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HIV, COVID-19 and health and well-being: a mixed-methods exploration of the impact of structural and social determinants

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I hereby declare that this thesis and the work reported herein was composed by and originated entirely from me. Information derived from the published and unpublished work of others has been acknowledged in the text and list of references. This thesis was supervised by Professor Helen Ward (Imperial College London), Dr Bethan Davies (Imperial College London) and Dr Adamma Aghaizu (UK Health Security Agency).

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"Keep Ithaka always in your mind. Arriving there is what you're destined for. But don't hurry the journey at all. Better if it lasts for years, so you're old by the time you reach the island, wealthy with all you've gained on the way, not expecting Ithaka to make you rich."

- C. P. Cavafy, "Ithaka" from C.P Cavafy: Collected Poems

Abstract

Advances made in the treatment and care of people living with HIV, including the ability to be 'undetectable', have shifted the focus of the HIV epidemic in the UK towards people living well beyond simply virological suppression. This mixed-methods thesis investigates the social and structural determinants influencing differences in health and well-being, with a focus on mental health, of people living with HIV in the UK. First, a systematic review identified a social gradient of health relating to social determinants and HIV clinical outcomes in high-income countries; people living with HIV who were more materially deprived were less likely to be virologically suppressed or adherent to ART, compared to those more advantaged. Secondly, online interviews with people living with HIV and/or working in HIV services during the COVID-19 pandemic shared diverse experiences including their perceptions of adaptions to HIV services and the impact on wider society. Concerns were raised about the emerging and widening health and social inequalities laid bare by the pandemic and the long-term impact on mental health and well-being. Thirdly, secondary data analysis of the 2017 Positive Voices study identified how individuals with poorer socioeconomic circumstances, including those unemployed or economically inactive, were significantly more likely to self-report poorer mental health as measured by the 12-item General Health Questionnaire (GHQ-12), than those socioeconomically advantaged. These associations remained after adjusting for demographics and clinical measures including age, gender identity and year of diagnosis. For instance, White British cisgender men who were unemployed were almost 4-times more likely to report GHQ-12$\geq$4, compared to those employed (aOR 3.77; 95% CI 1.87, 7.63). Finally, I applied findings to a theoretical framework and propose potential causal pathways to be explored in future research. The thesis has been in collaboration with colleagues at the UK Health Security Agency and Positively UK.

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Nomenclature

List of Abbreviations

ACE	Adverse Childhood Experience
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy/Treatment
AUDIT	Alcohol Use Disorder Identification Test
BHIVA	British HIV Association
cART	combination ART
CBPR	Community-Based Participatory Research
CDC	US Centers for Disease Control and Prevention
COVID-19	Coronavirus Disease
CSDH	WHO Commission on Social Determinants of Health framework
DAG	Directed Acyclic Graph
DIDE	Department of Infectious Disease Epidemiology
FPL	Federal Poverty Level
GBM	Gay and Bisexual Men
GED	General Educational Development
GHQ-12	12-item General Health Questionnaire
GIPA	Greater Involvement of People Living with HIV
GP	General Practitioner
GRIPP2	Guidance for Reporting Involvement of Patients and the Public
GUM	Genitourinary medicine
HAART	Highly Active ART
HARS	HIV and AIDS Reporting System

HIC	High-Income Country
HIV	Human Immunodeficiency Virus
HR-QOL	Health-Related Quality of Life
HSA	Health and Social Care Act 2012
IAS	International AIDS Society
ICU	Intensive Care Unit
ISCED	International Standard Classification for Education
LFT/D	Lateral Flow Test/Device
LIC	Low-Income Country
MEMS	Medication Event Monitoring System
MIPA	Meaningful Involvement of People Living with HIV
MSM	Men who have Sex with Men
NCD	Non-Communicable Disease
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NOS	Newcastle-Ottawa Scale
NPI	Non-Pharmaceutical Intervention
NPL	Neighbourhood Poverty Level
OECD	Organisation for Economic Co-operation and Development
OHID	Office for Health Improvement and Disparities
ONS	Office for National Statistics
PCR	Polymerase Chain Reaction test
PERC	NIHR Imperial BRC Patient Experience Research Centre
PHE	Public Health England
PIP	Personal Independence Payment
PPE	Personal Protective Equipment
PrEP	Pre-exposure prophylaxis
PROM	Patient-Reported Outcome Measure

SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SAVA	Substance Abuse, Violence and AIDS Syndemic
SDG	Sustainable Development Goal
SES/P	Socioeconomic Status/Position
SRQR	Standards for Reporting Qualitative Research
U=U	Undetectable=Untransmittable
UKHSA	UK Health Security Agency
UK	United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
US	United States
VL	Viral Load
WHO	World Health Organization

List of Measures

aHR	Adjusted Hazard Ratio
AIC	Akaike's Information Criterion
BIC	Bayesian Information Criterion
aIR	Adjusted Incidence Rate Ratio
aOR	Adjusted Odds Ratio
aPR	Adjusted Prevalence Ratio
aRR	Adjusted Relative Risk
χ^2	Chi-squared test
CI	Confidence Interval
CrI	Credible Interval
H-L	Hosmer-Lemeshow test
IQR	Interquartile Range
LR	Likelihood Ratio test

1

Introduction

In this Chapter, I will outline the history of progress in human immunodeficiency virus (HIV) care since the early days, the inequalities that persist and social determinants which may impact on the progress made. I will also introduce coronavirus disease (COVID-19) as a case study of a "syndemic pandemic" (1) among people living with HIV.[1]

[1] Throughout the thesis, I will use people-centred language to avoid the perpetuation of stigma, as recommended by the People First Charter (2).

1.1 The HIV epidemic four decades on: a global and UK perspective

1.1.1 History and epidemiology

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimate that around 38.4 million (33.9, 43.8) adults were living with HIV globally in 2021 of which, 76% (67, 87) of those aged 15 or older were accessing antiretroviral therapy (ART) (3). Overall, new infections are declining globally, however, some population groups remain more affected by the epidemic than others; key populations are more vulnerable to acquiring HIV and consequently displaying poorer HIV outcomes across the care continuum (4). UNAIDS defines key populations affected by HIV as sex workers and their clients, men who have sex with men (MSM), people who inject drugs, transgender people and people in prisons and other closed settings. These groups "continue to be marginalized and criminalized for their gender identities and expression, sexual orientation and livelihoods" (4). Additionally, the latest figures from UNAIDS estimate that one adolescent girl/young woman[2] acquires HIV every three minutes due to gender inequalities and discrimination including experiences of intimate partner physical and/or sexual violence (5). Additionally, data from multiple countries between 2017 and 2021 have found higher percentages of people (aged 15 to 49 years) living with HIV reporting discriminatory attitudes when they reside in rural areas, compared to urban areas, and similarly in relation to low and high wealth quintiles even after stratifying by gender (5). In 2021, 70% of new cases of HIV were accounted by key populations and their sexual partners, despite comprising less than 5% of the global population (5). However, we must also acknowledge that categorising people as "key populations" does not account for how inequalities intersect (e.g. relating to gender, sexuality and ethnicity) and may relate to vulnerability and risk (6).

The first cases of HIV in the United Kingdom (UK) were reported in the early 1980s (7). In 2020, approximately 106,890 [95% credible interval (95% CrI) 105,460 to 109,510] people were living with HIV in the UK, with an estimated 5,150 (95% CrI 4,000 to 7,770) undiagnosed; 2,780 people in the UK were newly diagnosed (8). Public Health England (PHE), which has now disbanded into the

[2] Defined as being aged between 15 to 24 years (5).

UK Health Security Agency (UKHSA) and Office for Health Improvement and Disparities (OHID), identify key populations by age, gender identity, acquisition of HIV (sexual contact or injecting drug use) and ethnicity (9). In 2017, around 30,000 women in the UK were living with HIV (10).

1.1.2 UNAIDS global targets

The UNAIDS set the 90:90:90 targets to enable the elimination of the AIDS epidemic by 2030 (11). These targets refer to 90% of people living with HIV to be aware of their HIV status, 90% of those diagnosed to be on effective treatment and 90% of those on treatment to be virologically suppressed (11). There have been calls for the addition of a 'fourth 90' – good health-related quality of life (HR-QOL), specifically in relation to co-morbidities and self-perceived quality of life (12, 13).

UNAIDS have also set the interim 95:95:95 targets to be met by 2025 which place "people living with HIV and communities at risk at the centre" of the targets across combination prevention, HIV/sexual health and reproductive health services access by women, virological suppression among other key indicators (14). These interim targets have been set to further progress towards the Sustainable Development Goal (SDG) target 3.3 of good health and well-being (14, 15).

The UK has met the UNAIDS 90:90:90 goals since 2017, with London exceeding the 95:95:95 targets in 2018 (11, 16). However, issues remain across the care continuum in the UK; for instance, about 4,660 (95% CrI 3,640 to 6,980) people living in England with undiagnosed HIV in 2020 have transmittable levels of the virus (8). The likelihood of being undiagnosed appears to be geographically biased, with double the number outside of London compared to those living inside London (3,000 compared to 1,650) (8).

Although significant achievements have been made in relation to clinical outcomes, concerns remain for late diagnoses, retention in care and HR-QOL – all of which have been further tested by the COVID-19 pandemic (8, 17).

1.1.3 Inequalities

Despite advancements made in HIV treatment and care globally, acquiring HIV remains context specific. Over the past decade, the prevalence of HIV has remained stable or is declining among heterosexual populations in high-income countries (HICs) but remains stable or is increasing among

MSM, with late diagnosis remaining a challenge (18). Beyrer et al. (19) identify geographic inequities within the United States (US) whereby the South represents most people living with HIV in the country; the highest prevalence of HIV is among racially minoritised groups (e.g. Black and Latino MSM) who face additional barriers including racism, poverty and intersectional stigma at the community level.

Social and structural factors, including gender and socioeconomic position (SEP), are associated with inequalities in global HIV outcomes which are perpetuated by historical social inequalities and structural racism (20–25). Marginalised groups living with HIV, including sex workers, migrants and people who are homeless, are often disproportionately affected by issues including criminalisation, xenophobia/racism and restrictions to healthcare access (26–29). For instance, homeless people have been found to have an absolute prevalence of HIV which is nearly twenty-times greater than the general population (0.3-21.1% vs 0.1-0.6%) (30, 31). These variations persist despite the progress of the Undetectable=Untransmittable (U=U) campaign (32, 33).

Additionally, the research and development of HIV medication has been politicised since the beginning of the epidemic, with branded single-tablet regimens a cost burden for HICs; however, license-free generic antiretroviral agents have rapidly scaled-up the provision of ART in low-income countries (LICs) since the early 2000s (34, 35). It has been estimated that the median lifetime costs for managing HIV ranges from $5,221 (IQR 2978, 11177) in LICs to $377,820 (IQR 260176, 541430) in HICs (36). A study based in England (37) found that HIV care costs could be significantly impacted by the introduction of generics by reducing average per person lifetime costs by 42-69%. Medication switches have also resulted in significant cost savings, with values between £240,404 (Atazanavir/ritonavir to *Evotaz*) and £6,956,811 (*Kivexa* to generic abacavir/lamivudine) (38).

1.2 The HIV care continuum: progress, developments and persisting inequalities

The HIV care continuum **(Figure 1.1)** refers to the internationally recognised public health framework of the diagnosis (or an individual being aware of their HIV status), treatment and care of people living with HIV until they achieve sustained virological suppression (or an undetectable viral load) (39, 40).

HIV care can now be viewed as a model for the long-term management of a health condition which is classified as "chronic" and which introduces challenges to long-term healthcare delivery as multiple co-morbidities become evident (41). Often, the continuum is referred to as a 'cascade', although this elicits a static representation rather than the fluidity of a spectrum of individual care engagement (40). Additionally, the care continuum does not traditionally account for time-updated factors nor loss to care across the life course or mortality (42). However, I will use the care continuum as a framework to examine progress made in a specific geographical context – specifically the UK – in line with the overall focus of this thesis.

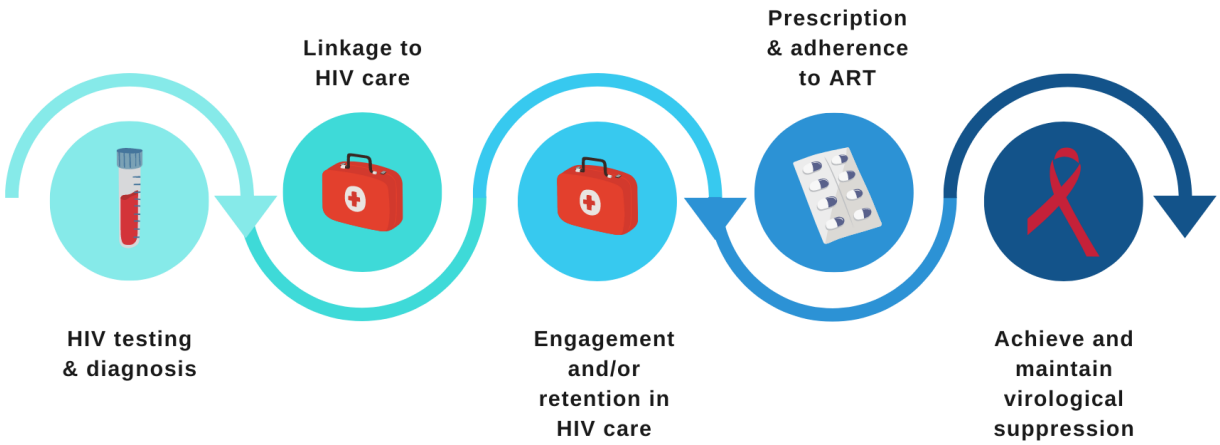


Figure 1.1: HIV care continuum – from diagnosis to virological suppression.

Critics have argued that a HIV care continuum approach to research often excludes those accessing care in rural settings and does not fully explore experiences across the full continuum, but rather at individual points of care (43). The latter can be explained by it being challenging to determine to what extent each point of care is contributing to overall poorer outcomes when individuals may be disengaged or lost at more than one stage (39). Research must begin to shift from traditional approaches of evaluating HIV care simply based on clinical measures to one that considers the HR-QOL of people living with HIV (12, 13, 43, 44).

In this section, I will introduce two core components of the care continuum – clinical outcomes as well as HR-QOL. These two outcomes will be explored in the quantitative chapter of the thesis – **Chapter 5**.

1.2.1 HIV services in the UK

People living with HIV in the UK are managed by their specialist HIV clinical care team based in outpatient services. Most people living with HIV in the UK are considered 'stable', in other words their viral load has reached 'undetectable' levels and they are therefore unlikely to pass the virus on ('untransmittable') (8); in 2020, 97% of people seen for HIV care in England and on treatment were virologically suppressed (VL$\leq$200) (8, 45). Therefore, people living with HIV who are established on ART attend monitoring appointments every six to twelve months for various investigations (46–48). Women living with HIV also undertake cervical screening in their HIV clinic (46). Therefore, the HIV clinic is built on a holistic model of care and manages people living with HIV beyond their HIV status.

In 2012, the UK government passed the Health and Social Care Act (HSA) which introduced several reforms across the National Health Service (NHS) including the funding, commissioning and provision of sexual health and HIV services in England (26, 49). The HSA 2012 was met with widespread criticism including a perceived 'fragmentation' of HIV and sexual health services which disrupted the HIV care continuum; for instance, the decommissioning of HIV services by some local authorities and an impact on the commissioning of HIV support services **(Figure 1.2)** (26, 50). Therefore, the funding, commissioning and delivery of HIV services is influenced by the socio-political and economic environment in which it operates. For instance, the introduction of policies relating to UK government austerity measures have impacted migrants accessing healthcare, including those living with HIV such as NHS charges to overseas visitors and concerns relating to data sharing between the NHS and Home Office (51, 52).

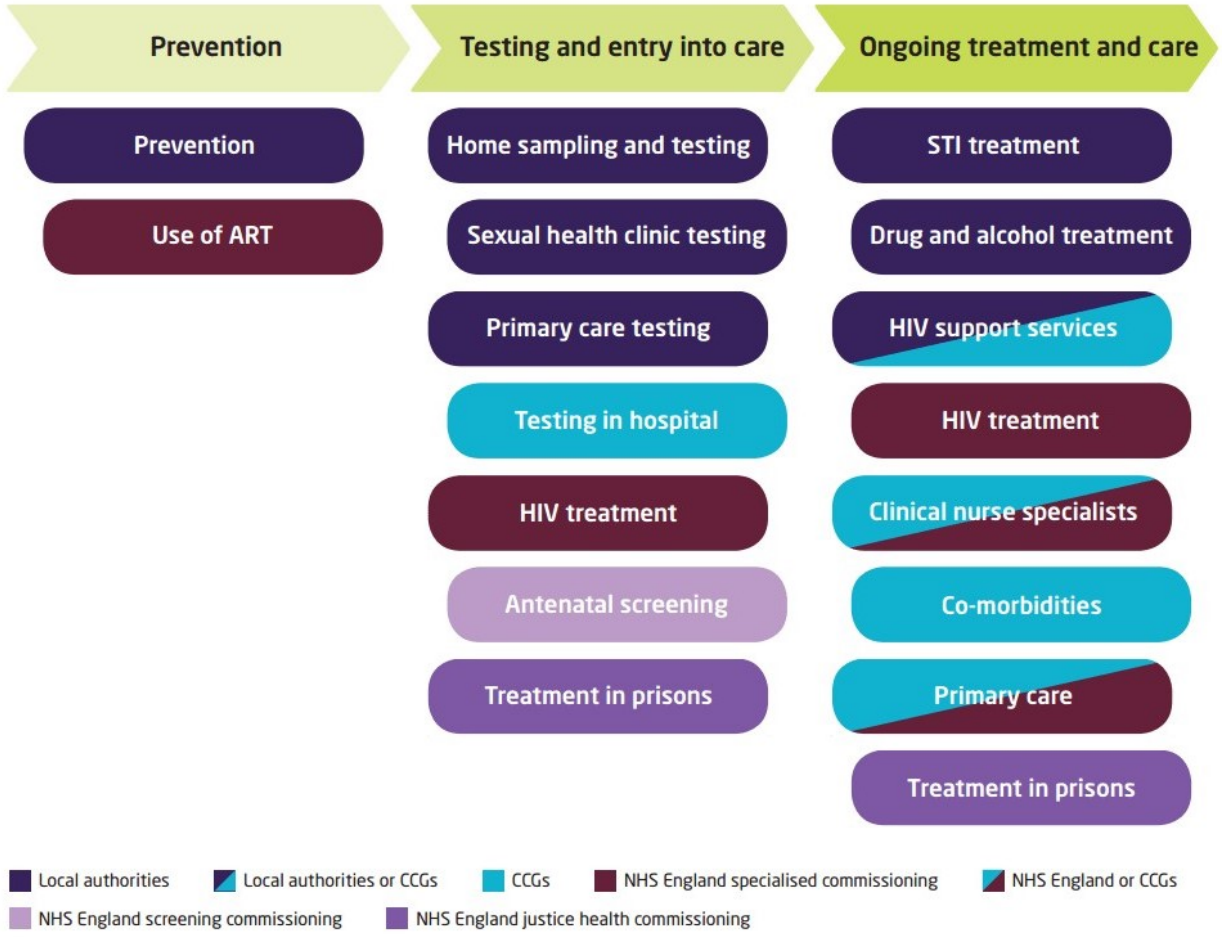


Figure 1.2: HIV commissioning of services in England. Reproduced from The King's Fund Copyright © 2017 (26).

1.2.2 Diagnosis

Early diagnosis of HIV can prevent significant morbidity and premature mortality as well as increased onward transmission; home testing is a major development in the diagnosis of HIV in HICs (17, 53). However, late diagnosis remains a challenge globally. In the UK, late diagnosis is defined as a "CD4 count$<$350 cells/mm^3 within 91 days of diagnosis" and although new HIV diagnoses continue to decrease in recent years, particularly among gay and bisexual men (GBM), late diagnoses rates remain high among older populations (50+ years), heterosexual populations, people who inject drugs and Black African men (16, 17).

1.2.3 Linkage and retention in care

Once people living with HIV receive a diagnosis, they should then be linked to HIV care services and remain engaged with their care. However, historically, disagreements for reaching a global consensus of defining 'linkage to HIV care' has existed (54, 55). Subsequently, a multi-stakeholder, expert meeting defined linkage to care as "patient entry into specialist HIV care after diagnosis, more specifically, the time between the HIV diagnosis date and either the first clinic attendance date, first CD4+ count, viral load date, or HIV treatment start date, with prompt linkage measured within 3 months" (54). Retention in care is particularly important as it has been shown to be strongly associated with all-cause mortality in some settings – specifically in the US (56).

In HICs, HIV services are often based on a person-centred model of care which aims to address multiple interrelated domains; for instance, welfare, psychological, social and physical needs (44). For instance, community health workers exist in some settings who help service users navigate the patient pathway, as well as providing social welfare support and improve engagement with care (57). Therefore, the role of community health workers extends beyond linkage and retention in care and often addresses the wider determinants of health, including housing stability, which have been shown to influence clinical outcomes (57). However, person-centred care remains a challenge to implement globally as often it is associated with a 'Western-oriented' concept in low- and middle-income countries; for instance, a study in Ghana found healthcare professionals and people living with HIV had shared views on the importance of HIV care that acknowledges financial constraints, accessibility, free from stigma and discrimination and addresses resource/personnel constraints (58).

1.2.4 Treatment

Maintaining adequate adherence to ART is essential for people living with HIV to remain virologically suppressed and ultimately undetectable and therefore untransmittable. Adhering to ART can be defined as the ability or "extent to which a person's behaviour of taking medications (...) corresponds with agreed recommendations from a healthcare provider" (59). However, determining a standardised and appropriate measure of ART adherence remains a challenge, particularly when considering the setting (clinical or research purposes) in which the assessment will be implemented (60).

ART adherence may be measured by pill counts (in clinic or over the phone), medication event monitoring systems (MEMS), pharmacy refills, HIV viral loads, interviews as well as a combination of these values or by generating a 'composite adherence score' (61, 62). Often, measures are self-reported which increases the likelihood of reporting biases (e.g. overestimation due to social desirability bias), are time consuming or are subject to large amounts of missing data; for instance, by record keeping in a personal diary or completing a structured questionnaire (e.g. the Adult AIDS Clinical Trials Group (AACTG) Adherence instrument) (61, 62). MEMS is often favoured as a method to measure adherence as it records each time the cap of a medicine bottle is opened by an electronic chip, although the precision of this is limited as the method is unable to record the number of pills taken each time the bottle is opened (62). CD4 cell counts are conditionally recommended to be used by the World Health Organization (WHO) (59), in specific contexts, to prioritise ART initiation, but also as an objective measure of adherence (CD4$>$200 cells/mm^3) among those defined as 'stable'.[3]

Determining the best time period and type of measurement also remains contested; for instance, Lu et al. (63) found that one-month recalls with participants rating responses to adherence may be a more accurate measure of adherence compared with other measurement formats (frequencies and percentages) and recall periods (3- or 7-days). Garfield et al. (64) also recommend the use of general adherence measures, rather than specific frequencies, for routine clinical use.

Issues with adherence have been linked to psychological and psychosocial factors, as well as intrinsic and extrinsic motivators including spiritual beliefs and relationships with the HIV care team (65–68). Associations between social determinants (e.g. age, gender, poverty, unemployment) and ART non-adherence, as well as ART interruption or discontinuation, have also been described across multiple populations and settings (69–71). Health literacy has also been shown to be a predictor of adherence among people living with HIV (72). Additionally, the National Institute for Health and Care Excellence (NICE) in the UK advocates for a person-centred approach to adherence promoting open, adaptable, non-judgemental conversations with healthcare professionals to enable patients to be involved in the decision-making process including decisions to not take medications (73).

In LICs, adherence has been associated with historical factors, accountability and agency which

[3] Defined as having received ART for 1 year or more.

has given rise to the term "therapeutic citizenship", or in other words, "the way in which people living with HIV appropriate ART as a set of rights and responsibilities"; it is both a personal engagement and political claim (74, 75).

1.2.5 Virological suppression

ART adherence is required to reach virological suppression; sustained virological suppression is essential for reducing morbidity and mortality, preventing onward transmission of HIV among sexual partners and ultimately the QOL of people living with HIV (76, 77). The specific level of adherence required to reach virological suppression may be regimen dependent and could be from as low as 75%, although the 'gold standard' is often considered to be $\geq$95% (76, 78).

Virological suppression is measured by HIV viral load and often relies on either self-reporting measures or linkage to clinical records. However, defining virological thresholds differs across settings (see **Table 1.1**). Significant differences can be found between HICs and LICs due to the available technology such as dried blood spots or plasma specimens and the limit of detection of the assay (79). For instance, the WHO (59) uses a broad definition of the percentage of those living with HIV (suppressed VL<1000 copies/mL) based on two consecutive measurements within 3-6 months. On the other hand, others use a more stringent cut-off of 200 copies/mL (77, 80, 81).

Table 1.1: Virological suppression thresholds from the British HIV Association (BHIVA) and World Health Organization (WHO) guidelines.

British HIV Association (46, 82)	**World Health Organization** (59)
VL<50 copies/mL: undetectable	**VL<1000 copies/mL**: virological suppression
VL<50-200 copies/mL (single then undetectable): virological blip	**VL≥1000 copies/mL**: virological failure
VL<50-200 copies/mL (confirmed): low-level viraemia	
VL<200 copies/mL: stable virologically suppressed	
VL>200 copies/mL: virological failure/virological rebound	

In the UK, people living with HIV who are engaged with HIV care (stable viral suppression) are recommended to be monitored every six months, or yearly, if a protease inhibitor is part of their ART regimen (46). The UK Collaborative HIV Cohort (UK CHIC) estimated that the rate of viral rebound (defined as a single viral load measure of >200 copies/mL or treatment interruption 1 month or

longer) in the lifetime of people living with HIV who are on ART remains low; specifically, the cohort found people of older age had reduced risk of viral rebound (83). Factors found to be associated with increased likelihood of virological rebound in the UK CHIC study were being of Black ethnicity and heterosexual which remained after adjusting for other factors (84). Other studies have found associations between social determinants (e.g. employment) and changes in immunological response and virological suppression shortly after ART initiation (85).

A major advancement in HIV care is the establishment of the global U=U consensus statement by the Prevention Access Campaign (32); the initial statement described "negligible" risk of passing on HIV if a HIV viral load is undetectable which has since been amended to be less ambiguous – specifying "zero" or "no" risk to avoid perpetuating fear and stigma and rather inspiring confidence (86). However, research has indicated mixed levels of understanding and/or inconsistencies of U=U messaging among people living with HIV and staff working in HIV clinics across geographical settings (87–90).

1.2.6 Health-related quality of life

As people living with HIV continue to age, the management of multiple health conditions (co- and multi-morbidities) and their relationship with self-perceived health-related quality of life (HR-QOL) remain key challenges; HIV is shifting to an era "beyond virological suppression" (12, 91). This is driving the need for the development and testing of culturally appropriate and contextualised patient-reported outcome measures (PROMs) that can record the first-hand experiences of people living with HIV to improve their outcomes and the quality of HIV care (13). A shift towards HIV care "beyond virological suppression" includes investment in integrated and people-centred health services and systems which, for instance, capture data on co-morbidities and implement interventions to challenge healthcare-related stigma and discrimination (12, 92).

HR-QOL measures include generic instruments for health, such as the Medical Outcomes Study (MOS) 36-item Short Form Survey Instrument (SF-36) which has been adapted to be specific to people living with HIV (MOS-HIV) (13, 93). Like others, Clayson et al. (93) suggests that a 'one-size-fits-all' measurement may not exist, but in fact several measures could investigate various dimensions and demographic characteristics of people living with HIV. The choice of which HR-QOL

to use should be driven by the specific research or clinical question, with attention paid to the responsiveness required to make clinical decisions by valid and reliable scales with easily interpretable scores (94, 95). Additionally, clinical HIV staff, health service researchers and people living with HIV have recently developed a brief, specific HIV PROM (the "Positive Outcomes" HIV PROM) to be used within routine adult HIV care which measures 23 items across 7 domains (priorities, global assessment, information, physical, psychological, social and relational) although this has yet to be validated (44, 96).

People living with HIV have persistently lower HR-QOL outcomes than the general population across geographical settings (97). Clinical HIV measures and social determinants have been found to be associated with self-reported QOL among people living with HIV, as well as having pre-existing mental health conditions. For instance, a meta-analysis (98) found that CD4<200 was negatively associated with QOL scores in four cross-sectional studies (pooled OR 0.29; 95% CI 0.22, 0.35). However, one study (99) in a setting with low HIV prevalence and a 'stable' HIV population (Finland) found no relationship between HIV-related measures (e.g. CD4+ cell count) and QOL. Despite this, most research on QOL measures are cross-sectional in nature limiting determinations of causality.

Stable social support (e.g. being married or living in a partnered relationship), employment status and finances have also been found to be significantly associated with QOL ratings in some settings (99–101). Other explanations for these associations could be structural/social factors including stigma relating to HIV status as well as gender and/or racial discrimination which have been the target of interventions, particularly among marginalised populations living with HIV (100, 102). Additionally, peer support can provide "mutual emotional support between peers" including a sense of belonging, reassurance of worth, guidance and the individualised approach that many require following their diagnosis (103). A recent meta-analysis (104) found that peer support leads to improved retention in care, ART adherence and virological suppression among people living with HIV.

Mental health

Much like HR-QOL, mental health is an increasing challenge with an aging HIV population; mental ill health disproportionately affects people living with HIV compared to those not living with HIV (105, 106). Specifically, people living with HIV may experience internalised HIV-stigma, loneliness,

social isolation and mental ill health (e.g. depression, anxiety) following a HIV diagnosis and which persists at each step of the HIV care continuum (105–107). Mental ill health will then manifest into physical symptoms (embodiment) such as problems sleeping or effects on the immune system through chronic immune activation (or inflammation) which is also exacerbated by living with HIV (105, 107). The pattern of mental health problems has also shifted since the HIV epidemic first emerged from acute (e.g. organic brain syndromes) to chronic conditions (e.g. anxiety disorders and depression) (108, 109).

As a result, an increased demand for mental health services has followed. For example, a study (108) reviewing referrals to a specialist psychological service in London across two decades (1990-2014) found an 811% increased demand for access as well as diagnoses of cumulative depressive and anxiety disorders (from 27 cases in 1990 to 246 cases in 2014). This demand is also now likely to be exacerbated by the ongoing COVID-19 pandemic to both people living with HIV and the wider public (110, 111). Some adaptations are required to make services more acceptable to people living with HIV in the UK. A recent report (112) has recognised that culturally competent services, including a representative staff workforce, could help to improve the experiences of people living with HIV accessing generic NHS England talking therapy.

It is well understood that mental health also exhibits a social gradient of health and can accumulate throughout the life course, however, mental health exhibits 'proportionate universalism'; in other words, all members of society may be affected (113). Women living with HIV have been found to be more likely to experience poorer mental health after adjusting for age, employment and treatment status (114); a UK study found that heterosexual women were 2.6-times more likely (aOR 2.63; 95% CI 1.16, 5.88) to report a high psychological distress score as measured by the Memorial Symptom Assessment Scale Short Form (MSAS$>$1.73) than heterosexual men (114).

1.3 Social and structural determinants of health

Social determinants refer to "the conditions in which people are born, grow, live, work and age"; they are the "causes of the causes" and include factors such as income level, educational opportunities and social class (115–117). Therefore, social determinants are inextricably linked to power, money and resources (117). Solar and Irwin (117) situate social determinants with their relationship to an individual's social hierarchical position or socioeconomic status (SES/SEP) and the socioeconomic-political context and social processes which generate social strata. However, combining social and structural determinants can be problematic as health inequalities are often unequally distributed across socioeconomic groups (117, 118).

Defining what constitutes a social determinant remains challenging, largely because determinants can be heavily interlinked and may involve several factors along a causal pathway working in multiple directions at once (119). Braveman et al. (119) suggest that conducting several distinct, interdisciplinary studies examining different parts of the causal pathway may help to uncover how social determinants influence this. For instance, the WHO Ottawa Charter for Health Promotion (120) defines social determinants as "fundamental conditions and resources for health", including shelter, education and food. Tarlov (121) estimates the relative influence of five major determinants; 'social and societal characteristics' and 'total ecology' are framed as factors that influence our health by over 50% compared to 'genes and biology', 'health behaviours' and 'medical care'. The US Office of Disease Prevention and Health Promotion defines five social determinants of health in the "place-based" Healthy People 2020 framework as: economic stability; education; social and community context; health and health care; and neighbourhood and built environment (122, 123).

Social and health inequalities

Social epidemiology uses methods to explore individual- and population-level health inequalities across society (124–126). To understand why social epidemiology may use SES/SEP as an independent variable influencing health outcomes, we must uncover its philosophical origins (127, 128). Marxism describes an individual's "means of production" which is controlled by the power exerted by the capitalist state system and its structures, of which class is a relationship that is socially constructed;

this is otherwise referred to as a struggle between the 'worker' and the 'capitalist' (117, 129). In contrast, Weberian philosophy defines SES through three dimensions across society — class, status and power — with the indicators of these dimensions being income level, "access to life chances" (e.g. social networks) and power in relation to political context (117, 130, 131). Functionalists focus more on social stratification but also credit the role of "structural features such as authority, position in the division of labor, and property relations in determining social position" — much like Marxism (132). A contemporary exploration of SES may explore changes across the life course as well as the intersectionality of the socioeconomic context including social class, gender and race/ethnicity (117, 133, 134). Indicators of SES could include education-, income-, housing- and occupation-based measures (129, 133, 135).

Social exclusion and discrimination can worsen health inequalities among the most marginalised in society (117, 118). Inclusion health aims to dismantle social and health inequities among those most excluded and can be addressed through policy, research and practice by for instance, advocating for participatory approaches or the development of multi-component and integrated interventions (136). An upstream approach to address the "causes of the causes" through policy and structural interventions may help to prevent downstream effects among those most socially excluded (136, 137).

1.3.1 Theoretical frameworks

Various frameworks have been proposed to investigate social inequalities in health beyond decontextualised and historically dominant biomedical and lifestyle-focussed theories to consider disease distribution (117, 138). For instance, frameworks exploring the mechanisms through which social determinants influence health across the life course or by causal pathways (117, 127, 128, 138). Therefore, these frameworks are not independent of one another, but are rather complementary adaptations (117). A summary comparing the main features of each theory outlined below, including their similarities and differences, is given in **Table 1.2**.

Table 1.2: Main features of conceptual frameworks

Conceptual framework	Main features
Life course epidemiology	• Considers biological, behavioural, and psychosocial processes • Considers context (time and place) • Considers changes in circumstances over lifetime • Can be used to uncover possible causal pathways and mechanisms
Psychosocial theory	• Combines biological and physiological responses • Mainly focuses on stress responses • Less consideration of actors, agents, sociopolitical environment, and temporality • `Environment' includes natural and social world
WHO CSDH	• Distinguishes some social determinants as `intermediary' (e.g. material circumstances) • Cannot explain how social determinants influence health equity (nor how this is measured) • Cannot represent temporality or transient nature of social determinants • Sexuality does not feature in model (unlike ecosocial)
Intersectionality	• Intersecting identities co-exist and co-construct each other • Considers interplay with systems of oppression, hierarchies and privilege • Considers historical influences
Ecosocial theory	• Core constructs: accountability, agency, embodiment • Considers processes including production, exchange, consumption and reproduction • Considers levels, pathway, and power • Life course and historical background featured

Life course epidemiology

Life course epidemiology recognises how an individual's circumstances, including health, may change for the better or worse during their lifetime (116). Negative historical influencers from early life, including psychosocial circumstances, behavioural factors and adverse childhood experiences (ACEs) are often linked to social factors and result in poorer health outcomes in later life such as mental and physical ill health (116, 139). Therefore, life course epidemiology considers an individual's context (time and place) and can be used to explore causality (140).

Psychosocial theory

Psychosocial theory combines biological responses with human interactions however, it is limited by less consideration given to the socio-political and economic context, epidemiological temporality and

role of actors and agents (128, 141, 142). For example, in psychosocial theory, the 'environment' refers to both the natural and social world, with the theory also largely focusing on neuroendocrine responses to stress (128).

Social and/or political determinants of health theory and the WHO CSDH

Social and/or political determinants of health focus predominantly on population-level risks and predictive factors derived from individual-level characteristics, whilst excluding the relationship and causal pathway between determinants and biology; however, this is captured through the WHO Commission on Social Determinants of Health (CSDH) model — **(Figure 1.3)** (117, 128, 143, 144).

