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Literature review: what factors promote disengagement from, and re-engagement back into, care for London PLHIV?



A GMI Partnership publication



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## EXECUTIVE SUMMARY

Despite recent advances in HIV prevention, treatment and care in London, and the UK generally, there are still a significant number of people diagnosed with HIV who become disengaged from HIV care. This is a predictor of poorer physical and mental health outcomes and carries a financial cost. The reasons for disengagement and factors that facilitate re-engagement in care at the London level are only partially understood and have not been collated in a literature review previously. In addition, these factors are changing because of recent advances in HIV treatment and prevention. This literature review responds to the pressing need for an up-to-date, London-based report on the topic, which can shape treatment and care interventions. The literature review takes a systematic approach looking at literature from London from the last 5 years to increase our knowledge around factors for disengagement and facilitators for re-engagement into HIV care in the capital.

Key findings show that disengagement from care appears to be strongly related to identity-related factors, such as gender, sexuality and age. In addition, literature implies that HIV stigma, poor mental and physical health and drug use are all predictors of disengagement from care, as are related social determinants of health, such as living in poverty. Finally, a lack of co-ordination and collaboration between different components of a patient's HIV care is an additional significant factor related to disengagement from care.

The literature suggests that facilitators for re-engagement in care include community and A&E HIV testing, stigma reduction, peer support interventions as well as the use of certain patient monitoring tools. As with research focusing on disengagement from care, studies suggest the need for improved collaboration and joint working from the different components of a patient's HIV care network. The research also suggests a shift from a binary understanding of patients as either engaged in, or disengaged from, care. This nuanced understanding of an HIV care engagement continuum is important when planning interventions.

The findings of the literature review, and the recommendations outlined will shape future interventions designed at retaining people living with HIV (PLWHIV) in care and re-engaging those currently less engaged or disengaged in care, ultimately improving the quality of life and health outcomes of PLWHIV in London.



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## LIST OF ACRONYMS

A&E – Accident and Emergency

ART – Anti-Retroviral Therapy

BASHH – British Association of Sexual Health and HIV

BIPOC – Black, Indigenous and People of Colour

DHSC – Department of Health and Social Care

EIC – Engagement in Care

FTC – Fast Track Cities

GBL/GHB – Gamma Butyrolactone/Gamma Hydroxybutyrate

GBMSM – Gay, Bisexual and Men who have Sex with Men

GMI - A consortium of three charities, Positive East, Spectra and Metro providing local HIV Prevention and Support

HAART – Highly Active Anti-Retroviral Therapy

HIV – Human Immunodeficiency Virus

IDU – Injecting Drug Use

LWHIV – Living With HIV

PEP – Post-Exposure Prophylaxis

PLWHIV – People Living With HIV

PrEP – Pre-Exposure Prophylaxis

RIC – Re-Engagement into Care

SDH – Social Determinants of Health

EJAF SIB – Elton John AIDS Foundation Social Impact Bond

VCSE – Voluntary, Community and Social Enterprises

WLWHIV – Women Living With HIV



## BACKGROUND

Since the first cases of HIV in the early 1980s the UK has made significant progress in terms of HIV prevention and treatment. From the first health campaigns in 1983, to the introduction of Highly Active Anti-Retroviral Therapy (HAART) in the 1990s and modern treatments such as long acting injectables, the health outcomes of people living with HIV have steadily improved. This has been accompanied by other developments, such as the availability of Pre-Exposure Prophylaxis (PrEP), and the introduction of NHS guidelines that recommend community HIV testing in 2001 (BASHH 2020).

In January 2019 the UK government committed to a new ambition to achieve zero new HIV infections, AIDS and HIV-related deaths in England by 2030 (Fast Track Cities London 2023). In order to do this the Department of Health and Social Care (DHSC) (2021) recognised it was important to reduce the number of People Living with HIV (PLWHIV) who are not currently accessing care and support. In other words, to prevent those PLWHIV from becoming disengaged from care, and to re-engage those PLWHIV who are not currently accessing care or support.

Overall, in 2022 there were an estimated 96,200 People Living with HIV (PLWHIV) in the UK (UKHSA, 2022). Of these 18,160 have a transmittable viral load, and of those an estimated 5,930 (33%) were undiagnosed. 3,890 (21%) were diagnosed but not referred to specialist HIV care or retained in care, 1,630 (9%) attended care but were not receiving treatment, and 2,110 people (12%) were on treatment but not virally suppressed (Towards Zero 2021).

There are many ways that increasing engagement into care (EIC) can be achieved. One recent approach in the UK has been opt-out HIV testing in Accident and Emergency (A&E) departments (this will be discussed in more detail subsequently). This approach has sought to engage hard-to-reach groups, provide holistic support, reduce late diagnoses and to enable rapid transfer into HIV support and clinical care. It is important to differentiate EIC, after initial diagnosis, from re-engagement in care (RIC), which applies to re-engaging those who were previously in HIV care and support but have since disengaged with care.

Over the last three decades, although our knowledge around interventions which promote EIC and RIC, and ways to reduce disengagement from care have improved, many PLWHIV are still not engaged in treatment and care. It is vital to engage PLWHIV in care after diagnosis in order that they can receive access to effective treatment and to reduce the likelihood of onward HIV transmission. There is also the financial cost of missed appointments for those who disengage from care. Remaining in care is also an indicator of improved mental health and wellbeing, and better quality of life outcomes among PLWHIV across the life course.

In the latest report of the UK Government's HIV Action Plan (DHSC 2021) four key aims are set out:

- 1) To prevent HIV
- 2) Test for HIV
- 3) Treat HIV
- 4) Retain PLWHIV in treatment.

In focusing on these four aims, the overall goal is to reduce new HIV diagnoses, reduce transition from HIV to AIDS and reduce deaths from HIV and AIDS. Particularly of importance to this literature review are aims 3 and 4, which, according to the Action Plan (DHSC 2021) are based on optimising rapid access to treatment, retention in care and improving the quality of life for PLWHIV and addressing HIV stigma.

This report is based on a systematic review of the literature on the topics of disengagement from and re-engagement into care. The literature review outlines current understandings on the complex and varied barriers and facilitators, for engagement into and disengagement from HIV care. Literature includes references to the NHS, primary, secondary/specialist care and integrated care systems given the geographical focus and healthcare context in the UK, and specifically London. The review specifically seeks to answer the questions outlined in the methodology section below and to distil insights concerning the reasons PLWHIV disengage from HIV care and support. The review concludes with recommendations on approaches for re-engaging populations who are most at risk from being disengaged from HIV care and support.

## METHODOLOGY

### INITIAL SCOPING EXERCISE

An initial scoping exercise was conducted to test the viability of several questions related to engagement into, and disengagement from care, and to determine whether there was sufficient literature on the topic to conduct a more in-depth literature review. Results of the scoping exercise validated the potential of an in-depth literature review, helped to fine tune the overall literature review questions, and determine the search criteria for the literature, which would include both peer-reviewed and grey literature.

### LITERATURE REVIEW QUESTIONS

**Overall research question: How can community-based HIV support services contribute to re-engaging PLWHIV back into healthcare in London?**

All sub-questions refer to the London area. Special attention should be given to London's health systems and services, and its demographic and geographic characteristics.

- 1) *What are the factors leading to disengagement from care?*
- 2) *Which groups are most likely to disengage from care?*
- 3) *What are the factors leading to re-engagement back into care?*
- 4) *What community interventions can lead to re-engagement in care, and prevent disengagement from care?*

### APPROACH OF THE LITERATURE REVIEW

In order to answer the research question and sub-questions above, the literature review took a PRISMA diagram approach, which was used to conduct the literature search and find relevant literature. This is based on:

- Identification – based on the research found
- Screening – based on the criteria used to filter the research
- Included – based on the final studies included in the literature review total. This includes academic and grey literature, mirroring recommendations from the scoping report

## INCLUSION AND EXCLUSION CRITERIA

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### GEOGRAPHIC FOCUS

In terms of geographic specificity, this review is limited to literature relevant to the health and population context of London albeit with references to the wider UK context. Consequently, potentially relevant literature, particularly from other European and US cities was excluded. It is beyond the scope of this literature review to consider such studies here, although a more in-depth review might benefit from their inclusion. Since sufficient, relevant literature was found on the topic in London this survey focuses on this region.

