligible for the study if you:

- Are 18 years and over
- Are born & identify as a female
- Are Living with HIV
- Have experienced violence in intimate relationships



#### What do we mean by violence?

Any incident or patterns of controlling, coercive, or threatening behaviour, violence, or abuse from an intimate partner

#### What will it involve and what do we offer?

You will be meeting with me for about 1h-1h30.  
Interviews can be virtual or in-person. If in-person, up to £10 in travel expense covered.\*

In appreciation for your time and taking part in research, you will receive £10. There will also be a prize draw for a £25 Amazon voucher.

\*For more information, please contact **Lea Beretti (Trainee Clinical Psychologist)** at Royal Holloway, University of London: [Lea.Beretti1@nhs.net](mailto:Lea.Beretti1@nhs.net) or **07999873846**

Version 4.3 - 30/07/2022—IRAS 312578



**Appendix C**  
**Consent Form**



**Study Title: Women living with HIV who have experienced intimate partner violence and their experience of accessing care.**

Please read through the consent form carefully and write your initials in the boxes next to each statement if you agree with them. Please do not hesitate to speak with the researcher should you have any questions about any of the statements, the research, or the process.

The last page contains options for opting-in to being contacted about the results of the research, providing contact details of your GP, and to entering the prize draw.

After you have signed the consent form, a copy of the form will be made for you to keep.

After you have signed the consent form, a copy of the form will be made for you to keep.

Write your initials:

The nature and purpose and potential benefits or risks of the study have been explained to me. I have read and understood the Participant Information Sheet and understand what this study involves. If I asked questions, they have been answered fully to my satisfaction.

I understand that my participation in the study is entirely voluntary and that I am free to withdraw at any time without giving a reason.

I agree that if I decide to withdraw from the study then the researchers can continue to use the data and information, I have already given them unless I ask for this to be destroyed.

I agree for the interview to be recorded, and I agree for the interview to be transcribed.

I understand that all data will be kept confidential, and that no personal identifying information will be disclosed in any reports on the project, or to any other party, unless there is an identified risk to myself for others.

If choosing to do a virtual interview, I confirm that I have access to a private and confidential space.

I understand that if the researcher has concerns for my safety or that of others, they will contact a person from the service I was recruited from, or other support services, to keep me safe but will try to have a conversation with me first.

I consent to the lead researcher contacting my GP to inform them of my involvement in the research. If yes, please provide GP details overleaf.

I agree for the researcher to use anonymised quotes (quotes which will not be identifiable to a specific person) from the interview transcripts in the final report and possible future publications.

I understand that the results for the research will be written up as part of a thesis, and may be shared outside of Royal Holloway, University of London (i.e., NHS Trust, HIV organisation, scientific journal or relevant conferences).

I consent to being contacted after the study to hear about the results. If yes, please provide contact details overleaf.

I agree to take part in the study.

Participant name: \_\_\_\_\_

Participant signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher name: \_\_\_\_\_

Researcher signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Contact details for opt-ins**

Please tick the boxes for which you wish to opt-in to:

**Informing GP of your participation in the study**

If consenting to informing your GP, please provide your GP's name and address below:

.....

**Being contact to hear about the results of the research**

**Entering the prize draw**

For opting-in to being contacted after the study to hear about the results, or entering the prize draw, please indicate please provide your email address or phone number below, if you have not already so:

.....

## Appendix D

### Interview Guide

#### Introduction

Thank you for taking part in the interview. It is part of a research study to find out about the experiences of women living with HIV who have experienced violence in their close relationships to find out how this affected their HIV care.

Thank you for completing and signing the questionnaire and the consent form we sent you. Please keep the information sheet as it has important information about the research and as well as our contact details. Do you have any questions before we start?

The interview should take between 60-90 minutes. We understand that some questions may bring up powerful emotions that you might find hard to control so please do let me know if you need a break or would like to stop the interview. It's fine to do that.

How are you feeling about doing this interview?

Are you happy for me to record the interview? The recording will be completely confidential and only used for the research itself. If you are happy for me to begin, I will start the recording and the interview now.

#### HIV

1. I am interested in any possible relationship between your HIV and violence you have experienced from a partner. So that we can better understand important factors, it would be helpful if you could start by telling me briefly about your HIV diagnosis.

*Prompts:* (1) When did you first learn that you were HIV positive? (2) how has your diagnosis affected your day-to-day life? (3) how do you feel about your HIV now? (4) how did you feel when you first learnt you had HIV?

#### IPV

2. As you know, I am interested in the individual experiences of women with HIV who experience abusive relationships.

*Prompts:* (1) was it one or more relationships? (2) How long were the relationships? (3) what form did the abuse take – physical/ mental/ and in what ways?

3. In which way, if at all, do you think that your health and/or diagnosis might have had an influence on your experience of violence from your partner?

*Prompts:* (1) How do you feel about that experience now? Have you made sense of that experience, with the benefit of time? (2) Do you think that how you feel might be, in any way, affected by your diagnosis?

### **Accessing Care**

4. Did you seek any help? If so, what help was available?

*Prompts:* (1) did you feel the people you spoke to understood your circumstances? (2) in what way? (3) If not, what would have been helpful for them to know/do differently?