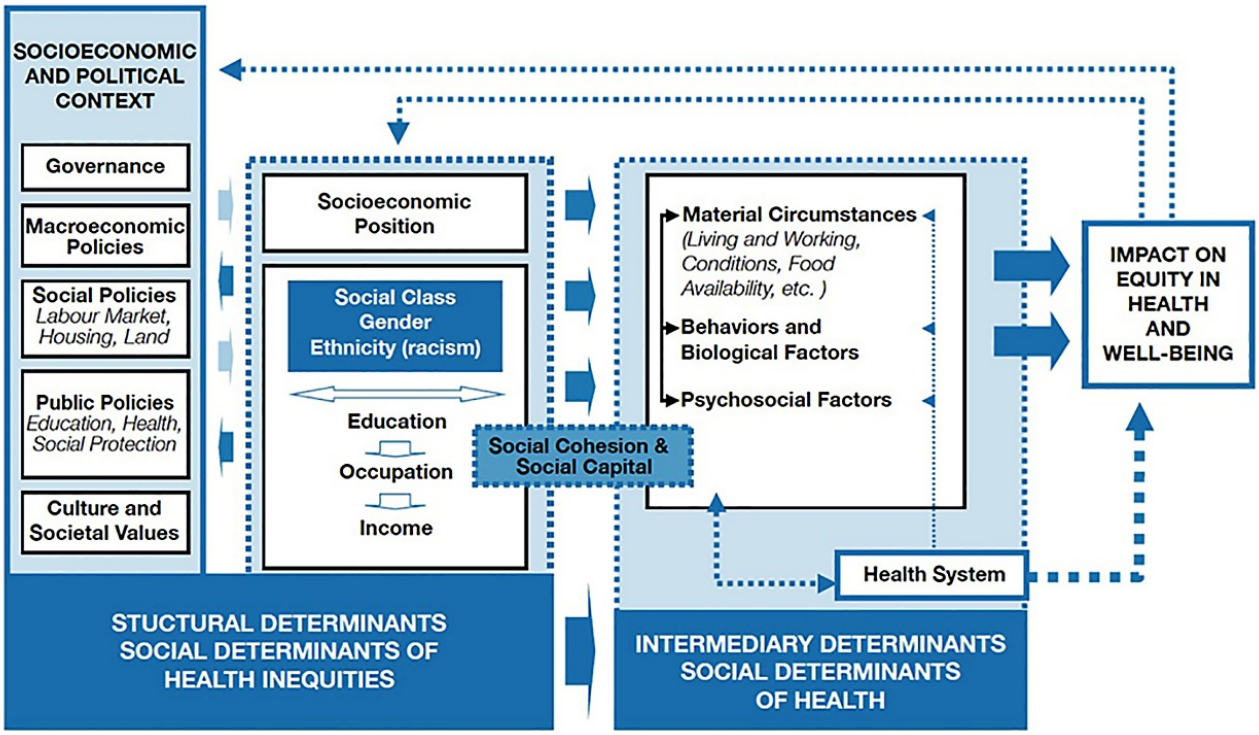


Figure 1.3: WHO CSDH Framework. Reprinted with permission from World Health Organization Copyright © 2010 (117).

The WHO CSDH model is the result of several decades of work looking at health inequities by various researchers and from differing theoretical standpoints. Primarily, Dahlgren and Whitehead's 1991 social determinants of health model (143) forms the foundations of the CSDH in establishing social determinants from individual to wider level societal factors. Additionally, Dahlgren and Whitehead's "rainbow model" complements Diderichsen's model which considers the mechanisms between social contexts and social stratification on health outcomes of which several iterations

have been built upon (117, 144–146). Ultimately, Diderichsen's model places social position at the centre and can be used as an empirical framework to explore causal mechanisms, unlike the Dahlgren-Whitehead model of health determinants (144, 145, 147).

Despite this, it has been argued that the CSDH model cannot be used to explain how social determinants influence health equity, nor how health equity can be measured (148). Additionally, sexual orientation does not feature in the model (117, 143, 149). Material circumstances[4], behavioural/biological factors[5], psychosocial circumstances[6], the health system (e.g. access and quality) and historical/early childhood development (e.g. ACEs) are all considered to be "intermediary determinants" by the CSDH model which display differences in exposure and vulnerability (117). Social cohesion and social support are viewed as cross-cutting examples of psychosocial factors alongside physical safety (or stressful living circumstances); however, this does not accurately represent the temporal and transitional nature of for instance, housing conditions and other contexts (117, 150). In other words, housing "can be seen as a 'vector' or 'vehicle' — an intermediary by which the pathogenic inequality that inheres in broader economic and political structures is carried to susceptible hosts" (151).

As a result, the CSDH model defines the "most important structural stratifiers and their proxy indicators" as "income, education, occupation, social class, gender, race/ethnicity" (117). For example, a causal pathway is described between educational attainment, occupational choice (and in turn occupational hazards and benefits), income and material circumstances, which are positioned to all be influenced by SEP (117). Structural determinants of health inequities are framed as the "socioeconomic and political context" and include governance, macroeconomic policies, public policies[7], social policies[8], culture and societal values.

Intersectionality

Intersectionality recognises the multiple identities held by an individual and emerged from Black feminist movements; it recognises that these identities (e.g. race, gender, sexuality, social class)

[4] Defined as living/working conditions, food security/availability, neighbourhood/physical environment (e.g. housing, transport, green space, geography).
[5] Examples include nutrition, physical activity, tobacco use, alcohol consumption and substance use.
[6] Examples include stresses, relationships, social support and coping style (e.g. social exclusion, discrimination/stigma).
[7] Examples include education, health and social protection.
[8] Examples include the labour market, housing and land.

co-exist and construct one another rather than being mutually exclusive or unitary (152–155). The perspective posits how multiple, intersecting social identities co-exist within systems of oppression, social hierarchies and privilege with historical influences (156). Since its emergence, intersectionality theory has been increasingly applied to qualitative research and more recently population health research, although limited guidelines exist for quantitative research (134, 156, 157). The nature of the co-existence and interaction of these identities, therefore, requires complex multilevel or hierarchical statistical models (e.g. mediation and/or exposure-mediation interactions) to be constructed, the inclusion of interaction terms in regression models and/or the stratification of models (156, 158–160).

Ecosocial theory

Finally, Krieger's ecosocial theory **(Figure 1.4)** looks across multiple levels that may influence the patterns of health, disease and well-being including politics, polities, social movements and reflexivity (127, 128, 138). Therefore, ecosocial theory builds on existing schools of thought such as the social production of disease or political economy of health as well as human rights-based approaches (128, 138, 161). The theory considers the influence of racism, sexism, gender binarism and heterosexism on disease distribution and health inequalities across populations including pathways, across ecological levels whilst considering power dynamics and equally valuing the perspectives of all stakeholders (127, 128, 161, 162). Accountability, agency and embodiment are fundamental concepts of ecosocial theory; for instance, embodiment focusses on how social and material factors are biologically incorporated across the life course (161, 163). Therefore, embodiment can be considered a dynamic and adaptive process through which the human body is impacted by biological mechanisms of endogenous and/or exogenous origin as well as socially patterned exposures which lead to a biological response (164).

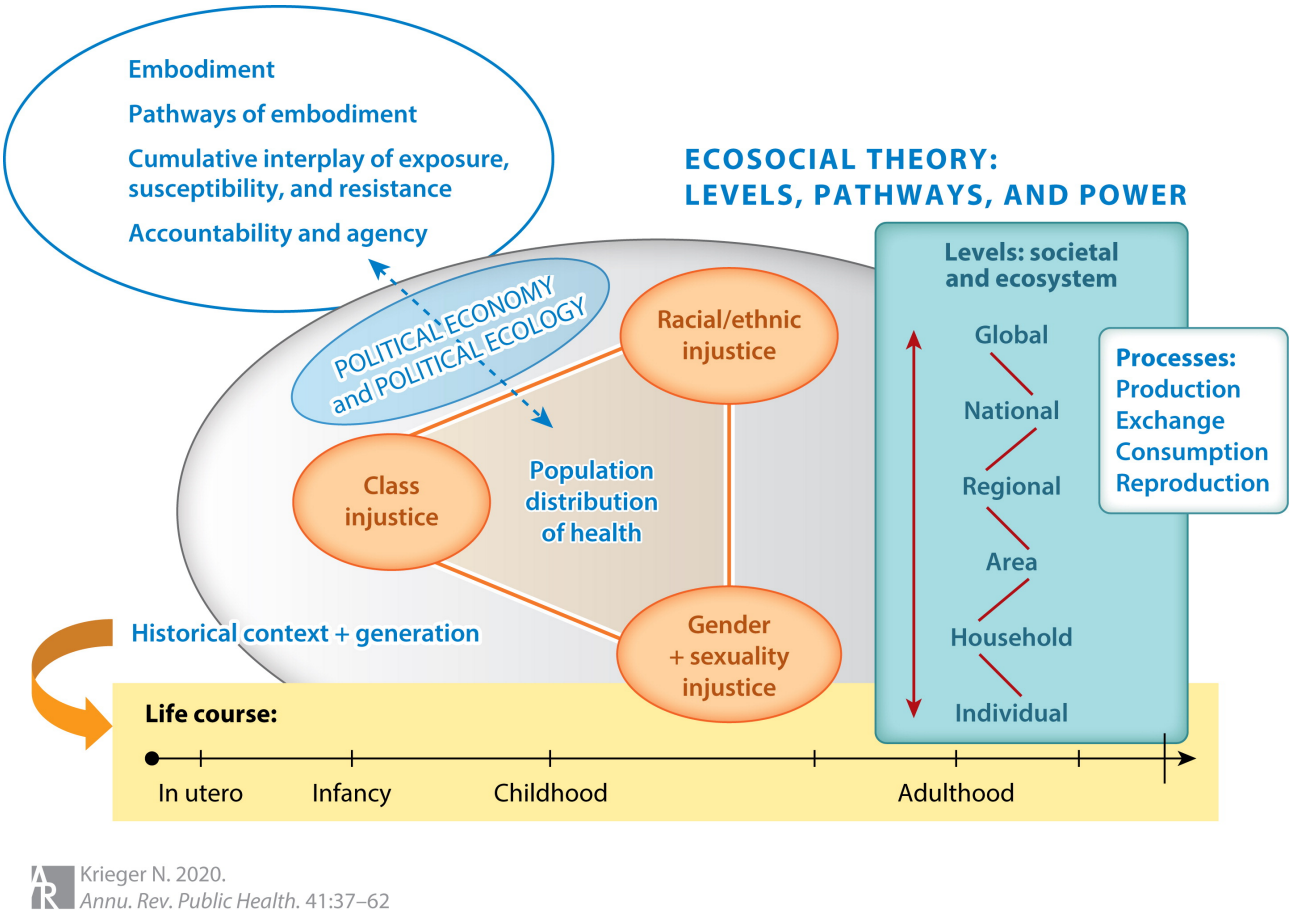


Figure 1.4: Diagrammatic representation of ecosocial theory. Reproduced from Krieger (161). Copyright © 2020 by Annual Reviews.

In **Chapter 6**, I will apply the findings of the thesis to ecosocial theory as an approach to interpret data triangulated from various data sources.

1.3.2 The social gradient of health

The 2010 Marmot Review (165) describes an evident social gradient of health (or 'health gap'); poorer health is found among those living in more deprived income-level, compared to higher income-level, neighbourhoods in the UK. Poorer health outcomes are visible among those socially disadvantaged with inequalities persistent due to absolute or relative material deprivation, inadequate social support or significant life stressors (165–167). Marmot et al. (165) also emphasise how both absolute and relative measures of inequality should be reported and the need for cross-cutting policies to be introduced by UK government to reduce persisting inequalities. For instance, the reporting of relative gaps are more favourable compared to event rates as are odds ratios compared to proportions or

percentages (168).

Ten years on, Marmot et al. (139) found trends of widening socioeconomic inequalities in England including stalling life expectancy and social mobility; a recent analysis (169) found that some communities in England have been experiencing a decline in life expectancy since 2010. Specifically, Marmot and colleagues (170) have identified declining life expectancy among the most socially disadvantaged in Greater Manchester (a devolved region in England and established Marmot City Region) and have proposed a framework to 'Build Back Fairer' which targets several social determinants including income, poverty and debt; housing, transport and the environment; and work and employment. The wider sociopolitical context may explain why inequalities are widening in England; specifically, a decade of austerity measures including public health cuts and a hostile environment which have only been further highlighted by the COVID-19 pandemic (171–174). Health inequalities during COVID-19 are further discussed in **Section 1.5**.

1.4 Social determinants of HIV

A similar health gradient has been described among people living with HIV, with persistent health inequalities among those socioeconomically disadvantaged (175–177). HIV has been described as "a pandemic of the poor" in that it predominantly affects minoritised and marginalised populations according to SEP, race/ethnicity, gender and sexuality (175).

Associations between SES and HIV treatment outcomes (virological and immunological responses) have been found across HICs, as well as wider mental health, healthcare services, lifestyle and sociodemographic factors (20). For instance, a dose-dependent relationship has been described to exist between socioeconomic determinants (including education and economic stability) and HIV care outcomes (retention in care, ART adherence and durable virological suppression) among adults diagnosed with HIV in the US and Puerto Rico (178). Inequalities in HIV acquisition and intersectional stigma and discrimination, linked to social factors including gender have also been described in the literature (179, 180). It is expected that a social determinants approach to HIV care would reduce health inequalities and could ultimately improve HIV care engagement and retention, such as among people living with HIV accessing care rurally (43). However, effective communication of these health

disparities remains essential to avoid perpetuating stigma and rather promoting trust and positive emotional responses (181). People living with HIV may also experience stigma and discrimination in the health system through the use of judgemental language, conditional care and breaching confidentiality (182). The relationship between material deprivation and HIV treatment outcomes is further explored in **Chapter 2**. Here, I will present overall definitions of social determinants and what is known so far about their relationship with HIV outcomes.

1.4.1 Poverty, deprivation and inequality

Poverty defines an individual's financial status whereas deprivation relates to other measures of unmet need (183). Townsend defines people who are deprived as lacking "...the types of diet, clothing, housing, household facilities and fuel and environmental, educational, working and social conditions, activities and facilities which are customary, or are at least widely encouraged or approved, in the societies to which they belong" (184, 185). The Index of Multiple Deprivation 2019 determines relative measures of deprivation at the small area level according to seven domains of: income, employment, education/skills/training, health/disability, crime, housing/services and living environment; therefore, it builds upon Townsend's definition of deprivation (183, 184). The Indices of Deprivation considers deprivation at the individual, household (or family) and neighbourhood (or community) level and sometimes at multiple dimensions (183).

Poverty and HIV are closely related; the Hardship Fund found that drivers of poverty for people living with HIV include immigration, unemployment, inadequate housing and insufficient benefits (186). Precarity may sometimes be described by intersections of "material-need insecurities" or material deprivation such as food, housing and income insecurity which contribute to health inequalities or poorer health outcomes (187). For instance, studies in the US have found associations between neighbourhood deprivation, poverty and poorer virological suppression, including at deliveries by pregnant women (188, 189).

1.4.2 Socioeconomic status/position

The terms SES and SEP are often used interchangeably however, SEP can be viewed as a theoretical construct underpinned by power, hierarchies and social positioning and should be considered a

time varying exposure (129, 132, 190, 191). This construct originates from Weberian, Marxist and Functionalist philosophies which are described in **subsection 1.3.1**. Therefore, a life course approach to measuring SEP across multiple indicators can allow for a more accurate exploration of health inequalities which are accumulated over time **(Figure 1.5)** (129, 135). Meanwhile, SES is often reported as a composite indicator but lacks the social context in which this construct is generated (192).

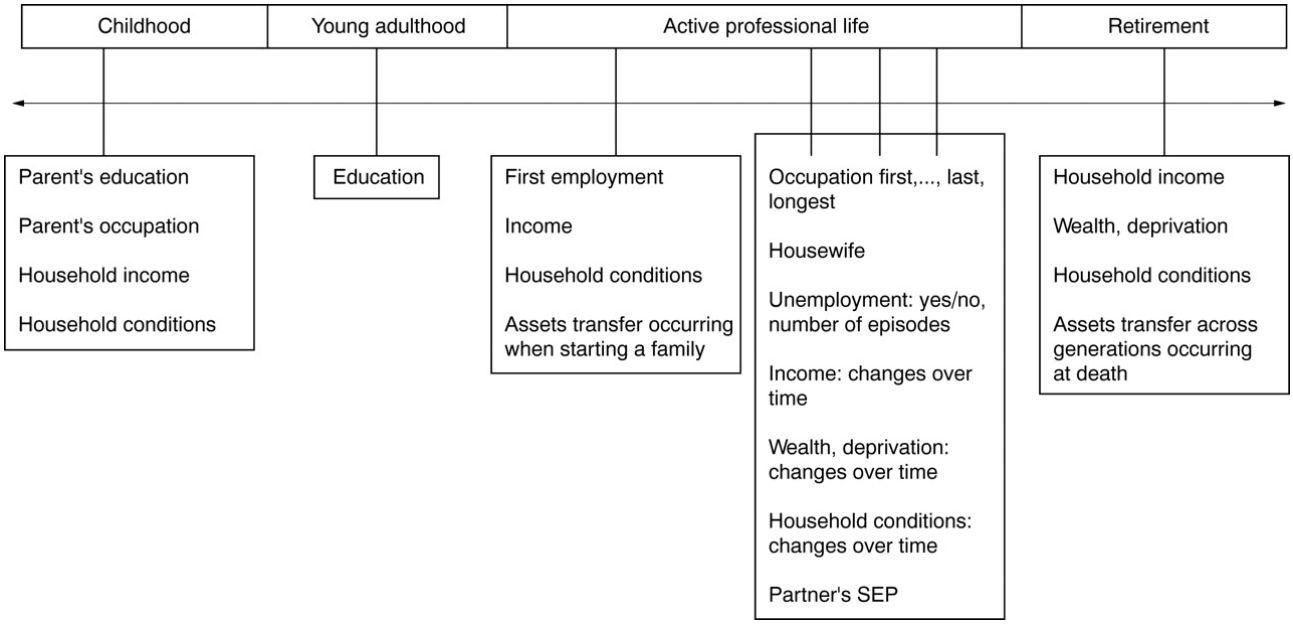


Figure 1.5: SES indicators across the life course. Reproduced from Galobardes et al. (135) with permission from BMJ Publishing Group Ltd Copyright © 2007.

There is growing literature exploring associations between SES/SEP and HIV outcomes; a notable study from the UK is the Antiretrovirals, Sexual Transmission Risk and Attitudes survey which found that low SES was associated with ART non-adherence, virological non-suppression and virological rebound (193). Specifically, Burch et al. (193) demonstrated associations between HIV treatment outcomes and specific socioeconomic factors (financial stability, employment, housing, education); for instance, people living with HIV who experienced financial hardship (inability to afford basic needs, e.g. food and heating) were 1.7 (aPR 1.74; 95% CI 1.46, 2.06) and 2.4 (aPR 2.35; 95% CI 1.60, 3.43) times more likely, respectively, to self-report ART non-adherence or be virologically non-suppressed (VL>50 copies/mL) after adjusting for demographic factors. Similar associations across various types of socioeconomic factors have been found in other settings (20).

I will present this construct according to the socioeconomic factors represented in the Index of

Multiple Deprivation 2019 (183) domains (education, employment, income and housing) in addition to food security. SES/SEP are also closely related to social class which is further detailed in **subsection 1.4.3**.

Education

Education can be considered in relation to educational attainment (categorical), years of completed education, fields of education, quality of education and/or numeracy and literacy skills (categorical) (117, 194, 195). For instance, the International Standard Classification for Education (ISCED) classifies educational attainment by levels of completion from ISCED level 0 (less than primary) to 8 (doctoral degree or equivalent) (194). Therefore, within a life course framework, education can be used as an indicator of early life SEP that can indicate both parental and individual SEP as well as influence future employment and financial status (117). Lynch and Kaplan (132) argue to look beyond years of education and to consider the "cognitive, material, social, and psychological resources gained through education." Educational attainment may impact health by influencing employment opportunities, health knowledge and behaviours and social standing due to all, or some, of these factors (119).

Among people living with HIV, education has been found to be associated with HIV outcomes including diagnosis, medication adherence and virological suppression (196, 197). For instance, adults living in the US with HIV who had a high school diploma or less were 2.3 times more likely (aOR 2.32; 95% CI 1.08, 5.00) to have active viraemia (unsuppressed viral load) compared to individuals who achieved more than a high school diploma after adjusting for age, gender, employment status and type of treatment (197).

Employment

Employment may be defined by status, type, grade, setting, skills/prestige or working relations and is often used an indicator for SEP or as a proxy of social hierarchy/status; for instance, exposures to occupational hazards and social networks (117, 129). However, employment can also be precarious and dynamic, therefore, there is limited understanding if no context is given (117).

People living with HIV can face specific barriers to gaining and maintaining employment. In

the US, some people living with HIV may not qualify for employment assistance or health coverage despite experiencing complications from their HIV as a result of differences in how HIV care is provided across states (198). Additionally, barriers may include being unaware of employment rights and laws which protect or support their employment, a lack of support from employers when initially diagnosed or fears of seeking employment due to HIV-related stigma and discrimination (198, 199). These experiences can be compounded by structural issues including racism and sexism among the most marginalised groups living with HIV (198). However, employment can also have a positive impact on health and well-being including improved physical outcomes, self-confidence, reduced likelihood of depression alongside material advantages (198, 200–202). Additionally, a meta-analysis of 28 studies found that people living with HIV in HICs who were employed were 33% more likely (pooled OR 1.33; 95% CI 1.02, 1.74) to be ART adherent (203).

Finances/income and wealth

Finances are an example of a material determinant of SEP and may be measured by income (household or individual), receiving welfare benefits/support (e.g. child support), stability (e.g. keeping up with bill/credit commitments), financial security (e.g. savings, dividends, assets) (117). From a life course perspective, income is highly transient in that the method, component or level can rapidly change based on life's circumstances (from first employment to retirement) (117). A large body of evidence supports the existence of a causal and dose-dependent relationship between income inequality and health (204). Wealth comprises both income and financial/physical assets and becomes relatively more important in later life; for instance, in relation to retirement and inheritance (129).

The healthcare system itself may also act as a financial barrier; for instance, in countries where universal healthcare coverage does not exist. In the US, insurance coverage and federally funded programmes across US states affect those living with, and at risk of, HIV (205); the Ryan White HIV/AIDS Program and Affordable Care Act are two examples of programmes introduced to support people living with HIV who are under and uninsured (206). However, the absence of a universal healthcare system, which is in itself complex, acts as a barrier for people living with HIV accessing care (19, 206). In the UK, welfare programmes such as Personal Independence Payment (PIP) are a source of income for people living with HIV who may need extra financial support for their

long-term condition, in relation to daily living and mobility activities (207). For instance, symptoms may fluctuate but also people living with HIV are more likely to have co-morbidities than the general population (207, 208).[9]

Food security

Food security is defined to exist "...when all people, at all times, have physical, social and economic access to sufficient, safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life" (210). Therefore, food security may be measured across four domains: availability, access, utilisation and stability; and household food security may also measure affordability (210).

A bi-directional relationship exists between food security and ART adherence; sub-optimal adherence is often reported among people living with HIV who are food insecure (211–213). Food insecurity can also be embodied in biological pathways through associations with virological non-suppression (higher viral load), poorer immunological responses (lower CD4 count) and poorer QOL outcomes (212–215). For instance, Wang et al. (214) report food insecure participants of the Veterans Aging Cohort Study being 37% more likely (aOR 1.37, 95% CI 1.09, 1.73) to have an unsuppressed viral load (VL>500 copies/mL) than food secure participants, after adjusting for social determinant covariates. However, the relationship between virological suppression and food security was not found to be mediated by ART adherence nor body mass index (214).

Housing

Housing can be defined by stability, ownership (or tenure), dwelling type, material properties (or household amenities/conditions) and/or occupancy (135). Housing needs may be "fluid" or temporal in nature (216).

A large proportion of HIV research and subsequent interventions focus on those affected by housing instability or conditions – notably homeless and/or jailed populations living with HIV. Aidala and Sumartojo (151) argue that "people are homeless or unstable housed not simply because of

[9] A recent cross-sectional analysis by Morales et al. (209) found that people living with HIV in the UK were more likely to experience conditions including bipolar disorder; pulmonary embolisms; and liver fibrosis, sclerosis and cirrhosis, than adults without HIV.

their individual traits or characteristics, but because of a confluence of interacting environmental influences." Housing stability has been consistently found to be positively associated with health-related outcomes among people living with HIV, including medication adherence, sustained virological suppression and access/retention to care, even after controlling for individual-level characteristics (150, 177, 216–218). Therefore, Aidala et al. (150) advocate for structural, HIV interventions focussing on living circumstances (e.g. providing immediate rental housing) and improving residential environments which has shown to be cost-effective through the Housing and Health Study (219, 220).

1.4.3 Social injustice

Injustices relating to gender, race and class are constructed simultaneously rather than in a multiplicative or additive manner (22, 221). For instance, ecosocial theory considers the influence of sexism, heterosexism, gender binarism and racism on disease distribution (161). Among people living with HIV, stigma and discrimination can result in poorer health and well-being outcomes, for instance due to HIV-related, intersectional and structural stigma (e.g. experienced poverty stigma) (222–224).

Social class

Social class can be defined as "social groups arising from interdependent economic relationships among people"; class is a "social relationship created by societies" which is categorical and nominal in nature (133). Therefore, social class is closely related to SEP and can be measured across ecologies – at the individual-, household- and neighbourhood-level (133).

Research on social class and HIV is limited and tends to conflate this with wider social inequalities including poverty and economic conditions (or SES) or use markers such as race/ethnicity (180). Additionally, most studies appear to focus on HIV prevalence, sexual behaviour or disease progression (180, 225, 226).

Gender and sexuality

Gender is a social construct which operates within social processes including roles, norms and power hierarchies, and can be viewed as a "core social determinant" (117, 227–229). People who identify to a gender different to that assigned at birth may be 'transgender' or 'gender diverse' compared to

'cisgender' (230). The WHO define sexuality as "...a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors" (231).

Evidence exists to suggest that gender and socioeconomic factors are closely related and may explain differences seen in HIV outcomes including antiretroviral response as well as self-rated health (193, 232, 233). In the US, poorer HIV outcomes are found among women of colour living with HIV, compared to White American women due to historical and structural factors (e.g. economic recessions) impacting social and welfare programmes which ultimately disproportionately impact women with caregiver responsibilities (22–24, 234). Caiola and colleagues (22) outline the "mutually constituted" vulnerability of African American mothers of racism, classism, gender inequality and HIV-related stigma on individual- and population-level health outcomes, navigated through access to, and quality of, care. Shokoohi et al. (233) demonstrate clear disparities in socio-structural determinants and health/self-rated health between women living with HIV compared to the general population in Canada. Poorer mental health outcomes are persistently reported among transgender and gender diverse populations living with HIV which can be explained by minority stress theory (230, 235, 236). Minority stress theory is where marginalised groups experience a higher burden of ill health, or exposure to excess stress, due to their minority and often stigmatised position within society; for instance, a high prevalence of mental disorders is found among gay, bisexual and lesbian populations compared to their heterosexual peers (236). This can be explained by distal minority stress processes or experiences of prejudice events and conditions (e.g. discrimination, violence) and proximal minority stress processes (e.g. expectations of rejection, concealment of sexual orientation, and internalisation of societal stigma) (236, 237).

Race/ethnicity

Ethnicity is a socially constructed categorical variable which is often imprecise and context-specific and can mask areas of inequalities through homogenisation and Eurocentricism (238, 239). Ethnicity is a multi-faceted construct which "includes multiple dimensions including country of birth, language, religion and culture" (239). Therefore, there are growing calls to shift towards the term minoritised as "individuals and populations, including numerical majorities, whose collective cultural, economic, political and social power has been eroded through the targeting of identity in active processes that sustain structures of hegemony" (238, 240).

Ethnic inequalities persist among people living with HIV in relation to clinical (e.g. virological non-suppression, non-retention in HIV care) and mental health outcomes (e.g. social isolation, current psychological distress) (241, 242). For instance, in the Positive tRansItions through Menopause (PRIME) study, Black African and Black Caribbean women were found to be 3.3 (aOR 3.34, 95% CI 1.38, 8.13) and 4.8 times (aOR 4.81, 95% CI 1.61, 14.41) more likely, respectively, to self-report current psychological distress than White British women (242). The same study (242) also found higher odds of social isolation among racially minoritised groups but not relating to a diagnosis of depression.

1.5 HIV and COVID-19: a syndemic of present day

1.5.1 Syndemic theory

Syndemic theory was first coined by Merryl Singer to describe the interrelatedness between multiple determinants (substance abuse, violence, AIDS or SAVA) that worsen health outcomes among materially deprived people living with HIV (243, 244). Since then, a syndemic relationship has also been described to exist between HIV and mental health (e.g. depression), stigma (e.g. HIV-related, intersectional), social disadvantages (e.g. unstable housing, poverty) and substance misuse (e.g. alcohol, drugs) (245–247).

1.5.2 COVID-19 pandemic

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) first emerged in Wuhan, China in late 2019. On 11 March 2020, the WHO declared coronavirus disease 2019 (COVID-19) a pandemic (248). Millions of people have been affected globally; over 16 million people in the UK have tested positive for COVID-19 since testing began (249).

1.5.3 COVID-19 and HIV syndemic

Comparisons have been made between the experiences of the HIV/AIDS epidemic and recent COVID-19 pandemic; they have been referred to as "intersecting epi/pandemics" (250–252). Subsequently, a syndemic perspective has been applied to explain the relationship between COVID-19 and HIV (253). Notably, Shiau et al. (253) use a syndemic framework to unpack how COVID-19 exists within a "syndemic of health problems" for people living with HIV including co-morbidities, psychosocial conditions and healthcare access.

Studies have explored COVID-19 outcomes among people living with HIV; notably, during the first wave of the pandemic in England (March to June 2020), the risk of COVID-19 death was over two times greater (aRR 2.18; 95% CI 1.76, 2.70) among people living with HIV than without, after adjusting for gender, age at death and ethnicity (254). People living with HIV in the UK have described COVID-19 as their "second pandemic" (255) with global concerns of increased social

isolation, loneliness (256) as well as impact to the social determinants of health (110). People living with HIV have shared their unmet needs during the pandemic, while others report personal and community level resilience through their lived experiences of HIV (257).

Similarly to HIV, COVID-19 has highlighted worsening and widening inequalities across societies globally (1, 4, 174, 258, 259). There has been an unequal impact of COVID-19 in terms of exposure, vulnerability, disease/social outcomes, control measures and the broader social determinants of health on marginalised groups (1, 239, 259, 260). For instance, in the UK, minority ethnic groups may be more likely to experience differential exposure due to occupation type (e.g. front-line caring responsibilities) or differential social consequences (e.g. due to stigmatisation of specific ethnic groups) (239).

Individuals providing HIV care and those living with HIV have had to quickly adapt to government restrictions, guidelines and emerging scientific knowledge on the SARS-CoV-2 virus and COVID-19 disease; this includes the acceleration of innovations in HIV care such as telehealth, self-testing and community-led services (4). All points of care were affected by disrupted health systems, adaptations to services and a shift of focus to curtail COVID-19 infections and treat patients; emerging data remains unclear regarding the susceptibility and outcomes for people living with HIV acquiring SARS-CoV-2, compared to the general population (4, 261–263). However, there are concerns due to high rates of co-morbidities among people living with HIV as well as the influence of existing social inequalities (263).

I will apply syndemic theory to interpret qualitative findings in **Chapter 4**.

1.6 Research question and aim of thesis

My thesis aims to identify the contribution of social and structural determinants on clinical outcomes and self-reported health and well-being among adults (aged 18 years and over) living with HIV in the UK, through the development of a conceptual framework. This will include the analysis of the 2017 Positive Voices dataset.

Due to the COVID-19 pandemic which was declared 6-months after my PhD start date, I also looked at the impact of COVID-19 on people living with HIV. Specifically, my research questions and objectives are outlined below.

1. **Do social determinants explain variation in clinical and health and well-being outcomes among people living with HIV?**
   (a) To identify the social and structural determinants that may influence self-reported health, well-being, and clinical outcomes.
   (b) To develop a conceptual framework based on existing theories (ecosocial theory; syndemic theory) and approaches (intersectionality) through the application to mixed-methods results.
   (c) To explore possible explanations for these associations and propose a causal pathway.
2. **What are the experiences of COVID-19 among people living with HIV and HIV community, charity and healthcare workers? How do these experiences vary among different social groups?**
   (a) To explore perceptions of the challenges, opportunities and adaptations made to HIV services during the epidemic.
   (b) To build new, and strengthen existing, partnerships with people living with HIV and those working in services through participatory approaches (including community involvement, engagement and peer research).
3. **What is the contribution of social determinants to inequalities in HIV outcomes?**

(a) To describe the historical and current health inequalities with HIV outcomes in high-income countries according to gender identity, ethnicity and sexuality.

(b) To identify the social determinants that may influence self-reported health, well-being and clinical outcomes among groups identified in objective 3a.

1.7 Study approach

Mixed-methods research is grounded in pragmatism, using multiple forms of data collection whilst focusing on the social and historical context of the research question (264, 265). The underlying assumption of mixed-methods approaches is that they can address research questions more comprehensively than a single study design, as they provide a level of completeness (266). Mixed methods also provide the opportunity to explore diverse research questions, expand on unexpected findings,[10] offset the weakness of each method, and mutually corroborate, or contrast, findings by triangulation (or convergence) (266).

My PhD has used a mixed-methods approach, specifically a convergent parallel design, since I analysed the quantitative and qualitative strands separately and then combined the results of both studies to provide completeness to the investigation (268). First, I conducted a systematic review to identify the gap in the literature. Next, I conducted a qualitative study of health workers and community-based organisations and then I analysed secondary quantitative data collected in the 2017 Positive Voices survey. I then randomly sampled participants from the survey to be interviewed in a co-produced study. Finally, I analysed secondary data to investigate associations between social determinants and self-reported mental health and then compared and contrasted the findings across studies. **Figure 1.6** outlines the overall study approach.

[10] Bryman (267) describes qualitative data as "putting 'meat on the bones' of dry quantitative data."

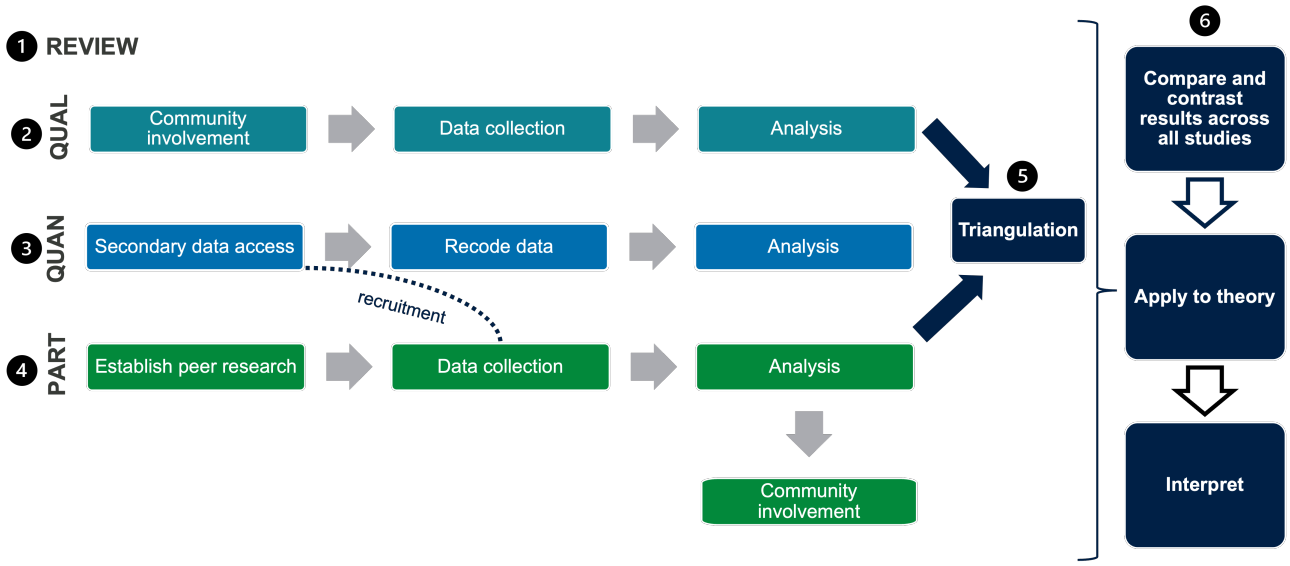


Figure 1.6: Summary of mixed-methods approach including order of each study. Abbreviations: QUAL, qualitative; QUAN, quantitative; PART, participatory.

1.8 Outline of thesis

- **Chapter 2**

  I will present a systematic review exploring associations between measures of material deprivation and HIV outcomes (specifically ART adherence and virological suppression) in high-income countries.