This limitation may present insights which are both applicable and relevant to other regions however some of the findings are not relevant as they may be determined by the particularities of the geography, both in terms of healthcare policies, systemic issues, local government administration as well as many population factors not least migration.

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### FOCUS ON DISENGAGEMENT AND RE-ENGAGEMENT

The literature review is focused on disengagement and re-engagement into HIV services, but not initial engagement into services to fit the focus of the overarching research question. The complexities of engagement and disengagement are explored in the conclusion, but for the sake of the literature review a broad focus is taken.

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### AGE OF LITERATURE

Research from the PubMed database has been included from the last five years for contemporary relevance, and partly to account for changing technologies (e.g. long acting injectables, PrEP, changing HIV medications etc.), changing demographics and shifting socio-cultural attitudes. However, this limitation will also include meta-analyses drawing on literature which references research published before this five-year timeframe.

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### IDENTIFICATION, SCREENING AND INCLUSION OF LITERATURE

Based on the initial scoping exercise, which included searching for literature and recording key words used in literature on the topic, the exact combination of words below was used to search the literature:

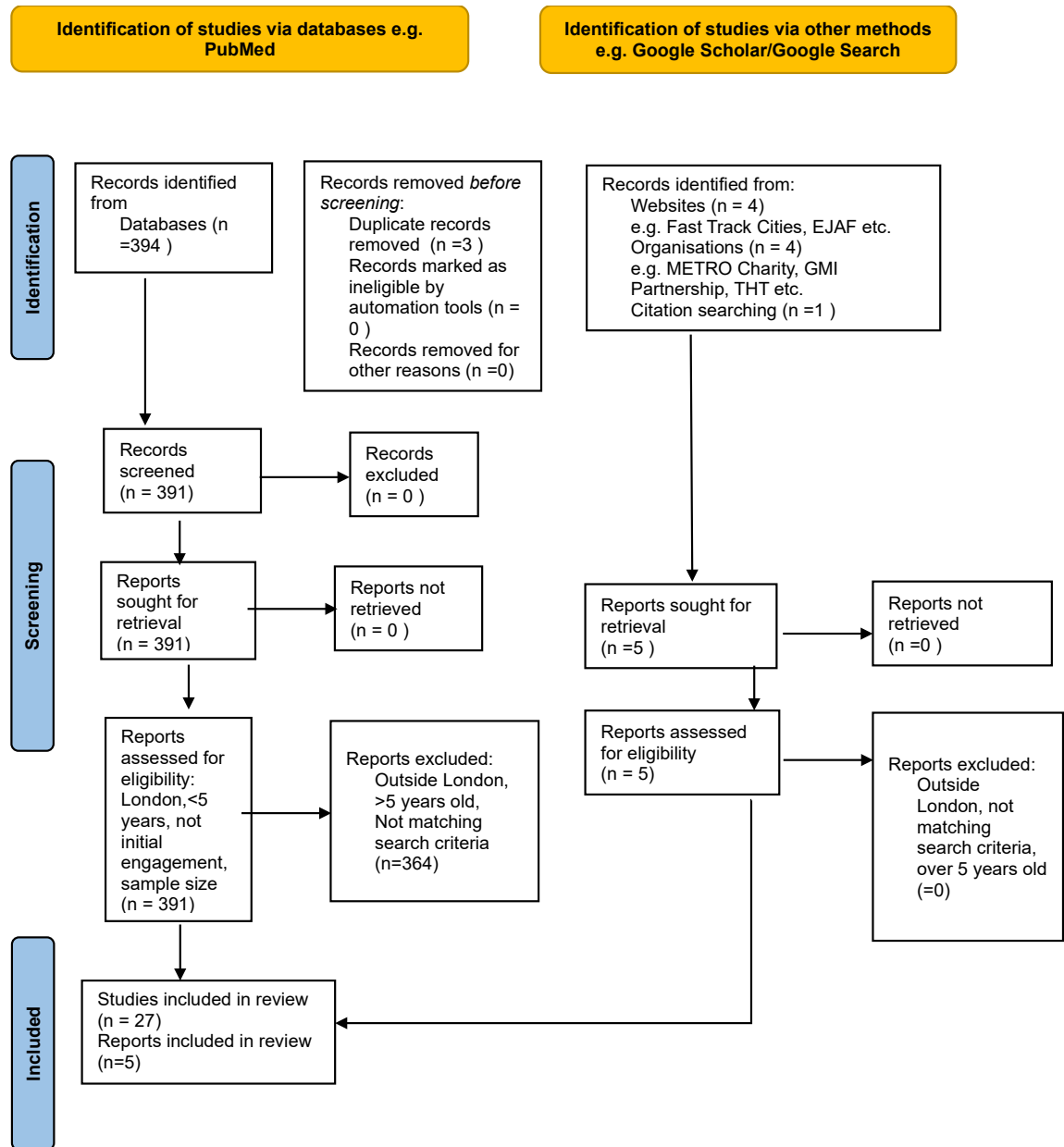
1. ***HIV + disengagement + London, 2018 onwards:*** (22 results, 3 met search criteria).
2. ***HIV + lost to follow up + London, 2018 onwards:*** 82 results, 4 met search criteria)
3. ***Re-engagement care + London + last 5ys:*** 30 results, 2 met search criteria)
4. ***Engagement in HIV care + interventions + London:*** (224 results, 14 met search criteria and one duplicate removed)
5. ***HIV adherence interventions London UK engagement:*** (36 results and 4 met search criteria – 2 duplicates were removed.)

These were the exact phrases that were used for the search using the PubMed database. In total there were 394 initial results using the criteria, of which 27 were determined relevant (i.e. related to the research questions, London based and not duplicates). The exact inclusion and exclusion criteria can be seen in the PRISMA diagram

below. In addition, the grey literature was also searched using Google searches using the exact phrases above. This resulted in the inclusion of additional literature, such as government and third sector reports.

This literature review took an approach aligned to a systematic literature review, in that it is structured and follows a specific methodology and uses a PRISMA diagram approach (see Figure 1), This was done to increase the reliability of the findings, and to increase the likelihood that the overall research and sub-questions can be answered satisfactorily.

**Figure 1 PRISMA diagram based on the screening criteria above (based on template Page et al, 2020)**



## LITERATURE REVIEW RESULTS

While interventions to encourage newly diagnosed persons to EIC, reduce disengagement from care after already being linked to care, and promote RIC appear to be similar, the literature does not allow firm conclusions on the extent of these similarities to be drawn. This is largely because the studies are not comparative, and many do not look at both reasons for disengagement and re-engagement in parallel, with the same populations or using the same definitions. For this reason, this literature review will focus on engagement and disengagement separately, although where there appear to be similarities and differences these will be highlighted.

### FACTORS FOR DISENGAGEMENT FROM CARE

Corresponding questions: [What are the factors leading to disengagement from care? Which groups are most likely to disengage from care?](#)

This section of the literature review will specifically focus on factors related to disengagement from care. While some studies on disengagement from care focus on factors and key populations in tandem (e.g. THT 2022, and Howarth et al 2021), others focus more specifically on populations (e.g. Chapell et al 2019, Lin et al 2019, EJAF 2020, Frost 2020, Okhai et al 2020 & 2021, Prevost 2022).

THT's (2022) 'Addressing Areas of Unmet Need' report makes various recommendations related to retention in care, including emphasising the importance of quality of life. The REACH study (Howarth et al 2017) analysed data from UK Collaborative HIV Cohort (UK CHIC) to determine cost-effective interventions around retention and engagement in HIV outpatient care.

Understanding disengagement from care is complex; one of the reasons is because the concept of disengagement from care is dependent on whether total disengagement, or irregular attendance (i.e. a partial disengagement), is being considered. The REACH study (Howarth et al, 2017) suggests that while factors for total disengagement and irregular attendance are similar, they are not identical. Other studies (THT 2022, for example) take a more binary engaged or disengaged approach. It could be argued that thinking about a continuum of engagement-disengagement might be a more accurate reflection of human behaviour, patient experiences, and cultural and socioeconomic factors. Throughout the literature review the language of the original studies around engagement will be used and if total or partial disengagement are differentiated, this will be noted.

Another complicating factor underpinning this topic is that understandings of engagement into, and disengagement from, care are often related to the HIV continuum of care. The patient's positioning along the HIV pathway and patient's life course<sup>1</sup> impact which factors influence engagement and disengagement and are important to consider when proposing, and answering this question (Jose et al 2018, EJAF 2020).