5. If you did not seek help, what stopped you?

6. What was helpful about any support you received?

*Prompts:* Did you feel the people you spoke to knew or understood about HIV and intimate partner violence?

7. In your view, what makes the difference between a good interaction with support services, and a bad interaction with support services?

*Prompts:* (1) does it affect your future access to support? (3) could you describe a good interaction that stands out in your mind? (4) could you describe a bad interaction that stands out in your mind?

8. Do you feel you have experienced any prejudices whilst accessing services?

*Prompts:* (1) what were they related to? (2) Who were they from? (3) how does it affect access to services?

### **COVID-19**

9. I think it is important to recognise the COVID-19 pandemic and the changing circumstances we have all had to deal with. Do you feel that the restrictions which were experienced in the pandemic affected your relationship in any way?

*Prompts:* (1) did it have an impact on your experience of intimate partner violence? (2) did it have an impact on your ability to access the right support? (3) if so, in what way?

**Resilience**

10. What has helped you cope?

*Prompts:* (1) what was helpful about these? (2) how do you feel thinking about these? (3) why were they important?

## Appendix E

### Participant Information Sheet

[INSERT LOGOS HERE]

#### **Women living with HIV who have experienced intimate partner violence and their experience of accessing care.**

My name is Lea Beretti. I am a trainee clinical psychologist doing a doctorate in clinical psychology at Royal Holloway, University of London. As part of my training programme, I am carrying out research, interviewing women living with HIV who have experienced violence in close relationships with a partner, and how this may have affected their HIV care.

#### **What is this study about?**

It is important to read this information carefully, as it will help you to understand why this research is being done, and what your involvement would be, if you decide to take part. Please take time to read this, and please ask Lea any questions that you may have. You can also discuss this research with the organisation where the study was advertised.

This study hopes to increase understanding of violence from people in close relationships, who we refer to as “intimate partners.” The violence could include incidents or patterns of controlling, coercive, or threatening behaviour, violence, or abuse from an intimate partner. We want to find out how this may affect the HIV care of women living with HIV. This includes seeking support, healthcare and treatment, and general engagement with services.

Research has highlighted that women living with HIV are more likely to experience intimate partner violence than other women. We therefore want to gain a deeper understanding of the experiences of women in the UK living with HIV. We hope that this research will increase our knowledge and so will help to improve support services for women living with HIV.

#### **Am I the right person for this study?**

You have been invited to take part in this study as you are a woman living with HIV. To be eligible to take part in the study, you must meet all of the following criteria:

1. Aged 18 or above
2. Born female, and identify as a female
3. Living with HIV
4. Answer Yes to two or more of the following questions:
  - a. Have you ever been humiliated or emotionally abused in other ways by your partner or ex-partner?
  - b. Have you been afraid of your partner or ex-partner?

- c. Have you been raped or forced to have any kind of sexual activity by your partner or ex-partner?
- d. Have you been kicked, hit, slapped or otherwise physically hurt by your partner or ex-partner?

We also ask that participants speak enough English to be able to take part in the interview, as we are not currently able to conduct interviews in other languages.

### **How is the project funded and who is involved?**

The research is being led by a Trainee Clinical Psychologist, Lea Beretti, and is being funded by Royal Holloway, University of London, as part of its doctorate programme in Clinical Psychology. The project is being supervised by:

Dr Michael Evangeli (Reader in Clinical Psychology at Royal Holloway, University of London)

Other collaborators, which make part of the research team Dr Olga Luzon (Senior Lecturer in Clinical Psychology), and Professor Yvonne Gilleece (Honorary Clinical Professor and Consultant in HIV Medicine & Sexual Health).

### **What will the study involve?**

If you want to take part in the study, you will be invited to meet with the lead researcher (Lea Beretti), when you will be able to ask any questions that you may have. Lea will then set up a mutually convenient time and date to meet to take part in the study. In this meeting, Lea will give you a consent form, which will include:

1. Consenting to your interview being recorded and transcribed.
2. Providing permission for the lead researcher to report your responses anonymously as part of a written thesis, results of which may be shared outside of Royal Holloway, University of London (for example, with the participating NHS trust and HIV organisations).
3. Providing permission for anonymised quotes from your interview transcript being included in any final reports or publications of the results of the research.
4. Choosing (or not) to being contacted after the study to hear about the results.

After agreeing to taking part, you will be asked to complete a questionnaire (*Participant Information Questionnaire*) which asks about demographic information (i.e. age, ethnicity...), and basic information about your HIV diagnosis (for example, the year you were diagnosed).

If you consent to take part, you will be invited to an interview where you will be asked about your experiences of accessing care and the role the intimate partner violence may have played. This interview may take place in person at an HIV clinic, or at Royal Holloway, University of London. The clinic will be either the Courtyard Clinic, St George's University Hospital NHS Foundation Trust, or The Lawson Unit, University Hospitals Sussex NHS Foundation Trust, or 10HB, Chelsea and Westminster NHS



Foundation Trust. The interview could also be carried out using a video call if you have access to the right technology and can use a private and confidential space to talk.

The interview will last approximately 60-90 minutes and will be audio recorded. The researcher will ask you about your journey with HIV, the role it may have played in your intimate relationships, and your experiences of accessing and engaging in care.