- **Chapter 3**

  I will outline the approach taken for a qualitative study of HIV healthcare and community-based staff and volunteers supporting people living with HIV during COVID-19 to explore changes to HIV services and experiences. In preparation for this work, I designed and led a community involvement event, in collaboration with the HIV support charity Positively UK, to design the interview topic guide. This community involvement event marked the start of my partnership with people living with HIV which continues throughout my PhD.

- **Chapter 4**

  I will outline a co-produced research study exploring the experiences of people living with HIV during the COVID-19 pandemic. I will also reflect on using a peer research approach

in a doctoral thesis.

- **Chapter 5**

  I will investigate the association between self-reported mental health and social determinants of health measured in the 2017 Positive Voices study, the first nationally representative sample of people living with HIV.

- **Chapter 6**

  I will triangulate data from my data synthesis, qualitative research and secondary data analysis and apply these findings to ecosocial theory, intersectionality and syndemic theory to help uncover how social determinants are associated with clinical and mental health outcomes among people living with HIV.

- **Chapter 7 and Chapter 8**

  I will present a discussion which summarises the findings across all chapters. This will include a reflection on the strengths and limitations of the work and implications for clinical practice, policy recommendations and future research. Finally, I shall conclude the thesis with a summary statement.

- **Chapter 9**

  I will present a list of outputs produced by me, including those that have direct relevance to the thesis.

1.9 Positionality statement

I am a second-generation, British-born Greek Cypriot female researcher who has grown up in London and apply an intersectional feminist approach to my research.

I have experience working with people affected by cancer and have worked in the field of public involvement in research since 2015; I am familiar with participatory approaches and I have been moving up "Arnstein's ladder" of citizen participation since my first role. I advocate for more inclusive

and participatory involvement each time. Therefore, I was keen to adopt a different participatory approach during my PhD which involved creative methods.

I found that conducting a qualitative study during a significant moment in history enabled me to quickly form a rapport with participants and co-researchers as we were all experiencing the pandemic at the same time. Participants were keen to speak over email and be kept updated on the topic as it was relevant and of interest. I recruited through existing channels and relationships built, for example, through an involvement opportunity with Positively UK as well as the Positive Voices study. Therefore, it is likely that I reached an already engaged group of people living and working in HIV services rather than those underrepresented in research. However, I also found that using my full name (and having a London accent) created some conversation with participants about where I was from and my background; this was also evident in the co-produced qualitative study where I worked with people with lived experience (co-researchers) from a diverse range of backgrounds. Building trust and rapport were essential in ensuring co-researchers felt comfortable, confident and able to contribute ideas as part of a research team.

My research aligns with pragmatism as it uses a mixed-methods approach to answer the research question. Before conducting the thesis, I was acutely aware of the social inequalities that are evident across sections of society and how these have worsened over the past decade due to austerity measures in the UK. Therefore, this may have influenced how I interpreted the findings from the body of evidence generated as well as the conduct of each research component. For example, in the qualitative studies, I was interested in exploring how each individual was experiencing the COVID-19 pandemic through an intersectional lens and how systems of power and oppression may interact with these lived experiences.

I am not living with HIV and this research is the first time I have worked with people living with HIV. Therefore, I was mindful that I would need to establish good relationships with people living with HIV in order to ensure the research remained relevant and could contribute to improving lives. I had, however, begun to engage with literature from HIV research in 2017 during my Masters of Public Health and then again in 2018 whilst working as a Research Assistant at Imperial College London. I spent several months working on a systematic review exploring the impact of pre-exposure prophylaxis on bacterial sexually transmitted infections among cisgender women. I learnt about the

language and terminology to be used (and avoided) in HIV research and the importance of this in combatting stigma. I also met the Positive Voices team in 2018 and spoke of my ambitions to pursue a PhD in HIV research, working together to help uncover how social determinants were associated with outcomes in the dataset. However, I remained open during the process to feedback from people living with HIV and from colleagues who had worked in the field over several decades and were familiar with the intricacies and histories of the HIV epidemic in the UK.

I hope that my doctoral research project provides useful insights to public health researchers and social epidemiologists interested in employing similar methods in their research as well as evidence for policymakers and clinicians working in the field of HIV. I hope that the co-researchers involved use the skills gained in future research projects and continue to mentor future co-researchers.

2

A systematic review of the relationship between social determinants and HIV outcomes in high-income countries

In **Chapter 1**, I provided an overview of HIV care worldwide and in the UK and examined how social determinants of health can explain some of the persistent inequalities in outcomes and progress.

In **Chapter 2**, I explore associations between social determinants and HIV outcomes (specifically adherence to ART and virological suppression) in high-income countries. I shall refer to a peer-reviewed publication **(Appendix B)** that I co-authored with my supervisors (Dr Bethan Davies (BD) and Professor Helen Ward (HW)) and colleagues (Emily Cooper (EC) and Ariana Singer (AS)) which focussed on measures of material deprivation (177).

HW and BD provided comments on this Chapter.

2.1 Abstract

A social gradient of health is a trend where people of less advantaged socioeconomic position display poorer health outcomes compared to those more advantaged and is seen across a distribution. I conducted a systematic review to identify evidence of social determinants that have an impact on HIV treatment outcomes (viral suppression, ART adherence) among people living with HIV in high-income countries. 83 observational studies were identified as eligible to be included. Most of the evidence was from studies conducted in North America. Overall, people living in unstable housing, who were food insecure, had a low income, or lived in a deprived neighbourhood, displayed poorer viral suppression and/or ART adherence, compared to those with no or lower material deprivation. A negative association remained when other social factors, including age and gender, were controlled for. These findings will be used to inform variables to be explored in later Chapters.

2.2 Introduction

Overall, new HIV diagnoses continue to decline in the UK; in 2021, a 33% decrease was observed compared to 2019 (4,408 to 2,955) and 0.2% since 2020 (2,961) (269). However, inequalities remain for late HIV diagnoses which are higher among heterosexual men and women compared to GBM, which in turn, increases risks of poorer outcomes (e.g. premature death) as well as the rates of declines in new diagnoses among population groups (8). For example, new HIV diagnoses in England among White as well as Black Caribbean heterosexuals fell in 2019 to 2020 by 40% (470 to 280 and 50 to 30) compared to 25% and 17% among Black African (400 to 300) and Asian (60 to 50) heterosexuals, respectively (8). In 2021, the proportion of late diagnoses was highest among people of Black African ethnicity compared to people of White ethnicity (56%: 174/312 vs 45%: 331/739) (269).

According to the WHO CSDH framework (117), living/working conditions (e.g. housing) and food security are considered to be "intermediary determinants" of social determinants that impact on equity in health and well-being. I argue that these factors should be considered core drivers that may influence outcomes among people living with HIV; for instance, housing is likely to influence someone's connectivity with wider social networks (e.g. someone living alone but in a neighbourhood with high social capital) (270), and their physical and psychological well-being as "access to housing structures intimate relations" (151) but also can help to develop and maintain social networks which offer emotional support (151, 271). Therefore, people living in unstable housing may not feel safe or have adequate materials to remain healthy, including access to social support networks (150). For example, cold homes due to fuel poverty are associated with poorer respiratory health (e.g. damp and mould can worsen asthma) and can contribute to excess winter deaths (272). Similarly, older buildings with poorer cleaning facilities and debris may attract pests leading to infestations and poorer health outcomes (271). There are several possible mechanisms for how housing instability may contribute to poorer HIV outcomes, and there is some evidence that investment in housing can contribute to improved health status among people living with HIV (151, 177, 219, 220). There is also evidence that rental housing assistance could reduce onward transmission and even be cost-saving (219, 220). Finally, as described in **subsection 1.2.6**, broad outcomes that look beyond virological

suppression are important and should include measures of quality of life such as HR-QOL, including the management of other health conditions (12, 91).

2.2.1 Study rationale

I built on a literature review by Burch et al. (20) published in 2016 that identified 46 studies, of any study design, in HICs and found that people living with HIV of poorer SES displayed worse ART responses than those with improved SES. In my study (177), I provide a more recent examination and, unlike the aforementioned study, I did not examine health insurance, mental health, lifestyle or health care factors because I was interested in determinants that can be specifically targeted by social and public health policies (117). Also, my outcomes were virological suppression and ART adherence as these are good indicators of the health of people living with HIV; HIV treatment is highly effective, therefore, these clinical measures indicate whether a person living with HIV is managing their HIV. Finally, I used the findings from the review to support interpretation of findings in future Chapters.

2.2.2 Research questions

1. What is the relationship between social determinants and treatment outcomes among people living with HIV in HICs?

2. What is the contribution of social determinants to inequalities in HIV outcomes?

2.2.3 Aim and objectives

To assess the effects of social determinants on HIV treatment outcomes among people living with HIV in HICs.

1. To develop a Populations of Interest, Exposures, Comparators, and Outcomes (PECO) statement and related inclusion and exclusion criteria for the systematic review.

2. To develop a search strategy, register the protocol and conduct various rounds of screening (including title, abstract, full-text) to ensure a systematic approach to the review.

3. To extract data and assess the quality of data included in the review using a risk of bias assessment.

4. To compare the direction, magnitude and effect measures of associations between measures of material deprivation (exposures) and outcome(s).

5. To conduct further statistical analyses (e.g. meta-analysis) of data where appropriate.

6. To use the findings to guide further research and suggest recommendations for implications for policy and clinical practice.

2.3 Methods

I registered my protocol on PROSPERO (Ref: CRD42020171850) and used the 2009 PRISMA checklist to design and perform the review (273, 274). Following completion of the review, the updated 2020 PRISMA checklist (275) was published which I used to write my peer-reviewed publication (177).

2.3.1 Search strategy and selection criteria

First, I established my PECO statement (adapted from the PICO framework) to help frame the research question and identify key concepts for the search strategy.

Population:

- **Adults (aged 18+ years old) living with HIV in high-income countries.**

I defined HICs[1] using the World Bank 2019 classifications (278) based on Gross National Income per capita$\geq$\$12,376. I also based this on membership in the Organisation for Economic Co-operation and Development (OECD) (279). This definition was previously used by Perry et al. (276). I limited this to HICs to allow for some comparison across settings, specifically in relation to similarities across the HIV care continuum (e.g. wide availability of advanced generations of ART and the provision of digital/remote HIV care) (177).

Exposure(s):

- Primarily, **material deprivation**[2] (defined as education, financial stability/income, housing, employment, food/bill security, food security and specific measures of SES/SEP and social class).

[1] HICs which met the systematic review eligibility criteria were: Australia, Austria, Belgium, Canada, Chile*, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, (South) Korea, Latvia*, Lithuania*, Luxembourg, The Netherlands, New Zealand, Norway, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden*, Switzerland, United Kingdom (England, Wales, Scotland, Northern Ireland), and the United States (of America). *Additional countries that met criteria but were not included in Perry et al. (276, 277) systematic review strategy.

[2] I selected exposures based on the WHO CSDH framework outlined previously (see **subsection 1.3.1**); however, I explored housing as an individual determinant of SES, rather than an intermediary determinant.

- Other **social factors**[3]: age, gender, sexuality, race/ethnicity, and migration status (or country of birth).
- **Intermediary factors**: psychosocial circumstances, behavioural/biological factors, historical and/or health systems.

Comparison:

- Exposure(s) compared across levels (e.g. employed, unemployed etc.)

Outcome(s):

- **Primary – HIV treatment outcomes**[4]
  - ART adherence: self-reports, pill count, pharmacy refill, medication event monitoring systems (78)
  - Viral suppression: viral load/CD4 cell counts
- **Secondary – other reported clinical/patient reported outcomes**[5] such as:
  - HIV diagnosis and care history (e.g. stage at diagnosis, presenting for diagnosis)
  - HIV care and treatment history (e.g. clinic attendance, ART initiation)
  - Self-reported health status and wellbeing (e.g. quality of life scores)

The secondary outcomes were not included in the published systematic review due to word count restrictions, but are included in this chapter to provide a more holistic understanding of associations along the care continuum. The measures of effect (adjusted and unadjusted) for the outcomes included: odds ratios, prevalence rate ratios, relative risks, hazard ratios, and χ^2.

[3] These variables were selected based on previous literature to align with ecosocial theory (161) as well as expert opinion (advice from my supervisors).

[4] These outcomes were based on those reported in the HIV/AIDS Reporting System (HARS) dataset (280, 281) and the Positive Voices survey (208).

[5] Secondary factors were only explored if the study reported the primary outcome(s).

Search strategy

My search strategy concepts were HIV, social determinants, HICs and HIV treatment outcomes. I developed the search strategy using published strategies from systematic reviews of similar concepts (20, 29, 282, 283) as well as the support of a librarian based at St Mary's Library and Cochrane guidance (284). I identified studies eligible for inclusion through hand searching based on the title and abstract, which then went through the screening process. My full search strategy and study inclusion criteria have been published elsewhere (177, 273).

2.3.2 Information sources

I conducted my search from the date of creation/first stored record to January and March 2020, with a complete list of databases searched reported in the published article (177). I also used complementary search methods of citation searching, hand searching (from conference abstract databases), follow-up references and snowballing (from systematic reviews and editorials) to ensure that I did not miss any eligible studies.

2.3.3 Data management

I imported all references to the online systematic review software, Covidence, for screening and to remove any duplicates (285). I used Microsoft Excel to export and manage studies eligible for inclusion, where data were extracted and recorded. I also kept a record of any hand searches conducted including the databases searched, search concepts used, dates of searches and researcher who conducted the search.

Selection process

I screened for the eligibility of articles in Covidence (285), alongside AS, by title and abstract and then by the full-text. We recorded any conflicts detected by Covidence (285) in the screening process and sought a second opinion from HW and/or BD if we could not agree on whether to include or exclude the article. Justifications for excluding studies at full-text were recorded on Covidence.

Some articles detected through the search process did not have a freely available text; therefore, I

contacted the study authors via the corresponding author and, if I received a message indicating that my email was undelivered, I then contacted study authors via ResearchGate[6] or their most recently available institutional email. Covidence has an in-built duplicate detection system, however, it may miss some duplicates therefore, I manually excluded any not detected by the full-text stage review.

I identified and grouped multiple reports from the same study and only included the most recent publication (or the latest complete publication, for example, journal articles were selected over conference abstracts) as the main study identifier to avoid the introduction of publication bias; in other words, one study overrepresented in the review (286).

2.3.4 Data collection

I piloted the data extraction table on the first ten studies eligible to be included and amended this to include: the main study (or where applicable, project name), the statistical approach and unit of analysis as well as any key findings (e.g. effect size measurement and any adjustments). I separated the exposure and outcome variables into broader categories with subheadings for the variable name, measurement, instrument, definition and/or timing and the baseline method of aggregation for each.

I extracted all the data to the data extraction table which was hosted in Microsoft Excel with study information, study characteristics as well as summary effect estimates recorded and was adapted from the Cochrane Handbook (287).[7] EC then cross-checked my data extraction table for consistency against the original source and noted any errors in another colour, along with a comment.

Data items

The specific items extracted are listed above in **subsection 2.3.1**. I also extracted data from secondary outcomes of HIV diagnosis, treatment and care histories and other health outcomes (e.g. quality of life) (150) to provide context on the included populations, some of which are presented below. I completed this step by filtering my data extraction Microsoft Excel database according to secondary outcomes extracted; in other words, where eligible studies looked at the primary outcomes alongside secondary outcomes.

[6] ResearchGate is a social networking platform for researchers.
[7] See sections 5.3.1 and 5.3.5 in Cochrane Handbook (287).

2.3.5 Data analysis

I grouped studies according to exposure (social determinants at ecological levels) and primary outcome (ART adherence/virological suppression) and then sub-divided them by design and population (e.g. geographical location — North America, Europe, Asia/Other). Following advice from my early stage assessors, I was able to conduct a random-effects meta-analysis[8] of studies that had investigated one exposure measure (housing status) and used the same effect measure (odds ratios) for outcomes as these were consistently defined in some included studies (177, 288). In the published article (177), I present effect estimates using forest plots; however, in this Chapter, I will present results as a narrative synthesis.

2.3.6 Quality/risk of bias assessment

Risk of bias among the included studies was evaluated using the Newcastle-Ottawa scale (NOS) (289); I adapted NOS to be used to assess bias within cross-sectional studies (290). I selected age, gender/sexual identity, social class, and race/ethnicity as the most important variables for studies to adjust for in the "comparability" section of the NOS form. I used the WHO guidelines (59, 291) of routine viral load monitoring/testing at 6-months following ART initiation to determine adequate follow-up for virological suppression and measuring ART adherence at 30 days.

[8] A random-effects meta-analysis assumes that each individual study is "estimating different, yet related, intervention effects"; therefore, it investigates heterogeneity that cannot be explained by other factors by considering any differences are random (288).

2.4 Results

Overall, 83 studies were eligible for inclusion in the review, relating to over 1.4 million adults living with HIV including various racial, gender and sexual minority communities. Most studies were either a cohort or other longitudinal design, explored education as a social determinant and looked at virological suppression. The majority of studies were from North America (n=61), with 20 based in Europe, one in Australia and one in Asia **(Figure 2.1)**. 9.6% (n=8/83) of studies included scored 'low quality' during the risk of bias assessment (177).

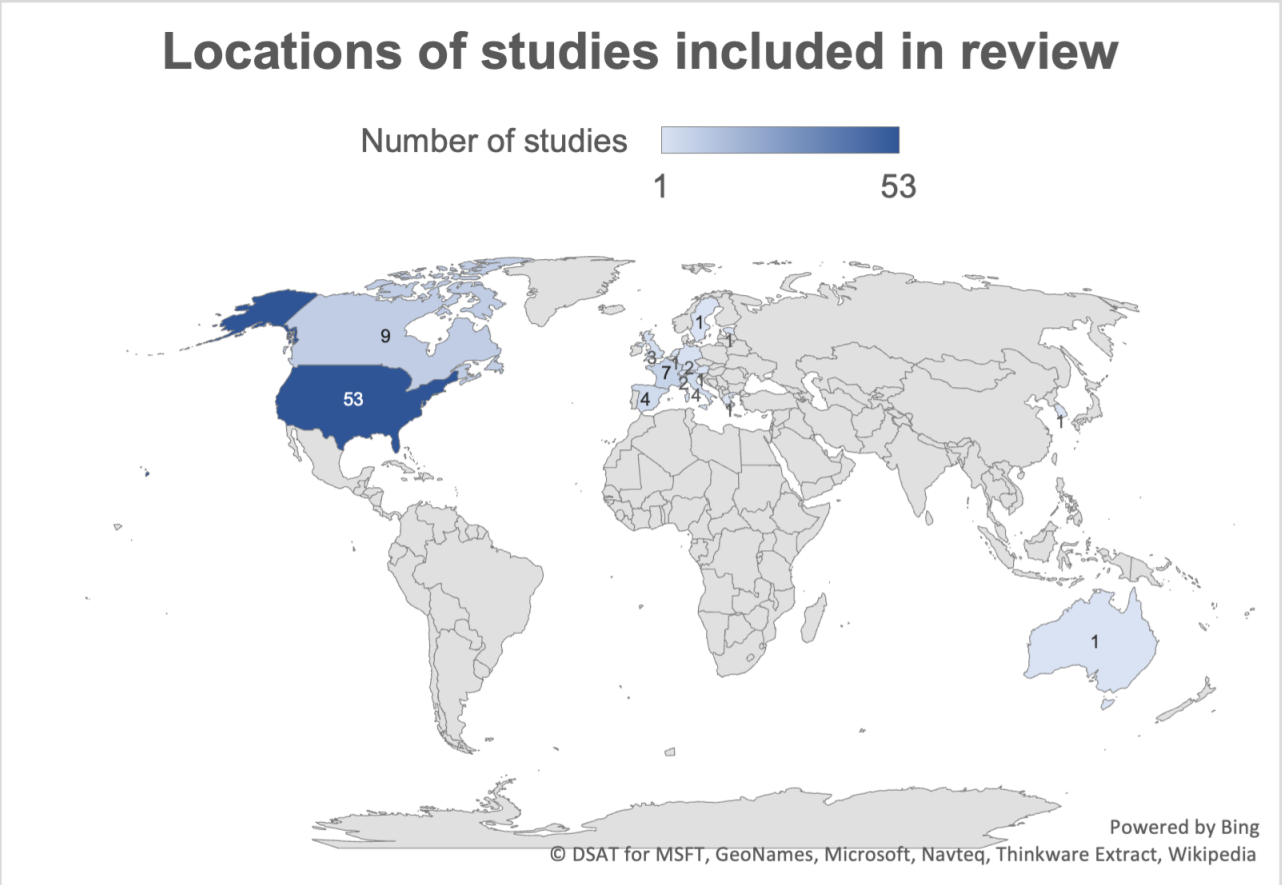


Figure 2.1: World map of studies[9] included in systematic review created using Microsoft Excel.

I identified several measurements for each social determinant which made comparisons between studies difficult **(Figure 2.2)**. This includes determinants that were not explored in the published review (177) but are included in this Chapter.

[9] N.B. Overall country number exceeds total studies included in review as some studies had multiple sites.

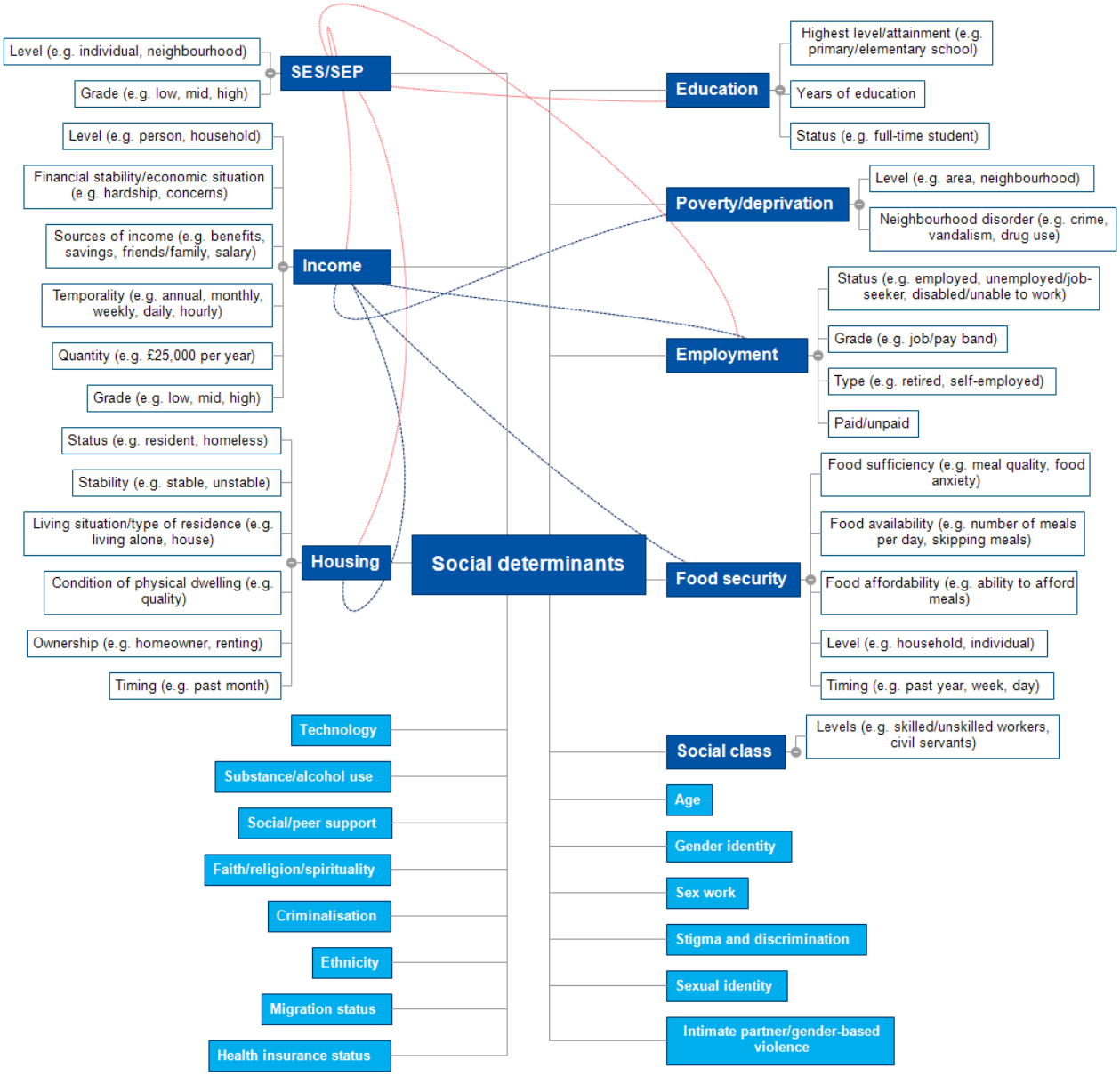


Figure 2.2: Measures of material deprivation (dark blue) which form focus of the review including examples taken from included studies. Additional social determinants which are not the focus of this review (light blue).[10]

In the published article (177), I found that only 10-20% of the studies included found significant associations between the determinants identified and HIV treatment outcomes. Some determinants were more clearly associated with the outcomes than others; for example, 1 in 5 (20%) studies investigated housing status and virological suppression (177). Of all social determinants, housing had

[10] Dotted red lines (...) indicate relationship between measures of SES/SEP. As outlined in **subsection 1.4.2**, indicators of SES can include measures of education, housing, income and employment (129, 133, 135). Dashed blue lines (- - -) indicate relationship between measures of income. This Figure was created using MindView 8.0 (292).

the most consistent associations in terms of direction with HIV outcomes investigated; specifically, unstable housing was associated with virological non-suppression and ART non-adherence, compared to stable housing. Therefore, I conducted a meta-analysis grouping studies using the same effect measure (odds ratios) and similar measurements of housing stability and found a pooled aOR of 0.48 (95% CI 0.33, 0.70) at VL<200 copies/mL (177). This association suggests that people living in unstable housing were 52% less likely to be virologically suppressed than people living in stable housing, after the results from individual studies were combined and averaged.[11] The direction and magnitude of this association remained similar when including studies with a threshold of VL<100 copies/mL (aOR 0.49; 95% CI 0.34, 0.69) (177). However, a high proportion of heterogeneity (89-89%) was determined across studies included in the meta-analysis investigating the relationship between housing status and virological suppression (177, 288). I also identified consistent associations between SES/SEP and virological suppression and food security and adherence, although not between education and adherence (177).

In the following sections, I will present significant adjusted effect estimates from studies not highlighted in the main article text of the published review (177); the data are presented in the supplementary file.

2.4.1 Education

The largest number of studies included in the review investigated associations with education (n=52, 62.7%) which was measured by years of education or highest level of achievement (177).

Overall, increased time or level of education was associated with greater virological suppression, while the evidence relating to medication adherence remained less clear. For example, people living with HIV in the UK who did not have a university education were 62% more likely to be virologically non-suppressed compared to those with a university education (aPR 1.62; 95% CI 1.22, 2.14) after adjusting for demographic factors (293). This direction of association remained when investigating virological rebound (VL>200 copies/mL) among adults without a university education, compared to those with a university education (aHR 1.50; 95% CI 1.05, 2.15) after adjusting for demographic

[11] A random-effects meta-analysis assumes that intervention effects follow a normal distribution based on chance and genuine variation in effects; therefore, the confidence interval describes "...uncertainty in the location of the mean of systematically different effects in the different studies" (288).

factors including gender/sexual orientation, ethnicity and age (293). Additionally, people living with HIV in Italy who had completed high school or university were 16% (aHR 1.16, 95% CI 1.01, 1.34) and 21% (aHR 1.21, 95% CI 1.03, 1.43) more likely, respectively, to have a VL<50 copies/mL compared to those who had completed elementary school only at any point in time during the study after adjusting for CD4 count, viral load, pregnancy status and smoking (294). The same direction of association was also observed among women living with HIV in the US who formerly/currently injected drugs and had achieved some College/above education associated with VL≤40 copies/mL compared to 8th Grade or less (aIR 2.60, 95% CI 1.00, 6.77)[12] after adjusting for substance use, mental illness, and other intermediary factors (295).

In terms of adherence, Burch (293) found that adults without university education had 1.2 times higher prevalence of ART non-adherence (aPR 1.18; 95% CI 1.05, 1.32) compared to adults with university education, after adjusting for demographic factors. However, another study conducted in the UK by Sherr et al. (114) found that women living with HIV with a university level education were 74% less likely (aOR 0.26; 95% 0.09, 0.76) to report ART adherence, whereas men with a university education showed no difference in adherence (aOR 2.64; 95% CI 0.63, 10.94) after adjusting for demographics including age and race/ethnicity.[13] Golin et al. (296) found a significant adjusted negative association between adherence and education among adults living with HIV in the US between high school education and adherence to ART after adjusting for social, behavioural and clinical characteristics.

Exploring associations along the HIV care continuum also shows a mixed picture. For example, in one study HIV testing was associated with higher educational status; Black MSM who had experienced homelessness in the past 12 months and with <high school or high school/General Educational Development (GED) qualifications were 40% (aOR 0.60; 95% CI 0.44, 0.82) and 21% (aOR 0.79; 95% CI 0.64, 0.98) less likely, respectively, to have tested for HIV in the past 6 months than Black MSM with Bachelor's degree or greater, after adjusting for sociodemographic and healthcare differences (297). No relationship was found to exist between those with some College education and HIV testing (297). Furthermore, men with medium or low educational levels (completed secondary

[12] This study (295) had a small sample size (n=383) which may explain why the lower 95% confidence interval shows no difference.

[13] It is difficult to draw significant conclusions from this small study (114) of 183 women and 76 heterosexual men living with HIV as well as other small studies in the review; this is explored further in **Section 2.5**.

education; no education or primary education only) were 1.5 (OR 1.5; 95% CI 1.2, 1.9) and 3 times (OR 3.0; 95% CI 2.2, 4.0) more likely, respectively, to receive a delayed diagnosis than those who had completed university education (classified as high educational level) (196). However, the opposite effect was observed in women with higher education having an increased likelihood of delayed diagnosis than those with lower education (196). Saracino et al. (294) found that people with higher educational levels were more likely to have initiated ART. However, education showed mixed associations for remaining in HIV care. For example, Oliver et al. (298) reported a positive association (aRR 1.29; 95% CI 1.02, 1.64) between less than high school education ($<$12th Grade) and poor retention in care among pregnant women living with HIV compared to women with GED or high school education or greater. Anderson et al. (299) found no significant association between people who had graduated from high school or higher and missed more than 33% of HIV clinic visits in the past year, after adjusting for confounders. Like Anderson et al. (299), a similar direction and magnitude of associations were found to exist between lower levels of education (less than High School/High School degree or equivalent) and not being prescribed ART, compared to some College or more (300).

2.4.2 Employment

Employment was measured in various ways across the studies including status and grade.

A varied association was found between employment, virological suppression and adherence (177). Haider et al. (301) reported that people living with HIV and receiving HIV care, in the US, were 4-times more likely (aOR 4.03, 95% CI 1.27, 12.83) to be virologically suppressed (VL$<$100 copies/mL) than those who were unemployed or unable to work, after adjusting for demographic and clinical characteristics.

Burch et al. (293) found that adults who were unemployed had a 1.3 times greater prevalence of ART non-adherence (aPR 1.29; 95% CI 1.16, 1.45) compared to those who were employed, after adjusting for demographic factors. In contrast, paid workers living with HIV in the US 30 days prior to being jailed, were over 2-times more likely (aOR 2.02; 95% CI 1.21, 3.36) to report $\geq$95% ART adherence, compared to unpaid workers after adjusting for demographic factors and intermediary determinants such as health insurance status (302).

Some studies found that employment status was not associated with HIV clinic attendance, retention in care, recent HIV testing or ART prescription status (297, 299, 300, 303). Meanwhile, Saracino et al. (294) found that unemployed people and students were more likely to have initiated ART compared to full-time workers.

2.4.3 Food security

Food security was measured in seven studies and was defined according to ecological level, time of meals, availability, sufficiency or affordability; therefore, sometimes food security was a composite measure with income or indicator of poverty/deprivation (177).

Only one study reported a significant association between food insecurity and virological suppression, as well as CD4$<$200 cells/mm^3 (304). The other six studies did not report significant adjusted associations between the exposure and outcome.

More evidence was reported that examined associations between food insecurity and adherence to ART. For example, Kalichman et al. (305) reported that adults living in the US who were food insufficient were 70% less likely to report 80% and 90% ART adherence (aOR 0.3; 95% CI 0.1, 0.8 and aOR 0.3; 95% CI 0.1, 0.9, respectively) after adjusting for education, unemployment, low income and several intermediary factors. The same main author conducted a similar study published in 2014 which found the same direction of association (aOR 0.43, 95% CI 0.20, 0.92) between adults in the US reporting food insecurity and 85% ART adherence, after adjusting for age, gender, residing in a food desert and other social determinants (306). Similarly, when exploring combination ART (cART) adherence at a higher threshold of $\geq$95%, Canadian adults living with HIV who were food insecure were 53% less likely to adhere to cART (aOR 0.47, 95% CI 0.24, 0.93) compared to food secure adults, after adjusting for age, Indigenous ancestry, homelessness status and other social factors (307). Weiser et al. (304) found that homeless and marginally housed individuals in the USA were 48% more likely (aOR 1.48; 95% CI 1.19, 1.85) to report $<$90% ART adherence, compared to food secure, after adjusting for sociodemographic and clinical factors.

One study (308) found no associations between food insecurity in the past 6 months and ever receiving primary care for HIV, compared to never being food insecure, among racially minoritised transwomen living with HIV in the US.

2.4.4 Housing

39 studies looked at associations between housing and the primary outcomes of interest and used various measurements including the type of residence, ownership status and quality of housing (177).

Overall unstable, compared to stable, housing was associated with poorer treatment outcomes. For example, Baguso et al. (309) found a large positive association (aRR 7.37; 95% CI 1.07, 50.88) between self-identified transwomen in the US living in unstable housing and a detectable viral load, compared to those not living in unstable housing and after adjusting for age, gender identity, race/ethnicity, other social and intermediary factors. Similarly, adults living in the UK who live in rented housing or with unstable housing status were between two and three times more likely to have a detectable viral load at both VL>50 copies/mL (aPR 2.12; 95% CI 1.49, 3.02 and aPR 3.04; 95% CI 1.97, 4.68) and VL>200 copies/mL (aPR 2.33; 95% CI 1.49, 3.65 and aPR 3.18; 95% CI 1.73, 3.65), compared to homeowners and after adjusting for demographic factors (293). According to Weiser et al. (304), recently homeless/marginally housed individuals living with HIV in the US were nearly two-times more likely (aOR 1.89, 95% CI 1.16, 3.07) to have a VL>100 copies/mL, after adjusting for sociodemographic and clinical variables. The same study (304) found that those recently homeless (defined as living in shelter/street in past 90 days) were more likely to report a CD4<200 cells/mm^3 (aOR 1.65, 95% CI 1.09, 2.49). Furthermore, Wilson et al. (308) found that transwomen of colour living with HIV in the US who reported having unstable housing often in the past 6 months had a 1.8 times higher prevalence (aPR 1.84; 95% CI 1.05, 3.26) of a CD4<500 than those who were never unstably housed, after adjusting for site, age, race/ethnicity, education and marital status.

Associations between home ownership and/or housing status and ART adherence were similar to virological suppression. Three studies found significant associations between unstable housing and poorer ART adherence (range: 1.4 to 3.3 times increased likelihood). First, Abgrall et al. (310) found that adults who had migrated from sub-Saharan Africa to France, and lived with others/unstable housing, were over 3-times more likely (aOR 3.30; 95% CI 1.04, 10.50) to report cART adherence failure compared to homeowners/renters. Secondly, adults in the UK renting or living in unstable housing were 36% (aPR 1.36, 95% CI 1.19, 1.56) and 62% (aPR 1.62, 95% CI 1.35, 1.95) more likely, respectively, to self-report ART non-adherence than homeowners (293). Thirdly, Siefried et al.

(311) reported that Australian adults living in subsidised housing were over 2-times more likely (aOR 2.5; 95% CI 1.0, 6.2) to report sub-optimal ART adherence compared to those not in subsidised housing. Two other studies that explored homelessness and adherence to ART reported the same direction and similar magnitudes of the associations (aOR 1.55; 95% CI 1.04, 2.32 and aOR 1.74; 95% CI 1.15, 2.63, respectively) (304, 312).

3 of 83 included studies found no significant associations between unstable housing status and access to HIV care, retention in care or ever receiving primary care for HIV compared to people living in stable housing (303, 308, 309). However, Blank et al. (303) reported that people living in institutional facilities were 60% less likely (aOR 0.40; 95% CI 0.18, 0.86) to be retained in care at 12-months compared to those with stable housing. Additionally, no significant associations were found between homelessness status and continuity of HIV care, retention in HIV care or ART prescription status (300, 313). One study found that housing status was associated with engagement in HIV care; people who were homeless were 39% less likely (aOR 0.61; 95% CI 0.41, 0.92) to have a HIV care provider within 30 days before being jailed compared to those who were not homeless after adjusting for sociodemographic and health factors (302). However, this association did not exist between homelessness and receiving ART 7 days before being jailed (302).