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<sup>1</sup> Life course theory provides a framework for understanding how our lives are influenced by interconnections between the individual, social and historical and how these influence decision-making and health outcomes over our life course. It emphasizes the importance of specific life events, such as career choices or marriage.

Figure 2 HIV Care Continuum Source: CDC (2023)



Jose et al (2018) suggest that a longitudinal approach, which uses a longer time frame, and examines mortality is important to understand those lost to follow-up (LTFU) or disengaged from care<sup>2</sup>. Following participants for 10 years, this research demonstrated that individuals were on ART 53% of the time and 75% of the time PLWHIV (i.e. those on ART 53% time) had a viral load under 200. The paper also showed that 25% of those became disengaged after 10 years, of which 26% transferred to other clinics and 6% died. As time increased, the likelihood of becoming disengaged decreased, and there was increased viral suppression.

In the studies considered, it is possible to group reasons for disengagement into several related categories: (i) protected identity characteristics, specifically race, sexuality, gender orientation, age, and pregnancy (ii) other related health issues such as mental and physical health and substance misuse (iii) Social Determinants of Health (SDH) (iv) HIV treatment, viral load and care, including stigma.

These will now be explored separately with reference to the literature.

#### PROTECTED IDENTITY CHARACTERISTICS AND OTHER FACTORS AFFECTING HEALTH

Two important concepts – intersectionality and ‘hard-to-reach’ groups were discussed in the literature as concepts relating to identity characteristics and communities that have a higher risk for disengagement from care.

#### INTERSECTIONAL IDENTITY CHARACTERISTICS

People living with HIV in London reflect multiple identities and many intersectional identity categories, which may also be subject to health inequalities and inequities. Consequently, these categories of identity can be seen as specific factors as well as related, and somewhat overlapping intersectional factors.

#### HARD-TO-REACH GROUPS

UK-based literature shows that certain groups are more likely than others to disengage from HIV care (Howarth et al 2017, Jose et al 2018, Lin et al 2019, Stevens et al 2019, EJAF 2020, Dhairyman 2021, Haag et al 2022, THT 2022). Lin et al (2019) uses the term ‘hard-to-reach’ groups to define several groups that they identify as having low levels

<sup>2</sup> Jose et al 2018 uses the term lost to follow up rather than disengaged from care. This literature review uses the term disengaged from care throughout and considers both to be synonymous.

of EIC. They also argue that these groups have low levels of treatment adherence, and by extension higher levels of disengagement, although they do not explore the causality. They define 'hard-to-reach' groups as homeless, sex-workers and Injecting Drug Users (IDU) and through a meta-analysis of 29 studies demonstrated that these groups had 45% less HIV treatment adherence. The reasons for this are not fully explored, but it is suggested that both low levels of social inclusion and increasing lengths of time on HIV treatment are correlated with adherence. One critique of the study is that the three specific groups are identified as 'hard to reach', although there are plenty of others who could have been considered, as this section of the literature review implies. Also, the classification of groups as 'hard to reach' problematises these groups, and perhaps even pathologises them, rather than focusing on the importance of, and approaches to, engaging them into care. Nevertheless, the study does indicate the importance of taking a population-level approach to understanding engagement and disengagement in HIV care. This is supported in the literature reviewed, as will now be highlighted.

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## RACE

Since the beginning of the HIV epidemic, we can see that certain identity factors have influenced disparities in HIV prevention, treatment, support and engagement in care. Racial and ethnic groups have been more affected by HIV than others, principally black Africans and other racially minoritised groups, indigenous and people of colour (BIPOC). Key factors include unemployment, health disparities (including limited access to quality healthcare, HIV testing, treatment and prevention), lack of cultural competency in healthcare systems, stigma and discrimination (including additional stigma as a result of socio-cultural factors and from those both within and outside of the communities), and cultural factors (i.e. cultural beliefs, practices and norms) (Marmot 2010 and Dhairyawan 2021). Nevertheless, it is also important to recognize that not all racially minoritised groups are affected equally by HIV and some groups, such as black gay and bisexual men and transgender women of colour, are disproportionately affected by HIV.

Not only are racially minoritised groups more likely to test positive for HIV (Bundle et al 2019), they are more likely to disengage from HIV services (EJAF 2020, Dhairyman 2021 & Prevost 2022) and show less adherence to HIV treatment (Howarth et al 2017). Whether there were cross-cutting gender disparities too seems unclear in the literature, but the EJAF (2020) report suggests this might be the case, indicating that it is black women, specifically, who are most likely to disengage.

Research by Dhairyawan (2021) demonstrated that heterosexual, racially minoritised people presented with lower CD4+ cell counts, spent less time EIC and were more likely to experience viral rebound than white people. Although 80% of the time the research cohort of heterosexuals from black, Asian and minority ethnic groups were EIC, this dropped to 70% for black African, and 74% for black Caribbean groups. Interestingly, there were no differences in treatment start or viral suppression by race. Whilst a study by Prevost et al (2022) also showed that EIC can be predicted by race, it was people identifying as Asian/mixed or those who 'prefer not to say' what was their race who were least engaged.

Although the literature considered in the review indicates that there is a connection between race and disengagement in care, there does not appear to be a consensus around which specific racially minoritised groups are more likely to disengage.

More broadly racial disparities are significant in the London and UK context in terms of the morbidity and mortality as most recently, and tragically, documented during the COVID-19 pandemic (ONS 2021). There are also well-evidenced systemic racism issues surrounding maternal care for racially minoritized women in the UK, likely bearing on the experience of pregnant women living with HIV in London (see below).

The research suggests the importance of community targeted interventions to maintain racially minoritised people in HIV care, however, the specific nature of any such interventions is not explored in the literature.

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## SEXUALITY

Although the studies considered in this review do not specifically consider the relationship between sexuality and EIC, two studies did refer to sexual behaviour. For example, Howarth et al (2017) suggests that men who acquired HIV through sex with other men had higher EIC as compared to that acquired HIV through other routes, and the EJAF (2020) report demonstrated lower EIC among heterosexuals. It is interesting that while HIV prevention work has often focused on Gay, Bisexual and other Men who have Sex with Men (GBMSM) in the UK, the research around EIC seems to indicate that it is heterosexual communities who are less likely to EIC. This is most likely a consequence of the success of HIV prevention and treatment campaigns working with GBMSM in the UK. Historically, the HIV pandemic of the 1980s and 1990s in the UK affected GBMSM predominantly, although heterosexuals IDU, haemophiliacs etc were also affected, and this has shaped public health promotion and targeting of HIV preventing and testing. However, the two studies that explicitly refer to sexuality seem to imply that interventions are now needed to target heterosexual communities as they may be less likely to EIC.

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## GENDER, WOMEN AND TRANS PEOPLE

Various studies indicate that being female is a predictor of lower EIC (Howarth et al 2017, EJAF 2020, Okhai 2020), and some studies connect this specifically to having children (Howarth et al 2017, EJAF 2020). Although the multiplicity of reasons for this are unclear in the studies considered, childbirth, economic status, patriarchy, misogyny and socio-cultural power differences are likely to be factors. Importantly, we were unable to find data around trans communities and EIC. This is a particularly significant omission in the available data and research given the high rates of HIV among trans communities in the UK (NAT 2017).

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## AGE

UK data shows age inequalities in PLWHIV's access to care and retention in treatment. Data appears to suggest that those at both ends of the age spectrum, those who are older (Howarth et al 2017, Okhai 2020, Dhairyawaman 2022), and those who are younger (Howarth et al 2017, Chapell et al 2019, EJAF 2020, Foster 2020) are more likely to disengage from HIV care. For example, Howarth et al (2017) suggest that while older people were more likely to demonstrate irregular EIC, complete disengagement in care was associated with being younger.

While 98% of PLWHIV are on treatment and 97% of these are virally suppressed, viral suppression is significantly lower among young people (EJAF 2020). This is supported by Chapell et al's (2019) research on the HIV cascade of care which identifies adolescents specifically as the group most likely to disengage from care and to have poorer health outcomes. For example, of all the different age cohorts of young people, those aged 15 to-24 were less likely to be virally suppressed (79% vs. 91% overall) and have poorer immune systems (with an average score of 78% vs. 94% overall). Foster (2020) also makes similar conclusions related to adolescents in transition from child to adult HIV services. In a sobering comment, Foster (2020) reminds us that adolescence is the only age group globally where HIV-associated mortality is rising and there are poorer outcomes at each stage of the HIV cascade among adolescents, compared with adults<sup>3</sup>. This research suggests that youth-friendly multidisciplinary services can help achieve high EIC and uptake of ART.