After the interview, you will be invited to debrief with Lea. This involves having an informal conversation about how you found the interview. You can also ask any questions you might have. The total estimated time taken to participate in the study will be no longer than two hours (i.e., questionnaire, interview and debrief).

### **What are the benefits of taking part?**

1. You will be given a £10 voucher as a token of appreciation for your time.
2. A maximum of £10 travel expense can be reimbursed if you are doing in-person interviews and are travelling to participate in the study. This will be calculated based on mode of transport used, as well as area which you came from, and service you are going to.
  - a. Please refer to section '*What are the possible disadvantages or risks involved in taking part?*' for travel costs above £10.
3. You can also enter a prize draw for a £25 Amazon voucher.
4. You may find it is a positive experience to share your own experiences about accessing care as a woman living with HIV who has experienced intimate partner violence.
5. You will be part of research for women living with HIV, and so the information that you share may help to inform care for women living with HIV.

### **What are the possible disadvantages or risks involved in taking part?**

We do not expect that you will encounter any risks because of taking part in this study. This study has been reviewed and approved in accordance with an NHS Research Ethics Committee as well as the College Research Ethics Committee at Royal Holloway, University of London. This means the research has been deemed safe to go ahead, any risks have been considered and kept to a minimum, and that it is completely voluntary whether you decide to take part or not. However, the interview will ask about personal experiences and views which some people may find emotive, personal, or sensitive. You can choose not to answer any questions during the interview that you may not feel comfortable with.

If you do feel distressed during the interview, it is important that you tell Lea. If Lea notices that you may be feeling distressed, she will pause the interview and offer you a break or end the interview if necessary. Lea will also provide some time at the end of the interviews to discuss how you feel. If you feel that the interview may have brought up issues that you would like to discuss further with a professional, support will be offered according to the organisation where you first saw the research (i.e., to a member of your clinical team, or provided with contact details to access several support services).

If throughout the interview Lea becomes concerned for your safety and wellbeing, or the safety and wellbeing of others, she may want, or need, to share her concern with a member of your clinical team. This is part of ethical, and good practice as a researcher. If you were recruited from a charitable organisation, if you were recruited from a charitable organisation, and you are not under the care of the NHS organisations involved in this study, Lea may look to contact emergency services to make sure you are safe. Lea may also offer you contact details for support services. Lea will do her best to have a discussion with you about this first, so that you are aware of third parties being informed. The information being shared will be limited to what is relevant for the party being informed to know.

Due to a limited budget, a maximum of £10 travel reimbursement can be offered for those who do in-person interviews. This has been calculated with the aim of ensuring all participants can have some, or all, of their travel costs reimbursed. Travel costs will be calculated based on area of residence, interview site you attend, and mode of transport which you take. It is encouraged to prove a proof of cost so you can be accurately reimbursed.

### **What next?**

If you decide to take part in the research after reading this information sheet, you can contact Lea, or you can give permission to your clinician or a member of the organisation for Lea to contact you.

Please contact Lea via email (lea.beretti1@nhs.net) or telephone (01784 414012). This phone number is an answering machine. Please say your message is for Lea Beretti, leave a message clearly stating your name and phone number.

### **How will we use information about you?**

We will need to use information from the *Participant Information Questionnaire* and the interview for this research project.

The consent form will also have a space for providing contact details. These contact details will be used to contact you about the results of the study, should you opt-in to this.

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 in the form of interview number, initial of first and last name and date of the interview (i.e., '1JS143') so that your interviews, consent forms and questionnaire are anonymised and cannot be traced back to you. People will use this information to do the research or to check that the research is being done properly.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

### **What are your choices about how your information is used?**

Taking part in the research is completely voluntary. You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. If you decide to take part (or not) this will not affect the standard of your care in anyway, or your relationship with any of the organisations involved.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- at [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- by asking one of the research team
- by sending an email to [lea.beretti1@nhs.net](mailto:lea.beretti1@nhs.net).
- by ringing us on 01784 414012.

### **Data storage**

The project follows the General Data Protection Regulation protocol (GDPR, 2018) to ensure your data is recorded and stored appropriately. Your raw data will be kept by the research team for up to a maximum of 10 years or until it is no longer needed for the purposes of research.

Only the lead researcher (Lea Beretti) will have access to the interview recording. Lea will transcribe the interview. The recordings will be deleted after it has been transcribed. The transcribed interview will be anonymised which means the information you will provide will be unable to be identified as belonging to you. Additionally, your questionnaire answers will also be anonymised and stored as such, meaning you cannot be identified. Because this study is part of a doctoral thesis in clinical psychology, examiners may ask to view the transcripts. These will be anonymised, and you will not be able to be identified.

All data will be stored on a password-protected database that only the research team will have access to.

In line with research quality standards for interview-based projects, direct quotes from interviews may be used to provide evidence to support the findings of the research. These quotations will be anonymous and cannot be linked to anyone participating in the study. If you would like to know more about this, please ask Lea for more information.

All participant related data (i.e., email address, telephone number, and GP details) which has been collected for the purpose of being contacted about the results, or the prize draw will be stored in a password protected file on an encrypted USB drive. This data will be kept until the end of the research project (i.e., June 2023).