2.4.5 Income

Income was the most inconsistently and heterogeneously defined determinant as it could be related to specific amounts, sources of income, frequency of payment, or measures of financial security (177).

As expected, people who had financial hardship (e.g. mostly, sometimes or never having enough money for basic needs) had a 1.6 (aPR 1.57; 95% CI 1.11, 2.22), 1.9 (aPR 1.87; 95% CI 1.29, 2.72) and 2.4 (aPR 2.42; 95% CI 1.67, 3.51) times greater prevalence, respectively, to be detectable (VL>50 copies/mL), compared to those who always had enough money and after adjusting for demographic factors (293). This direction remained among those who sometimes or never had enough money when viral load threshold increased to >200 copies/mL, but the association was no longer present in the "mostly" group (aHR 1.34; 95% CI 0.87, 2.09) (293). The relationship is less clear when exploring income from employment; for instance, Yehia et al. (314) reported that adults living with HIV in the US earning between US$20,000 to $49,999 were 34% more likely (aOR

1.34, 95% CI 1.15, 1.55) to be virologically suppressed than the lowest income earners (<$10,000); however, no difference was found among the second lowest earning group ($10,000-$19,9999) and highest earners (≥$50,000) after adjusting for age and other demographic and clinical factors.

Similar directions of associations were seen relating to ART adherence. For example, people living with HIV in Canada earning <CAD$15,000 were 53% less likely (aOR 0.47, 95% 0.31, 0.72) to report high highly active antiretroviral therapy (HAART) adherence (≥95%) compared to those earning >$15,000 (315). The same direction of association was seen in financial hardship and ART non-adherence, with adults living with HIV in the UK having 1.4 (aPR 1.43; 95% CI 1.24, 1.65), 1.9 (aPR 1.85; 95% CI 1.59, 2.15) and 1.8 times (aPR 1.78; 95% CI 1.50, 2.11) greater prevalence of non-adherence, respectively, if they mostly, sometimes or did not have enough money to meet basic needs, compared to always being able to meet their needs (293).

A similarly complicated picture was present between other HIV outcomes and income; for example, having a lower income ($0-$29,999) was associated with decreased likelihood of having had a HIV test in the past 6 months (aOR 0.84; 95% CI 0.71, 0.99) compared to people with higher incomes of $30,000 or more (297). Also, having no annual household income was found to be positively associated with not being retained in HIV care and not being prescribed ART; however, no significant associations existed between these outcomes and having financial concerns[14] in the past year (300). Finally, reporting any illicit source of income (e.g. stealing, drug dealing, sex work etc.) in the past 6 months was associated with being 22% less likely (aPR 0.78; 95% CI 0.65, 0.93) to ever receive primary care for HIV compared to only having licit income sources (e.g. employment) or receiving income from federal entitlement programs (e.g. Social Security Income) (308).

2.4.6 Poverty and deprivation

Nine studies explored associations with poverty and deprivation defined either by ecological level or specific measures, such as neighbourhood disorder (177).[15]

Tymejczyk et al. (317) found that individuals living in neighbourhoods with a high poverty level

[14] Measured by "trouble paying for food or other basic necessities versus not" (300).

[15] Neighbourhood disorder was a determinant investigated by Surratt et al. (312) and measured using a self-reported rating of social disorder (e.g. alcohol, drug use, crime, etc.) and physical disorder (e.g. graffiti, noise, vandalism etc.) with scores averaged on a 40-point scale; this is based on the 10-item scale first developed Ross and Mirowsky (316).

(>30% Neighbourhood Poverty Level, NPL) were half as likely (aOR 0.51; 95% CI 0.29, 0.89) to be virologically suppressed (VL<200 copies/mL) than those living in <10% NPL neighbourhoods. Additionally, people living with HIV in the US were 56% more likely (aOR 1.56; 95% CI 1.05, 2.44) to report a CD4<200 cells/μl if they lived at or above the median below the poverty line, compared to <median (318). Similarly, Gebo et al. (319) found that people living with HIV who ate less than two meals per day (defined as a measure of material deprivation) were over 3-times more likely (aOR 3.31, 95% CI 1.11, 9.92) to be <90% ART adherent. The magnitude of these associations increased when stratifying by injecting drug use and by gender (specifically women) to 17.5 times (aOR 17.54, 95% CI 1.92, 160.4) and 8.3 times (aOR 8.32; 95% CI 1.31, 52.8) (319).

2.4.7 SES/SEP and social class

Only four studies investigated either SES/SEP and one study look at social class which were explored according to levels (e.g. ecological) or grades (177).

Gueler et al. (320) found that individuals living with HIV in Switzerland in neighbourhoods with the highest SEP (quintile 5) were 52% more likely (aOR 1.52; 95% CI 1.14, 2.04) to be virologically suppressed (VL<50 copies/mL) compared to the lowest SEP (quintile 1) after adjusting for age and sex. The same study found no other significant associations across neighbourhood SEP quintiles 2, 3 or 4 (320).

No significant associations were found with respect to social class and CD4 cell count (321), nor SES/SEP and adherence outcomes.

Rebeiro et al. (322) investigated associations between levels of SES and retention in care and found that individuals with unknown SES levels were more likely to report lack of retention in care than individuals of 'not low' SES.

2.4.8 Other social determinants

In this chapter, I also include some findings for social determinants not explored in the published review, as these were not measures of material deprivation (or socioeconomic factors).

For example, one study found that alcohol and drug use were found to be associated with poorer HIV clinic attendance; Anderson et al. (299) found that people living with HIV who had an Alcohol

Use Disorder Identification Test (AUDIT)[16] score of 8 or more were over 2 times more likely to miss over one-third of HIV clinic visits in the past year, than people with an AUDIT<8, although this association did not remain significant after adjusting for sociodemographic factors, substance use and mental health measures. People who reported drug use in the past year were more than three times more likely (aOR 3.18; 95% CI 1.70, 5.92) to miss HIV clinic visits (299). Similarly, substance use was associated with poor retention in care for a study of pregnant women living with HIV (298). Severity of alcohol use was associated with having a detectable viral load in another study (324).

No significant associations were found to exist between race/ethnicity, insurance status, having lived in the US for less than 5 years and retention in HIV care in one study (303). However, another study found that women of Hispanic ethnicity or identifying as being of 'Other' ethnicity were 44% (aRR 0.56; 95% CI 0.33, 0.95) and 69% (aRR 0.31; 95% CI 0.11, 0.87) less likely, respectively to have poor retention in care than Black American women after adjusting for sociodemographic characteristics and clinical outcomes (298).

[16] AUDIT is a screening instrument used to determine alcohol use in the past six months (299, 323).

2.5 Discussion

2.5.1 Key findings

Overall, people living with HIV who are materially deprived (specifically homeless, unemployed, have a low income or living in an area of deprivation) have poorer virological outcomes and lower adherence to ART medication than those who are more socioeconomically advantaged (177). Gender minorities, homeless populations and others who may be marginalised across societies (e.g. prisoners) were at particular risk of poorer outcomes (177). These findings support those of previous systematic reviews focussing on housing status, food security, HIV and other health-related outcomes (150, 211, 217), and the most recent review conducted by Burch et al. (20). Additionally, some social determinants were found to be related to other areas of the HIV care continuum including testing, engagement and retention in care. For example, substance use was associated with HIV clinic non-attendance.

2.5.2 Strengths and limitations

The review found an abundance of literature which was systematically examined through the inclusion of independent reviewers at three major stages of the review: (1) screening studies, (2) cross-checking data extraction and (3) verifying quality assessments (177). Although publication bias was not considered, I did detect a large number of duplicate reports of studies at the final stage of screening which were grouped as one study, with the most recent report included in the review. Most studies included in the review scored either low or unclear risk of bias (177). The study was able to build on the original Burch et al. (20) review as this paper did not look at food security nor social class explicitly and only used PubMed in their search.

However, some limitations existed in the review process; specifically, the search criteria broadly included any social determinant, resulting in several thousand papers being found. I included a mixture of research articles, conference abstracts/posters and doctoral theses in the review, however, no grey literature were included; therefore, it is likely that any relevant evidence published using 'non-traditional' publishers will have been missed. Also, I was only able to conduct a meta-analysis on the housing exposure variable due to heterogeneous populations, geographical regions, definitions and

measurements of outcomes. As a result, mostly relative effects have been reported and the results may not be generalisable. Sample size was small in some included studies, impacting statistical power particularly when investigating several independent variables; 30.1% (n=25) of included studies had a small sample size (n<250) and 9.6% (n=8) even smaller samples (n<100). It was also difficult to assess temporal and/or causal relationships between exposures and outcomes due to study designs (observational) and measures. The measures used for social determinants were heterogeneous limiting comparisons between studies; for instance, composite measures of socioeconomic data at one ecological level and point in time, rather than what Krieger, Williams and Moss (133) suggest should be at multiple levels and points in time (177). Therefore, I was unable to accurately report on associations between some social determinants (particularly social class) and the outcomes of interest, which I identify as a research gap that needs to be addressed (177). Accordingly, further analysis looking at multiple levels of exposures at different points in time using hierarchical models may help to establish causal pathways. I also defined countries according to the World Bank definitions; however, it is important to acknowledge that dichotomising countries according to economic classifications may perpetuate hierarchies (e.g. donors and recipients) and gives little detail as to why countries are viewed as "low-resource" and along which dimension (325, 326). Consequently, I would agree with the recommendations of Khan et al. (325) of grouping according to distinct regions to recognise some sense of "collective identity"; this is featured in this review by grouping study settings according to context (e.g. North America) but could be further refined for others (e.g. distinguishing Europe in terms of Eastern, Western etc.). Furthermore, the outcomes of interest also used varying measurements and/or thresholds, again making robust comparisons between studies challenging; virological suppression is based on previous definitions typically using 'best-case' scenarios which do not account for people who are not in HIV care. Therefore, I recommend standardising these in clinical practice and research studies (or providing/depositing survey questions/de-identified data in an open access repository or pre-print server, where possible) to avoid problems during analysis (177). This would ultimately help advance understanding for designing public health interventions and social/health policies aimed at supporting the most socioeconomically disadvantaged living with HIV. The COVID-19 pandemic will have likely worsened the uncertainty of these statistics due to changes in testing capacities and the lack of in person appointments (327, 328). Specifically,

UKHSA estimates that given a 'worst-case' scenario, around 19,800 (or about 20% of 97,740 [95% CrI 96,400-100,060]) of people with HIV in England may have been virologically non-suppressed in 2020, with high numbers estimated to exist among younger age groups, GBMSM and heterosexual women (328).

2.5.3 Study implications and future research

The findings of this review will be used to inform later Chapters. However, I am limited by some factors beyond my control; for example, as I did not design or collect the data analysed in **Chapter 5**, I am limited by the social determinants included in the survey. I found in the review that medication adherence was the treatment outcome that was less consistently associated with social factors, compared to virological suppression. I also know that the data collected on adherence in the 2017 Positive Voices survey was affected by data quality (e.g. missing data). Therefore, in the quantitative analysis I will not be exploring this outcome. I have access to clinical data, including viral load counts, linked to the 2017 Positive Voices study and will be investigating this variable as an exposure, rather than an outcome, because clinical data are not complete (survey participants had to opt-in for linkage to their clinical record). Additionally, as a result of the findings from this review, I will be including themes on food security as well as questions which explore the temporal changes of social conditions (before, during and after the COVID-19 pandemic) in the studies presented in **Chapter 3** and **Chapter 4**. The subsequent qualitative studies will also help to inform which health/well-being outcomes should be explored in the quantitative study.

2.6 Conclusion

The review highlighted the complex nature and interactivity between social determinants of health, which makes the 'detangling' of such interactions challenging to uncover, particularly when studies are limited by data already captured. Using an ecosocial approach would enable researchers to uncover how social determinants interact with the population distribution of diseases and inequities in outcomes including the influence of histories and life course as well as structural inequalities according to discrimination (e.g. racism, classism and sexism) (177). Understanding the relative contributions

of these social determinants to HIV outcomes can help build a clearer picture that would help design interventions and integrated services that aim to address these exact determinants.

3

A qualitative exploration of the impact of COVID-19 on HIV healthcare, community and charity workers in the UK

In **Chapter 1**, I outlined how the COVID-19 pandemic has highlighted social and health inequalities globally as well as changes to HIV services during this time.

In **Chapter 3**, I will explore changes to HIV services during the pandemic as well as the experiences of people who provide these services, including perceived inequalities and impacts to social determinants of health. Therefore, I will outline the approach taken for a qualitative study of HIV healthcare and community-based staff and volunteers supporting people living with HIV during COVID-19. In preparation for this work, I designed and led a community involvement event in collaboration with the HIV support charity Positively UK, which is further outlined below. This community involvement event marked the start of my partnership with people living with HIV which continues throughout my PhD.

For this study, I collaborated with several people to support both the research and public involvement elements. Their contributions are highlighted by their initials — specifically, from the Patient Experience Research Centre: Jane Bruton (JB), Professor Helen Ward (HW), Emily Cooper (EC), Professor Sophie Day (SD) and Positively UK: Silvia Petretti (SP).

This Chapter is written using the standards for reporting qualitative research (SRQR) checklist (329) **(Appendix C)**. Some results were previously presented in ePosters at the International AIDS Society (IAS) conference 2021 (330) and AIDS 2022 conference (331).

HW, BD and JB provided comments on this Chapter. Two co-researchers (Joshua Anderson and Wezi Thamm) involved in the study described in **Chapter 4** also provided feedback on this Chapter.

3.1 Abstract

HIV service providers have had to rapidly respond to the COVID-19 epidemic by adapting services to follow government guidelines whilst continuing to provide support in a safe way that does not compromise the quality of care received. Some HIV health workers in the UK were redeployed to critical care during the early phases of the epidemic, while charities responded alongside facing a loss in fundraising income. I aimed to explore the experiences of HIV service providers in the UK since the start of COVID-19, including the challenges, opportunities and adaptations made to services. I also wanted to understand the impact of COVID-19 on their personal and professional lives and perceived effects on wider society. We conducted semi-structured online interviews with healthcare professionals (n=5) and community-based workers (n=9) supporting people living with HIV in the UK (England and Wales) between October and December 2020. Participants were recruited using a snowball sampling approach and our topic guide was informed by community involvement. The transcripts were analysed using an inductive-deductive approach that included the application of Krieger's ecosocial theory to explore concepts across ecological levels. I identified themes of individual/interpersonal, community, and societal ecological relations which were underpinned by notions of inequalities, accountability, and agency. HIV services rapidly adapted to changes in demand and COVID-19 government guidelines to prioritise services for those considered to be the most vulnerable (e.g. newly diagnosed). It is expected that many of these changes will have a long-term influence on HIV service design and delivery. Participants were concerned about a perceived increase in mental health problems reported by service users. COVID-19 has accelerated the anticipated developments in HIV services, namely a shift towards telemedicine, with varying levels of acceptability. A need remains to record the perceptions of these changes by service users. Any long-term changes to HIV services due to the pandemic should be co-designed with people living with HIV.

3.2 Introduction

In late 2019, the SARS-CoV-2 virus first emerged in Wuhan, China and by March 2020, COVID-19 was classified a pandemic by the World Health Organization (248). The pandemic has impacted the health and wealth of societies globally, which researchers predict will inevitably result in an economic crisis the scale of which is currently difficult to quantify (172). For example, the UK's 'real' Gross Domestic Product was the worst affected among comparable G7 economies (Canada, Italy, Germany, Japan, France, the US) by the end of September 2020 at an 8.5% shortfall compared to pre-coronavirus levels (332). COVID-19 mortality rates have varied worldwide, with the UK having one of the highest excess mortality rates in 2020 among under 65-year-olds compared to 26 European countries; this rate was only exceeded in December 2020 by Bulgaria (333). The UK was under nationwide restrictions from March 2020 with regional and local measures introduced at various points in time. Many NHS and support services (including sexual health and HIV clinics) have been cancelled, reorganised, or temporarily postponed.

COVID-19 has highlighted and widened persisting inequalities in the UK (174, 258). By March 2021, just one year after the first reported case of COVID-19 in the UK, more than 125,000 COVID-19 deaths were recorded with evidence of higher death rates among ethnic minority communities and individuals living in more deprived areas (258, 334, 335). Specifically, in July 2020, the mortality rate was two times higher in the most deprived areas, compared to the least, in England after standardising for age (3.1 vs. 1.4 deaths per 100,000) (335). Marmot & Allen (258) suggest that these disparities are likely to be explained by more than a decade of austerity measures by the UK government that have affected the funding and delivery of health services, particularly adult social care. COVID-19 will also undoubtedly present wider public health challenges for global health systems on the brink of being overwhelmed both in the short and long-term; for instance, the short- and long-term effects on mental health and well-being of populations due to enforced isolation and impacts on wider social factors, including unemployment and debt (111, 336).

Social conditions also influence an individual or community's ability or power to change their behaviour to protect their health, which in turn exacerbates health inequalities with respect to gender, socioeconomic position, and other determinants (337, 338). In the case of COVID-19, the ability to

adopt non-pharmaceutical interventions (NPIs), for instance self-isolation, early in the outbreak was highlighted as a significant barrier for some individuals including those with precarious or 'front-line' jobs and those with a limited disposable income (258, 337, 339). For example, a UK population survey (339) found that adults with lower household incomes were less able to self-isolate, compared to those with higher incomes, after adjusting for age, ethnicity, and employment status (aRR 0.92; 95% CI 0.88, 0.96). Adults with the least amount of savings were even less likely to self-isolate than their counterparts (aRR 0.90; 95% CI 0.85, 0.96) (339).

Comparisons were made early on between COVID-19 and the early days of the HIV epidemic; an emerging infectious disease of which we had little knowledge, with reflections on health-related stigma and the multidisciplinary response required to curb both epidemics (250, 251, 337, 340). People living with HIV have had to navigate their HIV care in accordance with protective behaviours recommended and guidance implemented by governments and local public health agencies (252). For example, in the initial stages of the epidemic, people living with HIV in the UK were mistakenly classified by NHS Digital as 'clinically extremely vulnerable' and placed on a 'shielded patient list' that advised them to reduce social contacts and protect themselves from the novel coronavirus (341, 342). This decision was eventually overturned and only recommended for people living with HIV with a substantial risk of severe COVID-19 (CD4$<$50 or had opportunistic illness in past 6 months) following advocacy by organisations such as BHIVA and Terrence Higgins Trust (342–344).

Preliminary data (345) show a reduction in service provision for sexually transmitted infections, HIV and viral hepatitis in England at the height of the COVID-19 epidemic (March to May 2020), with the extent of these disruptions yet to be disentangled. Similar disruptions in HIV services and a shift towards telemedicine and online consultations have been reported globally, with concerns raised about how a shift to digital care can exclude people with lower socioeconomic status, lack a confidential home environment, or do not have access to technology or data (251, 346–348). An analysis (349) of consultations in England found a 9% decline in HIV consultations between January and September 2020 compared to the same months in 2019 (151,618 to 138,321), with an eight-fold increase in telephone consultations, predominantly among 35-49 and 50-64 year olds. Initial research (350–352) suggests a high acceptability of telephone consultations among people living with HIV, although face-to-face consultations remain the preferred medium. Services were also required to defer

viral load monitoring at 6 months among service users, with initial data from service evaluations or the review of electronic patient records finding little variation in outcomes due to service adaptation (353, 354). However, these data do not report the experience of service users accessing clinics nor the experience of service providers using robust qualitative data. Therefore, a need remains to capture to what extent COVID-19 has impacted on HIV services across the UK, the adaptations made to overcome the challenges faced by service providers and how providers have felt during this time.

COVID-19 was declared a pandemic 6-months into my PhD studies. I therefore added an additional research question to understand this once-in-a-century event. I aimed to understand how the COVID-19 outbreak has influenced the experiences of people living with HIV in the UK from the perspective of healthcare workers and other sources of support.

3.2.1 Theoretical framework: ecosocial theory

Nancy Krieger's ecosocial theory explores how determinants at all ecological levels can influence the distribution of diseases and health inequities and is underpinned by the core concepts of embodiment, accountability and agency (127, 128, 138). Ecosocial theory considers how factors such as gender, race, sexual orientation and class interact, are embodied across the life course and are associated with health outcomes such as disparities in HIV acquisition among marginalised groups and stigma and discrimination experienced by people living with HIV (161, 179, 180). I use ecosocial theory to guide the deductive stage of qualitative data analysis and interpretation of the study's findings.

3.2.2 Research questions

What are the experiences of COVID-19 on the daily life, work and HIV services provided by community, charity and healthcare workers supporting people living with HIV in the UK? How do these experiences vary among different social groups?

3.2.3 Aim and objectives

Aim

To explore how the current COVID-19 outbreak is influencing the health and well-being of adults ($\geq$18 years old) living with HIV in the UK from the perspective of HIV healthcare workers, community workers, and charities.

Objectives

1. To explore the challenges, opportunities, and adaptations made to HIV services since the start of the pandemic from the perspective of service providers.

2. To record the diverse experiences of HIV healthcare workers, community and charity workers in the UK providing these services to help provide a richer, contextual understanding of these experiences.

3. To uncover the unequal impacts of the pandemic for different social groups, including marginalised populations.

4. To build new, and strengthen existing, relationships with key individuals working in HIV services, organising, providing, or commissioning these services, as well as individuals living with HIV to facilitate a future co-production study and dissemination of its results, thereby informing objective 5.

5. To help inform wider policy and guidance to support those living with HIV during a pandemic who may face challenges accessing routine care services, as well as HIV and other sexual health services.

3.3 Methods

Qualitative research during COVID-19 can investigate social responses during the pandemic, including health behaviours, the needs of marginalised populations, the medical response, and can also enable community engagement and involvement (355). Therefore, we conducted semi-structured, online interviews with those who support people living with HIV along the care continuum.

My study is underpinned by a social constructionist approach and an idealist ontology whereby there are multiple perceptions, realities, and understandings that are actively constructed by people within their social world (356–358). Social constructionism also acknowledges the role of the researcher in generating knowledge; in other words, describing all observations as 'theory laden' (357). Therefore, I aimed to investigate what mattered to participants whilst acknowledging my own situated interpretations of what was, and was not, said.

3.3.1 Public involvement and engagement

In June 2020, we[1] ran a community involvement event to gather rapid insights on the impact of COVID-19 on HIV care, in collaboration with the peer-led support charity, Positively UK (348). The event was hosted on Zoom with breakout rooms facilitated by a person living with HIV (a Positively UK member) and an academic staff member from the Patient Experience Research Centre (PERC) at Imperial College London (348). Further details on the event can be found in the published insight report included in **Appendix C**.

Insights from the involvement activity were used to design the themes explored in the interview topic guide for this study (348). For example, one of the key findings of the Zoom call was a concern for the wider determinants of health and well-being and the unmet needs and unanticipated challenges for some of the most vulnerable and marginalised groups living with HIV which was subsequently added to the interview topic guide (348).

[1] "We" refers to the Patient Experience Research Centre of which this project forms part of ongoing research on HIV.

3.3.2 Recruitment

I recruited participants using purposive (snowball) sampling methods by emailing personal and professional networks for healthcare, social care, voluntary and community workers, as well as participants of our involvement activity (348) and who had agreed to being recontacted. Potential participants were asked to read a participant information sheet, complete an electronic consent form (before being interviewed) and complete an optional short demographics survey (both hosted on Qualtrics (359)) to ensure we heard from a diverse sample **(Appendix C)**. We continued interviews until we had spoken to a range of participants, in relation to their role.

3.3.3 Data collection

A growing literature on remote methods emphasises the benefits of conducting qualitative research online, including accessibility, convenience, cost-effectiveness, and features to manage data effectively (360). For example, video conferencing platforms can overcome logistical and geographical barriers that may present during data collection although technological barriers remain a challenge (360, 361). Remote methods may also continue to exclude groups underrepresented in research due to issues of digital poverty (361). However, collecting data virtually may also help to reduce power imbalances relating to the time and space of the interview; for example, interviews do not need to be limited to office/clinic hours (362).

Semi-structured interviews were conducted and recorded online from October to December 2020 by three female researchers (VP, EC, JB) using Microsoft Teams with the audio transcribed using automated transcription software to follow institutional ethics procedures. Online interviews were conducted to comply with UK government social distancing guidelines and lockdown (or 'stay at home' orders) that were in place at the time (363). We were unable to separate audio and video files from Microsoft Teams recordings; therefore, interviewers' asked participants to turn cameras off to maintain their anonymity before we started recording.[2] All audio recordings were downloaded and saved in an encrypted environment and automated transcripts were checked and edited for consistency by two researchers (VP, JB).

An interview topic guide **(Appendix C)** was adapted from a larger study that sought to record

[2] All but one interview was conducted without videos.

people's experiences during the COVID-19 epidemic. The topic guide was pilot tested (VP, EC) with probes provided to encourage responses. Interviewers recorded their impressions afterwards to identify emerging topics for subsequent interviews; for example, we adapted questions based on changes in government guidelines and restrictions across the UK. I followed up with all participants after interviews and shared a list of resources that may be helpful for NHS workers and/or people living with HIV that participants' support **(Appendix C)**.

We had initially planned to re-interview all participants three months after their interview; however, we instead established a participatory project with peer researchers to explore the perspectives of people living with HIV **(see Chapter 4)**. However, I asked study participants to update us on their circumstances since their interview. Some provided an update with how their services were coping with a third national lockdown which began in January 2021.

3.3.4 Data management and analysis

Data were managed using NVivo (364) and analysed using an inductive-deductive approach with open coding, initially completed by me and EC, whereby the codes were then grouped and categorised into themes. I then used an ecosocial framework to deductively analyse how the themes determined from inductive coding related to the principles of embodiment, accountability and agency across ecological levels and the 'life course', which in this study was viewed as the COVID-19 pandemic (127, 128). This builds on a similar approach described in a study of mental health in jailed populations (365); I contacted the study author for advice before completing this type of analysis myself. The approach to analysis was discussed between me, EC, HW, JB and SD with a codebook developed at each stage. I then completed constant-comparison of all codes and themes to identify and map how these sit across the ecological levels **(Appendix C)**. I also considered the temporality of the themes in relation to the COVID-19 epidemic.

I randomly assigned all participants a pseudonym, when writing up the findings, by searching for popular baby names in the decade they were born (if shared) using Office for National Statistics (ONS) data on popular baby names in England and Wales since 1904 (366), to maintain confidentiality (367, 368). If I did not have their year of birth, I selected a frequently popular baby name in the UK, every ten years, from the past century.

I shared a summary report of preliminary findings **(Appendix C)** with all participants in June 2021.

3.3.5 Ethical approval

Ethical approval was granted by the Imperial College London Research Ethics Committee (ICREC Ref: 20IC5893) as an amendment to an existing study looking to record COVID-19 experiences among the general population. All participants gave their informed consent to participate in the study.

3.4 Results

14 semi-structured interviews of healthcare and community workers based in England and Wales were conducted on Microsoft Teams. Healthcare workers included physicians, nurses, and other allied health professionals. Community workers included peer support, peer mentors, charity workers, a peer mentor coordinator, and a case worker. Participants had recently experienced changes in their work schedule, responsibilities and environment. For example, five were hospital-based clinicians (doctors and nurses) of which two had experiences of being redeployed during COVID-19. Nine worked in community-based organisations, including charities, that had experienced a loss of income, changes in demand to services and issues with staff availability and referrals.

Interviews explored personal experiences during COVID-19, impact to services, perceived impact on service users supported in services as well as the complex interactions between these ecological levels. These interviews took place in late 2020, a period when the second wave of COVID-19 infections was being recorded across the UK following the lifting of several restrictions during the summer and at a time when the vaccination programme had not yet been widely rolled out. Therefore, participants mainly spoke of their experiences during the first wave of the pandemic and the first lockdown (March 2020) and disruptions to services since then until the date of interviews (October to December 2020). The interviews lasted between 45 and 90 minutes.

3.4.1 Participant characteristics

Participants were asked to complete an optional survey to capture sociodemographic factors **(Table 3.1)**. Most participants (n=12/14, 85.7%) completed the survey. Some participants shared that they were living with HIV themselves and that their diagnosis had motivated them to volunteer or work in HIV services with several having been diagnosed in the 'early days' (mid to late 1980s).

Table 3.1: Interviewee characteristics

Sociodemographic factors	**n (%)**
Age	Median 57 (IQR 45-61)
Gender identity	
Cisgender man	7 (50.0)
Cisgender woman	5 (35.7)
Did not answer	2 (14.3)
Ethnic group	
White – English/Welsh/Scottish/Northern Irish/British	11 (78.6)
White – Irish	1 (7.1)
Did not answer	2 (14.3)
Location	
England	11 (78.6)
London	6 (54.5)
South East	2 (18.2)
West Midlands	1 (9.1)
North West	1 (9.1)
Yorkshire and the Humber	1 (9.1)
Wales	1 (7.1)
Did not answer	2 (14.3)
Role	
Charity worker or volunteer (including peer support)	6 (42.9)
Healthcare professional (including doctor, nurse, other allied professional)	5 (35.7)
Other, please specify:	
Various	1 (7.1)
Did not answer	2 (14.3)
Key worker status	
Yes	7 (50.0)
No	2 (14.3)
Unsure	2 (14.3)
Did not answer	3 (21.4)
Experience of HIV (could select multiple)	
Currently living with HIV	5 (35.7)
Loved one of someone living with HIV	1 (7.1)
Health professional supporting people living with HIV	6 (42.9)
Social care worker supporting people living with HIV	2 (14.3)
Charity worker supporting people living with HIV	6 (42.9)
Community worker supporting people living with HIV	5 (35.7)
HIV advocate supporting people living with HIV	7 (50.0)
Other, please specify:	
Volunteer supporting people living with HIV	1 (7.1)
HIV academic/researcher	1 (7.1)
HIV policy	1 (7.1)
Did not answer	2 (14.3)
Years living with HIV (personally or loved one)	
3-4 years	1 (7.1)
5-10 years	1 (7.1)
11-20 years	4 (28.6)
Did not answer	8 (57.1)
Years working in HIV	
1-2 years	2 (14.3)
3-4 years	1 (7.1)
5-10 years	1 (7.1)
11-20 years	4 (28.6)
30+ years	3 (21.4)
Did not answer	3 (21.4)

3.4.2 Ecosocial framework

Figure 3.1 outlines all themes and sub-themes identified, including those discussed further in this Chapter.

Overall, interviews explored the impact of COVID-19 on HIV services, both from the perspective of service planning and delivery (community level) as well as the experiences of those providing the services and their work-life (interpersonal and individual). Participants also shared their perspectives on how people living with HIV accessing services were experiencing the pandemic and HIV care as well as wider implications to health and well-being including existing and emerging inequalities and longer-term challenges to the economy, individual livelihoods and wider areas of health and social care (societal level). These themes were then mapped to core concepts of ecosocial theory.

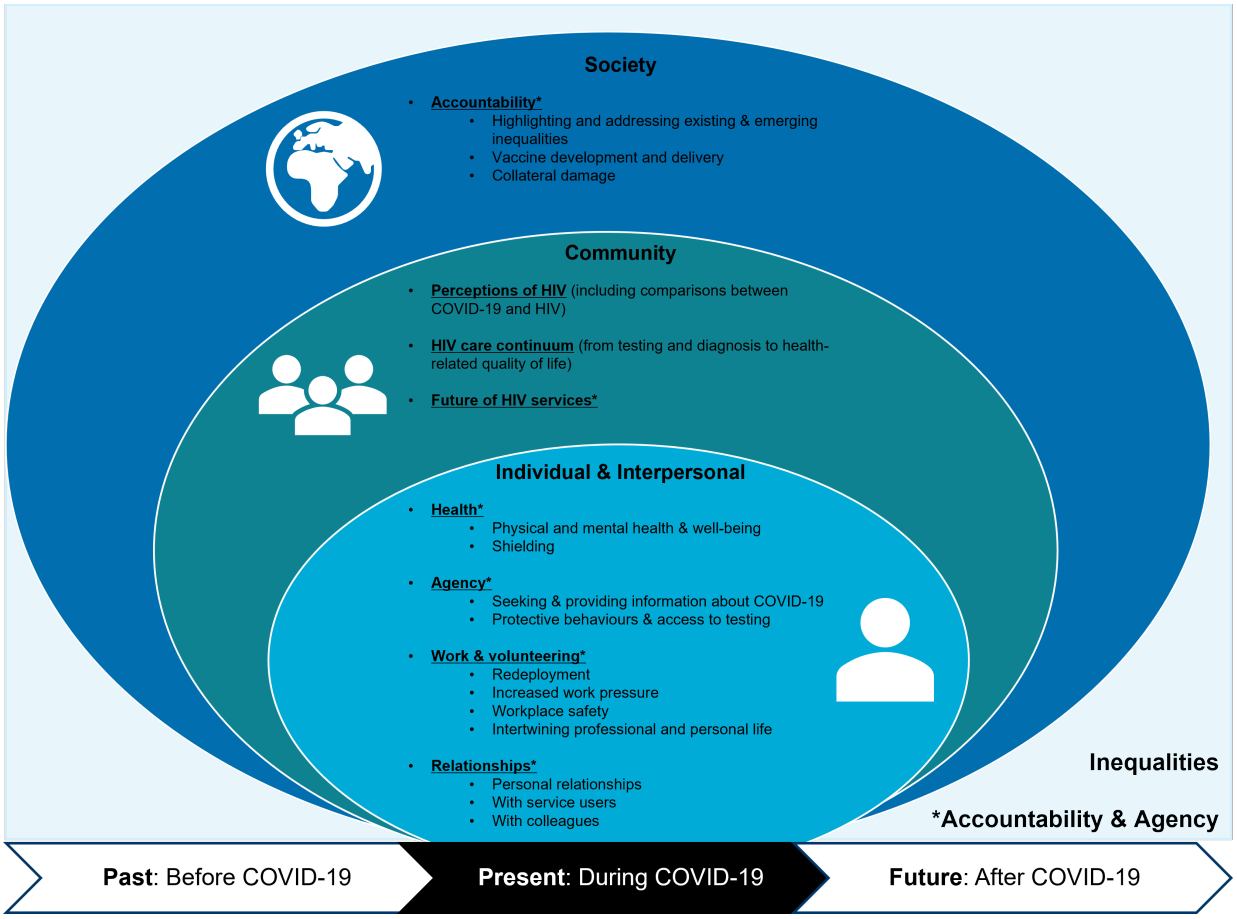


Figure 3.1: Concept map of **themes** and sub-themes identified from analysis which are mapped to key concepts of ecosocial theory (see blue Box), according to ecological level and COVID-19 timeline. Adapted from Enane et al. (369, 370).

"... the HIV department stopped. Everything was transferred to phone calls. Everybody's visits were deferred."

Linda, HIV Physician

3.4.3 Individual and interpersonal levels

Initially, we asked participants to reflect on their life before COVID-19 in relation to their health, employment, personal life, and relationships. We then asked follow-up questions on how this had changed during COVID-19 and what they anticipated would be the situation after the pandemic.

Health

The theme of health was an existing topic incorporated in the interview guide and was explored in relation to changes to physical and mental health and the impact of shielding during COVID-19 at a personal level but also on behalf of others (interpersonal), including the ability to deliver services and on service users themselves. I begin with reflections on the impact on service providers (individual level) and then reflected on how messaging around shielding affected how providers delivered services, as well as the perceived impact on service users.

Physical and mental health and well-being

COVID-19 had a clear emotional toll on people interviewed, whether it was in their home environment, work experiences or relationships. Some described feeling anxious about acquiring COVID-19 at work or elsewhere, or in a low mood due to lack of physical and social contact. This had impacted on their emotions, sleep, and general well-being. Some had used exercise, hobbies, writing about their experiences, or speaking to a professional therapist to cope with their emotions, as well as learning from previous training (e.g. pattern changing). Others found the increased demand for services stressful, with perceived difficulties in separating work from home and the limitations of the service and support that could be provided.

Shielding

Advice to shield, which was given in England, was confusing; participants were unsure why some service users had received text messages or letters to shield although some speculated this was due to their co-morbidities or being 'coded' by the General Practitioner (GP) as immunocompromised. Several described a 'panic' and anxiety among service users that caused challenges in the delivery of services due to an increasing number of communications written in such a way that people were afraid to leave their homes. Interviewees' anticipated that shielding had a negative impact on mental health, with service users feeling increasingly isolated and lonely, including some who had histories of trauma or mental health difficulties. Phil described two clients who reported feeling depressed and having suicidal ideations from shielding and issues at home.[3] Concerns were also noted among people who did not receive messages to shield,

> *"But even those who weren't asked to shield, which was the majority, (...) they basically lived as if they were. They were very afraid. They didn't go out the house at all (...) if they had a 10-year-old, they would be sent out once a week to do the shopping, but no one else would leave the house. And hardly any of them were getting any fresh air on a daily basis."* [Sarah, Charity Worker]

Shielding also raised issues of confidentiality and the involuntary sharing of HIV status within the workplace and other settings. Jack was based in a rural clinic in the North of England within *"conservative, old-fashioned areas"* where issues of homophobia persist,

> *"So, we had a lot of patients that were like 'I might need to isolate, but I don't wanna tell people why I need to and how do I navigate that?' And a lot of them were like terrified that this was going to be the time that they would be forced to like out themselves either as gay or queer or having HIV."* [Jack, Charity Worker]

Lisa used the opportunity to speak with service users to see whether they had received letters and check whether their home environment was safe, particularly women living with HIV. Several also referred to the important role of BHIVA in providing timely and accurate guidance for those providing services which could be referred to by health workers but also in advocating for the rights of people living with HIV in accessing COVID-19 testing as well as vaccinations.