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<sup>3</sup> Although UK data appears to show declining mortality rates across all age-groups (Simmons et al 2013).

Okhai et al's (2020) study shows that EIC is lower for both older men and women, and that viral suppression is lower and viral rebound is more likely among older women (specifically when comparing those over and under 50), although there were no differences among heterosexual men.

The importance of interventions around EIC targeting older women was highlighted by Dhairayman et al (2022) whose research suggests that women ageing with HIV countered the 'violence of invisibility', that is an aggressive social invisibility, which can be seen in a corresponding lack of HIV interventions. They argue that through self-organisation and forming communities with older women living with HIV they are 'rejecting stigma and enacting a personal form of advocacy through care for others' and are more likely to be EIC.

The data suggests a pressing need for targeted support for young people (specifically adolescents) and older people (specifically women) to encourage retention in care.

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## PREGNANCY

Two studies looked at the connection between EIC and pregnancy (Okhai et al 2021 & Peters et al 2021). Okhai et al's (2021) study suggests that engagement in HIV care is higher during pregnancy, and that women are most likely to EIC post-partum, although the reasons for this are not explored in detail. Peters et al (2021) looks at infants born to women living with HIV (WLWHIV) and demonstrates that vertical transmission is most likely to occur where the mother has difficulties engaging with ART, where antenatal booking was late and where HIV testing declined before pregnancy. They also identify a connection between social circumstances and vertical transmission, with many of the women with children diagnosed with HIV experiencing uncertain immigration status, housing problems and intimate partner violence.

Pregnancy represents an important opportunity to (re-)engage WLWHIV in care and to reduce infections, improve ART adherence. It is important that a holistic approach is taken, which recognises the social context faced by pregnant women, and, increasingly, trans men (Oakes-Monger, 2022).

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## MENTAL HEALTH AND DISABILITY

The literature considered suggests that physical and mental health are important predictors of disengagement from care. In terms of physical health those that required HIV hospitalisation, and those that had complex health needs were more likely to disengage. Neurocognitive impairment was also related to irregular EIC (Howarth et al 2017).

Solomon et al (2021) and Haag's (2021) recent studies looked at the health of menopausal women and found a link between EIC and severed somatic and psychological symptoms. Women who reported severe menopausal symptoms were found to demonstrate suboptimal ART adherence and suboptimal clinic attendance Haag et al (2021) found that antiretroviral therapy adherence was lowest in three of five menopausal groups considered, (1) those with history of depression, with elevated current substance use, (2) those with history of depression with current psychological menopause symptoms and (3) those with high previous and concurrent mental health problems. Those in the last group were more likely to have missed one or more HIV clinic appointments in the past year than those in class (1) (34%, vs. 17% in the lowest group). Overall, women with a history of depression, current anxiety or depression, and current menopause-related mental health symptoms were more likely to have poorer clinical outcomes.

Similarly, other studies also indicate that those with mental health diagnoses, such as depression, were recognised as more likely to disengage from care, as were those who felt they had little control over their lives (Howarth et al

2017 and Prevost et al 2022). Individuals who have self-harmed are also more likely to have poor EIC. (Prevost et al 2022).

The studies above suggest the importance of managing physical health symptoms and mental health to improve engagement in HIV treatment and care. Some of the recommendations at an intervention level are considered later in the literature review.

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## SUBSTANCE MISUSE

Recreational drug use and alcohol dependency were recognised as factors for disengagement from care (Howarth et al 2017). Non-attendance and irregular attendance were found to be associated with drug use. For example, Howarth et al 2021 showed that sub-optimal clinic attenders were more likely than regular attenders to report chemsex drug use in the past year (46.9% vs. 33.2%). In particular, those having taken chemsex drugs in the past five years were more likely have sub-optimal attendance, and those with suboptimal attendance they were more likely to have injected drugs in the last year (17.1% vs. 8.9%). One in five sub-optimal attenders had missed an HIV clinic appointment because of taking recreational drugs.

Other studies show that those who acquired HIV through IDU have lower adherence to treatment (EJAF 2020), and this may imply that continued IDU could be a factor for disengagement. Yalin et al's (2021) study shows higher rates of HIV diagnoses and lower rates of treatment adherence among chemsex users. It also suggested that there were significantly higher rates of stimulant, GBL/GHB (Gamma Butyrolactone/Gamma HydroxyButyrate) and psychedelic use among PLWHIV than those that were not HIV positive. In addition, the EJAF (2020) report suggests that the nature of HIV acquisition appears to have an impact on treatment adherence and viral suppression. Although viral suppression (which can be used as a crude measure for engagement in care), is high, at around 98% for PLWHIV in general, this drops to 89% for those who acquired HIV through injecting drug use 91% for those that acquired HIV through vertical transmission.

Other studies around chemsex and use of PrEP might shed some light on useful approaches to prevent disengagement from care and promote treatment adherence among chemsex users LWHIV (Stevens et al 2019, Yalin et al 2019 and Maxwell 2021). For example, Maxwell et al's (2022) study into PrEP use among men engaging in chemsex showed that participants employed a variety of strategies to help them adhere to PrEP, which included restricting the amount or intensity of chemsex they engaged in, strategic placement of PrEP and external triggers to remind them to take PrEP. This could help inform useful interventions for chemsex users LWHIV.

## SOCIAL DETERMINANTS OF HEALTH

Various studies directly and indirectly refer to the impact of social determinants of health (SDH) on EIC. The WHO defines these as 'the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life' (WHO, 2023). Low income is seen as an important factor in disengagement from care (Howarth et al 2017, EJAF 2020). For example, not having money to meet basic needs and having to take public transport were seen as factors related to disengagement from care. In addition, not being a homeowner was also a significant predictor of engagement in care (Howarth et al 2017). Such SDH are specifically likely to impact disengagement in a city like London where spiralling housing costs mean home ownership rates are lower compared with the rest of the UK (English Housing Survey 2020), and where transport costs are relatively high.

Peters et al (2021) show that factors such as immigration status, partner violence and housing impact EIC and treatment adherence while Howarth et al (2017) demonstrate a connection between lower levels of education and

non-attendance at HIV clinics, and between being registered with a GP and non-attendance<sup>4</sup>. In addition, Dhairayman (2022) identifies a connection between being part of a community (among older women living with HIV) and higher levels of EIC and treatment adherence.

These studies suggest that it is crucial that interventions do not focus solely on the biomedical factors related to engagement and disengagement from care, but also on SDH. Data from these studies can help focus interventions on specific SDHs and deficits, such as poverty, education, immigration, partner violence and housing, as well as assets such as community networks.

## FACTORS RELATED TO TREATMENT, CARE AND DIAGNOSIS

The THT (2022) report, 'Addressing Areas of Unmet Need', mentions that lack of a systematic and co-ordinated healthcare approach is also a key factor in disengagement from care. Within the NHS and voluntary sector, it seems that there is lack of communication between different individuals and organisations involved in a patient's healthcare. For example, Howarth et al (2017) identified that patients' not feeling listened to by those involved in HIV care, such as nurses was a factor related to disengagement from care (Howarth et al 2017) and implies a need for health workers' training around patient interaction and care for those living with HIV, in particular, to ensure that HIV stigma is reduced.

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### STIGMA AND LACK OF KNOWLEDGE

Two studies identify stigma as a factor for disengagement from HIV care (Howarth et al 2017 and THT 2022). The report by Howarth et al (2017) suggests that both self-stigmas, related to lack of acceptance and denial of one's HIV status, and fear of societal HIV stigma, such as from one's own community, were related to disengagement from care. One predictor of irregular engagement in services, for example, is HIV status remaining undisclosed within families among PLWHIV (Howarth et al 2017). In the THT (2022) report, stigma in care homes was mentioned specifically as a key factor, and reducing stigmatisation was seen as crucial for facilitating retention in care. Nevertheless, the exact nature of what such interventions would look like was not explored and would be a useful avenue for future research. In addition, the THT (2022) report recognises low levels of HIV literacy among persons working in non-HIV services, including care homes as an additional factor leading to disengagement. It is clear that interventions to increase HIV knowledge and reduce stigma are (unfortunately, still, in 2023) required to reduce disengagement from care.