### **What will happen with the results of this study?**

**The submission of this research will form part of Lea’s qualification as a clinical psychologist. The written thesis will be reviewed by examiners, who will also ask questions about the study. This will be based on an oral presentation that Lea will give to the panel. This thesis will be available online on Royal Holloway, University of London website and a hard copy will be kept by the university.**

**The research team also hopes to publish the study to relevant scientific journals and possible share the results in related conferences. Participants will in no way be identifiable from any write-up, publication or presentation resulting from this research. Any identifiable information will be omitted.**

### **Confidentiality**

As a trainee clinical psychologist, Lea is bound by confidentiality requirements. **Your information and responses will be kept completely confidential unless you tell us something that indicates you or someone else is at risk of harm.** Lea will attempt to discuss this with you before telling anyone else. If Lea feels concerned about a risk of harm, she may have to discuss this with the organisation or clinic providing you care or support, or contact other services such as A&E. This is routine practice (please see ‘possible disadvantages or risks involved in taking part’ section).

### **Have experts by experience been involved in the design of this study?**

Yes, the researcher has consulted with two individuals with lived experience to review drafts of the information provided on this form and to review questions to be asked during interviews. This was to check the sensitivity of questions being asked of participants. This was also to check if there were any areas researchers had not thought to ask about in interviews, but that might be relevant to answering the research question.

### **Who should you contact with questions or concerns?**

The main person to contact for this project is Lea Beretti, Trainee Clinical Psychologist as the Department of Clinical Psychology, Royal Holloway University of London. You can get in touch in the following ways if you have any questions about the research at any time.

- Email: Lea Beretti ([lea.beretti1@nhs.net](mailto:lea.beretti1@nhs.net))
- Phone: 01784 414012 (this is an answering machine - please say your message is for Lea Beretti, leave a message clearly stating your name and phone number).
- You can also contact the supervisors and collaborators of the project, Dr Michael Evangeli ([Michael.Evangeli@rhul.ac.uk](mailto:Michael.Evangeli@rhul.ac.uk)), Dr Olga Luzon ([Olga.Luzon@rhul.ac.uk](mailto:Olga.Luzon@rhul.ac.uk)), Prof Yvonne Gilleece ([y.gilleece@nhs.net](mailto:y.gilleece@nhs.net)).

### **What if I want to complain?**

If you are unhappy with any part of the study, please contact Lea Beretti or the study lead supervisor, Dr Michael Evangeli, using the details above. If you wish to complain about how your data is being used, you should contact the research team in the first instance. 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 you can complain to the Information Commissioner's Office ([www.ico.org.uk](http://www.ico.org.uk) or 0303 123 1113).

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

## Appendix F

### NHS REC & HRA Approval (10/08/2022)



Miss Lea Beretti  
Department of Psychology  
Royal Holloway, University of London  
Egham, Surrey  
TW20 0EX

Email: [approvals@hra.nhs.uk](mailto:approvals@hra.nhs.uk)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

10 August 2022

Dear Miss Beretti

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

**Study title:** Exploring help-seeking in women living with HIV who have experienced intimate partner violence.  
**IRAS project ID:** 312578  
**Protocol number:** N/A  
**REC reference:** 22/LO/0416  
**Sponsor:** Royal Holloway, University of London

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 **312578**. Please quote this on all correspondence.

Yours sincerely,  
Laura Howe

Approvals Specialist  
Email: [approvals@hra.nhs.uk](mailto:approvals@hra.nhs.uk)  
Copy to: *Dr John Francis*

## List of Documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [Recruitment poster w track changes]	4.3	30 July 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]		23 July 2021
Interview schedules or topic guides for participants [Interview Guide]	6	27 April 2022
IRAS Application Form [IRAS_Form_19052022]		19 May 2022
Non-validated questionnaire [Participant Demographic Questionnaire]	4	19 April 2022
Organisation Information Document [OUTLINE_20_May_2022_Organisation_Information_Document_NonCommercial_v3_0.docx]	1.0	20 May 2022
Other [REC submission response]	1	19 May 2022
Other [Response to request of further information (30/07/2022)]	1	30 July 2022
Other [Confirmation of sites]	1	19 May 2022
Other [Participant Receipt Form]	1	14 July 2022
Other [Provisional Opinion Response IRAS 312578]	4.2	14 July 2022
Other [Risk & Distress Protocol]	2	30 June 2022
Other [Post-interview Debrief]	2	19 April 2022
Participant consent form [Participant consent form w/ track changes]	4.4	30 July 2022
Participant information sheet (PIS) [Participant Information Sheet]	4.5	30 July 2022
Referee's report or other scientific critique report [Approval Letter]		01 February 2022
Research protocol or project proposal [HIV/IPV proposal w/ track changes (other versions are below)]	5.2	30 July 2022
Schedule of Events or SoECAT [Schedule of Events]	2	19 April 2022
Summary CV for Chief Investigator (CI) [CI/Student CV [Miss Lea Beretti]]		
Summary CV for supervisor (student research) [Supervisor CV [Dr Michael Evangelii]]		
Validated questionnaire [HARK Screening Questionnaire]	1	16 May 2022



### 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 in accordance with the contracting expectations detailed.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type.	The sponsor has detailed its proposals with respect to whether any study funding will be provided to participating NHS organisations of this type in the relevant Organisation Information Document. This should be read in conjunction with the relevant Schedule of Events/SoECAT which details the cost implications of the study for participating NHS organisations.	In line with HRA/HCRW expectations a Local Collaborator should be appointed at participating NHS organisations of this type.	Where an external individual will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold a Letter of Access. This should be issued on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed).