[3] This is further outlined in the sub-theme on mental health.

Agency

At the individual/interpersonal level, agency related to how knowledge is expressed and gained (128) and how this may be associated with decisions to take protective actions against COVID-19.

Seeking and providing information about COVID-19

Participants sought information about COVID-19 from various sources including government and public health agencies, local hospital Trusts, professional bodies and colleagues, research journals and mainstream/social media. These were categorised according to accessibility, trustworthiness, and relative importance at distinct stages of the epidemic. Some also reflected on the little information at the beginning of the pandemic which impacted on conversations with service users,

> *"...Certainly from me there was a little bit of downplaying of it (...) maybe that was partly to reassure people I didn't want to go into panic stations with patients (...) And looking back on some of the conversations that I had thinking about them I probably was a bit like 'I think it will be over in a few months.' (...) 'I mean come in now get your bloods done, we'll cut you some more meds but like I'm sure we can see you again in May' [laughs]"* [Chris, HIV Nurse]

There was also an emphasis on the role of charities and professional bodies, particularly BHIVA, in developing guidelines and information specific to people living with HIV in a timely manner to dispel misinformation. Participants felt responsible for providing accurate information and keeping updated on the latest advice alongside increasing workloads and work pressures. Jacqueline also reflected that many of the COVID-19 experts were also involved in HIV, which has made it easier to keep up with reliable and trustworthy information although found it *"easy to get overload."* It was recognised that the Internet is essential to keeping up to date with the latest information. However, rumours and misinformation has circulated among people living with HIV through social media, messaging platforms, and communities, raising concerns about health literacy. For example, Jack participated in online outreach through hook-up sites and received questions about whether HIV medication or pre-exposure prophylaxis (PrEP) can protect against COVID-19. Nicola described how a similar approach to HIV prevention could help to improve health literacy relating to COVID-19,

> *"I don't think they're given the right information about COVID (...) knowledge is power, isn't it? And if people were provided the right knowledge they could make (...) their own*

> *choice couldn't they about what risks they're willing to take."* [Nicola, Peer Support Worker]

Additionally, Sarah shared how service users who they support, for whom English is not a first language, had purchased individual bottles of drinking water from fear of acquiring COVID-19 through water. There were concerns for newly diagnosed people with HIV feeling confused by the 'infodemic' and the circulating misinformation and that they had no one to contact to verify the information. Vaccine hesitancy among the general public was also a concern.

Protective behaviours and access to testing

A consensus was agreed in individual and collective responsibility to reduce transmission, whether through testing or protective behaviours. We asked participants about their agency to adopt protective behaviours including face masks, hand washing and social distancing guidelines; some also described creating 'support bubbles' and the importance of ventilation at home and work settings. Adopting protective behaviours were described in relation to home, work and social settings with a general notion that these were relatively 'easy' behaviours to adopt with an appreciation that some behaviours were altruistic to protect others (e.g. face masks).

Sarah described a 'balance' of risk within the workplace, particularly in relation to social distancing whereby they did not feel *"drastically unsafe"* but were unlikely to have always kept two metres apart as per government guidelines. Another described the initial reluctance by a service user to wear a mask who required some encouragement, suggesting a potential role of peer support in advocating for protective behaviours,

> *"He doesn't wear a mask. . . I gave him a thing to wear the other day, which he loved it at first. He absolutely loved it, but two days later he said it. . . was giving him panic attacks, which of course it wasn't. Just his way of having to wear it or forget where he put it."* [Phil, Peer Support Worker]

Another peer support worker (Nicola) described the formation of a 'COVID bubble' with service users, particularly those who were most vulnerable alongside their colleagues, friends and family; for example, those living in supported accommodation. However, those attending HIV clinics themselves, believed the measures in place were strict enough to reduce any potential risk and found the adaptations to the service well organised and planned.

Some participants had access to antibody and antigen testing through their participation in COVID-19 research studies.[4] Although no one interviewed tested positive for antigens, one person had tested positive for antibodies and several described suspected symptoms of COVID-19 in the early stages of the pandemic. Some discussed preparations if they acquired COVID-19 in relation to support networks and practicalities of arranging food shops.

Work and volunteering

We asked participants about their experiences of working in HIV services during the pandemic, specifically redeployment to COVID-19 services and feelings and attitudes towards workplace safety which may relate to wider institutions (e.g. NHS structures).

Redeployment

We heard stories of redeployment from the perspective of people who had been redeployed (Chris, Lisa), people whose colleagues had (Linda, David, Jack) and how this had impacted the service and their relationships with colleagues. **Case studies 1-3** present first- and second-hand experiences of redeployment during the pandemic. They emphasise the speed at which redeployment occurred across NHS and community services at the start of the pandemic.

[4] Examples given included the ONS/University of Oxford COVID-19 infection survey and the Public Health England studies: ESCAPE (Enhanced Seroprevalence for COVID-19 Antibodies) and SIREN (SARS-CoV2 Immunity and REinfection EvaluatioN).

Case study 1: HIV nurse's first-hand experience of redeployment

Chris, a nurse based in a well-resourced sexual health clinic, was redeployed to critical care for seven weeks, alongside colleagues. Their decision to be redeployed was driven by previous experiences dealing with 'higher-level' patients in a HIV ward and considering the risk to others at home. Initially, Chris was concerned about service users *"falling through the gaps"* (and became emotional when talking about this). They began redeployment in April 2020 (near the peak of infections at the hospital); their experience was challenging, mentally and physically. There is usually one nurse for each patient in an Intensive Care Unit (ICU); during the pandemic, there was one ICU nurse for every eight patients,

> *"People were really, really sick when I got there. People were dying. Everyone was there with the same thing. Everyone was there with COVID (...) At the forefront of your mind is looking after people and making sure that you know your patient stays alive in intensive care and that you can hand over things to the next nurse."* [Chris, HIV Nurse]

Chris reflected on how they were able to transfer knowledge and skills from their HIV training,

> *"...what I think HIV nurses are very good at is (...) listening and learning. Being open, being non-judgemental, obviously, and willing to (...) change and adapt."* [Chris, HIV Nurse]

Case study 2: Healthcare worker's first-hand experience of redeployment

Lisa, a hospital-based worker, was redeployed for a few days. Lisa reflected on her experience and that of other staff whose sexual health service shut down when they were redeployed. Lisa described the burden on those 'left behind' with an increased workload. Those redeployed would work 12-hour shifts for four days disrupting childcare responsibilities at home. Lisa felt guilty for not being able to support a COVID stepdown ward. Lisa described physical and mental exhaustion, pressure from senior clinicians to join wards, guilt, and was concerned that colleagues might consider them 'dispensable' if they had managed without them,

> *"...some people who don't work with us have not really ever belittled what we do (...) you can't help feel, because we're not at the frontline people don't really feel that we're doing a very important job."* [Lisa, Healthcare worker]

Case study 3: HIV physician, nurse and community-based worker who were not redeployed

Linda (a HIV physician) was concerned about workplace safety and decided not to be redeployed; instead, they offered to provide remote support by ringing service users. Linda soon learned that this service had a limited life and felt redundant,

> *"...the HIV department stopped. Everything was transferred to phone calls. Everybody's visits were deferred. I made a few phone calls to tell patients that the clinics weren't going to be running to check they got drugs, but other than that... it was quite an explicit, almost an order. 'Please don't bother us, we're busy, we'll call you if we need you.' Um? So, I sort of watched [hospital] from the sidelines a bit and it was quiet worrying..."* [Linda, HIV Physician]

An HIV nurse based in a rural area in England (David) had colleagues who were redeployed across the hospital, some into critical care and others to address the anticipated NHS emergency. This had made David feel more isolated working from home with no face-to-face interaction with other staff or service users. David reflected that some redeployed colleagues had enjoyed the change to the normal work routine, whilst others reported unfamiliar and frightening experiences with little or no induction. However, the longer-term impacts of redeployment are now being experienced by some services who are clearing through a backlog of appointments, particularly clinical monitoring. Similarly, Jack (community-based worker) had direct reports that were redeployed to community care due to a surge in demand for community services. They described many of their service users as long-term with complex needs and so this had a significant impact on their relationships, particularly as building trust takes time, and this was a sudden change with no warning.

Increased work pressure

Several participants discussed changes to their own behaviours at work including an initial increased pressure at work: working longer hours, difficulties 'switching off' and feeling overwhelmed, which resulted in burnout and an increasing number of colleagues signed-off with stress. This was particularly highlighted by individuals based outside of London who, at the time of interviews, were experiencing rising COVID-19 hospitalisations,

> *"...people were off sick and are still off sick for all sorts of reasons (...) it doesn't take much, especially now for people to be off sick. The goodwill has gone, and people are off for a long, long time now. And people (...) went off because they didn't want to work on the wards."* [Lisa, Healthcare worker]

Workplace safety

Concerns of personal safety at work were three-fold; (1) acquiring or dying from COVID-19, (2) onward transmission to friends or family, and (3) patient safety. For instance, Chris described feeling anxious after hearing stories of younger nurses who had acquired COVID-19 at work,

> *"And you think that could be me like? Or it could be my colleague who I'm working with; why isn't that person in work today? What's happened to them? (...) I was worried (...) that I could get sick..."* [Chris, HIV Nurse]

No participants on the frontline experienced shortages of personal protective equipment (PPE); however, Jacqueline acknowledged that initially, a limited understanding of the virus and underappreciation of the importance of PPE may have resulted in unintentional onward transmission,

> *"...there was a lack of recognition that people were asymptomatic shedding in the first wave (...) what tended to happen was then when someone was positive and on ITU they got full PPE. But then some of the (...) junior doctors when they were (...) seeing people that were ill with symptoms that (...) were not recognised as being related to COVID. (...) then they would not use any PPE at all. Not even face masks (...) you know really early on. And then of course four days later they were finding these people were developing symptoms of COVID and then they were going down with COVID."* [Jacqueline, HIV Physician]

Some alluded to a 'blame culture' among colleagues who had unintentionally spread the virus at work, which was sometimes targeted at more junior colleagues. Jacqueline also described how some colleagues who had decided to shield based on their ethnicity had faced a backlash from others as standardised risk assessments had not taken this perceived risk into account. Alternatively, it was thought that others had overcompensated by putting themselves at greater risk to challenge these opinions.

Intertwining professional and personal life

The epidemic presented a challenge for participants; for most, their personal and professional lives

became intertwined due to the change to remote work. Lisa found that although their personal life had changed significantly, their work environment had not.

A shift of focus of work to COVID-19 was, as expected, a common thread in the work life of the participants and adaptations were made to how services were delivered and prioritised. For example, Linda described a 'pause' of all research, the continuation of some PrEP studies but that *"the idea of setting up new studies was 'non-starter'."* Similarly, an injectable clinical trial was postponed during lockdown with all participants returning to tablets. James described the challenges presented by COVID-19 for volunteer mentors who were no longer able to collect referrals, run drop-in support groups nor organise ad-hoc mentoring opportunities due to COVID-19 restrictions in the clinic.

We asked all participants about hobbies or methods they had used to socialise or remain in touch with friends and family and had adopted to meet restrictions. For some, this offered time away or a welcomed distraction from the stresses of work and other areas of their lives.

Relationships

Social and peer support remain essential factors in improving the health and well-being of people living with, and supporting those living with, HIV. We reflected on the importance of personal relationships, relationships with service users, and colleagues.

Personal relationships

We asked participants about the impact of COVID-19, including government guidance, on personal relationships. Video call technology and social media had played a role in helping people feel connected; however, there was a distinct sense of loss of the physical connection between friends and loved ones. Lisa described how neighbours had cooked food for them and would join the weekly 'Clap for Carers' to thank them for their contribution as an NHS worker. However, they also recounted a negative experience from some neighbours who were worried about acquiring COVID-19 from them, which they compared to the stigma experienced by service users they support who are living with HIV,

> *"...that whole idea of sometimes we have felt a bit stigmatised, and we have said as a team at work when somebody's had that sort of situation, it gives you a little insight*

> *into the stigma that some of our patients experience with being HIV positive."* [Lisa, Healthcare worker]

Relationship with service users

Participants described their experiences of sharing their HIV status with others (if they were living with HIV) or the experiences of services users sharing their status with others, including experiences when seeking healthcare, particularly primary care:

> *"...something I did notice at the start was some people who had never disclosed to anyone sort of thinking, maybe I should, you know, just in case anything happens. Maybe I'll tell my family or my close friends, or rather than having this thing hanging over me (...) Within the HIV team, we might be the only people that know about these people, diagnoses. So, they might be under other services. They might, you know their GP might not know the (...) other clinical services might not be aware of it"* [Jack, Charity Worker]

For many people living with HIV, their specialist is the same person who had delivered their diagnosis. The importance of trust and a strong relationship with the HIV specialist was highlighted by participants, often reflecting on face-to-face interaction, which had been limited during COVID-19 to be by phone instead,

> *"But that one to one (...) that special relationship you have with your specialist around HIV is so important. You know because you also build up a trust with those people as well."* [John, Peer Support Worker]

Although most people interviewed who were living with HIV had good relationships with their HIV service providers, one (Matthew) shared a mixed view,

> *"I mean there are some arseholes working in HIV medicine, let's be clear, and nurses. But I mean I've been the beneficiary of remarkable treatment and care that is side-effect free, drama free, delivered with excellence, kindness, compassion and great, great love."* [Matthew, Charity Worker]

However, COVID-19 had added pressure to these relationships; one participant (Linda) described feeling "uncomfortable" with their clinic restructuring during the pandemic for service users to see whoever was on duty at the time. This participant had worked in the service for more than 30 years, had long-standing relationships with women and children who were service users and described feeling

that these strong relationships helped to deliver what would otherwise have been disappointing news of reduced face-to-face services,

> *"So mostly on the whole I was ringing people I know really, really well (...) we didn't need to do the preliminaries... we knew where we were coming from with a very strong and long historical you know back story between us. I very rarely had to ring up somebody I didn't know or didn't know well (...) It was they were mostly conversations about, 'we'll get through this' (...) 'this is the plan'."* [Linda, HIV Physician]

Peer mentors (or support workers) are people living with HIV who support those newly diagnosed or who may be experiencing difficulties in their social circumstances. Therefore, community-based organisations played a role in advocating for people living with HIV accessing services even prior to COVID-19,

> *"I have no qualms in coming to the clinical service and telling them if they do something wrong advocating on behalf of the patients."* [Jack, Charity Worker]

However, the role of the 'activist' was challenged by Matthew,

> *"Being proud of people living well with HIV rather than keeping the cookies in the jar? I think I may be a bit of an anti-HIV activist 'cause I'm not going to give you the pity party version."* [Matthew, Charity Worker]

Chris described how some service users had shared that they were feeling isolated, but that their access and adherence to medication was otherwise uninterrupted; generally, service users described wider determinants including being furloughed, job losses, or relationship issues that were impacting their mental health. Issues of the stability of relationships were also described by Kevin,

> *"... if you weren't set up with a partner right at the beginning of the epidemic, then you would have experienced the isolation of (...) shutdown completely differently to the intimacy of shutdown."* [Kevin, Charity Worker]

Relationship with colleagues

Overall, COVID-19 made participants recognise the importance of good working relationships to provide support, advice, and mentoring. Several described missing social interactions on the job, but for many, work colleagues were a major source of support during the pandemic, with professional relationships strengthened during COVID-19. Collaborations across all aspects of HIV services

were essential in ensuring services remained open; for example, pharmacies, transport and food deliveries. Some experiencing difficult working relationships pre-pandemic found remote working to be a welcomed change and often, colleagues provided emotional support away from the home.

However, the emotional burden of COVID-19 had also negatively impacted some working relationships. For instance, Lisa described infighting among staff due to low staff numbers from redeployment and staff sickness or bereavement. Despite the support for one another remaining, morale was *"rubbish"* overall (Lisa). Some described colleagues who felt a level of 'unfairness' between those working on the frontline who were seeing service users face-to-face and being exposed to the risk of acquiring COVID-19 compared to those working remotely,

> *"...one could feel angry and annoyed that you've carried the burden (...) for eight months um in a way. I mean, I suppose the thing is, is that if I'd caught COVID during work and no one else had, I think I might feel different. [laughs] Yeah? The fact I've come through COVID when I was the only person doing face-to-face in the service and haven't caught it, I'm very chuffed with myself. [laughs]"* [Jacqueline, HIV Physician]

Tensions had arisen among others regarding following government guidelines of mask wearing in the workplace,

> *"We were telling them (service users) 'if you leave the main room to go to the canteen, or go to the toilet etc, you have to put on your face mask to walk around the building'. But then they were saying, 'well, the staff aren't' (...) Then another colleague comes in behind me, no mask on, just stands right next to me, shoulder to shoulder and starts talking. So I then made an official complaint. You know I said, 'I didn't, whether I needed to or not, I didn't spend months shielding just to then come in to work and be put at potential risk because colleagues are too lazy to follow the guidelines'."* [James, Peer Support Worker]

Finally, there were concerns about furloughed staff due to the inability to provide services and the expected long-term effects on staff retention, particularly within community-based organisations.

> *"For my clients I worry of course for their well-being and mental health, specifically the mental health"*
>
> John, Peer Support Worker

3.4.4 Community level

Although it is misleading to imagine a homogeneous community of people living with HIV, some concerns were shared among people living very differently with HIV,

> *"...seeing the differences between people is just as important as seeing HIV as a unifying issue."* [Kevin, Charity Worker]

Perceptions of HIV

We asked participants about the demographics of service users who access their services as well as comparisons made between COVID-19 and HIV. As anticipated, participants described a change in service users during the pandemic (including unmet needs); however, less agreement existed in relation to comparisons being made between the COVID-19 outbreak and HIV epidemic.

Sociodemographic characteristics of service users

Depending on the geographical location of the service, the demographics of service users can vary. For instance, those based in urban cities such as London or Birmingham have a much more diverse cohort of service users, including Black African and South Asian communities as well as individuals living in neighbourhoods of high deprivation; however, one London-based clinic described seeing predominantly *"Caucasian MSM and GBM from Europe."* More rural or coastal areas described seeing predominantly GBMSM of White ethnicity although some areas are beginning to see an increasing number of heterosexual men and women, including migrants. One clinic also saw people living with HIV from the military, as well as young adults and paediatric adolescents. Health professionals who had started working in services in the early stages of the HIV epidemic described how their cohorts had grown, from the tens to the hundreds and even thousands. Older service users are also now living with other health conditions alongside their HIV (co-morbidities).

Most participants described service users as 'stable'; in other words, having an undetectable viral load and adherent to medication with a large majority being 'long-term survivors'. However, participants also described particularly vulnerable service users such as those living with co-morbidities (e.g. poor mental health, cancer, neuropathy and diabetes); those with substance use problems; homeless or living in precarious housing; transgender women; migrants; people in prison; people who have experienced sexual assault; pregnant women and mothers; those who are newly diagnosed and those who struggle with adhering to medication.[5] COVID-19 has also inevitably affected the lives of some service users who access clinical services; for instance, financial circumstances, being furloughed, job losses as well as issues related to housing. However, some (Jacqueline, Lisa) reported that they had received no reports of any issues of housing or food security during clinical consultations, although reflected that this may have been raised with community support workers.

Comparisons between COVID-19 and HIV

One question asked participants if they had "ever experienced anything like this before", which alluded to the early days of HIV; however, some participants compared the COVID-19 outbreak to the HIV epidemic without prompting. Comparisons were made in relation to community response, the early days of HIV and public attitudes to HIV particularly stigma and discrimination.

First, there was recognition of the strong community-led response to HIV which Jack described as *"bubbling back"* due to COVID-19. Health professionals reflected on several of the 'key players' or experts in the HIV field (both medical and research) that had been involved in the COVID-19 response; for example, Linda emphasised the work of HIV clinicians addressing health inequalities but also in ensuring people living with HIV participate in COVID-19 trials and research (e.g. vaccine development). In addition, Jacqueline reflected on having insight that services would require PPE following their experiences of the early days working in HIV and sexual health services. Participants acknowledged that the medical advances in HIV have been driven by activism in the community for an emerging infectious disease of which medical knowledge and understanding continues to be uncovered. However, John, reflected on the delay in progress for the advancement in HIV care and speculated on the implications for COVID-19,

[5] Some of these groups would be considered "clinically extremely vulnerable" according to the NHS Digital Shielded Patient List (371) being used at the time of interviews.

> *"I think it's going to absolute years before they get on top of this. And looking at HIV drugs, for example, (...) I mean, 40 years on and we've just got to a level now that we're able to make patients undetectable..."* [John, Peer Support Worker]

Chris described that although COVID-19 is not seen as a long-term manageable condition like HIV, lessons could be learned for those living with long COVID. Similarly, Jacqueline described how long COVID will require a multidisciplinary and holistic approach bringing various clinical specialists together but also how in the early days of HIV, people were initially diagnosed through the specialty they first presented at, which draws similarities to SARS-CoV-2. Additionally, several of the organisations which have rallied together during COVID-19 to support people living with HIV are *"a legacy from the original HIV pandemic"* (Phil). Some referred to people living with HIV already as having lived through one pandemic and now experiencing another,

> *"We know how to support each other, and we still have some of the organisations that were set up in the in the 90s."* [Phil, Peer Support Worker]

Secondly, participants appreciated that lessons from the early days of HIV could also be applied to COVID-19, although there was an appreciation that the political climate and society differed from the early 1980s (Chris). Nicola said *"I already live with a virus"* and compared the initial resistance in the early days that HIV only affected gay men, with a similar view among people who do not identify as being 'at risk' of COVID-19. However, James described how these comparisons have driven a debate in the HIV community; he reflected on how his own diagnosis has led to his belief that comparing HIV and COVID-19 is a *"false comparison"*,

> *"I think for some people it's brought trauma back to the surface about how they were treated (...) and what was going on during the 1980s. I think for other people, and I think I probably include myself in this camp, I don't, I think it's a false comparison. Although of course I was aware of HIV in the 80s and went to more funerals than I maybe wanted to um I wasn't living with HIV then, so I didn't feel that personal stigma and discrimination. You know I was diagnosed a lot, a lot later so for me I don't see that comparison between the 1980s of HIV and the COVID pandemic now."* [James, Peer Support Worker]

A charity worker (Sarah) also described how COVID-19 had triggered difficult memories among older service users yet they had remained resilient in challenging circumstances. Phil reflected that although the death toll of COVID-19 is higher than those of HIV-related illnesses, it felt the same

due to the deaths of HIV being *"so concentrated amongst the gay community in the 80s and 90s."* However, Jack shared that they did not think COVID-19 had *"brought up too much for the patients"* although they described that delays in appointments or cancellations of elective procedures among older service users had been difficult; Jack was worried that this would remind older service users of being rejected and stigmatised in the early days of HIV.

Thirdly, we asked participants about their personal (or other) experiences of stigma or discrimination during COVID-19; John was unaware of anyone who had experienced stigma due to COVID-19, suggesting that stigma was likely due to HIV being related to sexual health. Nicola recounted an experience of explaining to a relative how the stigma and discrimination experienced by COVID-19 is like HIV, as well as the assumption that COVID-19 would only affect the elderly and dying. Additionally, Phil described how COVID-19 had provoked feelings that people living with HIV were *"not treated well in those early days."*

HIV care continuum

COVID-19 saw some service users re-engage with care; however, participants were concerned about those who did not re-engage with care, including those with increased vulnerabilities such as people experiencing domestic violence, the newly diagnosed or those who had recently moved and may be missing from care or were requiring additional support. Participants explained how they felt that service users who had anxiety and depression, or issues relating to substance use, before COVID-19 required closer observation during the pandemic.

Service provision and the role of the Third Sector

Participants described their services before the pandemic from testing to pharmacies and physiotherapy. Community organisations physically reside within some HIV clinics, whereas for others they provide support remotely from the service. Other organisations are separate entities; overall, the set-up depends on historical partnerships, geographical locations, commissioning, and leadership behind clinical services. For example, some HIV services are within sexual health services or infectious disease departments. Additionally, some HIV services offer an in-patient unit to support people living with HIV in general or for specific issues such as opportunistic infections or mental health support.

Participants described Third Sector initiatives that are offered based on the needs of specific groups, including women and young people living with HIV. For instance, Sarah described a weekly service and a support programme for people in London depending on ages; from early years (0-3 years) to adults. This included dedicated physical spaces for equipment and resources such as yoga and music designed to meet the needs of service users. There are also specific programmes to support good nutrition, mental health, and psychological well-being to reduce feelings of loneliness. Larger community-based organisations offer physical and physiotherapy support, such as a massage service. The Third Sector also plays a role in educating and training health professionals about HIV as well as providing information for those newly diagnosed. For instance, Nicola trains junior nurses who are able to ask her questions about her experiences of living with HIV as well as social work students to teach them about the rights and needs of people living with HIV. Meanwhile, Kevin produces treatment information in non-technical language for those living with HIV as well for doctors.

It is common for HIV services to be based on a holistic care model. David's clinic credits a holistic approach to aiding relationships with providers and a model of care which is patient-led and patient-centred,

> *"...I guess we'd take a more holistic view of health. Uh. And I think it's great that we hold onto that, and it's helpful because sometimes patients tell us things they don't tell other practitioners."* [David, HIV Nurse]

Additionally, Linda described her HIV clinic as having all the resources required for service users such as a computer, green space, providing benefits advice and food/transport vouchers,

> *"...it's clear that if you provide things that people need rather than the things you think they ought to have, if people need advice on how to get money for food and you provide that, you can probably get an opportunity to measure their viral load while you're doing it. But if you just measure their viral load, they might not come if they don't have money for food."* [Linda, HIV Physician]

Rapid clinical service adaptations were made in the early phases of the epidemic to align with government advice and respond to a reduction in available staff. These changes were often implemented suddenly overnight with an immediate shift from walk-in clinics to appointments only and telephone triage. Therefore, COVID-19 resulted in the reduced delivery, adaptation and temporary closure of some services supporting people living with HIV. Services mostly cancelled or rescheduled

in-person visits, although some smaller services continued to provide face-to-face support for smaller groups, with the most vulnerable service users typically prioritised, including those newly diagnosed and sexual assault victims, where possible. Clinics were physically updated to be 'COVID secure' (e.g. installing Perspex screens and positioning chairs in waiting rooms) for those who needed to continue accessing face-to-face appointments. Community workers also prioritised the most vulnerable service users, although this approach was adapted as the epidemic became more controlled,

> *"Our Community Support Worker was given a list of (...) the older vulnerable people so that she could phone them on a regular basis to see if they were OK (...) So she was the fail-safe, keeping an eye, keeping in touch."* [Jacqueline, HIV Physician]

However, the rapid change to services was particularly difficult for vulnerable service users to adapt to,

> *"...it has been very difficult because (...) of the nature of the service, working with the most complex service users, those are the ones that have sort of not been able to adapt very well. They're the ones that maybe don't have regular access to the Internet, aren't as comfortable using it or maybe don't have a fixed address, (...) or don't have access to the phone all the time, so it's very difficult to continue working with the sort of most complex service users that we had. We've sort of done our best to try and keep them engaged through various means (...) like arranging for some funding to be available for them to access (...) tablets and access the Internet."* [Jack, Charity Worker]

Additionally, sexual health services were affected by changes to HIV services,

> *"...the sexual health services actually got a little bit quieter because people didn't want to come in for sexual health screens unless people were having sex. So there were less people coming in with symptoms, um sort of STIs, so that could free up some capacity to kind of think about how the HIV service was going to be run."* [Chris, HIV Nurse]

However, as the epidemic progressed and restrictions eased, some services began to see more service users again,

> *"...and things were getting a bit busier with, with the sexual health side of the service, 'cause (...) I guess the lockdown rules ease slightly and people were (...) having more sex (...) more people coming in for GUM [genitourinary medicine] sexual health stuff."* [Chris, HIV Nurse]

Participants also described actual or perceived barriers to HIV care during COVID-19 and actual or proposed solutions to combat these **(Table 3.2)**.

Table 3.2: Actual and perceived barriers to HIV care during COVID-19 pandemic with solutions shared by participants

Point of care	**Actual/perceived barrier**	**Actual/proposed solutions**
Testing and diagnosis	Access to testing; late diagnosis	Home-based sampling kits; point-of-care testing
Treatment	Ensuring adequate supply; adapting regimens	Postal/courier deliveries; collection/delivery by community-based organisations and clinic staff; remote support
Retention/engagement in care[1]	Digital poverty	Providing tablets/laptops; 'doorstep' technological assistance; face-to-face options; providing funding for Internet/Wi-Fi access
Achieving and maintaining virological suppression	Postponed 6-monthly clinical monitoring appointments	Shifting appointments to online or in a 'socially distanced' way (e.g. at a train station)
Health-related quality of life	Food insecurity	Providing food parcels/deliveries of food shopping by community-based organisations
Across the continuum	Social isolation and loneliness due to social distancing	Virtual support groups; in-person support as restrictions were eased (e.g. sitting in gardens)

[1] Including peer support

I outline the impact of COVID-19 on the HIV care continuum in the following sections as well as anticipated short- and long-term developments in services at each point.

HIV testing and diagnosis

COVID-19 presented a challenge to HIV testing; for instance, Kevin explained that most HIV-related testing was temporarily halted to focus on COVID-19. However, some viewed COVID-19 as an opportunity for people to be tested who may have otherwise presented at a later stage,

> *"...of the people who've had diagnoses (...) made during this time, I think we've lost one of them. Everybody else has been engaged because they've all been supported from the beginning of the process all the way through in a way that if we could do that you know, not (...) in a non-COVID world would make a difference."* [Linda, HIV Physician]

Additionally, participants (Jacqueline, Lisa) described coincidental diagnoses among patients with COVID-19 at the point of admission, sometimes with suspected Pneumocystis pneumonia.

However, John perceived a "spike" in diagnoses as worrying and a healthcare worker (David) also anticipated a potential increase in HIV cases, and subsequently the HIV service, within their geographical region following the Christmas holidays. There were general concerns that people would

be diagnosed during the pandemic when there was social distancing measures and enforced isolation. For example, Nicola described how often physical contact (hugs) or touch can provide support to those newly diagnosed at a vulnerable point in time, but this was no longer possible. Karen, however, presented a case of somebody newly diagnosed who shared that the distancing measures allowed them to come to terms with their diagnosis,

> *"He said 'it was quite good that I could...I didn't have to go out and see people. I could stay at home lick my wounds. Spend a few days not having to see anybody and not having to make any excuses through, not having to see anybody and then come out of it stronger so you know you know from that.' I thought that was great. It could go the other way I guess."* [Karen, Peer Support Worker]

Participants reflected on how HIV testing might transform after COVID-19; for example, shifting to sexual health clinics (James), promoting, and providing home sampling kits or delivering HIV diagnoses by telephone, as introduced into some sexual health services during the pandemic (Matthew).

Peer and community support

Before COVID-19, peer support remained a key feature of community-based HIV care often playing a role in encouraging medication adherence, sharing the U=U message and providing a regular source of social support. Some peer support involved attending hospital and GP appointments with service users or identifying organisations to best support their needs. Mentees are often newly diagnosed or those experiencing difficult personal circumstances. Peer support is often the first time someone newly diagnosed may meet somebody else living with HIV and as Nicola explained, can have a profound impact on their mental health,

> *"...but without them (peers) I don't know where I'd actually be right now. If I hadn't gone, met all those women I don't, well who knows where I'd be, because obviously you know that was the changing point."* [Nicola, Peer Support Worker]

Referrals to peer support are dependent on the location; sometimes through GPs, self-referrals, community support or through the HIV clinic. Some community-based organisations provide training to peer support workers in key skill areas including mental health (e.g. adult safeguarding and suicide awareness) as well as counselling styles (e.g. motivational interviewing) and organise supervision as a safe space to raise concerns with others. James explained that the frequency of meetings depends on the availability of the mentor and level of support required.

COVID-19 resulted in an increased workload for peer mentors but also limited how they could support their peer mentees. Phil's client group increased by 42% (19 to 27 people) since the start of the pandemic, several of whom have had relatives die from COVID-19 or have general anxieties about the pandemic due to other co-morbidities making them "clinically extremely vulnerable", although responses differed. For instance, one client who was particularly vulnerable and lived in supported accommodation did not follow government guidelines to shield or wear a mask whereas another was isolating a month before government recommendations and *"was happy doing so."* The majority of Phil's peer support was remote, although a reduced day service had since resumed at the community-based centre; he described not seeing some clients for 6-months but using texts to stay connected. Similarly, John had been supporting peer mentees who were struggling during lockdown by email and telephone and reported having an increased workload which he believed was due to people feeling lonely and isolated. Two peer mentees were fearful leaving the house but John had been able to contact and support all his peer mentees during the pandemic so far.

However, the reduction in social support left community-based groups worried for their members who are mostly restricted by email and telephone conversations and potentially setting back their progress, which was affecting the emotional well-being of service providers,

> *"And for a lot of the service users where we were making some progress on some sort of very long-term and serious issues, that clock has sort of been reset now which has been frustrating. There's one service user in particular I'm thinking of. I've worked with her since day one. Was finally getting somewhere with her it and now it's just all been reset and I'm thinking like that's a year and a half nearly with this person like wasted and that's like really frustrating. And has been fatiguing emotionally."* [Jack, Charity Worker]

However, James described a reduction in referrals which he speculated was due to clinical staff being *"busy with other things and it wasn't in the forefront of their mind"* although the situation was improving more recently. James also described the "matching" of mentors to mentees appeared to be less successful during COVID-19 which he believed was due to a lack of face-to-face interaction,

> *"It was hard for them to build up any sort of relationship with their volunteer mentor and start cold by telephone. So, the two or three that I did try to get going weren't very successful."* [James, Peer Support Worker]

Peer and community support also had to adapt to government restrictions, including both online

spaces and social distancing measures. For larger organisations, remote support was already established although the capacity was increased due to demand; one organisation (Sarah) supported over 2000 people, with over 6000 remote calls during April, May and June 2020. For other organisations, establishing remote support promptly was required. During the pandemic, Karen helped establish an online peer support service for a charity either by live chat, Zoom or WhatsApp (with or without video). One peer mentor (John) emailed his mentees and arranged telephone calls as and when they were needed,

> *"I did a telephone call with one of my mentees and she was going through a really hard time in lockdown. So, I gave her a call and we had a really good chat for about an hour and a half, and she felt a bit better."* [John, Peer Support Worker]

Some noted service user concerns regarding the confidentiality of online spaces and an initial reluctance to participate because of lack of privacy or digital poverty. Consequently, some organisations continued to provide in-person support for emergencies or for the most vulnerable service users. As restrictions eased, some services provided opportunities for service users to meet in small numbers although most remained remote.

Additionally, James described a shift in attitude from telephone-based to video-based mentoring as the epidemic has progressed. Remote support groups, such as for women and families, have been hosted using Zoom; however, James described how mentoring services did not transition online which he anticipates is due to mentoring being *"quite an intimate conversation and people were used to doing it face-to-face."* Some organisations (James, Jack) provided funding for, or access to, laptops and tablets for service users to circumvent issues of digital poverty, while others (Sarah) provided large print instructions or sent volunteers to explain, on the doorstep, how to access remote support groups. However, issues of access to a private, safe space, confidentiality and living in shared accommodation were less easy to navigate.

Peer support also helped service users to deliver and purchase food and prescriptions. For instance, Phil partnered with other HIV community-based organisations to deliver food twice weekly to people living with HIV which he associated with the long-standing collaborations built during the 'early days' of HIV. Jacqueline's clinic employed a community support worker who prior to COVID-19 would be in the clinic daily to help support service users with issues including housing, food security and finances

as well as visit people at home to identify any areas of unmet need. However, during COVID-19 they had been based remotely and would prioritise the most vulnerable service users[6] once a month for check-ins with the community support worker (e.g, housing, emotional and psychological well-being).

Despite the anticipated benefits in saving costs and travel time due to remote working, the importance of meeting face-to-face was also acknowledged by community-based organisations, whether for networking purposes, providing services or office-based work. There were also concerns regarding the potential financial implications to charities and community-based groups in terms of funding for venues, running costs and paying staff following a year of reduced income but an increased demand on services which had to initially be reactive to the situation. However, Sarah remained hopeful that relationships built between organisations during COVID-19 will make future collaborations easier.