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### PLWHIV DIAGNOSED LONG-TERM VERSUS THOSE RECENTLY DIAGNOSED

Although two of the studies identified time living with HIV and age of diagnosis (Jose et al 2018 and EJAF 2020) as factors around EIC, the findings appear inconclusive. For example, in their longitudinal study Jose et al (2018) posit that as time since diagnosis increases the chance of being disengaged from care decreases. However, EJAF's (2020) Social Impact Bond (SIB) report suggests that non-attendance (i.e. complete disengagement in care) at HIV clinics is more likely among those who have been diagnosed with HIV for longer. There appears to be a lack of London-focused data to conclude the relationship between time since diagnosis and EIC.

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### ADHERENCE AND VIRAL LOAD

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<sup>4</sup> This is likely to have been exacerbated by increasingly poor GP access post-COVID19, although there is not currently literature on the topic.

One study suggested that those with a lower viral load and higher levels of adherence were more likely to remain EIC (Prevost 2022). This seems to support previous research (Jose et al 2018, EJAF 2020) which suggests that those that have been diagnosed with HIV for longer are more likely to remain in care, as these groups are more likely to have lower viral loads and to be on effective treatment.

The importance of interventions to reduce viral load and achieve higher levels of adherence are implied by such studies.

## POLYPHARMACY

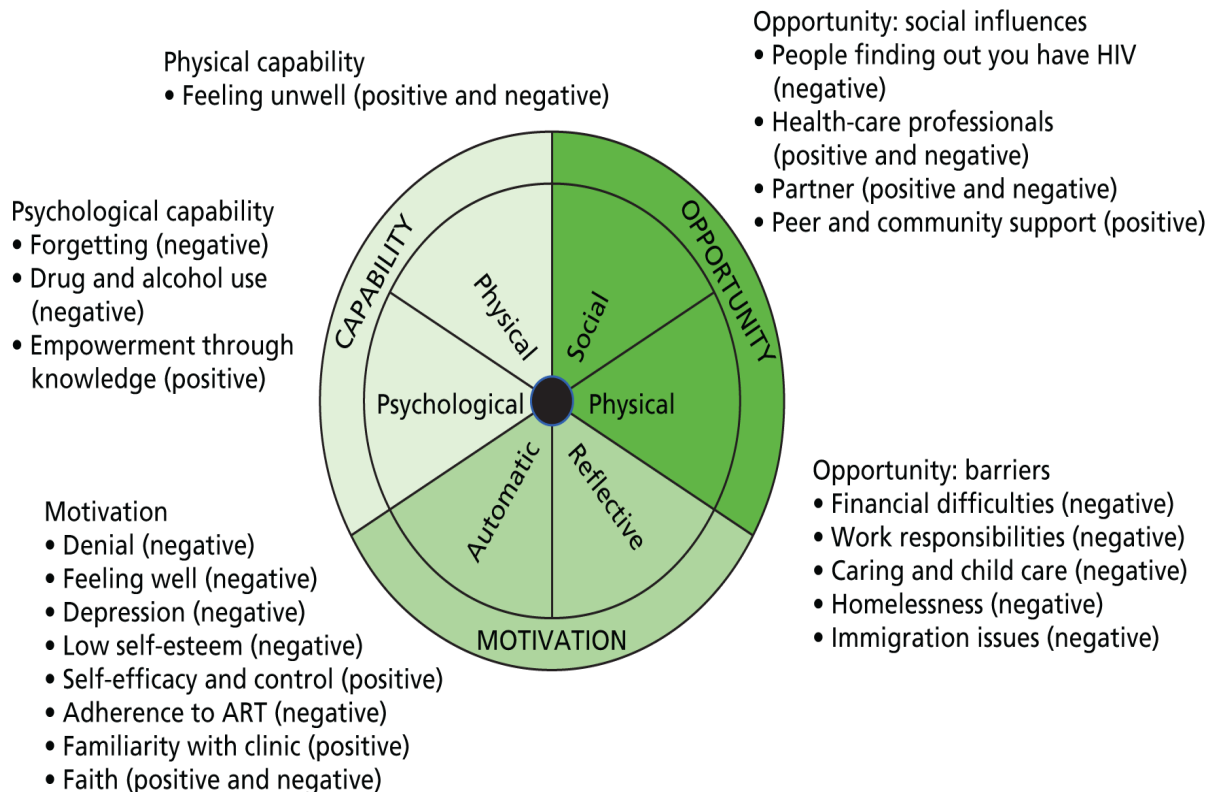
One study identified polypharmacy i.e., those taking multiple medications for different illnesses simultaneously, as a factor related to disengagement from HIV services (THT 2022). This might be a useful group with whom to target future interventions given the propensity of this group to disengage from care.

## INTERVENTION RECOMMENDATIONS FOR REDUCING DISENGAGEMENT FROM HIV CARE

Corresponding question: [What community interventions can lead to re-engagement in care, and prevent disengagement from care?](#)

Many of the factors above are addressed in the following diagram in the REACH report (Howarth et al 2017), which classifies by categories, such as physical, psychological capabilities, motivation, opportunity (social influences), and opportunity (barriers).

Figure 3 Key Factors of HIV clinic attendance – REACH study (Howarth et al 2017)



The report suggests that each of these factors can then be separated into enablers and barriers to clinic attendance, thus reducing disengagement. The enablers will be discussed in the next section related to EIC.

**Table 1 Enablers and barriers – HIV clinic attendance (Howarth et al 2017)**

<b>Enablers</b>	<b>Barriers</b>
Peer support Familiarity with clinic Self-efficacy and control Empowerment through knowledge	Financial situation Work responsibilities Caring and childcare Homelessness Immigration issues People finding out about HIV status Adherence to treatment Low self esteem Depression Denial Feeling well Drugs and alcohol Forgetting

Based on the literature reviewed in this section it is possible to identify specific intervention and target groups to reduce disengagement from HIV care.

**Table 2 Table of intervention recommendations for reducing disengagement from HIV care – based on the literature reviewed**

<b>Focus of intervention</b>	<b>Example interventions</b>	<b>Target group</b>	<b>Potential provider</b>
Reduction of HIV stigma and increasing HIV knowledge	Training of healthcare professionals and training in care home staff	Healthcare professionals Care Home Workers	GMI Other Community-based organisations NHS
Psychological interventions to deal with mental health	Mental health and wellbeing groups, counselling and psychotherapy to increase agency among PLWHIV	PLWHIV experiencing poor mental health	GMI IAPTs <sup>5</sup> Mental Health Providers
Measures to combat the impact of living in poverty	Transport support, and wider poverty reduction work – policy and practice influence	PLHIV living in poverty	GMI Poverty reduction charities Poverty policy and practice organisations
Interventions around alcohol and drug use	Chemsex interventions possibly building on learnings from PrEP	PLWHIV engaging in chemsex	GMI Drug and alcohol service providers

<sup>5</sup> Improving Access to Psychological Therapies

Focus of intervention	Example interventions	Target group	Potential provider
	adherence interventions with chemsex users.		
Interventions focusing on with people of colour <sup>6</sup>	Community designed and led interventions focusing on language, cultural barriers, stigma, homophobia and heteronormativity	Racially minoritised communities	GMI Organisations working with BIPOC
Targeted interventions based on age	Interventions focused on adolescents and interventions focused on older women LWHIV	Young people Older people	GMI Organisations working with younger and older people
Interventions focused on the social determinants related to disengagement from care.	Interventions targeting pregnant women that recognize the socioeconomic factors.  Interventions focused on factors such as poverty, housing, intimate partner violence, education.	Pregnant women  Those living in poverty Those experiencing partner violence	GMI Voluntary organisations working in poverty Domestic Violence organisations Housing and homeless charities
Healthcare co-ordination, collaboration and connectedness	Treatment plan formulation, care co-ordination, holding client cases, communicating with healthcare providers	PLWHIV	GMI HIV clinics HIV Charities Mainstream organisations

Some of the literature (Jose et al 2018, EJAF 2020) considered suggests that, generally, it is important to focus on EIC as a continuum, rather than a binary. In this way, it appears that ‘increasing engagement’, rather than aiming for ‘complete engagement’ is probably a more useful and achievable way to frame the interventions outlined above. In addition, much of the literature considered implies that interventions must be targeted towards heterosexual communities (e.g. EJAF 2020), which have often not been the focus of HIV campaigns and interventions thus far, and which show lower rates of EIC. Although the literature considered does not provide pointers as to how this might be achieved, which represents a limitation to answering the overall question around planning interventions.