### Other information to aid study set-up and delivery

<i>This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.</i>
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.



# Health Research Authority

## London - Stanmore Research Ethics Committee

2nd Floor  
2 Redman Place  
Stratford  
London  
E20 1JQ

**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

10 August 2022

Miss Lea Beretti  
Department of Psychology  
Royal Holloway, University of London  
Egham, Surrey  
TW20 0EX

Dear Miss Beretti

<b>Study title:</b>	<b>Exploring help-seeking in women living with HIV who have experienced intimate partner violence.</b>
<b>REC reference:</b>	<b>22/LO/0416</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>IRAS project ID:</b>	<b>312578</b>

Thank you for your letter of 1<sup>st</sup> August 2022, responding to the Research Ethics Committee's (REC) 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.

### 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.

### Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

### Conditions of the favourable opinion

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

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device

- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers](#)).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

#### Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

**N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.**

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

**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
- Reporting results

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 taking part in the study, 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:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [Recruitment poster w track changes]	4.3	30 July 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]		23 July 2021
Interview schedules or topic guides for participants [Interview Guide]	6	27 April 2022
IRAS Application Form [IRAS_Form_19052022]		19 May 2022
Non-validated questionnaire [Participant Demographic Questionnaire]	4	19 April 2022
Other [Post-interview Debrief]	2	19 April 2022
Other [Participant Receipt Form]	1	14 July 2022
Other [Provisional Opinion Response IRAS 312578]	4.2	14 July 2022
Other [Risk & Distress Protocol]	2	30 June 2022
Other [REC submission response]	1	19 May 2022
Other [Response to request of further information (30/07/2022)]	1	30 July 2022
Participant consent form [Participant consent form w/ track changes]	4.4	30 July 2022
Participant information sheet (PIS) [Participant Information Sheet]	4.5	30 July 2022
Referee's report or other scientific critique report [Approval Letter]		01 February 2022
Research protocol or project proposal [HIV/IPV proposal w/ track changes (other versions are below)]	5.2	30 July 2022
Summary CV for Chief Investigator (CI) [CI/Student CV [Miss Lea Beretti]]		
Summary CV for supervisor (student research) [Supervisor CV [Dr Michael Evangelii]]		
Validated questionnaire [HARK Screening Questionnaire]	1	16 May 2022

### Statement of compliance

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

### 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/>

<b>IRAS project ID: 312578    Please quote this number on all correspondence</b>
----------------------------------------------------------------------------------

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

Yours sincerely  
pp.



**Ms Sunder Chita**  
**Chair**

Email: stanmore.rec@hra.nhs.uk

*Enclosures:*                      "After ethical review – guidance for  
researchers"

*Copy to:*                              Dr John Francis

*Lead Nation*

[approvals@hra.nhs.uk](mailto:approvals@hra.nhs.uk)

A Research Ethics Committee established by the Health Research Authority

## Appendix G

### REC & HRA Amendment Approval (26/10/2022)



London - Stanmore Research Ethics Committee

2nd Floor  
2 Redman Place  
Stratford  
London  
E20 1JQ

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

26 October 2022

Miss Lea Beretti  
Department of Psychology  
Royal Holloway, University of London  
Egham, Surrey  
TW20 0EX

Dear Miss Beretti

<b>Study title:</b>	<b>Exploring help-seeking in women living with HIV who have experienced intimate partner violence.</b>
<b>REC reference:</b>	<b>22/LO/0416</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>Amendment number:</b>	<b>Amendment 1.0</b>
<b>Amendment date:</b>	<b>20 September 2022</b>
<b>IRAS project ID:</b>	<b>312578</b>

The above amendment was reviewed on 18 October 2022 by the Sub-Committee in correspondence.

#### **Ethical opinion**

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

**Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Completed Amendment Tool [Exploring help-seeking in women living with HIV who have experienced IPV]	1.0	20 September 2022

**Membership of the Committee**

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

**Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

**Amendments related to COVID-19**

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

**Statement of compliance**

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

**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/>

<b>IRAS Project ID - 312578:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely

pp. 

**Ms Sunder Chita**  
**Chair**

E-mail: stanmore.rec@hra.nhs.uk

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

*Copy to: Miss Lea Beretti*



**London - Stanmore Research Ethics Committee**

**Attendance at Sub-Committee of the REC meeting on 18 October 2022, via correspondence.**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Ms Sunder Chita	Health Research Manager and PPI Lead	Yes	Chair of the REC
Mrs Yasmin Shaik	Administrator	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Richard Reed	Approvals Administrator

## Appendix H

### REC and HRA Amendment Approval (22/02/2023)



#### London - Stanmore Research Ethics Committee

2nd Floor  
2 Redman Place  
Stratford  
London  
E20 1JQ

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

22 February 2023

Miss Lea Beretti  
Department of Psychology  
Royal Holloway, University of London  
Egham, Surrey  
TW20 0EX

Dear Miss Beretti

<b>Study title:</b>	<b>Exploring help-seeking in women living with HIV who have experienced intimate partner violence.</b>
<b>REC reference:</b>	<b>22/LO/0416</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>Amendment number:</b>	<b>Amendment 2.0</b>
<b>Amendment date:</b>	<b>02 February 2023</b>
<b>IRAS project ID:</b>	<b>312578</b>

The above amendment was reviewed on 21 February 2023 by the Sub-Committee in correspondence.