Community support overlapped with support neighbours, local authorities and mutual aid groups who were providing cooked meals or collecting and delivering shopping and collecting prescriptions. Participants said that mutual aid groups were newly established nationally so neighbours could support those shielding. For example, Nicola helped deliver food parcels and provide support to service users but also vulnerable adults for the council, including those who lived alone. Phil also described food insecurity among several service users who are older, with limited mobility and living on benefits, building connections with local community groups to overcome issues; for instance, providing a client with a kitchen appliance. However, Sarah described barriers to accessing mutual aid groups among service users who were more familiar and trusting of existing relationships with their organisations,

> *"...or they didn't have the money to give to a local mutual aid group, or they were just too fearful of working with other volunteers or other organisations they didn't know."*
> [Sarah, Charity Worker]

It was anticipated that the set-up of future peer and community support would depend upon government guidelines and the preferred method of support by service users and the financial situations for charities and community groups following a year of increased demand on services and a reduction in income. However, most participants predicted that these would return to normal, in other words face-to-face, as service users overwhelmingly prefer this. Additionally, one peer support worker

[6] Jacqueline described the most vulnerable to be older people living with HIV, people with pre-existing mental health conditions (anxiety and depression) and people who were known to misuse alcohol.

(Phil) was preparing to visit service users in person, with appropriate PPE, once lockdown was lifted assuming that they allow him into their homes; however, he was *"not looking forward to that at all."*

Clinical monitoring

People living with HIV who are 'stable' (established on antiretroviral therapy, adherent and tolerating it well with an undetectable viral load) are seen twice yearly in England and Wales. However, David, described how about 20% of their service users require more intensive monitoring due to difficult personal circumstances, mental health issues, changing medication regimen, living with comorbidities or being newly diagnosed and requiring more support. A specific example given was the need for pregnant women to remain undetectable; therefore, David's clinic prioritised pregnant women to have more regular monitoring during government restrictions, particularly as they approached their due date. Other people prioritised included those who were not yet undetectable as they had not been on treatment long enough, new service users, those who were not adherent to treatment as well as the occasional individual who "blip"; in other words, they have a viral load which is detectable, *"...because undetectable means something different from zero"* (David). Chris's clinic prioritised service users based on their most recent blood tests results and would provide medication rather than scheduling further tests if their last results were stable. For David's clinic, most service users were reassured if they had stable clinical indicators, although some remained concerned,

> *"...and one guy rang me each week to see if he could now come in. And in the end I said 'well, why don't you? If it's better to come in and have the blood test taken, then we could do that and then you won't be worrying about the fact that you're not being checked even though you're very stable' and it turned out everything was still OK."* [David, HIV Nurse]

COVID-19 resulted in a temporary stop to face-to-face clinical monitoring with a switch to telephone consultations. Clinicians used telephone consultations as an opportunity to monitor the well-being of service users, learn more about them and identify those who may require additional support from community-based workers; for instance, alcohol and drug use, finances, housing stability and emotional coping. Jacqueline believed that the telephone consultation had allowed service users to be more honest with them than a face-to-face consultation. However, it was also appreciated that teleconsultations are not *"a substitute in communication for all of those non-verbal cues"* yet

providing the opportunity to be seen remotely was a relief for older service users who were worried about attending the clinic "unnecessarily" [David]. One hospital (Lisa) adapted their blood tests to be compliant with social distancing by moving it to the local train station, whereby service users were able to receive their clinical monitoring. They reflected on this approach as being helpful for younger people living with HIV who live in the city centre.

At the time of interviews, HIV services were facing a backlog of cancelled and delayed appointments; however, generally, clinics were able to monitor the situation to ensure disruptions to the care of service users was not detrimental to their health,

> *"We were able to track people quite closely just because everything is on a computer, so you can see when their last check was when they lost, got their medicines and work things out. So, nobody really fell out of the system at all (...) Some people, as is always the case, (...) require a bit more chasing up in a few more texts and all of that. I can think of a man who, you known been quite anxious about him for some time. He's had a dip in his circumstances, has been using drugs quite a lot and not hasn't seen us for quite a long time, although he occasionally replies to a text. And he's always grateful that we keep in touch (...) And in the end, he accepted my advice (to visit a clinic for monitoring) without me, reminding him..."* [David, HIV Nurse]

As circumstances began to improve, Jacqueline described how her clinic had begun to see everyone face-to-face for their bloods but had maintained telephone consultations,

> *"From a medical point of view, we did the... text, phone. 'We'll see you' if they've got any issues and we ran that and (...) we only saw face-to-face those that we felt that had illnesses that needed (...) had symptoms, and those that really need to have their blood monitor tests. Then, as the pandemic sort of relaxed a little bit, we got more confident in our process, so we started actually just seeing everyone face-to-face for their bloods but still have maintained the telephone consultation."* [Jacqueline, HIV Physician]

Kevin reflected on their own experience accessing HIV care during COVID-19 positively as he had found making an appointment much easier, with shorter waiting times and quieter clinics.

Several participants reflected on their experiences of HIV care in the 'early days', the advancements in HIV treatment and care and their anticipation for the future of HIV care. With the UK's successes in testing, treatment and care, a large proportion of those living with HIV have an undetectable viral load, there is a push to reduce the frequency of visits to once a year. For instance, David explained the shift in the frequency of clinical visits over time as advancements were made in HIV treatment and care. He described the lack of effective treatments in the mid-1980s, caring for sick patients who

would deteriorate and require frequent visits and support. He then noted the advent of treatments, people beginning to live *"a bit better with HIV"*, monitoring every three months and the introduction of viral load measures in the mid to late 1990s. Finally, David described shifting to monitoring every four months and the present day check of every six months. He explained that clinics need to be flexible once again to reduce monitoring and visits which would provide service users with confidence in their progress,

> *"The clinics in some ways need to find a way to let go again, probably, and be confident that the majority of people are living very healthily and self-managing their HIV and perhaps even less frequent visits than six monthly well may be appropriate for the majority."* [David, HIV Nurse]

However, Phil described that some service users felt worried about having a yearly clinical visit in case of medication failure.

Ultimately, participants highlighted the importance of service user feedback and a continuation of a co-design approach in the delivery of services after COVID-19.

Medication access, supply and adherence

At the start of the epidemic, having an adequate supply of antiretroviral therapy was a key priority for HIV clinics, with staff (Chris, Lisa) working in collaboration with pharmacies and transport to deliver medication nationally but also internationally. Clinics quickly reacted by contacting all service users to check whether they had an adequate supply and prescribed medication for an additional six months if these were running low, with some delivering medication themselves if delivery services would be delayed. Although most participants described few issues regarding medication adherence or supply, Phil described one service user who had been having difficulties in getting medication from the HIV clinic but that he anticipated this could be due to a wider issue as the service user declined help when offered. One peer support worker also described delays in receiving information about medication which they again anticipate may be due to a loss of communication between clinics and pharmacies. Lisa shared that several service users were uncontactable during the height of the pandemic and despite colleagues remaining hopeful that they would contact the clinic if their supply were running low, they remained worried about them,

> *"I say we had a pile of prescriptions for people that we weren't able to get hold of. And some of them (other service providers) would say, 'well, I'm sure they're in Africa' or 'oh, I'm sure they'll ring when they run out of medicines.' And some of them have. Um I'm particularly au fait, of course, with the adolescent cohort. They know where we are, but it would be nice to see them. . . "* [Lisa, Healthcare worker]

Some larger clinics (Jacqueline, Lisa) have a HIV pharmacist attached to dispense antiretrovirals although more clinics were encouraging home deliveries prior to the pandemic. Due to the uncertainty of the pandemic, Lisa's clinic provided a four-month supply of medication with hope that the situation would have improved by the summer which meant that the initial workload was burdensome. Lisa also described how a substantial number of service users were *"stuck abroad running out of medicines"* which involved coordinating with clinical colleagues based abroad in Africa, India and in some cases prescribing their medication for a friend or family member to collect and post to them which proved increasingly challenging as air travel was stopped. She shared a specific example of adapting a medication regimen remotely,

> *". . . and this lovely lady who was works as a (...) health advocate in Gambia. She couldn't. . . we couldn't get any medicines to her because there were no planes. So, we had to change her regime. And most of that we actually did by email in the end."* [Lisa, Healthcare worker]

However, this example is a rarity; in most cases, switches were postponed. Medication switches are typically instigated due to side effects of the medication (e.g. renal function) which requires blood tests to monitor any changes; Lisa continued to explain that completing these assessments by telephone is *"not terribly straightforward"* and COVID-19 had also delayed any switches to generic medications,

> *"...you have to say you know, 'stop taking that blue, big blue one and we're going to give you a small blue one instead' (...) also then people couldn't have follow-up blood tests. And also things like with the advent of generics (...) we have been told to choose... to change medicines to cheaper ones. So, we kept people on more expensive regimes because we hadn't gotten the facility to see them face-to-face to make those changes. Those that needed to be done because of resistance or failure, we would do [Interviewer: yes]. Those that you know we review somebody and say 'well actually you know we'll review his kidney function in three months, six months and see whether it's still going down'. That sort of... and simplification regimes. You know, the in thing is of course one tablet once a day. But we didn't do any of that just because it's nice, because changing any regime you know has to be followed up closely afterwards."* [Lisa, Healthcare worker]

Adhering to medication was not found to be a major issue among service providers although some did describe service users who had been less adherent before COVID-19, such as children (Lisa). Jack described having more regular check-ins previously to encourage individuals having issues with adherence and prevent resistance but that COVID-19 had resulted in them disengaging with care again. Similarly, Nicola described the difficulties with service users requiring more support but were not eligible for social services.

Despite most clinics having established home deliveries of ART, some service users in remote locations preferred to collect their prescriptions for confidentiality reasons (Jack, Jacqueline). Finally, most participants thought home delivery would continue beyond COVID-19.

Health-related quality of life

Mental health is a fundamental aspect of HIV care and an area of need for people living with HIV. Several participants described having a counselling service or psychologist either embedded or attached to the service (clinic or community-based) although smaller HIV clinics would refer externally. Several participants recognised that social isolation was an existing issue among service users prior to COVID-19, and that *"lockdown came along and just made that 10-times worse for them"* (James). Phil explained how some people living with HIV who were dealing with isolation prior to the pandemic reflected that COVID-19 *"...hasn't changed my life much because my life is already quite isolated."* Issues of isolation had been previously existent among older people living with HIV whose social networks had become smaller over time.

During COVID-19, participants were acutely aware of service users with existing mental health conditions who may require additional support and would either prioritise face-to-face support or conduct more frequent check-ins. For instance, service users with a history of trauma, traumatic memories from their HIV diagnosis, or from fleeing conflict were 'triggered' at the height of the pandemic. Peer support workers were worried about the mental health of their mentees, particularly issues of loneliness and isolation during lockdown, which may ultimately have an impact on their own well-being,

> *"For my clients I worry of course for their wellbeing and mental health, specifically the mental health (...) But I just hope that I can keep for myself. I can keep the strength*

> *to be able to support other people. You know, I think if I need time out, I'll have time out."* [John, Peer Support Worker]

Some mental health support was provided solely remotely with service users being referred for loneliness and isolation with the hope of face-to-face support when it was more appropriate. Some felt mental health had worsened during the pandemic with individuals with pre-existing conditions and a HIV Nurse (Chris) was concerned that some may have *"slipped through the net"*, specifically those with conditions difficult to diagnose or discuss by phone. Participants also recognised that telephone consultations may not be an appropriate medium to discuss and assess mental health, but that this was necessary given the circumstances of a pandemic,

> *"But I suppose we were faced with unprecedented situation (...) You know, we responded in the best way that we could, but I think certainly it's probably reflected (...) in some of the discussions I've had with people living with HIV around, you know, feeling isolated and not being able to... feeling that they can't go in to see to see someone in their HIV clinic 'cause they're not allowed. Or they could only go in if they were physically unwell. Or they could only go in if they wanted to. You know, if there was a pressing physical issue and I feel like maybe some people with mental health issues, whether that was pre-existing or you know, kind of long-term or it was kind of brought about due to COVID might have been missed if it were well which kind of upsets me a little bit."* [Chris, HIV Nurse]

However, it was also felt that time for reflection and the enforced slowing down of life could help improve mental health.

Service providers (Linda, Phil, David, Lisa) recognised that the pandemic had left them unable to refer to psychological and mental health services due to the redeployment of staff, increased demand, and less face-to-face appointments resulting in reduced capacity. Suicidal ideation was reported by some service users of which referrals still remained an issue,

> *"...the elderly chap (...) who has severe, anxiety, loneliness, and you know, like 'is this it? is this my life?'. He said (...) 'I'd just like to end it.' (...) So that told me that this is somebody that needs help. So, I refer him (...) the services are fractured (...) It feels like they just don't have capacity anymore."* [Phil, Peer Support Worker]

One participant (Lisa) had experienced bereavements of service users during COVID-19 although nobody else interviewed had experienced a personal death or hospitalisation from COVID-19. Some did, however, discuss supporting friends, service users and colleagues who had lost a loved one.

For some community-based organisations, this particularly resonated with older service users of the trauma experienced during the early days of HIV – specifically memories of bereavement, stigma, and discrimination,

> *"The day service sessions that people would, started talking about people getting ill back in the 80s. But at the beginning they were very matter of fact about it. And 'Oh yeah, now it's, you know, we've been through this before.' (...) It also erm stirred up memories for lots of people about what it was like in the 80s and 90s of living through an epidemic of people dying around them (...) It stirred up anxieties, and then so we have to start managing peoples er, they're trying to manage their anxiety."* [Phil, Peer Support Worker]

Sarah recognised that older service users were equipped with the resilience to persist through such challenging times. However, some were less sure about comparisons with HIV, yet recognised that this may be due to being diagnosed at a later stage of the epidemic,

> *"But I know for a lot of people it's brought back a lot of sort of unwelcome memories, yeah? Uh, so I think you can't say who's right and who's wrong because we all have different perspective and different histories."* [James, Peer Support Worker]

Phil described a colleague who had experienced stigma when self-isolating and how this had compounded with her HIV status,

> *"...she had a really tough time... her sister wouldn't come into her house. Her sister would only push things through the window and even after she had been passed as negative of COVID (...) I was speaking to her a lot during that time and she said to me, 'Is this it? Is this another virus I have to live with?' And (...) I sort of said 'No, it's gonna go. This one's gonna go'."* [Phil, Peer Support Worker]

It was felt that isolation and loneliness would be the major issues after COVID-19 despite the efforts by community-based organisations to remain connected with service users.

Future of HIV services

Although life 'after COVID-19' remained unclear, participants speculated on the possible implications for their day-to-day work, the HIV service, and the experiences of service users.

Some participants reflected on changes that have improved the efficiency and experience of service users accessing HIV clinics may be carried forward in service delivery, in the short and long term. For

example, Chris described a continuation of a 'COVID type' or reduced service in anticipation of more 'waves' of COVID-19 and the redeployment of staff meaning a continuation of phone consultations and home deliveries, thus freeing up the capacity to see those patients who are more vulnerable face-to-face. Advances in the digitisation of NHS systems and the offer of remote services were anticipated to continue in the longer-term. For Linda's clinic, it is likely that service users will see different clinicians at each visit according to who is 'on duty' rather than the same consultant each time,

> *"...those days of 'you are my patient, and I will be the person you see' I think are going to be very different."* [Linda, HIV Physician]

Some described that several changes made during COVID-19 will continue due to positive feedback from service users on how they receive more efficient services and more personal attention. Matthew disagreed with the notion of restoring services 'to normal' or *"keep the status quo"*; he believed that services and treatment provision will not return to previous delivery due to digital health and automation being *"cheaper, better, faster"* including home sampling test kits. Jack described how the anticipated changes had been sped up due to COVID-19,

> *"...with the cohort we've got in particular, with so many of them sort of stable (...) but still having to come into clinic every six months for blood tests and for our long appointments. And for some of these people, they're sort of travelling from an hour, maybe from rural [location] for their appointment. So, we were sort of looking at doing video consultations and then they would just go to a local phlebotomy service for their bloods. So that has sort of that has definitely been accelerated in terms of rolling that out..."* [Jack, Charity Worker]

Participants spoke of the anticipated longer-term changes in HIV care, including a shift to primary care services, the potential impact of this on the HIV profession, and less frequent monitoring. There were discussions of how HIV testing will transfer back to sexual health clinics, which generated mixed feelings. Some were concerned by a shift to primary care, with the perception that GPs are "not qualified" and do not have the level of trust seen with their HIV clinician (John). Others were more hopeful although cautious that this will depend on the level of training received particularly in relation to treatment and stigma and discrimination (James).

Discussions ensued on the role of the HIV profession and how HIV specialists will remain for those living with serious conditions related to their HIV (James). Concerns for the mental health

of healthcare staff was described by several participants. For example, Matthew described medical professionals who have now *"become call centre operatives"* in a specialism that *"isn't that special anymore."* Others (Chris, Lisa) described colleagues and staff who were fatigued and burnt out from being redeployed or providing services during COVID-19 and general concerns for the future of their roles.

Others described a hybrid model of primary and HIV care, with blood tests completed by GPs and HIV clinicians having access to escalate if there were concerns; Jacqueline remained sceptical of this approach, *"that would be a big step and I'm not sure if it's a step that we want to go down."* However, Matthew viewed a potential shift to primary care preferable for him.

Some felt that COVID-19 had highlighted how people living with HIV have remained relatively stable and so perhaps yearly viral load monitoring would be appropriate although there could be some service users who are disadvantaged by this. However, David was sceptical as to how quickly some of these changes may be implemented within the NHS and the cost-saving implications which may drive decisions rather than patient need or demand,

> *"In some ways, the NHS is a cautious organisation. (...) I think managers and finance departments will probably like the sound of doing half the number of tests. Reduce visits. But the danger is that they only see that and don't understand that there's different ways of managing people that, you know, still nurses and doctors and others will need to be engaged in. Uh. Just because they're not in the room with you doesn't mean that you're not engaged in health care because I think that's the way that things might go. I think patients, you know, some patients find it reassuring to sit down with a doctor once a year and be told everything is fine, and it may well be the doctors find it hard to find much to talk about. Certainly, I hear them say that."* [David, HIV Nurse]

Other anticipated longer-term changes were how services are commissioned and structured; for instance, Matthew shared the need to broaden HIV into sexual health, reproductive health and bloodborne viruses, and scepticism towards national HIV programmes and the belief that sexual health commissioning *"will become a luxury"* due to the widening of social determinants due to COVID-19 (specifically mental health, food poverty, and debt). Also, Matthew shared how he believed COVID-19 will shift specialisms within the NHS to be more streamlined due to the rapid developments in technology which he views as being apparent during COVID-19 to be *"possible, practical and effective."* However, there were also concerns of how COVID-19 may lead to a *"deprioritisation of*

HIV" due to a shift in focus towards a "new pandemic" which may hamper the progress already made (Linda).

Finally, several participants highlighted the importance of service user feedback and a continuation of a co-designed approach in the delivery of services after COVID-19, which Chris noted is particularly important following the rapid changes during COVID-19 which he *"... didn't even feel involved in things changing."* He reflected that COVID-19 has provided the opportunity for services to consider changes required to improve services and the experience of service users. Jack described how often the feedback received is unprompted and honest; however, he believed the challenge will be in presenting this to commissioners in an acceptable and appropriate way when redesigning the service, as the commissioners typically require evidence of access and improved results. Jack said that this was easy for him because he has a small cohort of service users. Jacqueline mentioned that service users will be asked about how they have found adaptations made during COVID-19, and whether they would like these to be continued, such as, home deliveries and telephone consultations, which she believed had worked for them.

> *"...I think a lot of people that are living in digital poverty are living in a food poverty, are living in emotional poverty, mental health poverty, because they're living in poverty..."*
>
> Matthew, Charity Worker

3.4.5 Societal level

COVID-19 raised concerns around accountability in pandemic preparedness; participants alluded to the biopolitics of public health which polarised society and blamed "lockdown flouters" (Nicola), conspiracy theorists, "anti-mask" and "anti-lockdown" groups (Jack). Some anticipated a third national lockdown in England which occurred after interviews were completed (in early January 2021).

Accountability

Overall, participants were frustrated by the speed of government guidance and restrictions in the UK. For instance, the use of Tiers and different counties or nations being at various stages of restrictions and confusion about government messaging, particularly in the early stages of the pandemic, with a loss of confidence at specific points,

> *"And then the trouble was that people started to lose confidence in it and the Cummings affair I think was quite important and a lot of patients and other people in my life have spoken about that as you know, 'one rule for them and another for us', and 'they don't even follow their own guidance'."* [David, HIV Nurse]

Highlighting and addressing existing and emerging inequalities

2020 was also the backdrop for social movements including Black Lives Matter protests.[7] Participants recognised that persistent and widening inequalities were highlighted by the pandemic and reflected on how some communities had been disproportionately affected by COVID-19; for instance, Sarah's

[7] Black Lives Matter is a response to the structural and interpersonal racism experienced by Black communities (including Africans, the African diaspora and people of African descent) "daily and for the past 400 years under the many cloaks of colonial rule" (372, 373).

community-based organisation also supports young adults living with HIV who have faced challenges around job security. Kevin and Karen described the discriminatory nature of government policies, for instance, the exclusion of people living with HIV from antibody testing.[8] However, COVID-19 also presented an opportunity for cross-sectoral collaborations to rapidly address inequalities among marginalised populations. For example, Linda described a London-based initiative of HIV, syphilis and blood-borne virus testing and providing temporary shelter in hotels for people who were homeless (375). This initiative involved collaborations across sectors (e.g. public and Third sector) which was easier to establish because there was "less bureaucracy."

Participants acknowledged that the social determinants of health are inextricably interlinked and can influence the lives of people living with HIV,

> *"...I think a lot of people that are living in digital poverty are living in a food poverty, are living in emotional poverty, mental health poverty, because they're living in poverty..."*
> [Matthew, Charity Worker]

Vaccine development and delivery

Similarly to HIV, several community-based members were highly knowledgeable about COVID-19 and the vaccines being investigated; Kevin felt optimistic that vaccines may provide the solution required but emphasised the need to not become complacent in terms of adhering to the guidelines and restrictions. Some participants spoke of colleagues involved in the running of trials, service users who were taking part in trials as well as their own interest in joining a vaccine trial in the future, if they were a suitable candidate. Interestingly, John reflected on the progress in vaccine development in relation to HIV drugs and the need for a sense of caution due to potential, unforeseen limitations,

> *"I think eventually we'll (...) just have to succumb to the situation that we have to live with it... And treatment I think will be the (...) key here. I think it's the treatment that's gonna be the biggest beneficial side of things for the first, you know at least five years or so. (...) I suppose I'm not jumping up and down about a vaccine at the moment."*
> [John, Peer Support Worker]

A healthcare worker (Jacqueline) discussed the role of HIV services in delivering vaccinations and described how their clinic had now begun to deliver the influenza vaccine which they had not done for several years,

[8] This was subsequently overturned in November 2020 following challenges by BHIVA and others (374).

> *"A lot of them have told me that they've you know things like they've been able to access their flu vaccine much easier this year because they're HIV positive and there's COVID, which in the past they've had to fight for their (...) vaccination."* [Jacqueline, HIV Physician]

The day before Lisa's interview, the first vaccine was administered in the UK; we asked Lisa to reflect on this in her interview. She shared that this was a common question among relatives and service users but expressed concerns that this may result in complacency among some, which she viewed as what was happening with being tested twice weekly,

> *"...I think that's a good thing and I think you should have it (the vaccine) and well don't stop doing what you're doing right now, but hopefully yes, that will help."* [Lisa, Healthcare worker]

Collateral damage

Participants spoke of the collateral damage, or indirect consequences, of COVID-19 to the economy, wider areas of health and social care, individual livelihoods, and health,

> *"...those underlying issues are really going to come to the forefront eventually and I you know, I hate to say it, but I do believe that more people have died from other things than the COVID."* [John, Peer Support Worker]

First, the economic impact of COVID-19 on already precarious jobs and finances (e.g. the hospitality industry or charities reliant on donations). One community-based volunteer (John) described the possibility of a reduction in working hours or the closure of services due to the pandemic. There were concerns that a lack of fundraising income will negatively impact community-based organisations reliant on donations from the perspective of employees, volunteers, and Trustees for charities. Specifically, Jacqueline, who is a charity Trustee and HIV physician, described a responsibility of the medical community to financially support these personally as higher earners and who benefit from referring to these services. There were also concerns about the financial implications to local authorities facing "bankruptcy and special measures" which will face an increase in demand for other services; Matthew speculated that this may result in the de-prioritisation of sexual health services,

> *"There's going to be mental health, food poverty essentially, and debt rehabilitation for many people. So I really question whether there's going to be any money for sexual*

> *health services and provision, and that in tandem with organisations that are in place hanging onto each other like limpets"* [Matthew, Charity Worker]

Secondly, some reflected on the long-lasting effects of health avoidance behaviour due to a fear of acquiring COVID-19 which may continue,

> *"I think lots of people just dropped off and lots of people, because of concerns about catching coronavirus let medical symptoms go untreated."* [Kevin, Charity Worker]

For example, Sarah described an experience with a service user avoiding healthcare despite having had COVID-19 which resulted in the organisation she works for becoming involved as they were worried for their safety as the individual had been in intensive care for over a week afterwards. There were notable concerns of the potential implications to the postponement of services or treatments, such as cancer care, in the early phases (April and May 2020) of the epidemic which resulted in *"very bad consequences"* and which one participant worried may also occur within HIV (David). Chris described how COVID-19 has highlighted disparities within the NHS. Kevin described fears of preventable deaths that will have emerged from the pandemic due to these delays and the re-prioritisation of care,

> *"...so people will die because of this and that's (...) the shocking thing. Shocking that COVID hospitals weren't set up and the rest of the health system was allowed to (...) run more safely."* [Kevin, Charity Worker]

Thirdly, concerns were raised about the long-term effects of COVID-19; specifically long COVID among service users and how this relates to HIV. A healthcare professional (Jacqueline) recognised the potential similarities of requiring a holistic care approach for individuals with long COVID, which was equally not available during the early days of HIV,

> *"And you know there was no such thing as a HIV physician 30 years ago (...) and maybe they need to actually look at someone that's got (...) a special interest in long COVID that actually can bring all these sub-specialties together to actually support these individuals."* [Jacqueline, HIV Physician]

3.5 Discussion

3.5.1 Key findings

The COVID-19 pandemic is a biopolitical "crisis of power" which has highlighted and increased inequalities across borders, societies and communities (376). Interpreting our findings through an ecosocial theory lens suggests that agency remains located in individuals and organisations; those with positions of 'power' for instance, in the workplace, may have more negotiating power when making decisions to be redeployed or work remotely. Accountability was referred to across the ecological levels; at the individual level with adopting protective behaviours, at the community level whereby HIV services were adapted (often overnight) and at the societal level in relation to the UK government's pandemic response.

The uncertain nature of the pandemic, particularly transitional government guidelines, affected emotional well-being and work experiences of HIV service providers. We found that UK services rapidly adapted by shifting from face-to-face to online provision. Although prior research (347, 352) has indicated some people living with HIV preferred virtual consultations during COVID-19 to face-to-face appointments, our study identified that online services are not a "one-size-fits-all" approach and some service users continue to benefit from in-person services. For instance, telephone or video-based services raise issues of accessibility due to digital poverty as well as privacy issues (347, 348). COVID-19 also provided the opportunity for innovative approaches of rapid HIV testing interventions among marginalised communities (375). Any changes made to services should continue to be service user-led with a person-centred approach that does not exacerbate inequalities (330).

Our study adds to increasing literature on experiences of NHS and other health workers during COVID-19 (377–379). Similarly, we uncovered issues around additional work pressure and power inequalities, particularly among those redeployed (377) as well as the importance of work-based support systems (379) and an increasing backlog of clinical monitoring appointments (380). The blurred boundaries between work and home, including caregiver responsibilities, added pressure to the lives of those interviewed. Among the community organisations interviewed, anxieties around loss of income were prevalent; concerns have been raised around the consequences of a Third Sector funding crisis to an overstretched NHS (380). The pandemic has also highlighted an underlying need

to increase the capacity of mental health services and community outreach.

3.5.2 Strengths and limitations

To our knowledge, this study is the first to explore the experiences of front-line HIV community and clinic-based workers in the UK. We were able to interview a range of people, some of whom were living with HIV themselves which enabled us to explore the impact over time, including the anticipated short- and long-term changes to service provision. We also feel that conducting research during a pandemic affecting both the participants and researchers helped to build rapport as well as enhance the trustworthiness of the data (362). However, conducting interviews online may have changed the relationships built with interviewees (381). During the study we were unable to separate audio files from video recordings on Microsoft Teams therefore, we decided to ask participants to keep cameras off to ensure the anonymity of participants. All but one person kept their cameras switched off once recording began which will have impacted the rapport built; however, by switching cameras on before and after recording, interviewers were still able to gather insights on body language and to build an initial relationship with the interviewee. Qualitative research is also limited in terms of its generalisability; but it is assumed some experiences may be transferable to other contexts (382, 383). Finally, utilising an ecosocial approach helped to identify themes across individual, community and societal levels; however, several themes and ideas were cross-cutting and therefore did not 'neatly' fit into distinct categories. I was also unable to apply "embodiment", which is a core concept of ecosocial theory, as I was restricted by collecting purely qualitative data from participants which did not specifically focus on physiological responses (163, 365). However, mental health, poverty and digital exclusion are embodied and mentioned by most interviewees, although to varying degrees.

3.5.3 Significance of research, study implications and future research

This study helped capture the adaptations made to HIV services during the first 6 months of the pandemic as well as the experiences of those working in both community and clinical settings. Participants highlighted concerns for the mental health and well-being of service users and the imbalance of the supply and demand for these services. Significant investment in mental health services, including peer support provided through non-statutory organisations, could help alleviate

existing pressures on the NHS. Some concerns were also raised for the long-term health of people living with HIV who may develop long COVID and how HIV services may need to adapt to manage these service users.

Future work should explore the experiences of service users during the pandemic to see how these compare to the findings outlined in this study. This could include a more in-depth analysis of the impact of several national lockdowns and limited face-to-face services on the health-related quality of life of people living with HIV. Additionally, this could use an ecosocial analysis to see how factors including age, gender, ethnicity, sexual orientation, and social class may guide the interpretation of findings.

3.6 Conclusion

COVID-19 has undoubtedly changed how HIV services look now and, in the future, with differing acceptability among service users. Collaborative cross-sectoral efforts have been fundamental in minimising disruptions to HIV care, as well as the wider determinants of health. However, concerns remain for the longer-term impact on charities and community-based organisations which have faced a loss of income over the past year whilst facing an increase in demand for services. Despite its exploratory nature, this study contributes to our understanding of the impact of COVID-19 at the societal, community and individual levels. Further work is needed to understand the experiences of people living with HIV and their perceptions of the changes to service delivery during the pandemic, particularly potential negative impacts to health-related quality of life.

4

A co-produced qualitative exploration of the impact of COVID-19 on people living with HIV in the UK

In **Chapter 3**, I presented the findings of an interview-based study of people who supported people living with HIV in the UK, in both clinical and community settings, during the COVID-19 pandemic. This included the impact of COVID-19 on social determinants and persisting and widening inequalities.

In **Chapter 4**, I will outline a co-produced research study exploring the experiences of people living with HIV during the COVID-19 pandemic. I will also reflect on using a peer research approach in a doctoral thesis.

I collaborated with several people on this project to help with both the research and the extensive public involvement required; this project included a collaboration with the peer-led support charity Positively UK. Contributors are highlighted by their initials, specifically, from the Patient Experience Research Centre: Jane Bruton (JB)[1], Helen Ward (HW), Halle Johnson (HJ), Kabelo Murray (KM); peer researchers: Husseina Hamza (HH), Karl Dsouza (KD); Advisory Group members: Wezi Thamm (WT), Joshua Anderson (JA), and Silvia Petretti (SP).[2] I also acknowledge the Positive Voices study team (notably Adamma Aghaizu and Carole Kelly) for their support with recruitment to this study along with the contributions of those interviewed.

This work was supported by both my LISS DTP Case Studentship and additional funding I applied for and was awarded by Imperial College London's Societal Engagement Team 2020 Rapid Response Seed Fund. Additionally, further funding was received through Imperial College Societal Engagement Team's 2022 Participatory Research Seed Fund to support co-producing the dissemination of the research findings and reflections from working together.

I have prepared this Chapter using the SRQR checklist (329) as well as the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist (384) **(Appendix D)**. Some results were previously presented in an ePoster at the AIDS 2022 conference (331).

HW, BD, JB, JA and WT provided comments on this Chapter.

[1] JB is a Trustee for Positively UK.
[2] SP is the CEO of Positively UK.

4.1 Abstract

During the COVID-19 pandemic, people living with HIV have experienced adaptations and disruptions to their HIV services. I aimed to explore the experiences of COVID-19 among people living with HIV including changes to their social environment and HIV care. I used a peer research approach of training people living with HIV (or co-researchers) in qualitative research methods. This project ran from January to September 2021 and was supported by additional funding from Imperial College London's Rapid Response Seed Fund. Co-researchers were involved at various stages of the research cycle, including amending an ethics application and advising on the wording and/or addition or removal of interview questions. Co-researchers conducted and analysed interviews with a sub-sample of participants from the 2017 Positive Voices Study. As a team, we interviewed 19 people living with HIV (5 peer interviews) and used elements of both thematic analysis and the DEPICT model to analyse interview transcripts. The involvement of co-researchers ensured that our interview questions were relevant to people living with HIV accessing services and that the study remained meaningful for people with lived experience. Our study found that COVID-19 has highlighted social and health inequalities among people accessing HIV services. Although adaptations made to services were perceived to be acceptable to most interviewed, participants favoured prior models of engagement. Since completing the project, our co-researchers have helped to ensure that we disseminate findings in an accessible way for people living with HIV.

4.2 Introduction

4.2.1 HIV and COVID-19

There is growing concern that the COVID-19 pandemic has caused disruptions throughout the HIV care continuum (385). Globally, large-scale HIV prevention trials are being paused, reduced, or postponed; mathematical models have predicted that interruptions to HIV services (and ART treatment) in low- and middle-income countries (e.g. South Africa) may result in excess deaths from HIV/AIDS (386, 387). HIV services adapted to lockdown measures by transitioning to telemedicine and home deliveries of medication (388, 389).

Comparisons have been made between COVID-19 and previous outbreaks, including the HIV epidemic (251, 263, 390, 391). For example, an effective, community-led and evidence-centered response should continue to be applied to COVID-19 such as that displayed by previous pandemics (e.g. Ebola) and the human rights response to the HIV epidemic (340, 391–393). Also, learning from HIV to prevent and address social stigma including the use of inclusive language and less stigmatising terminology can be applied to the COVID-19 response (340, 394, 395).

Prior to the pandemic, some HIV services in the UK had already begun a transition towards a model of self-care or 'collaborative care' (e.g. online consultations, HIV community nursing), particularly with more 'stable' patients; however, for other patients this sudden shift would have been a new and unfamiliar experience (396). Additionally, at the beginning of the pandemic, people living with HIV in the UK were initially added to the NHS Digital shielding patient list, although most have an undetectable viral load and therefore do not have depleted immunity so would not be considered "clinically extremely vulnerable" (342, 371). The COVID-19 pandemic has also raised concerns regarding the wider determinants of health affecting people living with HIV in the UK, including employment rights (397).

4.2.2 Participatory research

Arnstein's "ladder of participation" was developed as a typology to characterise citizen's power when involved in planning projects and programmes and advances from "non-participation" to "degrees of

citizen power" at the top of the ladder (398). The ladder can also be adapted to health research; at the highest rung of the ladder lies co-produced research that aims to include people with lived experience from the beginning to the end of the research cycle. However, critics of Arnstein's ladder argue that the typology does not accurately represent the complexity of those involved (e.g. underlying motivations, interests and motives) nor the broad spectrum of types (and breadths) of participation that exist and the dynamism of involvement (399).

Despite various terms for participatory approaches being used interchangeably, distinct differences exist. First, participatory approaches encapsulate "a core philosophy of inclusivity and recognising the value of engaging in the research process (rather than including only as subjects of the research) those who are intended to be the beneficiaries, users and stakeholders of the research" (400). Participatory research combines action and participation; in other words, it uses a "research-to-action" approach with participants actively involved in the research cycle (401, 402). This has been described as a possible benefit of applying participatory approaches to various aspects of epidemiological research (403). Therefore, the term participatory action research describes research that "seeks to understand and improve the world by changing it" by using research to enable action through a reflective cycle and data collection whereby people "take actions to improve their own health" (402). Similarly, community-based participatory research has been defined as having "...the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities" (404, 405).