**FACTORS LEADING TO RE-ENGAGEMENT INTO CARE**

Corresponding question: *What are the factors leading to re-engagement back into care?*

**OVERVIEW OF DIFFERENT INTERVENTIONS LEADING TO RE-ENGAGEMENT INTO CARE**

<sup>6</sup> Although there is considerable literature on the topic, the research considered does not describe the nature of needed interventions to increase EIC among BIPOC in sufficient detail to make more specific recommendations. However, recent reports, such as the HIV Commission (2020) suggest the need for community responses that are culturally and linguistically tailored and that focus on stigma.

The EJAF SIB report evaluated funded projects’ success in re-engagement into care (RIC) of PLWHIV who had previously disengaged from care. The data indicates the number of PLWHIV, their CD4 counts, and the cost per person of four different interventions:

**Table 3 Table of interventions for re-engagement into care - based on EJAF (2020) report**

Intervention	Number of people RIC	CD4 count less than 350	Cost per person
HIV clinic audit and recall	153	63	£3000
Opt-out testing	53	54	£5200-6300
Primary care audit and recall	45	51	Less than £10,000
Voluntary, Community and Social Enterprises contacting people as ‘trusted contacts’	4	40	Less than £10,000

Despite the significant time needed to establish rapport with patients the data implies that HIV clinic audit and recall is the most cost-effective way to reach relatively large numbers of people with low CD4 counts and re-engage them in care. However, the study also suggests that currently there is a lack of funding for Voluntary, Community and Social Enterprise (VCSE) organisations to assist HIV clinics with audit and recall work.

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## PEER SUPPORT

There is a growing body of literature pointing to the importance of peer support to facilitate re-engagement into HIV care (Thompson 2012, Howarth et al 2017, Berg 2021, Stevenson 2021, DHSC 2022 & Higa et al 2022), and some of these studies give clear guidance in terms of the efficacy of different peer support approaches.

A recent DHSC (2022) report suggests that peer support is crucial, especially when individuals may struggle to prioritise care and treatment because of other factors, such as housing, immigration and mental health. Indeed, it states *‘Peer support models, where assistance and encouragement are provided by an individual considered equal, is not only a highly effective approach for referring to and retaining people living with HIV in care and treatment, but also meets wider individual wellbeing needs in holistic ways’* (DHSC, 2022, p 30).

Berg et al (2021) explored the efficacy of peer support for PLWHIV through a meta-analysis, arguing that peer support alongside clinical support is superior in linking, re-engaging and retaining patients in care. They looked at ART initiation, CD4 cell count, quality of life and mental health, concluding that peer support appears to be a feasible and effective approach to link to care. Programme differences, and inconsistent measurement and reporting did make comparisons difficult though, and they were hesitant in drawing firm conclusions about efficacy.

Similarly, the REACH study (Howarth et al 2017) also looked at what influence peer support had on facilitating re-engagement into clinical care, and despite a small cohort, the study findings indicated that becoming ill, receiving phone calls from clinics (e.g. reminders about appointments), and contact with community organisations were factors facilitating RIC.

Literature from the United States on the topic chimes with UK-based literature considered for this review. The CDC (2023) Prevention Research Synthesis Project on HIV prevention began in 1996 and to date provides insight into evidence-based interventions (comparative studies, rigorous with large cohorts) and evidence-informed interventions (not comparative with smaller numbers) and best practice, with a focus on the US. The CDC (2023) overview document based on the findings so far indicated that using patient navigators, providing strengths-based case-management, offering information and education about HIV care (e.g. displaying posters and brochures in waiting rooms, having medical providers present brief messages to patients) are potential strategies for improving linkage to, and retention and re-engagement in, HIV care. The findings of this research also indicated that addressing structural- and system-level barriers (e.g., offering transportation, helping with appointment coordination, providing colocation of services) may help engage and retain persons in HIV care.

Similarly, reports by Higa et al (2016 and 2022) indicated that psychosocial support, appointment help, and offering transportation may be helpful for retention in and re-engagement in HIV care. This is mirrored by recommended strategies, such as patient navigation and strength-based case management, which are recommended by the International Association of Physicians in AIDS Care (Thompson et al, 2012).

One of the reasons peer support appears effective is that it can create a community network. Stevenson et al's (2021) paper demonstrates that older women living with HIV were able to create a 'vital space of safety' with spaces where they could seek support, get advice and create meaning related to living with HIV. Another factor in the efficacy of peer support is that it may help individuals to prioritise care and treatment, which might otherwise be de-prioritised by other issues, such as housing, immigration and mental health (DHSC 2022).

The literature around peer support models provides useful pointers in terms of effective approaches. For example, Hazell et al (2022) looked at interventions and viral suppression among young adults before and during COVID and concluded that while remote consultation was useful for stable patients, face-to-face peer support appointments maintained high levels of EIC and viral suppression among vulnerable<sup>7</sup> patients.

In addition, Beck et al 2022 concluded that the EmERGE programme, which enables individuals to communicate with caregivers via their smart phone is an effective intervention. CD4 count and viral load were reduced, and patient activation and quality-of-life were increased. They argue it was a cost saving intervention (9% reduction in costs) and resulted in patients remaining engaged and clinically stable. However, one possible criticism of the study was that 94% of the participants were men, and there are uncertainties to the replicability and applicability for other groups.

One focus for peer support could be on engaging with patients around their pre-treatment beliefs as they start ART. A study by Horne et al (2019) indicates that patients' pre-treatment beliefs about ART predict the subsequent reporting of side effects and adherence to treatment. Pre-treatment concerns about ART were associated with significantly more side effects at 1 month and 6 months (side effects at 6 months predicted low adherence at 12 months ( $p < 0.005$ )). These findings have implications for the development of interventions to support patients initiating ART. Approaches to pre-empt, discuss and challenge beliefs are likely to result in higher adherence and EIC.

Horne et al (2019) are currently evaluating another programme – 'The Supporting Uptake and Adherence' intervention, which consists of four tailored treatment support sessions delivered by a research nurse utilising a

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<sup>7</sup> The term vulnerable is used to refer to those with complex medical, psychosocial or mental health needs. It is not possible in this review to unpack or critique their use of the term, although it is problematic.

collaborative Cognitive Behavioural Theory and Motivational Interviewing approach. The sessions were tailored to patient need and barriers to ART and used an intervention manual and animation series. The final results, which have not yet been published, are likely to provide more guidance in effective peer support interventions around RIC for PLWHIV, in addition to those outlined above.

Overall, the research considered suggests that peer support is effective at meeting the needs of PLWHIV in a holistic manner including engaging and retention in care and provides some clear guidance on effective peer-support approaches.

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## HIV STIGMA

Research suggests that addressing HIV stigma is crucial in order to re-engage PLWHIV into care (Howarth et al 2017, Cane et al 2018, EJAF 2020, THT 2022).

It is important to note that HIV stigma can be broken down into two related categories: (1) social stigma – negative attitudes, beliefs and stereotypes society holds towards individuals living with HIV, and (2) self-stigma, which is internalised negative beliefs, shame and feelings of inferiority internalized from society. For the sake of the literature review they are considered together.

Howarth et al (2017) highlight the negative impact of stigma on attendance and the importance of interventions to boost retention, and engagement, in care. They suggest specific interventions, such as peer support, holding clinics in alternative locations and training staff to increase EIC and RIC. A report by THT (2022) casts further light on the specific nature of stigma-based interventions that might be useful. These include those with a focus on the intersectional nature of our identities, and stigma reduction and HIV awareness training for healthcare professionals, especially those working outside the HIV field. This is consistent with findings of the EJAF (2020) report, which identifies fear of stigma as a barrier to re-engagement in care. This includes stigma from healthcare professionals as well as from one's own communities. Addressing self-stigma is also seen as crucial as the shame, isolation and lack of acceptance of one's HIV status can be linked to less engagement in services. As suggested in the EJAF (2020) and THT (2022) reports, a recent DHSC (2022) report reiterates the need to address stigma through HIV awareness and stigma reduction training, including with healthcare staff and mainstream services to re-engage PLWHIV in care.