#### **Ethical opinion**

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

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Completed Amendment Tool [Help-seeking in women living with HIV who have experienced IPV]	2.0	02 February 2023

### Membership of the Committee

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

### Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

### Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

### Statement of compliance

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

### 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/>

<b>IRAS Project ID - 312578:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely

pp. 

**Dr Anthony Kaiser**  
**Vice Chair**

E-mail: stanmore.rec@hra.nhs.uk

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

**London - Stanmore Research Ethics Committee**

**Attendance at Sub-Committee of the REC meeting on 21 February 2023, via  
correspondence**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Michael Grossman	Retired Pharmacist	Yes	
Dr Anthony Kaiser	Consultant Neonatologist	Yes	Vice Chair

## Appendix I

### Royal Holloway REC Self-Certification



#### Ethics Review Details

You have chosen to submit your project to the REC for review.	
Name:	Beretti, Lea (2013)
Email:	ZYVA279@live.rhul.ac.uk
Title of research project or grant:	Exploring help-seeking in women living with HIV who have experienced intimate partner violence.
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Dr Michael Evangelini & Dr Olga Luzon
Email address of Academic Supervisor:	Michael.Evangelini@rhul.ac.uk
Funding Body Category:	No external funder
Funding Body:	
Start date:	08/09/2022
End date:	30/06/2023

#### Research question summary:

Research has found that if you are a woman living with HIV you are more likely to experience intimate partner violence (IPV) compared to other women (Campbell et al., 2008). It is also known that stigma and lack of specialist services are a barrier for accessing the right support for these women. Most studies have been done in other countries such as Kenya, Uganda, South Africa, India and the US, with very different cultural contexts and services available to these women. There is currently no research to help us understand how best support women in the UK who have experience both, HIV and IPV. Furthermore, barriers towards help-seeking has been highlighted. For example, 58% of women living with HIV have reported having experienced some form of abuse, with only one in five women accessing the sources of support they needed (Terrence Higgins Trust, 2018).

This project aims to interview six to ten women to understand their experiences of accessing care and support. Interviews will be analysed using IPA, which allows researchers to understand personal experiences at the same time as deriving common themes. We hope to be able to provide guidelines on services needed for these women, ways to improve access to services, and better understanding about their lived experiences.

#### Research method summary:

Potential participants will be identified by clinicians at identified NHS sites, and charitable organisations via a poster. An identified staff member at each recruitment sites will provide potential participants with some brief information about the study, and gain consent for the researcher to make contact with them (using the @nhs.net email address). An information sheet containing the IPV screening questionnaire (HARK; Sohal et al., 2007) will be shared by clinicians, or lead researcher, with potential participants, outlining what the research will involve, confidentiality, ethics principles, risk management protocols, and relevant contact information. Potential participants will have the opportunity to ask questions about the project to the chief investigator prior to participating, via email or telephone. There will be a cooling-down period between receiving the information sheet and consenting to, and participating in the study. A time and date will be made with participants who wish to take part in the interview. At the set time and date, participants will be offered another opportunity to ask questions and will be asked to sign a consent form, complete the demographics questionnaire and participate in the interview. This research will aim to recruit between 6-10 participants.

Inclusion criteria: Aged 18 or above; Born female, and identify as a female; Living with HIV; Answer 'Yes' to two or more of the following questions (Sohal et al., 2007): Have you ever been humiliated or emotionally abused in other ways by your partner or ex-partner? Have you been afraid of your partner or ex-partner? Have you been raped or forced to have any kind of sexual activity by your partner or ex-partner? Have you been kicked, hit, slapped or otherwise physically hurt by your partner or ex-partner. This research also asks that participants speak enough English to be able to take part in the interview.

#### Working with participants that are 'at risk'

Will the research involve any of the following 'at risk' participants?

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 at risk due to personal, emotional, psychological or other reasons,

Yes

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

Yes

Details,

The information sheet provides a clear step-by-step outline of what participation in the study will involve, as well as what the consent form will outline. In the initial stages, it will be made clear that the engagement, decline to engage or withdrawal from the study will not impact their relationship with the service/organisation. After participants have read the information sheet, they will be offered an opportunity to ask questions, and set a time and date to participate in the study, at a mutually convenient time. At this meeting, they will be asked to consent to a recording of their interview to be taken, with it being fully explained on the information sheet and consent form prior to participating. The information sheet and consent form clearly explains that the recording will be stored securely until the point of transcription, at which point the recording will be deleted and interview anonymised. The information sheet and consent form will clearly communicate that once the interviews have been transcribed, the data will not be removable as it will have been made unidentifiable. Prior to taking part, participants will also be informed that direct quotations from their interviews may be used in the write-up and results, but will be non-identifiable. Participants will also be made aware that recommendation for clinical practice, services, and future research may be made from the results of the research, and that these may be disseminated via various modes (i.e., conferences, scientific journals, presentations). Participants will be asked to consent to this, on the understanding that all information will be anonymous and unidentifiable. Participants will be asked to consent to the interview recordings to being stored securely until they are transcribed. The interview recordings will be confidential, with only the lead researcher having access to them for the purpose of transcription. Once the recordings are transcribed, they will be permanently deleted. The anonymised transcripts will then in turn be stored securely within the research team.