In the UK, patient and public involvement is the umbrella term used for all types of public engagement and involvement; the National Institute for Health and Care Research (NIHR define public involvement as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (406). Several approaches to public involvement in research exist each with various forms of power and influence given to members of the public (406). Additionally, creative techniques are being increasingly used to disseminate research findings and communicate results beyond traditional academic mechanisms, which may also be co-produced with public partners; for example, illustrations, podcasts, infographics, and blogs (407).

According to the NIHR, co-production is "...an approach in which researchers, practitioners and the public work together, sharing power and responsibility throughout the life of a project; from start

to finish" (408). Co-produced research is based on the development of meaningful partnerships while addressing traditional power differentials in research (408). In other words, co-produced research aims to transfer or share the power from researchers to participants including knowledge generation and sharing responsibility (398, 406, 409). Co-produced research is based on a number of key principles including reciprocity, respect and inclusion (406, 408). Therefore, arguments supporting co-production centre around being substantive, instrumental, normative, and political; for example, improving the quality and impact of research, being the fair and ethical thing to do for publicly funded research, and enabling empowerment and inclusion (410–412).

Peer research

Peer research is a type of co-produced research, where people with lived experience lead and conduct the project to generate knowledge from the social or geographical context to which they belong; it has commonly been used in research involving young people, mental health and marginalised populations (409, 413–417). Kilpatrick et al. (409) describe the inherently "flat structure" aimed for in peer research,

> *"By involving peer researchers, they can have a stake in the creation of knowledge and the process of developing that knowledge is empowering, consciousness-raising and skills enhancing"*

Therefore, peer research is beneficial as it can help to activate communities, enhance the quality of data collected and empower peer researchers (409, 413). Peer researchers may build better rapport with participants and help them to feel relaxed and comfortable during the process (418–420). However, peer research can also be emotionally laborious and resource intensive for both the researcher and stakeholders (i.e. co-researchers), as well as restricted by ethical and institutional requirements; for example, peer researchers may be inexperienced in interviewing techniques (410, 418, 419, 421–423).

Participatory approaches are not new to HIV research; in fact, the Greater Involvement of People Living with HIV (GIPA) was first formalised in 1994 and is a principle that people living with HIV should be shared decision-makers in actions that affect their lives including in policymaking, programme development and implementation, and advocacy (424). Furthermore, the Meaningful Involvement of People Living with HIV (MIPA) embodies the principle of *"Nothing About Us Without*

Us" and has been endorsed since the beginning of the epidemic to help recognise the contribution of people living with HIV as equal partners in the community response, as well as promoting their active participation (425).

4.2.3 Theoretical framework: the HIV and COVID-19 'syndemic'

The term 'syndemic' was first coined by Merrill Singer to encapsulate how multiple health conditions interact and cluster with each other in conjunction with the social environment within which they operate; this results in worse health outcomes, increased transmission, morbidity and mortality (1, 244, 426, 427). Singer applied this theory to the SAVA syndemic seen among materially deprived people living with HIV in an urban US city in the late 20th Century (243, 428). Syndemic theory has also been applied to the current COVID-19 pandemic – one which has highlighted and exacerbated existing inequalities across social, economic, health and political levels (1, 429). I use a syndemic lens to explore the experiences of people living with HIV during the COVID-19 pandemic, in an approach similar to that of Shiau et al. (253) who conceptualise the syndemic in relation to psychosocial and structural burdens.

4.2.4 Research questions

What are the experiences of COVID-19 among people living with HIV in the UK? How do these experiences vary among different social groups?

4.2.5 Aim and objectives

Aim

To explore how the current COVID-19 outbreak influences the health and well-being of adults ($\geq$18 years old) living with HIV in the UK, including perceived impacts on the HIV care continuum and whether these experiences can be compared to the 'early days' of the HIV epidemic.

Objectives

1. To develop a more in-depth approach to understanding the impact of the pandemic on wider societal factors on a specific sub-group of people living with a lifelong condition and therefore, the scope to be adapted for other groups.

2. To recruit, appoint, and train two peer researchers (public contributors living with HIV) to undertake and analyse interviews with people living with HIV.

3. To recruit, appoint and train two advisory group members (public contributors living with HIV) to advise on the overall strategy and progress of the project.

4. To record the diverse experiences of people living with HIV in the UK during the COVID-19 pandemic therefore providing a richer, contextual understanding of these experiences.

5. To uncover the unequal impacts of the pandemic for different social groups, including marginalised populations.

6. To build new, and strengthen existing, relationships with people living with HIV (and other key stakeholders) to facilitate future co-production through prioritising study findings and disseminating results, thereby informing objective 7.

7. To help inform wider policy and guidance to support those living with HIV during a pandemic who may face challenges accessing routine care services, as well as HIV and other sexual health services.

4.3 Methods

My approach was based on the reflections and recommendations of Dewa et al. (417), and my study is based on initial interviews with HIV health, charity, and community workers **(see Chapter 3)**.

4.3.1 Participatory approach: working with co-researchers

A co-produced was considered to be the most suitable to explore this question in order to provide nuanced insights into the intricacies of living with HIV, specifically since nobody in our academic research team had lived experience although one member (JB) was a nurse in the early days of the epidemic (415, 430). Also, by collaborating with the peer-led support charity Positively UK (431), I hoped to activate the HIV community and upskill members of the organisation to enable future qualitative research projects to be led by community members (430).

Positively UK (SP), KM and JB supported the recruitment process of co-researchers which included a brief application form and short interviews. We appointed two men and two women as co-researchers; most had been involved in either co-produced research or interacted with Positively UK before however, one person had never engaged with research or community groups before. We trained two peer researchers (HH, KD) to conduct and analyse interviews. I also recruited and trained an additional three advisory group members (JA, SP, WT) to guide the team on the overall strategy and progress of the project, as well as provide feedback at various stages of the research cycle. Therefore, both groups are referred to as 'co-researchers'. Co-researchers were offered honorariums based on NIHR Centre for Engagement and Dissemination guidance (432).

Training and support

At the start of the project, I asked all co-researchers to complete a 'skills review' to understand their current research and public involvement skills and to identify training needs (433). I collated the feedback from all co-researchers and worked with HJ to identify which skills would be essential to cover in training sessions. Originally, we had planned a two-day training event, however, as this was going to be completely online, we decided to split this into four shorter training sessions by Zoom. I designed a series of training sessions using recommendations and advice after speaking with

existing peer researchers and consulting the available literature (417, 434, 435). I received input on the training materials from JB, HJ and KM. Training and meetings with co-researchers focussed on:

1. GDPR and research data management (e.g. handling sensitive data)
2. Ethical principles of research – including the importance of confidentiality and respecting individual's boundaries
3. Discussing emotional topics and peer interviewer well-being
4. How to use Zoom (specific nuances of the research) and conducting interviews online
5. How to analyse interview transcripts
6. How to interpret research findings and present these in academic writing (specifically writing conference abstracts)
7. Reflecting on their skills development during the project

I have since deposited this training and supporting material[3] as a resource for other academic researchers and public involvement practitioners interested in training co-researchers in qualitative methods (433, 436).

At the beginning of the project, I asked the co-researchers to complete a reflection point document[4] to identify what they enjoyed at the first meeting, what could be improved, and what they were looking forward to.

Assessing the impact of involvement

I qualitatively assessed the impact of co-researchers' involvement in the project through Google Jamboard exercises, email exchanges, group meetings, one-to-one meetings and feedback from people interviewed in the study. I conducted a quantitative assessment of the evidence of impact by reviewing the interview transcripts for content, format and time lengths. Specifically, I evaluated the

[3] This includes a specific Zoom interview 'how to guide' for peer researchers to use before their interviews as well as a list of resources and support for peer researchers and participants of the project (433).

[4] This document was based on one created by a fellow PhD researcher, Carmel McGrath, as part of her doctoral research (not yet published).

impact using similar methods to Jørgensenet al. (418). For example, I quantified different types of questions in the interview transcripts and compared these between academic researchers and peer researchers by thematic coding using nine distinct categories.[5] I assessed the significance of the difference between these group averages by calculating the variance and then using the Student's two-sample t-test assuming equal variances.

4.3.2 Participant sampling, recruitment and consent

I sampled participants from the 2017 Positive Voices study, which was the first nationally representative survey on the health and well-being of people living with HIV in England and Wales (208). The Positive Voices study team emailed participants who agreed to be re-contacted about further research, could give informed consent online and had access to either a telephone or computer. Participants' contact details (emails and phone numbers) are securely stored and held by the Positive Voices study team (part of the UKHSA and formerly PHE). To comply with institutional ethics, peer researchers did not receive the contact details of study participants and instead recruitment was coordinated by me – interested participants directly contacted me for further information.

Recruitment strategy

As almost 1,000 Positive Voices participants agreed to being recontacted about future research, we proposed a recruitment strategy to maximise the diversity of the sample selected which is outlined in **Figure 4.1**.

[5] The nine categories used are "(1) questions; (2) confirming comments (e.g. yes, mm.); (3) short non-confirming comments (e.g. "Really?" "Are you sure?"); (4) personal narrative, attitudes, thoughts, or experiences; (5) advice; (6) answering questions; (7) wondering/querying comments (e.g. "well," "hmm"); (8) small talk or meta talk (e.g. "ok, let's move on"); and (9) reflection on what had been said, continuation of sentences or repetition of what the interviewee had said" (418).

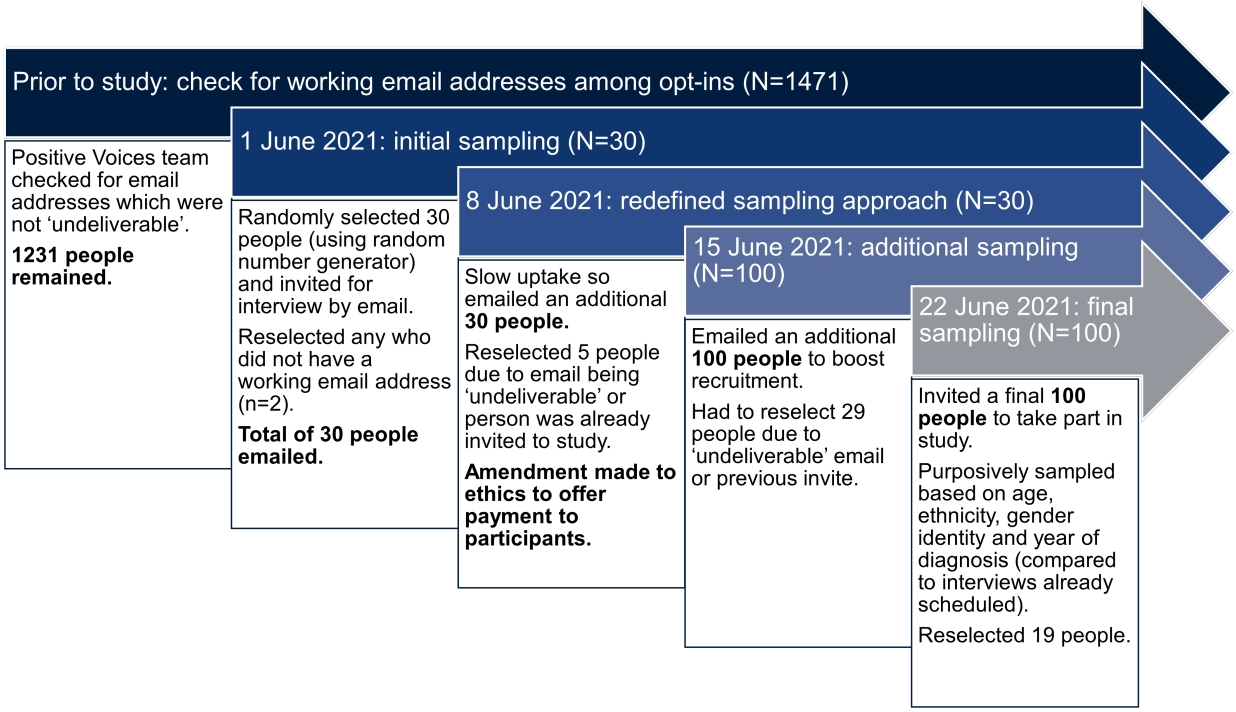


Figure 4.1: Recruitment strategy and approach

First, I selected a sample of 30 people using a random number generator and invited them by email to be interviewed. I anticipated receiving 'bounce back' emails from some addresses as these were almost four years old, therefore the Positive Voices study team provided me with a spreadsheet whereby the latest contact details had been retrieved. I then reviewed the characteristics of those who responded and consented to the study based on their Positive Voices study data, as I had a non-identifiable code to cross-check against, specifically:

- Gender identity
- Age
- Ethnicity
- Year of HIV diagnosis

In total, my objective was to interview about 20-30 participants. After initial slow recruitment, we submitted an amendment to our ethics application so that participants were offered a £25/hour honorarium to recognise their contribution to the research. This amount is recognised by the NIHR Centre for Engagement and Dissemination (432), and payments were arranged using non-payroll fee forms.

4.3.3 Data collection

Participants were invited to participate in a semi-structured online interview recorded by Zoom with an academic researcher (VP, JB) or a trained peer researcher (HH, KD). As a team, we selected Zoom to conduct interviews after receiving feedback from our co-researchers that most peer support for people living with HIV were being hosted using the platform at the time and because members of the public generally find it much easier to access than Microsoft Teams. Both peer researchers conducted a pilot interview to receive feedback and also shadowed two interviews with more experienced qualitative researchers (VP, JB) before they completed their first interview alone. I assigned peer researchers to interviewees based on their background (e.g. gender and/or ethnicity).

All interviews were scheduled using the PERC Imperial College London's Zoom Pro account (including those conducted by peer researchers). This allowed me to ensure that the correct security settings were enabled to maximise security, for example:

1. Participants needed a password to join
2. Screensharing was set to "Host only"
3. "Join before Host" was disabled so people could only gain access once they had been identified
4. "File Transfer" was disabled to reduce the possibility of digital virus sharing
5. "Allow removed participants to rejoin" was disabled so any ejected participants could not rejoin the meeting
6. Once the participant joined, the meeting room was "locked" so nobody else was able to join

Interviews were recorded using the Zoom Pro settings (cloud recording function) with access to the account only given to specific members of PERC (VP, JB). Zoom Pro recordings were downloaded by me as soon as they were available and deleted from the cloud after being quality checked. The recordings were saved and stored in the CPE drive in the Department of Infectious Disease Epidemiology (DIDE) network. The audio recordings of the Zoom meetings were transcribed verbatim by a qualified professional (UKTranscription.com) with whom a confidentiality agreement exists with Imperial College. The transcripts present the literal wording used by the participants and

therefore demonstrate linguistic variety, including dialect (437). Video recordings were not used as part of the study.

The interview topic guide **(Appendix D)** was originally created following a community involvement event in June 2020 (348) which we then adapted as a group. Participants were encouraged to expand on any issues they raised with more general questions also available to enable participants to answer using a flexible ordering of questions. Prompts were used to encourage a more in-depth exploration of the topic areas.

4.3.4 Data management and analysis

Data were managed using NVivo software (364) with participants assigned a non-identifiable code during analysis and a pseudonym during the write-up. Data are stored in an encrypted, password-protected electronic environment on the Departmental servers at Imperial College London. Specifically selected anonymised and password-protected transcripts were shared with co-researchers using Microsoft One Drive.[6]

The interview topic guide provided an initial framework for analysis with the data analysed thematically. Each co-researcher (KD, HH, WT, JA) was given at least one transcript to analyse and an academic researcher (VP, JB) who acted as a "buddy" and met with the co-researcher to discuss their experiences coding and generating themes. These codes and themes were added to a Google Jamboard to help identify commonalities and differences across the interviews. We based our collaborative approach to analysis on the DEPICT model (438).[7] However, given the timing of analysis coinciding with summer holidays, only one peer researcher was actively involved in analysing the transcripts from interviews he conducted. I analysed all the transcripts, which were then also coded by either KD (for the three interviews he conducted) or JB (all other transcripts). I met and discussed the coding process with KD and JB also met with two other co-researchers (HH, WT) to discuss how they had found reading the transcripts as well as the peer researcher's (HH) experience of interviewing two participants. I then inputted all the codes developed by KD and JB into NVivo

[6] The transcripts shared were from interviews completed by peer researchers.

[7] DEPICT stands for the various steps to the "collaborative qualitative data analysis approach" – "**D**ynamic reading, **E**ngaged codebook development, **P**articipatory coding, **I**nclusive reviewing and summarising of categories, **C**ollaborative analysing and **T**ranslating" (438).

and combined these with mine. I condensed the codes (i.e. collapsed categories that were repetitive) into a consistent framework and then discussed the key findings with the whole group at a research team meeting where we finalised our major themes, subthemes, and overarching concepts, in line with the DEPICT model (438).

All participants received a summary infographic **(Appendix D)** of the key preliminary findings of the study after data analysis that was co-designed with co-researchers.

Participants were allocated randomly generated pseudonyms based on the same approach outlined in **subsection 3.3.4**.

4.3.5 Ethical approval

Ethical approval was granted by Imperial College London (ICREC Ref: 20IC5893) as a sub-study of a larger qualitative research project. Participants were sent a participant information sheet and asked to complete an online consent form on Qualtrics (359) before taking part in the study which specified whether they would be happy to be interviewed by a peer researcher.

All co-researchers reviewed the study documents, the topic guide being the document that was most amended; specific changes are outlined in **Table 4.1**.

Table 4.1: Feedback received on ethics documents from co-researchers and actions taken

Document	Feedback received	Action taken
Topic guide	1) Add prompt to reassure about confidentiality (e.g. receiving benefits and working)	Updated
	2) Change wording from "are you working?" to "tell us about your working situation..."	
	3) Add question on any changes to quality of care during COVID-19 compared to 2-years ago	
	4) Add question on whether anything missing/missed from care	
	5) Add prompt on receiving paperless HIV care	
	6) Add prompt on expected 'worst-case scenario' from outcome of acquiring COVID-19	
	7) Add prompt on co-morbidities and accessing care during the pandemic	
	8) Change wording from "any concerns" to "how did you feel about attending appointments during the pandemic?"	
	9) Add question on perceptions of vaccine and willingness of COVID-19 vaccination uptake	
	10) Add prompt on how they have acquired information during the pandemic (e.g. fake news)	Did not action as already covered by a prompt around 'trust' of information sources in Q13
PIS	1) Merging 'what if something goes wrong' and 'complaints' section	Did not action as needed to meet College requirements for the PIS
	2) Clarification whether everyone would understand words 'demographic' and 'aggregate'	Added simple definition for each in the PIS
Survey	1) Add 'not applicable' option for Q12 ("is everyone in your household related to you in some way?")	Updated
	2) Add free-text option for people to add their role if working in HIV services	Did not action as already covered by prompt in Q6 of "what is your job title?"
Resource list	1) Add organisations that are specific for trans people living with HIV	Added details for cliniQ to the list

Abbreviations: PIS, Participant Information Sheet.

Informed consent

I sent all potential participants a participant information sheet and asked them to sign an electronic consent form **(Appendix D)** hosted on Qualtrics (359). Here, participants were able to state their preferred level of participation (e.g. interview, online survey via Qualtrics) and whether they would be happy to be interviewed by a peer researcher. All participants were asked to sign this consent form before the online interview was arranged with an assigned member of the research team. Electronic consent forms were stored on Qualtrics and then downloaded to the DIDE server and stored in a folder accessible only to members of the research team (VP, JB, and HW).

Specific ethical considerations for participatory research

I also recognised that specific ethical considerations should be examined due to the participatory approach of the research project. First, Positively UK arranged for Disclosure and Barring Service (DBS) checks of peer researchers, and I also designed and provided four training sessions for co-researchers; one session covered ethics and safeguarding specifically **(see subsubsection 4.3.1)**. Additionally, I recognised that COVID-19 was a challenging time for everyone involved (co-researchers, researchers, and participants), so I encouraged discussions of challenging experiences or difficult conversations in research team meetings (held monthly) to encourage feedback in a supportive group environment. Peer researchers were required to contact me in the case of a serious event that would be reported following standard procedures, with the Principal Investigator (HW) being contacted first.

Data storage and retention

Peer researchers, Advisory Group members and the CEO of Positively UK all read and signed a non-disclosure agreement which outlines the importance of handling any sensitive data. Any research study data that needed to be shared with co-researchers (e.g. anonymised transcripts for analysis but not contact details of participants) were password-protected before electronic transfer through an Imperial College Microsoft OneDrive for Business folder accessible to the research study team only. General study documents (e.g. interview topic guide) were stored and shared using Microsoft OneDrive for Business. OneDrive for Business is authenticated to comply with Imperial College policy

and European Union data protection regulations. Any data collected are held securely on DIDE's server at Imperial College London, with access granted only to named members of PERC (VP, JB, HW).

Dissemination and research impact

Since October 2021, we have been planning and disseminating our research findings in multiple formats to reach public and academic audiences. This approach has been driven by a dissemination plan which we developed as a group **(Figure 4.2).**



Figure 4.2: Google Jamboard from co-researcher meeting in September 2021 to determine how, where and who to share findings with.

We applied for, and received, additional funding to help disseminate our findings in accessible formats from Imperial's Societal Engagement Participatory Research Seed Fund in March 2022.

4.4 Results

In total, 260 participants from the 2017 Positive Voices study were invited to participate, 20 consented to participate and 19 interviews were completed; the response rate was just under 10%. One person decided to not take part after consenting to the study. Interviews lasted between 50 and 90 minutes and interviews were conducted between June and August 2021. Five interviews were completed by peer researchers (HH, KD) and 14 by academic researchers (VP, JB).

4.4.1 Participant characteristics

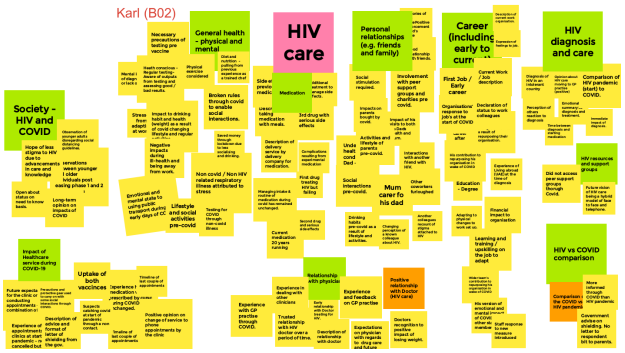
The majority of those interviewed were born in the UK (n=14, 73.7%) and lived in London or the South East of England (n=14, 73.7%). Some (n=8, 42.1%) received letters to shield **(see Table 4.2)**.

Table 4.2: Interviewee characteristics

Pseudonym	Age (years)	Gender	Ethnicity	Years living with HIV	Interviewer (and gender)
Adam	45-54	Cisgender man	White	5-10	Academic (F)
Lee	55-64	Cisgender man	White	30+	Academic (F)
Stephen	55-64	Cisgender man	White	11-20	Academic (F)
Michael	65+	Cisgender man	Any other White background	30+	Academic (F)
Mark	35-44	Cisgender man	Any other White background	11-20	Academic (F)
Emma	45-54	Cisgender woman	White	5-10	Academic (F)
Nick	35-44	Cisgender man	White	11-20	Academic (F)
Anthony	Unassigned	Cisgender man	White and Asian	5-10	Academic (F)
Kenneth	Unassigned	Cisgender man	African background	21-30	Peer (M)
Andrew	55-64	Cisgender man	White	21-30	Academic (F)
Thomas	35-44	Cisgender man	White	11-20	Academic (F)
Robert	65+	Cisgender man	White	30+	Academic (F)
Paul	Unassigned	Cisgender man	White	21-30	Peer (M)
Julie	Unassigned	Cisgender woman	White and Black African	11-20	Peer (F)
Susan	55-64	Cisgender woman	White	5-10	Academic (F)
Claire	45-54	Cisgender woman	White and Black Caribbean	11-20	Peer (F)
Peter	65+	Cisgender man	White	11-20	Academic (F)
Ronald	65+	Cisgender man	Indian	30+	Peer (M)
Alan	65+	Cisgender man	Any other White background	21-30	Academic (F)

Abbreviations: F, female; M, male. Note: White ethnicity is defined using ONS ethnic group categories (439) and includes English/Welsh/Scottish/Northern Irish/British.

As a group of academics and co-researchers, we categorised the codes/themes identified from interviews coded by me, JB and KD and used Google Jamboard to organise them into main themes, subthemes and overarching concepts (**Figure 4.3**)



(a) Example of codes from transcript by KD



(b) Example of codes from transcript by me



(c) Example of themes and sub-themes generated by the research team.

Figure 4.3: Coding framework generated on Google Jamboard by KD, VP and all co-researchers during a research team meeting hosted on Zoom.[8]

[8] Key for colours of notes: green, major themes; yellow, sub-themes; orange, context; pink, overarching concepts; blue, missing concepts.

4.4.2 Syndemic theory

I then mapped our findings to the HIV and COVID-19 syndemics and intersections between these two health conditions, as well as the 'states of living' (in relation to the COVID-19 measures) – see **Figure 4.4.**

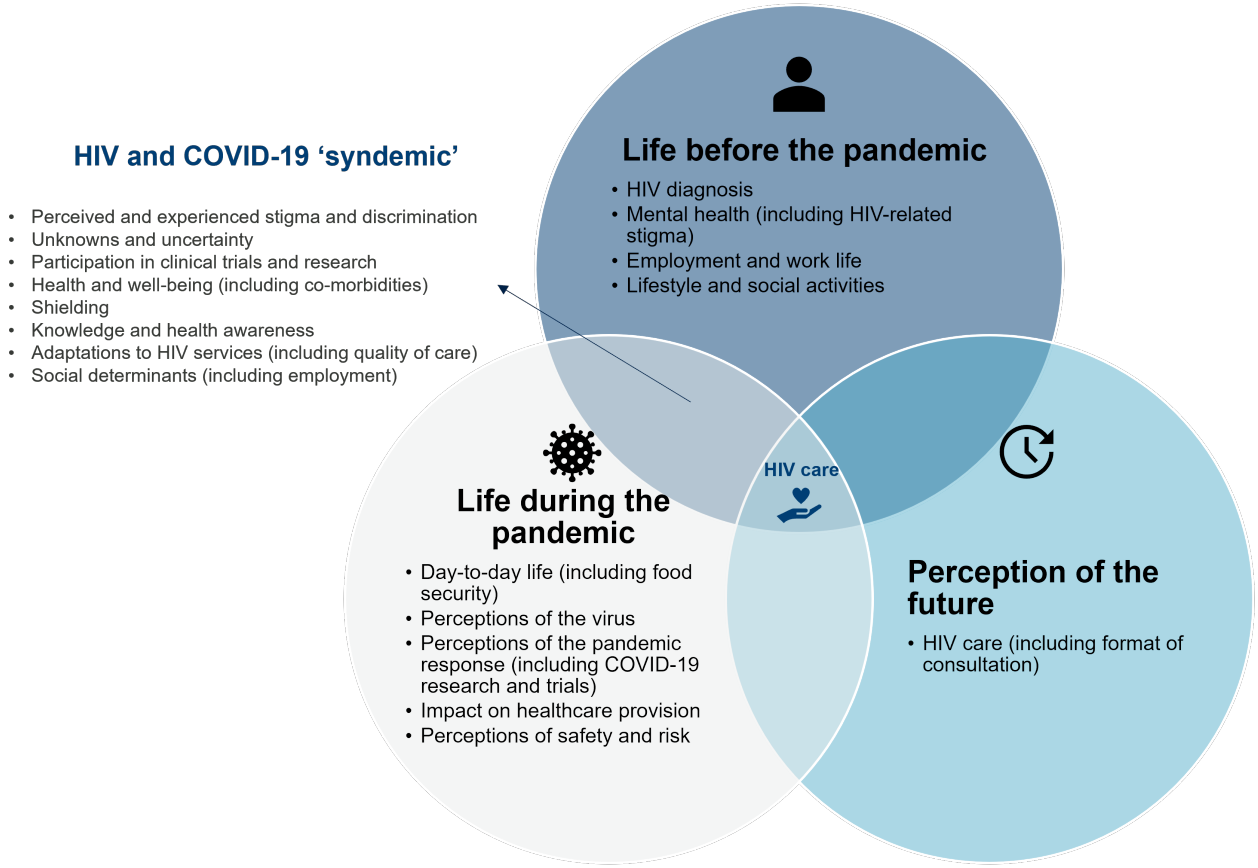


Figure 4.4: Venn diagram highlighting how each theme maps to one another, according to syndemic theory

The themes were grouped using a temporal dimension of life before and during the pandemic as well as perceptions of the future. Life before the pandemic tended to focus on experiences of being diagnosed, mental health (including HIV-related stigma) and experiences of accessing HIV care including relationships with GPs, the HIV clinical care team and charities/support groups. We also asked questions on employment history, lifestyle and social activities to later compare these to experiences during COVID-19. We asked broader questions about changes to daily life during the pandemic which covered wider determinants of health such as food security, home life and work. Other themes identified focussed on perceptions of the virus, the pandemic response, safety and risk

and the impact to healthcare. I then explored how HIV and COVID-19 interact with one another through syndemic theory including perceived experiences of stigma and discrimination; unknowns and uncertainty and knowledge and health awareness. Finally, how participants perceived the future – broadly to their life as well as to HIV care specifically.

> *"I mean, there's no doubting there's still elements of stigma. There's still elements around me not being able to disclose, because of how that would be perceived."*
>
> Adam

4.4.3 Life before the pandemic

We began interviews by focussing on life before the pandemic; this identified themes such as experiences of receiving a HIV diagnosis, mental health and accessing HIV care.

HIV diagnosis

At the beginning of the interviews, we asked all participants to *"tell me a little bit about yourself and your background; whatever you think is important to share about your life up until now."* All shared their experiences of being diagnosed with HIV. Most (n=15, 78.8%) were diagnosed at least 11 years ago, of which just over a quarter (n=4, 26.7%) were diagnosed over 30 years ago in what is commonly referred to as the 'early days'.

Almost all were shocked by their diagnosis and some had previously experienced HIV-related complications, which has affected their ability to work. Additionally, those diagnosed in the 'early days' spoke of no or limited availability of effective treatment at the time, which lead to them being enrolled in early clinical trials. For most, receiving a diagnosis of HIV had a negative impact on their mental health; an HIV diagnosis was a traumatic and life-changing event, particularly those diagnosed in the 1980s and 90s. However, one participant viewed their diagnosis as an opportunity to have a second chance at life,

> *"...I think that unfortunate as it is to get the diagnosis, it then changed me to kind of think, "Well, I'm going to live for now or not for tomorrow and I'm going to focus on what now is about"."* [Adam]

Mental health

Several people spoke openly about existing mental health diagnoses, including bipolar disorder, anxiety, and depression. Some participants also shared their history of substance misuse and addiction related to either their HIV diagnosis and/or wider life events (e.g. bereavements) and the role of peer and social support in their recovery,

> *"...I have definitely benefited from integrated care systems, peer support and mutual aid, compassionate organisations giving me chances and kind of like that whole third sector, multidisciplinary kind of support network"* [Nick]

Some also described accessing psychological therapy privately, through the NHS or their HIV clinic; however, it was recognised that the former option may not be available to those most socioeconomically disadvantaged, who would also be limited by freely available NHS therapy.

HIV-related stigma

Mental health was also discussed directly or indirectly in relation to perceived and experienced HIV-related stigma. Some had not yet shared their status with friends and family and spoke of fears of rejection or judgement when establishing new romantic partners, seeking medical care or requesting adjustments from their employer,

> *"I mean, there's no doubting there's still elements of stigma. There's still elements around me not being able to disclose, because of how that would be perceived. I mean, if I wasn't in a relationship, there's elements around negotiating intimate contact with people, those things. Yes, I can't hide from them. They're still there. They're not only in the background for me. They exist. They float around. But I get on with other things."* [Adam]

Some participants also raised the intertwining issue of stigma and culture,

> *"Because where you are coming from is family, friends and things like that. You know, with us Africans, we have a way of looking at issues differently. And it is a challenge in itself, because you can't open up to them, unless somebody is willing to listen."* [Julie]

> *"There are so many different stigmas depending on what culture you're from and I know for certain cultures women will be too afraid to say anything because they're worried about breastfeeding and then straight men have a problem because it's associated with gay men."* [Susan]

Experiences of HIV care

Before the pandemic, most participants visited the HIV clinic in person every 4 to 6 months for clinical monitoring and to collect repeat prescriptions. Several participants described their undetectable HIV status and the reassurance given by clinical monitoring appointments,

> *"I have always been stable.*[9] *Actually, I have been stable from the day we started my- In those days there was no viral load measurement. It was just a T-cell count measurement. So those were steady. And when I started doing the viral load things I had what you call a zero- I am not sure what is the correct term. Undetectable viral load."* [Ronald]

Almost all participants spoke positively about their HIV care, although some described incidents of miscommunication with their clinical care team, delayed appointments, or seeing different healthcare professionals, which is not favourable. The holistic model of HIV care was also explicitly or implicitly described by participants and was largely accepted, although some of these services have now moved to primary care,

> *"And I do miss that. And the clinic used to look after my high cholesterol, which is probably a result – or partly – of the pills, the HIV medication. They used to take care of all of that. And now that's been hived back out to the GP service, which is okay. You know, I understand the reasons why"* [Paul]

Relationship with GP

The nature of relationships with GPs were context-specific; some had good relationships with GPs knowledgeable on HIV. However, others described negative experiences; some had never met or felt that they did not have a relationship with their GP or felt that their GPs did not have sufficient specialist knowledge to deal with their HIV (e.g. they had previously been prescribed medications that interacted with their ART).

Relationship with HIV clinical care team

Most of the participants still see the same clinician who provided their initial diagnosis, which in some cases means that they had worked together for a decade or more. They described meaningful, trusted and honest relationships which were highly valued as they felt holistic and person-centred care was provided,

[9] 'Stable' refers to a viral load count indicating virological suppression (an undetectable status).

> *"...my consultant, has always taken the care to talk me through all the different drug options and what the ramifications of them were, and got me very, very involved in making the decisions. (...) So I suppose I have built a level of trust over 30 years that he knows what he's talking about."* [Lee]

Similarly, good relationships with HIV nurses and the wider clinical care team, including pharmacists, were described,

> *"I have a really good two-way relationship with my specialist nurses, and the department as a whole. So I knew that when they said, "This is what we're trying to do," I knew and was empowered and confident enough to say, "Actually, no, my needs are a little bit different. These are my needs. Have we got a problem with that?" And they were like, "Oh, yes, no, that's absolutely fine."..."* [Nick]

> *"Because the hospital pharmacists are fantastic. I mean, their knowledge. They have been so supportive to me and they have helped me learn so much. And I get on so well with them. I'll tell you an expression they have said, they have said they regard me as an expert patient. That feels great. I hate being called a patient, because to me, a patient is somebody who is incapable of dealing with stuff. (...) But when somebody says, "He's an expert patient," yes, that's okay, I quite like that."* [Alan]

Charities and support groups

Participants also described the role of charities and support groups with initially coming to terms with their HIV diagnosis as well as providing emotional and practical support; for instance, peer mentoring/buddying, welfare support or religious and faith-based organisations. Participants often associated with charities that they felt represented their backgrounds, culture, or world view and accessed them remotely or in person. For example, Julie described the significant role that accessing peer mentoring through a church has played in the role of accepting her diagnosis. Interestingly, this church differs from her upbringing, due to stigma and 'othering' within some sects of Christianity,

> *"I could not even tell them this is the issue that I am going through because it's like they will never understand, they preach against it. But amongst themselves, they don't go for testing. Which is really hypocritical. Because I grew up there, I can't leave, I am sort of stuck there. To them, I am somebody else, and I have to maintain that face to them, so that's a challenge on its own. And at times it takes its toll on you as well, because you have got to maintain all these different faces to different people..."* [Julie]

Some participants were themselves trained as peer mentors while others did not associate with support groups either because they did not feel the need to or had support from elsewhere (e.g. partners, family, friends),

> *"I probably don't feel part of many societies or many, kind of... I mean this new word, 'tribes of society', I probably don't feel part of any tribes. I'm probably too strongly independent and like to get on with things on my own, really. Some of that is to kind of keep me psychologically strong, because what I find that people often come to me with a need and there's only so much need I can kind of support. And to counteract that, I tend to distance myself from people to kind of immune myself off, really, because otherwise I end up concentrating too much on their emotional needs and wants."* [Adam]

Employment and work life

Participants spoke about their employment history, specifically how this had changed when they received their HIV diagnosis; participants highlighted positive and negative experiences in relation to living with HIV and their career. For instance, some described adapting their career following their HIV diagnosis by either working or volunteering for HIV charities. However, others experienced issues relating to employment once they shared their status with their employer and colleagues. For example, some spoke of the impact of their HIV status on their ability to work and ultimately their financial situation; Kenneth was unable to work and received a long-term disability allowance. Similarly, Paul spoke of receiving Disability Living Allowance when he received his diagnosis in the early days when effective treatment had only recently been introduced[10], although they are now employed. Additionally, Robert described how those diagnosed in the late 1980s were advised to stop working immediately and received welfare benefits due to the prognosis of an HIV diagnosis,

> *"...the official advice at that time was to give up work straight away, you were given the DS1500 which is the social security form that basically says you've only got six months to live."* [Robert]

Similarly, for Nick, living with HIV impacts his work as a healthcare professional as he is required to follow specific guidelines including clinical monitoring every 12 weeks. However, Nick also reflected on previous issues due to his HIV status and employment role, specifically in relation to the 'Green Book'[11] which he perceived as a discriminatory policy,

> *"I was a victim of that archaic process. [...] I was taken away from frontline service and shoved in an office to do audit for 18 months and kind of went fairly crackers. And then*

[10] Despite treatment being available on the NHS since 1987 (*Zidovudine*), more effective treatment (e.g. HAART) was not introduced until 1996 (440).