One useful approach identified by Cane et al (2018) is for PLWHIV to work with HIV support workers to facilitate access to resources and complex healthcare systems. They argue that the importance of HIV support workers should be recognised and as they often represent trusted professionals with whom PLWHIV can address stigma, discrimination and barriers to services. Although the focus of the study is on PLWHIV accessing fertility and adoption services, this could also prove a useful approach for accessing HIV services based on research suggesting the need to address stigma and self-stigma to achieve RIC (Howarth et al 2017, EJAF 2020, DHSC 2022, THT 2022).

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## TESTING

Research suggests that HIV self-testing and opt-out community testing<sup>8</sup>, such as in A&E departments, is crucial to EIC and RIC of PLWHIV (Hill-tout et al 2016, Philips 2016, Parry et al 2018, Bundle 2018 & Witzel 2020).

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<sup>8</sup> Some of the literature in this review refers to A&E department testing as 'community testing', although many voluntary sector organisations would not. Here the term is used to match how it is used in the literature reviewed, although it is recognised this is not how organisations, such as GMI, might use the term.

As commented above, a key strand to the UK's HIV prevention and treatment approach has been to roll-out opt-out testing at specific A&E departments across the country where HIV prevalence is high. Data suggests that this is a successful approach, both in terms of diagnosing PLWHIV and linking to care, as well as subsequent re-engagement in care. For example, a report by Philips (2016) followed a London acute medical unit over 21 months. 32.5% admissions had HIV tests and 0.48% tested positive. This resulted in 20 diagnoses (of which 17 were new). Importantly, two long-term defaulters to HIV care with very advanced disease re-engaged resulting in excellent clinical outcomes. 11 patients are now on treatment with undetectable HIV viral loads. The study highlighted A&E department testing as an important opportunity for both initial EIC and RIC. This was reiterated by Hill-tout et al (2016) whose study demonstrated that not only did screening identify those not in traditional 'high risk' groups, but also re-engaged patients who had defaulted with HIV care.

Witzel's (2020) study evaluated HIV self-testing and concluded that it is an important health intervention with high rates of acceptability. In their study respondents who tested HIV positive were quickly linked to care. However, it should be noted that DHSC (2022) report also notes that referral into care is quicker from hospital infectious disease unit testing (98% within 2 weeks) than with self-sampling (75% in two weeks). This should be considered when future interventions are planned.

In keeping with the conclusions of the THT (2022) report, it appears crucial to extend opt-out testing to areas outside London, and to all high prevalence areas, and to extend availability of online postal testing to EIC and RIC PLWHIV in London.

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#### COLLABORATIVE AND MULTIDISCIPLINARY APPROACH

Reports by THT (2022) and DHSC (2022) both argue that a collaborative working approach involving the people, organisations and providers involved in the support of PLWHIV is crucial. THT's report (2022) suggests that increased collaboration is needed between HIV clinics and VCSE and primary care collaboration to support RIC. They argue that improved collaboration between health and social care services is needed. Similarly, the recent DHSC (2022) report argues that collaborative working, and system leadership is needed, especially to RIC those with complex needs.

The above reports do not explore what this collaboration might look like in-detail, but working with patient care teams who hold and formulate the patients care plans and direction (as in the London-based Support and Advice on Sexual Health (SASH)<sup>9</sup> project's care coordination) as well as interdisciplinary and inter-organisational professional meetings to discuss and refer client cases could be important starting points.

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#### HIV CONTINUUM OF CARE APPROACH

Some literature suggests that when planning interventions around EIC and RIC it is useful to think of the 'continuum of care model' outlined above (Jose et al 2018). At certain stages in the continuum of care model patients are more likely to become disengaged and the barriers and facilitators to RIC change depending on the stage PLWHIV are [within the healthcare system]<sup>10</sup>. For example, there is evidence that PLWHIV are more likely to disengage from care and show lack of adherence to treatment as time increases post-diagnoses (EJAF 2020). Other research indicates that there are certain windows of opportunity around the diagnosis stage, which allow PLWHIV

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<sup>9</sup> Sexual Health Support in London - <https://www.sashlondon.org/>

<sup>10</sup> This is not to say that PLWHIV move chronologically in one direction or statically occupy one stage. This is suggested with the understanding that PLWHIV may move back and forth between different stages, or even occupy more than one stage simultaneously.

to be engaged, and hopefully retained in care, as demonstrated in A&E department testing, and HIV testing of pregnant women (Peters et al 2013).

## TOOLS AND MEASURES

Two of the studies considered focused on specific tools and measures that might be useful in EIC and RIC of PLWHIV (Bristowe 2019 and Howarth 2021). Bristowe et al (2019) explored the pros and cons of using a model of person-centered care incorporating HIV-specific Patient Reported Outcome Measures (PROMs). The data collected from stakeholder interviews shows that there are perceived benefits of using PROMs in routine HIV care including improved person-centeredness, patient empowerment, fewer missed concerns, increased engagement with services, and informed planning of services. Although, there were also potential challenges and access barriers including heterogeneity of PLWHIV, literacy, and utility for those who struggle to engage with care. Thus, although it might not be suitable for everyone, the use of PROMs in routine HIV care could bring benefits for PLWHIV, as well as others involved in their care and service providers, and could help increase EIC and facilitate RIC.

In a different context, Howarth et al (2021) suggest the importance of (1) systematic assessment of drug use and (2) development of tools to aid routine assessment. They argue that chemsex drug use should be addressed in interventions with PLWHIV, partly through use of an assessment tool, and that doing so will improve EIC (at least for GBMSM LWHIV).

## INTERVENTION RECOMMENDATIONS FOR INCREASING RE-ENGAGEMENT INTO HIV CARE

Corresponding question: *What community interventions can lead to re-engagement in care, and prevent disengagement from care?*

**Table 4 Table of intervention recommendations for improving re-engagement into HIV care – based on the literature reviewed**

Focus of intervention	Examples interventions	Target group	Potential provider
HIV testing	Extending emergency department opt-out testing to areas outside London and extending online postal testing.	PLWHIV – those diagnosed and ‘hard to reach’ and those disengaged from care	GMI NHS Other HIV and sexual health organisations
Stigma reduction	Self-stigma and social stigma reduction interventions e.g. working with HIV support workers, training healthcare and mainstream support workers, as well as addressing community and self-stigma. Peer support and alternative clinic locations.	PLWHIV Wider community Healthcare staff Mainstream support workers	GMI Other HIV and sexual health organisations
Peer Support Interventions	Healthcare navigators, psychosocial support e.g.	PLWHIV	GMI

Focus of intervention	Examples interventions	Target group	Potential provider
	motivational interview-based interventions, collaborative CBT and those addressing beliefs related to ART. Appointment support, smart phone communication.		Other HIV and sexual health organisations HIV clinics
A collaborative multi-disciplinary working approach	Patient referral and support meetings, as well as setting up HIV care support teams.	Stakeholders involved in HIV patient care	GMI, other HIV and sexual health services, HIV clinics, healthcare providers, mainstream services
Tools and measures	Use of PROMs, and chemsex use tool could be incorporated into HIV assessments and interventions.	Service providers	HIV care providers, including clinics, drug and alcohol providers

## DISCUSSION

### LITERATURE REVIEW QUESTIONS

The literature considered in the review provides good insight into the populations most likely to disengage from HIV care, reasons for disengagement and interventions that can facilitate re-engagement in care. In this way the literature considered successfully helps to answer the questions outlined in the outset.

#### POPULATIONS MOST LIKELY TO DISENGAGE FROM HIV CARE

The literature clearly indicates differences in propensity to disengage from HIV care. Certain populations are more likely to disengage, namely racially minoritised communities, drug users, those with poor mental health, young people – especially adolescents, older people, heterosexuals and pregnant women. Differences between those who have recently been diagnosed and started treatment, and those living with HIV for a longer amount of time seem to be inconclusive.

London is one of the most diverse cities in the world and the literature implies that approaches to prevent disengagement from HIV care must reflect not only this diversity, but the complex reasons why certain populations are more likely to disengage.