Whilst the researchers do not anticipate that the participants will be at risk of harm from participating, they will be aware that the topic and nature of the research and questions being asked may evoke distress (i.e., their experience of HIV and intimate partner violence). The nature of the questions will be communicated to the participants prior to engaging, confirming their interest and consenting to take part. The questions have been reviewed by the research team and experts-by-experience to ensure sensitivity and appropriateness of the questions and language used. Participants will be invited to communicate the need to stop or pause the interview at any time, should they become distressed at any point, and the lead researcher will also assess this throughout the interview. Participants will be asked to consent to the researcher sharing any concerns they may have for the participant's safety or that of others with their named clinician or organisational point of contact, should any such information be shared in the interview. Time for a debrief following the interview will be made, as well as signposting to support services should this be needed.

Participants will be reimbursed for their time and expertise given throughout the research. They will also be invited to hear about the results of the study. Through this process, the researchers hope that the outcomes of the study will benefit participants and others who have had similar experiences by facilitating recommendations for future research and healthcare practice.

invited to communicate the need to stop or pause the interview at any time, should they become distressed at any point, and the lead researcher will also assess this throughout the interview and use their clinical skills to decide whether the interview may need to be paused or stopped.

Participants will be asked to consent to the researcher sharing any concerns they may have for the participant's safety or that of others with their named clinician or organisational point of contact, should any such information be shared in the interview. If having a discussion with the participant is not possible but the lead researcher feels that the participant's safety is at risk, the participant will be aware that the lead researcher may look to contacting emergency services.

Time for a debrief following the interview will be made, whereby the chief investigator will check-in with participants. The chief investigator will also provide the participant with an information sheet with contact details to signpost to appropriate support services (i.e., HIV, sexual health, IPV, health, mental health, emergency).

### 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,

N/A

### Risks to Researchers, Research Collaborators, and Royal Holloway

Does your research present any of the following risks to researchers, research collaborators, or Royal Holloway?

Is there a possibility that researchers or research collaborators could be exposed to emotional or physical risks (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, by working in countries in which there is unrest, accessing archives with troubling content, or by examining material that may cause secondary trauma)?,

Yes

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)?,

Yes

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

No

Could any aspects of the research mean that Royal Holloway has failed in its duties of care?,

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,

The lead researcher will be conducting interviews either in the HIV clinic setting, HIV charitable organisation, or Royal Holloway, University of London. The interviews will be conducted either in-person, or on video call. There, therefore, will not be any lone working. The lead researcher will also have regular supervision, in which they will be able to disclose and process any secondary distress they may experience from hearing some of difficult experiences which are being shared.

With regards to ethical compromise, the participants will be made aware via the information sheet, and sign a consent form, prior to participating highlighting that the researcher may share any concerns they may have for the participant's safety or that of others with their named clinician or organisational point of contact, should any such information be shared in the interview. They will also be aware that if this informing them about this is not possible, and they appeared to be in immediate danger, emergency services may also be contacted.

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, ZYVA279

Date:	03/05/2023 22:05
Signed by:	Beretti, Lea (2013)
Digital Signature:	
Certificate dated:	5/3/2023 10:15:51 PM
Files uploaded:	Debrief sheet.docx HIVIPV Proposal v5.2.docx Interview Guide.docx Participant Consent Form v4.4.docx Participant Information Sheet v4.5 w track changes.docx Recruitment poster v4.3 w comments.pdf Risk Protocol.docx Submitted IRAS form.pdf IRAS Project ID 312578 - Favourable opinion on further information[6613].pdf IRAS_312578_(Approval)_Initial_Assessment_Letter_24_05_2022[4972].pdf IRAS_312578_(Approval)_Letter_of_HRA_Approval_10_08_2022[6614].pdf REC clarifications 30thJuly2022.docx REC response 15thJuly2022.docx Response to REC review of IRAS project 312578 19thMay2022.docx Participant Information Questionnaire.docx OUTLINE_20_May_2022_Organisation_Information_Document_No nCommercial_v3.docx Full-Review-3383-2022-08-19-11-23-ZYVA279.pdf



Participants will also have an option to opt-in to informing their GP about their participation in this study.

## Other considerations when working with people and their data

Does your study include any of the following?

Will it be necessary for the research that people take part in the study without their informed consent at the time?,

No

Will the research, however briefly, be managing identifiable or special category data as defined by GDPR? (Please see the Royal Holloway's research ethics intranet page for guidance),

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 involve NHS patients, staff, premises, resources, data or tissue samples?,

Yes

If so what is the NHS Approval number,

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 work with a dataset that requires a data sharing agreement?,

No

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,

Whilst the researcher do not anticipate that the participants will be at risk of harm from participating, they are aware that the research topic and questions being asked may evoke distress (i.e., their experience of HIV and intimate partner violence). The nature of the questions will be communicated to the participants prior to engaging, confirming their interest and consenting to take part. The questions have been reviewed by the research team and experts-by-experience to ensure sensitivity and appropriateness of the questions and language used. Participants will be

## Appendix J

### Safety and Distress Protocol

**[Insert Logos Here]**

The safety of participants is paramount and has been kept in mind throughout the design of this project, including considerations of management of possible distress arising from taking part in the study. Furthermore, individuals who are experts in the field have been consulted as to ensure the material is accessible, appropriate, and sensitive.

Please see the protocol below.

Research team provisions:

1. The lead researcher will have a point of contact for each service the participants will be recruited from. They will be contacted in the instance that any concerns about the participants' safety or that of others arise during participation in the study. Participants will be made aware of the limits of confidentiality.
2. The lead researcher will have access to supervision from Clinical Psychologists, where they will be able to access support should safety/risk issues arise.

Before the interview:

1. Potential participants will be given the *Participant Information Sheet* which will explain various aspects of the research ranging from the aim, methods, and data protection, privacy, and management of risk, which includes contacting a member of the recruiting site should issues around safety arise. The *Participant Information Sheet* can be read through with the researcher or in their own time.
2. Potential participants will be given a minimum 24-hour cooling off period to think about whether they would be interested in engaging, as to not feel pressured to consent.

3. The lead researcher will contact potential participants to ask whether they are interested in taking part in the study, offer the opportunity to ask questions, and book in a time to conduct the interview.
4. On the scheduled date and time, participants will be asked to complete a consent form for participating in research, which will highlight key aspects of the study, such as confidentiality, data protection, and safety protocol (please refer to bullet point 2). The limits of confidentiality will be restated, and consent will be obtained.
5. Participants will be reminded that they can stop the interview at any point, and that doing so will not affect their relationship with the researcher and/or service they were recruited from.

During the interview:

1. Participants will be offered to participate in in-person or virtual interviews.
  - a. In-person interviews will be conducted at one of the NHS recruitment sites, or at Royal Holloway, University of London, where a confidential room will be allocated for the interview.
  - b. For virtual interviews, the participants will be encouraged to have a private and confidential space to participate in the interview, as to ensure their safety.
  - c. The online platform used will be MS Teams, which is a secure NHS approved tool for video conferencing. MS Teams does not require an account and can be used with a stable internet connection.
2. The lead researcher will use their clinical skills to monitor and assess participants' emotional states. Should a participant become visibly distressed, the lead researcher will offer to pause, or stop, the interview.

After the interview:

1. If concerns about safety arise, participants will be involved in an open conversation with the lead researcher. The lead researcher will then contact the point of contact in the service they were recruited from and be made aware of the concerns. Only the information which was relevant to the identified risk

would be shared. If risk was perceived to be immediate or imminent, emergency services would be contacted.

- a. If participants were recruited from *4 Mentor Mothers* or *Sophia Forum* and are not under the care of one of the NHS trusts involved in this study, a point of contact may not be available. In this instance, emergency services, Single Point of Access, or the Police would be contacted, as per usual NHS service protocol.
2. The lead researcher will contact the supervisor or collaborators to seek for advice on how to best support participants.
3. Participants will also be offered a debrief period following the interview.
4. Participants will also be offered a helpful list of contact details of intimate partner violence, mental health and HIV healthcare services and charities that can offer support, safety, and help.

## Appendix K

### Cohen's Kappa SPSS Output

#### → Crosstabs

[DataSet1] D:\trainee research\Lea\Cohen's kappa data - 19.12.22.sav

#### Case Processing Summary

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
Inclusion * Inclusion	82	100.0%	0	0.0%	82	100.0%

#### Inclusion \* Inclusion Crosstabulation

Count

		Inclusion		Total
		Not Included	included	
Inclusion	Not included	54	6	60
	Included	13	9	22
Total		67	15	82

#### Symmetric Measures

		Value	Asymptotic Standard Error <sup>a</sup>	Approximate T <sup>b</sup>	Approximate Significance
Measure of Agreement	Kappa	.344	.118	3.208	.001
N of Valid Cases		82			

a. Not assuming the null hypothesis.

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

## Appendix L

### Cohen's Kappa SPSS Output for Reliability of Critical Appraisal

➔ **Crosstabs**

#### Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Criteria Met * Criteria Met	70	100.0%	0	0.0%	70	100.0%

#### Criteria Met \* Criteria Met Crosstabulation

Count

		Criteria Met		Total
		Criterion Not Met	Criterion Met	
Criteria Met	0	17	1	18
	Criterion Met	4	48	52
Total		21	49	70

#### Symmetric Measures

		Value	Asymptotic Standard Error <sup>a</sup>	Approximate T <sup>b</sup>	Approximate Significance
Measure of Agreement	Kappa	.823	.076	6.922	.000
N of Valid Cases		70			

a. Not assuming the null hypothesis.

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