#### FACTORS FOR DISENGAGEMENT AND FACILITATORS FOR RE-ENGAGEMENT

Despite the challenges of defining disengagement and re-engagement there are many factors that can still be identified as increasing the propensity to disengage from HIV care in London and others that facilitate re-engagement. In some cases, the factors preventing disengagement and those promoting re-engagement are the same, although there appear to be differences too. Similarities include the social determinants related to the socio-economic context and include factors such as housing, poverty, intimate partner violence and immigration status. Another similarity is HIV social-stigma and self-stigma, which includes stigma experienced in accessing HIV

and wider support services. Finally, an additional similarity is the presence of a collaborative and connected approach across the multidisciplinary services involved in a patient's HIV support, which is identified as both reducing the risk of disengagement and an important factor in facilitating re-engagement. Other factors were only mentioned within the context of disengagement or re-engagement, but not both. For example, chemsex use was identified as a factor contributing to disengagement from care. Others such as peer support programmes and community HIV testing were identified in the context of being important enablers for re-engaging PLWHIV in HIV care.

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## INTERVENTIONS

The literature reviewed outlines interventions that are useful to reduce the likelihood of disengagement from HIV care and services, and others that can facilitate re-engagement in services. Some of these overlaps, whereas others appear not to do so. For example, interventions identified that can reduce disengagement from HIV care include those that increase HIV knowledge, reduce HIV stigma and self-stigma, provide mental health support, and those focused on wider social determinants of health such as poverty reduction, drug-based support, specific interventions for younger and older PLWHIV, community-created and owned interventions for racially minoritised communities, and a more collaborative and multi-disciplinary approach to patient care and support by service providers.

Interventions identified that promote re-engagement in care show some similarities to those focused on reducing disengagement, such as a focus on HIV stigma and self-stigma reduction, a collaborative and multi-disciplinary approach and approaches focused on wider social determinants of health. However, some interventions appear specifically suited to re-engagement in HIV care, including community HIV testing, peer support and specific patient tools and measures.

It is crucial to develop targeted interventions that address the specific needs and challenges faced by the populations most likely to disengage from HIV care. In other words, an overarching approach is needed to prevent disengagement and support re-engagement that intrinsically considers identity and intersectionality regardless of the intervention; an inclusive approach must be taken, which relates to complex identity needs to inform both the design and delivery of a particular intervention.

It is also important that interventions provide comprehensive support including mental health and peer support, and strategies to address HIV stigma. This would increase engagement in care, treatment adherence and overall health outcomes. It is also crucial that interventions take a nuanced approach that move away from a binary based on either engagement or disengagement and focus on increasing engagement.

## FUTURE RESEARCH OPPORTUNITIES

There are several areas identified or implied in the literature review, that could potentially provide avenues for future research, which could help extend understanding on the topic of disengagement and re-engagement in HIV care in London. This could include (1) an in-depth focus on specific populations with a detailed exploration of the complex reasons for disengagement and re-engagement from HIV support and care, (2) life course research to better understand the connection between stages of the HIV care pathway and age and disengagement and re-engagement in care, (3) exploration of the impact of differences in definition on the data collected and definition of disengagement and re-engagement and the impact this on understandings of disengagement and engagement, in practice (4) comparative studies, such as those focused on different populations or cities, and, finally, (5) research around new technologies, such as long-acting injectable HIV treatment on disengagement and re-engagement in care. The latter is an unexplored and important area that must be better understood as new

treatments are changing the way PLWHIV access and take medications. Current research in this area is almost non-existent and is based on feasibility studies (Fletcher et al 2023, for example), Clearly, developments in treatment have the potential to greatly impact engagement and retention in care, but currently there is insufficient knowledge on in what ways and what this might mean in terms of HIV interventions.

## LIMITATIONS

### TAKING A SYSTEMATIC APPROACH

One of the key challenges was to conduct a literature review taking a systematic approach in a relatively brief piece of work. This literature review successfully employed systematic techniques, which included focused research questions, clear explanation of literature sources, screening criteria (as per PRISMA diagram), critical appraisal and a thematic focus, which increase reliability and relevance of findings. However, it would be naïve to ignore the fact that there is literature on the topic that was not included due to the strict inclusion and exclusion criteria. For example, the review used PubMed as a source of articles, although a longer review could use other databases to include a wider breadth of literature.

Of course, it was impossible to include all relevant articles on the topic of engagement and disengagement in HIV care. London was chosen as a focus, but articles on other contexts, such as UK wide studies, or those based on potentially comparable cities, e.g. New York, Berlin or Amsterdam, were not included. To some extent this was mitigated through use of meta-analysis reviews, which referred to wide amounts of literature on the topic. Furthermore, systematic literature reviews often take a statistical analysis approach, to increase reliability of findings. This was not possible for this literature review due to the relatively small number of studies considered; however, a larger literature might consider a statistical analysis approach.

### DEFINING DISENGAGEMENT

While conducting the literature review it became clear that there is no consensus on how to define what disengaged from care means. Disparate definitions mean comparisons across literature are difficult to make. For example, while Andrea et al (2019) take a definition of three months late for an appointment, in other research disengagement is quantified by the number of clinic visits, or a more complex formula based on algorithms (Prevost 2022). Howarth et al (2021) use the term 'suboptimal clinical attendance', which was used to refer to one missed appointment in the last year, or not being engaged at all in over a year. As with literature relating to EIC and RIC, studies focused on treatment adherence also showed disparities in definitions. For example, in the meta-analysis by Lin et al (2019), which considered various studies, adherence ranged from 80% to 100% treatment compliance and the cut-off point for adherence varies from two days to one year.

Although it has been possible to tease out factors related to engagement and disengagement, and populations most likely to disengage, the variation in definitions means data does not exist to make clear and rigorous comparisons.

Interestingly, and in another vein, Koester et al (2019) note that patients are not routinely asked what EIC means for them. They suggest that patients' own tacit understandings of the 'good' engaged patient and 'bad' disengaged patient themselves influence behaviours around care and engagement and, or disengagement. Future research might usefully explore how patients themselves define engagement and disengagement.

In addition, the REACH study (2021) demonstrates there can be different factors related to irregular attendance rather than non-attendance and indicates a spectrum of engagement understanding might be more useful than a

binary approach, as argued previously in the review. The literature points to the complexities of socio-economic and personal factors related to engagement in, and disengagement from, HIV care as well, and complexities of human behaviour at play. Research implies a more nuanced understanding of engagement and disengagement is needed and that interventions should move beyond this binary too. In this way, and based on the literature reviewed, the goal of interventions could be to increase engagement (i.e. movement along the spectrum) rather than prevent disengagement or achieve total engagement. Thus, not only must we problematise binary understandings of engagement and disengagement, but also take this approach to the planning of interventions around engagement and re-engagement in HIV care.

## CONCLUSION

Despite the limitations outlined this literature review does allow conclusions to be drawn relating to the overall question and sub-questions in ways that are useful to those providing services to PLWHIV in London, and beyond.

Overall, the studies focusing on different populations give us insight into who is likely to disengage from HIV care – racially minoritised communities, heterosexuals, adolescents, older people, those on multiple medications, women, drug users and those with higher viral load and low levels of treatment adherence. In addition, those affected by certain social barriers, such as living in poverty, those in poor housing and facing immigration challenges and experiencing family violence are also more likely to disengage from HIV care. Of course, these groups are not mutually exclusive, and an intersectional understanding of their identities should be taken when understanding disengagement from care, and planning interventions. It is clear that interventions focused on retention in HIV care must be tailored to these intersectional populations and they must take a multi-disciplinary approach which recognise the SDH, as well as providing adequate supported related to mental and physical health and drug use.

It is crucial to address the barriers to engaging in HIV care and support, reasons for disengagement, and facilitators for re-engagement back into care to provide ongoing and effective support to individuals living with HIV. Doing so is important to ensure PLWHIV receive the necessary support they require and that they can manage living with HIV effectively. This literature review illuminates some of the factors related to disengagement from care, and facilitators for re-engagement in care, as well as the populations more likely to disengage from care. Importantly, it also provides clear, evidenced-based, indications of useful interventions to reduce disengagement and to achieve re-engagement. Focusing on interventions that can reduce disengagement and promote re-engagement in care enables organisations like GMI Partnership in London, and those across the UK and globally, to contribute to achieving the 95-95-95 targets<sup>11</sup> set up by the WHO, and ultimately towards ending the HIV epidemic by 2030. This is a hugely ambitious but obtainable goal, if we, the communities and organisations working in HIV, ensure we commit to reducing disengagement from care, and work to re-engage those that have become disengaged from HIV care. Then, and only then, can we realistically end the HIV epidemic.

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<sup>11</sup> This refers to the WHO goals that by 2030 that 95% of PLWHIV know their status, 95% of people diagnosed receive treatment and 95% PLWHIV achieve viral suppression.

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