[11] The 'Immunisation against infectious disease' (Green Book) outlines UK procedures for all vaccine preventable infectious diseases including those required for individuals with underlying medical conditions (441).

> *just the stress of the situation and kind of like the ridiculousness of the, sort of, '80s legislation, kind of saying, "You can't come anywhere near a patient because of your risk of infection," and all those kind of things..."* [Nick]

Lifestyle and social activities

Participants also reflected on life before the pandemic, specifically socialising with friends and family, travelling, and the wider support networks they accessed, specifically for HIV or for other purposes (e.g. addiction support).

> *"COVID's just sort of come down like a ton of bricks on everybody's lives."*
>
> Michael

4.4.4 Life during the pandemic

Day-to-day life during pandemic

Participants were asked about how their daily life may have changed during the pandemic; specifically, most spoke of changes in their daily habits such as socialising or shopping online rather than in person, and restricting travel due to government guidelines,

> *"I guess the biggest impact really is the lack of socialisation, the inability to be able to see friends. Which didn't hit me too hard, to be honest, because I was so focused on work, that really did take over. You'd get to a point where the only person that I'd seen in a month was my other half. That was quite difficult"* [Thomas]

Technology played a key role in keeping people connected to others. Despite changes in government guidelines that meant socialising was less restrictive, some still described feeling nervous about negotiating physical contact,

> *"So, it just makes me wonder, when will it return to the point where I feel secure enough to meet people without having consider all this rigmarole of- You know, when will you be able to hug your friends and things. I've missed all that sort of tactile aspects of socialising and all that sort of thing."* [Michael]

Others spoke of hobbies they had developed during the pandemic or changes in their exercise regime. Several spoke of exercise as a coping mechanism for their mental health,

> *"I think this thing started when I developed some mental health problems, I started walking. And during the lockdown, it actually did help me as well, I walked every day, at least 5km. I just feel, if I haven't gone out, I have missed something..."* [Julie]

Some also spoke of changes in diet and alcohol consumption. Some described reduced or no alcohol intake, while others used alcohol to cope with the pandemic,

> *"My life before very much revolved around going to the theatre and going out for dinner with friends, and that's what I enjoyed doing. But that actually drives you to drink much more. And actually, what I've done is drunk much, much less during this period and actually lost 10 kilos in weight."* [Lee]

> *"The way I dealt with the stress in the first lockdown was to pretty much lock myself away, to eat too much, to drink way too much. So, by the time I got to December, I had actually put on about 9 or 10 kgs in weight, so I had put on way over a stone."* [Thomas]

> *"I have noticed that, since the lockdown began, I've been drinking, drinking alcohol, definitely. Not to excess but certainly more or less, every night. I mean, I have noticed that and that's just a way to take the edge of things, I think."* [Stephen]

Food security

Food security did not appear to be a major issue for those interviewed. One person (Michael) who was classified as clinically extremely vulnerable received food packages from the local council, although he was unable to eat much of the food provided due to dietary requirements. Robert was involved in delivering food shopping vouchers to vulnerable people living locally and Julie also used food services provided by her local community group,

> *"...there was a community group, which was just going around the houses and just delivering some food stuff. And then I also had deliveries from my church, because they've got a food bank. I would get deliveries every month, like a box of £50 worth of stuff. So, yes, that was- For food, I was okay. I wouldn't say I went hungry, I was okay."* [Julie]

However, Julie was also aware of others who had to prioritise food above other provisions,

> *"And some of these people have got children. Instead of buying mobile top-up, they would rather buy food for the child or themselves."* [Julie]

Work situation and home life

Workspace, place, and time changed during the pandemic. Work practices adapted to the increasing demands and provision of PPE, particularly for those working in health/social care, community outreach settings, or with COVID-19 patients specifically,

> *"...working on a COVID ward, where we are severely understaffed, and we are all running around like headless chickens. And we had lack of PPE, which was basically a stupid mask, a visor and theatre scrubs. And having nine COVID patients each with not much healthcare assistance. That needed a lot of care."* [Emma]

However, one person described the opportunity to apply their skills and training during a pandemic as a 'once-in-a-lifetime' opportunity,

> *"My experience at work was driven by, and this sounds so egotistical, and I kind of apologise for that, but I'm also a little bit proud of that, and that kind of keeps me ticking, which is a good thing. I remember thinking, '...I work with really vulnerable people. This is where I step up and do my job and look after people'."* [Nick]

Some participants (those not on the 'frontline') were required to work from home and had adjusted to this including adapting to changing environments although this had blurred the boundaries between work and home life,

> *"...I've gone back to the way I used to work years, ago, where I was working all hours, and finding it very difficult to stop..."* [Alan]

This had left some people experiencing work-related stress,

> *"I think I just struggled more with my mental health, I struggled more with anxiety and depression. But I think a lot of that was work-related. I think it was a combination of work and lockdown (...) The anxiety, I can definitely say is more to do with work than the pandemic."* [Nick]

Given the timing of interviews, Thomas had begun to return to the office although this was at reduced capacity with social distancing measures in place.

Job security was referred to in relation to the furlough or redundancy of others, including friends and colleagues,

> *"When I compare myself to friends, I was very fortunate because I could a) work continuously, and b) I had enough money to survive. It was a bit annoying, taking a hit, but, with everything going on, I was actually just relieved that it all worked out. I was very lucky."* [Anthony]

> *"...we had staff that were furloughed and we had 3 staff members who interpreted the COVID situation more chaotically than other people did. And we've had to be more understanding. Well, we don't have to be, but as a charity we want to be more understanding and lenient about them."* [Lee]

Some participants (Anthony, Robert) spoke of volunteering for community organisations and the NHS during COVID-19 including as an NHS Responder[12] and a steward at vaccination centres.

Perceptions of the virus

Nearly all participants spoke about their own or others' (e.g. partners, family, friends, neighbours) perspectives of the virus and suspected or confirmed cases of COVID-19. One person was interviewed whilst self-isolating with a confirmed case of COVID-19. Some felt they had symptoms of COVID-19 or had close contacts with cases early in the pandemic when tests were not widely available. Others spoke of accessing polymerase chain reaction (PCR) or lateral flow tests (LFTs) later in the pandemic or being afraid of accessing tests,

> *"To be truthful, I don't know. Because at times you just feel there is something wrong with my body, I feel funny, but you are not very sure what it is. I was so scared of going for a test (...) But after the jab, I got my rapid testing kit and I am doing it at home, which is good..."* [Julie]

A few participants spoke of bereavements relating to COVID-19 or long COVID — neither were explicitly asked in the interview topic guide. Some references were made to others who may now be experiencing long COVID which had manifested as fatigue, tiredness, and unrecovered sense of smell.

Participants also referred to others' perceptions of COVID-19 — typically scepticism and therefore, opposition to vaccinations or masks ('anti-vaxxers' and 'anti-maskers'). Some sceptics were known to participants (e.g. family members, colleagues, friends), while others were unknown (e.g. general members of the public). Participants felt frustrated and angry towards those who were sceptics,

> *"When there is this conspiracy theory. And it's like, it's not about you, it's about- It's okay where it's my right, my body, but if it affects other people- Alright, don't get a vaccine, just wear a mask or something. But when it's my body, my right, you know, not when it affects other people."* [Emma]

Perceptions of the pandemic response

Participants referred to the pandemic response in relation to the government and the NHS, specifically the NHS Test and Trace programme and the vaccination efforts led by the NHS; the former was

[12] NHS Volunteer Responders were established between NHS England, NHS Improvement, the Royal Voluntary Service and GoodSAM app to support vulnerable community members and help steward vaccination centres.

viewed negatively, the latter more positively,

> *"I think the roll out of the vaccination programme has been incredible. It's been done by the NHS, not by the Government. By the companies who have completely ballsed up the trace and track systems, and a lot of people made an awful lot of money out of that and that makes me very angry."* [Michael]

Several spoke of a mistrust of government officials,

> *"...don't really trust the government, and I'm like many people, because they're all self-serving."* [Claire]

Others spoke of the response at the community level; for instance, Nick described how health information was developed for homeless populations that was appropriate based on their needs – specifically, weatherproof, pocket-sized, and visual.

COVID-19 research and trials

The COVID-19 pandemic response has been driven by advances in testing and treatment through increased funding and the focus of clinical and epidemiological research. Some participants reported knowing someone, or personally being, invited to participate in COVID-19 community testing programmes (either antibody or antigen). One participant decided to take part in a COVID-19 vaccine trial, and another spoke of a willingness to participate but feeling disappointed when it was revealed they were not eligible.

COVID-19 vaccine

The NHS COVID-19 vaccination programme was launched in the UK in December 2020, with the UK being the first country globally to administer a vaccine outside of a clinical trial (442, 443). Following a suggestion made by a peer researcher when reviewing the topic guide, we included a vaccination question – specifically *"What are your views on the COVID-19 vaccine?"* and *"If offered, would you accept the vaccine? Why?"* All of those interviewed had accepted their invitation from the NHS to be vaccinated; some received an earlier vaccine due to their work situation (e.g. health and social care workers) or by volunteering themselves at vaccination centres. References were made to general media reports on vaccine side effects, specifically in relation to the Oxford/AstraZeneca vaccine. Although vaccine hesitancy did not appear to be a direct issue for those interviewed, some

scepticism had arisen about the effectiveness of the vaccination programme in reducing case numbers, which had left some feeling vulnerable,

> *"...And then you begin to think, "What is the purpose of being vaccinated? What is the purpose for it?" You can still get the virus, you can still transmit it, you still have to wear a mask (...) It's scary (...) I thought people were being vaccinated and things would go down. No, it's going up instead."* [Kenneth]

Some sought the reassurance of friends and family members who were healthcare professionals. Additionally, one participant described some hesitancy at the start of the vaccination programme; interestingly, they describe this as scepticism rather than hesitancy,

> *"I was a little bit sceptical about it, I have to say. I didn't think there was enough data, certainly didn't think there was enough data about how it might affect me in terms of my other, you know, immunosuppression. But I very quickly came around to the idea that, you know, firstly, it would be a way of travelling and, secondly, you know, I've had all my other jabs..."* [Paul]

However, several participants described friends, family members, and colleagues who were hesitant to get vaccinated or who had decided not to get vaccinated. For instance, Claire describes colleagues who are not vaccinated but decided to be vaccinated herself following reassurance from a trusted healthcare professional and after considering this in relation the flu vaccine,

> *"I work with a lot of other cleaners and their attitude is they are anti-vaccines, and they don't trust in it and stuff like that. So I've got all that going on in my ear, and then my consultant said that she'd had it, she'd had the AstraZeneca, and it was fine. So because I trust her... And also, I have the flu vaccine every year, so I actually felt, "Well, I have the flu vaccine, so I can't really justify not having it." So yes, I had it. Yes. But I did feel pressure from a lot of people not to have it, like, "Oh, why are you having it?"* [Claire]

Additional comparisons were made between COVID-19 and flu,

> *"That way, we can learn to live with COVID, in the same way as we do with the flu"* [Stephen]

Vaccinations had left those interviewed feeling less vulnerable and more reassured as restrictions eased; some described acting cautiously despite being vaccinated, whereas others described returning to pre-pandemic activities,

> *"I think it did make me feel psychologically a little bit more secure about things. If what I read is correct and I have no reason to doubt it... Yes, I do feel more secure about things"* [Michael]

COVID-19 testing

Participants working in health and social care, described testing requirements to work (weekly PCR or bi-weekly LFTs).

Most found testing acceptable; Alan, however, described a mixed picture with testing becoming more acceptable over time,

> *"I hated doing them [LFTs] to begin with. I'm not saying it's pleasant at all. (...) But I do them. And now I am used to doing them, it's a lot easier, because I know what to expect. But to begin with, I was spitting everywhere and coughing, it was horrible..."* [Alan]

However, Alan then explains why he decided to test – ultimately to reduce any potential risks of transmitting COVID-19 to those who are clinically extremely vulnerable,

> *"It was simply I suddenly thought, "Well, actually, it would be good just to ensure- What if I have picked up COVID and I've got no symptoms?" (...) I also have a friend who is very, very severely ill with cancer. And I go to see them and I would not want to put them at risk at all. So, obviously we take all precautions possible. But I don't want to put anybody else at risk."* [Alan]

Rules, regulation and government guidance

Interviewees spoke of their ability to adopt NPIs and general adherence to government guidelines by themselves or others. NPIs described included washing hands frequently, wearing face masks/coverings and social/physical distancing.[13] Interviewees self-reported wearing face masks in public spaces including shops and on public transport, although observed a noticeable decline in other members of the public wearing face masks at various points of the pandemic which had left them feeling frustrated or nervous, particularly when they had not yet been vaccinated,

> *"Oh God, it drives you mad, because I think, "Well, it is easy. You just have to kind of do it. What's the deal?" You know, particularly since I wear a mask so that I don't*

[13] The UK government ran a public health messaging campaign of "hands, face, space" during the pandemic which was later updated to include the importance of ventilation.

> *pass anything to somebody else. And when you think, ultimately, if you pass COVID to somebody else and they died from it, then they've had a connection to you. And I kind of think, "Why don't you have that kind of connection?" It's a simple measure and you could actually stop somebody from being hospitalised or stop somebody from dying."* [Adam]

Some participants who had worked or travelled abroad, specifically in Asia, described using face masks as a social norm whenever someone is feeling ill, compared to the UK,

> *"In Southeast Asia, when I was working, it was quite common to see people wearing a mask if they have a cold or anything like that. They took it as being polite."* [Ronald]

Others described 'rule breaking' to see friends when social (or physical) distancing was enforced. Nick described the temporal nature of government guidelines and the impact of this on their social interactions,

> *"You know, we were reducing contact with people that we weren't regularly in contact with. So it was good fun. And then second wave, alright, but kind of just becoming really tedious at the end. You know, by May we were allowed to do things, I think I was bored, and I've learnt that when I'm bored, that's probably quite an unhealthy place to be, and boredom is something that I have the ability to bring myself out of. (...) And I've learnt that I need to make an effort for me, because if I'm not well, then that's where it all starts. If I'm not well, I can't be good for my friends, family, my job and everything that is part of my life..."* [Nick]

For Kenneth, physical distancing had a negative impact on his mental health and had left him feeling lonely and isolated,

> *"The social relationship, the family networks – gone, more or less. Gone. And as I said, human beings are social animals (...) You need to socialise, you need to meet physically, you need to hug, you need to greet, you laugh together. You know, you go to church in big numbers."* [Kenneth]

Others described friends who had become hypervigilant during the pandemic and would actively avoid passing people in public; for instance, Peter described an incident where someone had coughed at him.

We also asked participants of their views on the government's handling of the pandemic and received a mixed picture; however, most responses were critical. For instance, some felt that the government had been too slow to respond, the pandemic had been mishandled and the response

was "chaotic". Scepticism and suspicion towards government was often grounded in concerns for the wider political context; for instance, Paul referred to the Police, Crime, Sentencing and Courts Bill 2021 and threats to the privatisation of the NHS.

The impact of lockdown[14] measures were described by nearly all participants, either in the COVID-19 epidemic (e.g. incidence) or on their daily life and practical challenges. Participants described how the first lockdown was perceived to be the most disruptive to their daily life. For example, some referred to stockpiling that occurred by others; however, older participants, as well as a person who had experienced martial law in the past, described being familiar with the restrictions imposed by lockdown. Others referenced specific issues relating to working from home (e.g. childcare, home schooling, etc.), moving house during the pandemic or access to outdoor space,

> *"...my daughter, it affected more because she was still at school, so she no longer could go to school. Then, her lessons eventually went online, but then she suffers from anxiety at times, so she doesn't like to do things online."* [Claire]

Some participants also created "support bubbles"[15] with friends to support each other during the pandemic.

Other government NPIs described by participants related to testing (specifically NHS Test and Trace) and stricter enforced measures (specifically lockdown). These two measures appeared to be the most controversial for participants. For example, Paul was critical of government spending and decided not to download the NHS COVID-19 mobile application for contact tracing,

> *"And I think a lot will come out about how this could have been handled much differently, you know, all the huge waste of money on track and trace. I've never downloaded the app. I'm not interested in it. (...) I don't think it's particularly helpful. You can see now with all the chaos that it's causing, I don't like the idea of being tracked or traced."* [Paul]

He continued to explain his opinion that contact tracing should have been led from the community level and that failures of the programme may lead the government to justify funding cuts,

> *"And, unfortunately, I can see that the present government are going to use that as an opportunity to, in the longer term, blame the NHS and then sell off more services*

[14] England experienced three national lockdowns in March 2020, November 2020 and January 2021 as well as local lockdowns across the pandemic for instance, in Leicester/parts of Leicestershire in July 2020.

[15] 'Support bubbles' were introduced by the government in June 2020 as a mechanism for those living alone to socialise, in close contact, with another household when physical distancing remained strictly enforced.

> *because they'll say they can't cope, "We're going to privatise it." (...) This could have been managed much more effectively, at a community, a local community level, using different strategies to track and trace depending on which community you were track and tracing in."* [Paul]

At the time of interviews, the government had announced a forthcoming "Freedom Day" whereby most restrictions would be lifted on 19 July 2021.[16] Most interviewed were concerned about "Freedom Day" given the case numbers being reported and the potential long-term consequences of this,

> *"There'll be a rise in deaths. The transmission, it's almost like in my own view is, it's Operation Petri Dish. Let's see, you know, and I think it's a gamble. And, unfortunately, there will be collateral damage. People are going to lose their lives by this opening in the way he's doing it. That, unfortunately, didn't need to lose their lives or won't need to lose their lives and it's going to happen..."* [Andrew]

However, others praised the government's vaccination programme and were sympathetic to responding to the uncertainty of a novel infectious disease.

Impact on healthcare provision

Several participants anticipated the impact of COVID-19 on the NHS, specifically a backlog of cases, preventable deaths, and longer waiting lists due to a perceived shift in focus to COVID-19 infections and staff shortages due to redeployment. Some described the indefinite postponement of their participation in research studies, delays in receiving referrals/outpatient appointments for other health concerns that had left them feeling concerned or being unable to access walk-in clinics at their GP. Some specifically compared their experience of HIV care to cancer services which had been heavily reported in the media at the time,

> *"It is what it is. I'm still luckier than cancer patients because they haven't had any care. So, it's not bad."* [Mark]

Participants described both positive and negative experiences of accessing NHS services during the height of the pandemic,

[16] "Freedom Day" led to the removal of a recommended 'work from home' order, legal requirement to wear face masks in public, legal restrictions on social gatherings and the introduction of "COVID passports" for nightclubs and music venues.

> *"Yes, both (GP appointment) by phone consultation. Which has worked for the reasons that I needed. And in fact, I suppose there is probably an argument to say that, for certain things, they should move to a phone consultation permanently. Because you actually get to speak to a doctor a lot quicker..."* [Thomas]

> *"People have been found dead in their homes because other illnesses are not being taken care of. The main concern now with medical teams is COVID – COVID vaccination, COVID, COVID. Other illnesses... You see 5 something million people on the waiting list."* [Kenneth]

For many interviewed, the shift in focus of the NHS service as well as a perceived "closure" of several services has left people more fearful of the long-term impacts to their health and perceived preventable death and worse ill health of others. Paul viewed the decision to close the services as *"political."*

The shift of face-to-face to telephone appointments was widely accepted by participants although there were concerns that this adaptation is not suitable for all people accessing healthcare, particularly the elderly and may miss diagnoses,

> *"But some treatment, you cannot do just over the phone or through Zoom. You need to be physically checking or monitoring. Physical."* [Kenneth]

Perceptions of safety and risk

Participants were concerned about the increase in cases of COVID-19, hospitalisations and deaths, as well as emerging variants; at the time of the interviews, the UK reached more than 60,000 new cases a day[17] and there was a sense of disbelief that the vaccination programme had not yet had a significant impact on reducing this,

> *"And as I said, I thought the vaccination would change things. But now, the [Health Secretary] said, "We might get to a point where you are going to have 100,000 cases a day."..."* [Emma]

One participant who worked as a hospital cleaner felt afraid in her work setting, with the fear of acquiring COVID-19 and also facing death at work that affected her mental health,

[17] The UK recorded 61,994 new cases on 15 July 2021 (249).

> *"...Excuse my language, but it was fucking awful. It was terrifying. I remember walking into A&E not long after lockdown to start my shift and I could feel the fear from the consultants, from the doctors, from the senior nursing professionals. I could feel the fear because it was designated into blue and red areas, and blue was the COVID, so for suspected COVID patients. So they were all going into those areas, and to go into that area, you had to have full PPE. Everyone was just terrified. So obviously, I used to go in after the people had either died in there and then... I had to go in and clean after, and I was just terrified. (...) I was crying when I was doing it. I still did it. It was horrible."* [Claire]

Other participants were fearful of accessing the hospital setting for medical care during the pandemic and acquiring COVID-19,

> *"So, it was a little freak out because I knew that if it would go into pneumonia, unfortunately it would mean hospitalisation (...) hospital is not the place I want to be now. Because with all my client, if someone got COVID, they got it from the hospital. So it's like, no, I don't want to go to the reservoir of the virus, so let's try to work out something else. Yes, it was not the best time."* [Mark]

Another participant working in social care described supply issues with PPE, although this improved over time. However, most felt reassured when they had accessed services and seen the infection control procedures in place,

> *"And I then was able to physically see the protocols that they went through, and I gradually became more and more comfortable with the way everything was done, the way that everybody was sitting, the distance apart. (...) And temperature-checked before I went in an everything. So, suddenly, I went from being surrounded in fear to being, "Okay, actually I'm comfortable with the process and the procedures that are in place. And that I am going to be safe in this environment." So, it completely changed my perception."* [Alan]

We asked participants whether they had made any plans for if they acquired COVID-19; most had actively decided to not think about the possibility however, some had considered how they might self-isolate whilst living with others or alone. For example, Peter lived alone and is elderly, so he had decided that he would attend A&E if he acquired COVID-19 and became poorly enough to require medical attention as he did not have sufficient social support.

> *"I mean, you know, I always say to people, 'This is the second pandemic that I've lived through'."*
>
> Paul

4.4.5 HIV and COVID-19 syndemic

Participants were asked whether they *"...had ever experienced anything like this before"* which alluded to the HIV epidemic. However, some participants made comparisons between HIV and COVID-19 without prompting. Comparisons were made with public health messages, experiences, and/or histories of stigma and discrimination (e.g. fears of transmission) and the unknown long-term complications of both viruses. Some were hopeful that the progress seen in the development of COVID-19 vaccinations may translate into HIV treatment in the future.

Perceived and experienced stigma and discrimination

The most common comparison between the epidemics was made in relation to stigma and discrimination; specifically, that stigma was a real driving force behind the HIV epidemic and delayed response,

> *"I think, obviously, COVID's been taken a lot more seriously because HIV was just affecting particular groups, at the beginning. So, it's much more marginalised and I think it was stigmatised as well."* [Stephen]

However, Alan did believe that COVID-19 also highlighted stigma issues, but that they had not manifested itself as a target for marginalised groups,

> *"But I think, with COVID, yes, I think there is definitely stigma there (...) In exactly the same way that stigma was focused towards certain people with HIV, it may be different groups of people, but very much focused on, "You're not taking responsibility and everything," so it is unreasonable."* [Alan]

Some described re-experiencing trauma from their HIV diagnosis or deaths during the early stages of the HIV epidemic,

> *"It reminded me of how things were in the '80s and early '90s and funerals were quite often sort of the biggest social events you had because you had them with such regularity. You know. My friends in their 30s, and what have you, were dying on a regular basis. And it was a far tighter group of people, rather than COVID as being more wide ranging to that."*[Michael]

> *"I mean, you know, I always say to people, "This is the second pandemic that I've lived through." The first one, hardly anybody noticed because they didn't think it affected them, but you know, as a young gay man moving to London in 1983, I was, you know, front and centre of it. And all my friends were terrified, I was terrified"* [Paul]

> *"I really feel for those older positive people, purely because they went through the AIDS pandemic and they lost a lot of friends through that, and that gave me a lot of empathy with them. I can imagine that COVID probably, emotionally, hit them a lot harder than those of us who are lucky enough to have not experienced the AIDS pandemic at the beginning."* [Thomas]

However, not all participants agreed with this comparison,

> *"So, I don't think I've experienced any kind of change or COVID didn't remind me of being diagnosed. Or it didn't remind me of having HIV or anything like that. There was no connections like that at all for me."* [Adam]

Unknowns and uncertainty

The uncertainty and unknowns in the early stages of both epidemics, particularly in relation to transmission was another comparison made,

> *"Well, early on, very much, that fear of, what does it feel like, have I got it? How easy is it-? Exactly the same as, go back to the early days of HIV. You can't catch HIV from a toilet seat, you can't catch HIV from kissing, you can't catch HIV from using somebody else's utensils. But that was the sort of stuff that we were taught in the early days. So, all of that was crap."* [Alan]

However, Lee did not find the comparisons made between the epidemics to be fair; he believed knowledge and public health messaging had improved during the COVID-19 pandemic,

> *"...I think, as the public- although there are some dissenters who think that COVID is a hoax, in general the public is more informed. And if I think back to the 1980s and the messages that were sent out, we had a public there who were frightened"* [Lee]

This perception of the disparities between the two epidemics had left some feeling frustrated but had also made them reassess sharing their HIV status,

> *"I wouldn't think of them as being the same. The one thing that it did make me think is just it did make me reassess about being HIV, in the sense that thinking, "I've just got a virus," which is what coronavirus is. People don't have any shame about saying, "God, I've got coronavirus. I had two weeks off." (...) it caused a bit of a shift in me that I would be less wary or less shamed about admitting my status, but I don't really see the parallels, because at the beginning of the AIDS crisis I don't think most people cared, whereas, at the beginning of this, everyone did."* [Anthony]

Participation in clinical trials and research

Participants spoke of their participation in both HIV (in the early days) and COVID-19 research studies, including COVID-19 vaccine trials. The participants spoke of their altruistic motivations to participate,

> *"And you are helping towards the development and the evolution of new treatments. To me, I am so pleased to be able to do that. And I am so proud of all the pharma companies and everything that they have done, and all of the healthcare professionals, to actually move forward. It's phenomenal, what we have achieved in this period, since '96."* [Alan]

Health and well-being

Co-morbidities

Several participants were managing other health conditions alongside their HIV – this included non-communicable diseases (NCDs) (e.g. cancer, mental health), communicable diseases (e.g. hepatitis C) and chronic pain/fatigue. Some of these experiences were prior to the pandemic, others during; managing co-morbidities during the COVID-19 pandemic made the lives of those interviewed more complicated. For instance, mental health worsened or living with cancer/other health conditions meant that they were considered to be "clinically extremely vulnerable". People were navigating the pandemic both by living with HIV and by managing and treating other health conditions. One person (Lee) felt they had developed a respiratory infection which was "COVID stress-related", which alludes to a sense of embodiment.[18]

[18] Embodiment relates to the process where we as humans physically embody the environment we exist within, or in other words what "our living bodies tell about our lives, whether or not these are ever consciously expressed" (163).

Mental health

As expected, all participants reported conversations about mental health. Some had pre-existing mental health conditions that they described as worsening during the pandemic – specifically anxiety and bipolar disorder – whereby medication dosages had to be increased during various stages of the pandemic (e.g. lockdown), or they faced difficulties securing appointments with psychiatrists during the pandemic,

> *"And when the pandemic was slowly getting over and this, that and the other, I had a bout of depression and just relapsed all of a sudden. Then life got back to normal, I relapsed again in the winter and then relapsed again in the summer. It completely happens out of the blue."* [Emma]

The uncertainty of the pandemic left participants feeling anxious and stressed, particularly when restrictions around social mixing would be eased, as well as increased workloads and pressure to return to work or "normality",

> *"I know one of my elderly neighbours, she went through that (fear of returning to face-to-face). I mean, she doesn't have HIV, but she went through that with that re-joining. She was terrified, and she experienced huge amounts of panic. You know, panic attacks from going out again?"* [Claire]

> *"I think, for me, there has been an impact, in terms of not being able to get on with plans, not being able to get on with life. Also, to some extent, the sheer boredom of it. Particularly during that very strict lockdown. I think, beyond that, generalised anxiety."* [Stephen]

When asked *"how the COVID pandemic has affected you emotionally?"*, Robert said it had made him be more future-focused, but negatively,

> *"I suppose it's made me think more about what's going to happen to me in the future. It's made me think more about what's the point of the rest of my life because in many ways there isn't any. I'm just sitting waiting to die. I think more about what's going to happen to the cats if I'm not around to look after them than I do about me..."* [Robert]

Others described a sense of hypervigilance,

> *"But I am just a bit worried, even for myself. Where I was before is not where I am now, because now I am so cautious of everything. I am so suspicious of everybody. And it's not healthy..."* [Julie]

Loneliness and isolation were frequently described by participants, either through personal experiences or others. However, for some, the isolation during COVID-19 felt *"no different"* from what they had experienced when they were first diagnosed with HIV,

> *"But because my life has been very insular because I was doing the therapy, working and studying, and when I had my diagnosis in 2012, I withdrew from life because I was very frightened... So during COVID, my life, really, was no different."* [Claire]

> *"I suppose it's reinforced the sense of isolation which has always been there because, especially, having been diagnosed in those early days of HIV, it was very much something that people were afraid of, and therefore you ended up withdrawing from social situations to a degree because you didn't want them to find out because then they would be afraid of you. So, you end up isolating yourself to a degree and, obviously, COVID has emphasised that really, about how isolated I actually am and have been for a long time."* [Robert]

Some managed their mental health through medication, hobbies, therapy, and exercise, although the success of this was less agreed upon,

> *"And it's really difficult. Because yes, I have a consultant psychiatrist, but it is literally once every three months or so. And that is what support you get from the mental health during the pandemic. It was really appalling."* [Emma]

Shielding

We asked participants whether they were told to shield (e.g. in the form or letter or text from their GP, HIV clinic or the NHS generally). In the survey, 40.9% participants (n=9/22) revealed that either they, or someone they knew living with HIV received a letter to shield. In the interviews, 10 participants described receiving a communication to shield themselves and five participants spoke about others who received a communication to shield themselves. This communication came in the form of letters (n=11), emails (n=2), texts (n=1), phone (n=1) or in person conversations (n=1). The senders of these communications were identified to be the government (n=3), the NHS (n=2), the local council (n=3) or from their GP (n=4) and HIV clinic (n=1). Others (Paul, Thomas, and Alan) mentioned that they had not received any information about shielding, which left some feeling uncertain. Thomas described feeling disappointed that he had not received any contact from his HIV clinic and Julie shared that her HIV clinician was unaware of her shielding,

> *"But last month, I managed to see my consultant, and we had quite a lot of things to talk about, because many things had happened during the lockdown. And he didn't even know that I was shielding, because I received a letter to shield. You can imagine, it takes a toll on you. (...) Because I was sort of expecting it (to be asked to shield). Because when we have a lot of issues and your immune system is compromised, you have to make sure you are covered on both ends, because you don't know what is happening. Because with this COVID, it's a new thing, and we didn't know what it was, and I just had to protect myself."* [Julie]

Claire received a shielding letter saying she was vulnerable, but did not feel vulnerable herself,

> *"Well, first of all, it's kind of like, "Oh, what about me? Maybe I should shield?" but then my more rational thinking is, "Well, I don't need to shield because I'm not at risk. But I double-checked with my consultant to make sure I was not at risk because if I'm aware the government didn't... I don't think they informed everybody or some- You know, it's easy to get missed, isn't it, with so many millions of people?"* [Claire]

Peter also received a shielding letter from his GP but was unsure whether it was because of his age rather than his HIV status that would put him *"...in that bracket"* but decided to stay in and follow the rules which was not difficult to do. Similarly, Ronald questioned the reason behind receiving a letter in relation to his HIV status,

> *"And I said, "Why?" Now this sounds strange, but I talked to my HIV doctor, actually. I said, "Being HIV, do you think I am more likely to have it or not?" He said, "We don't know, but we don't think so, because you are perfectly healthy and so on, and I don't see why you should be." I said, "Fine." And I think the only reason they asked me to shield was because of my HIV status rather than anything else. (...) Because I had no other illnesses."* [Ronald]

Participants spoke of the impact of shielding from their own perspective, as well as others. For several, isolation was a major issue; for instance, Kenneth was considered to be "clinically extremely vulnerable", which made any social interactions during the pandemic difficult,

> *"Because you are being told you are more extremely vulnerable with others, don't associate with any person at all not living in your house (...) Being locked up (...) is worse on mental health. Particularly just by yourself. You are not shielding with some other person in another room, but your entire flat, where you live, I am just by myself. That's it."* [Kenneth]

Although Alan never received a shielding letter himself, he shared how it *"caused major distress"* for people he knew who did. Additionally, confusion remained as to whether people living with HIV should have been recommended to shield,

> *"But I think the NHS just lumped HIV-positive people as extremely clinically vulnerable, whatever your status, whether you have got undetectable viral load or undetectable- You were lumped together as extremely clinically vulnerable from COVID. And that was it, so you have to be shielding."* [Kenneth]

Knowledge and health awareness

We asked participants where they sought information about COVID-19 and whether this was related to their HIV or more generally. We heard examples of both statutory and non-statutory organisations and various formats including word of mouth, social media and mainstream media. Some also sought information from journal publications and conferences. Most sought information from government departments or non-executive agencies (specifically PHE) and BHIVA. Some also sought information from HIV charities or trusted individuals – specifically their consultant or HIV clinic – to determine *"whether I was at any increased risk"* [Emma] or whether they needed to shield,

> *"I think I would go by the advice of my consultants first, especially infectious diseases because they would know more about it."* [Susan]

> *"...I felt quite reassured from my consultant that I wasn't at risk, my health was okay"* [Claire]

> *"So I spoke to my infectious disease department and I kind of said, "What's your advice on this?" And they said, "Well, you know, generally I think you're good to carry on as you are. You're well." We screened my CD4 count at the time just to make sure what that was, and it was 460. So that was fine to carry on. The treatment was working. Just follow, be like a normal person, or an uninfected person is probably more appropriate to say. So that's what I did."* [Nick]

However, some were less positive about their experiences with their HIV care team,

> *"It was really hard to find any information, and I have to say that the clinic down here in [Location] were about as useful as a chocolate teapot. And I have a few positive friends locally, and four or five of us were messaging each other, going, "Has anybody contacted you? Have you spoken to the clinic? What is the deal? Are we meant to be completely locking ourselves away?" There was quite a lot of confusion (...) All the clinic did was refer us to the NHS website, which was utterly confusing."* [Thomas]

There was a general feeling of having to navigate various sources (with the avoidance of information overload and mixed messages – specifically from government) and determining whether the information was misinformation or not,

> *"The government messages (...) The mixed messages are not helpful. You know, you have the vaccination, they say the vaccination only protects you from not getting seriously ill and not being hospitalised. But it doesn't prevent you from contracting the virus, it does not prevent you from transmitting it."* [Kenneth]

Adaptations to HIV services

Changes to appointments

HIV clinics quickly adapted to the pandemic early on by changing any in-person appointments to online or by phone. Teleconsultations were viewed with a mixed response; Adam found it difficult to express challenges he was experiencing with his HIV medication and felt the calls were less personalised than in person,

> *"But I felt that I was saying I was struggling on the medication, saying it wasn't easy. But I don't think that resonated so much over the phone. The phone call felt a bit routine. It felt a bit like the person was in a rush and they were like, "Okay, well keep going." And that was it. And then I was only on, probably six-monthly checks anyway (...) So then that was another six months of psychological torture, really."* [Adam]

Adam felt frustrated and *"a bit fed up"* with telephone appointments when the consultant is delayed and then rings when it may be inconvenient to take that call. Adam and Emma also expressed a lack of privacy when taking calls at home or at work,

> *"So there was some stress around navigating the time and when we were going to ring and then I was having to, kind of, say, "Let me just go outside and try and find somewhere quiet on the street where we can talk to you." I couldn't really ultimately achieve that, because there would be some people walking past. So I couldn't really get a private space to do that kind of call."* [Adam]

> *"And that was hard, because it's telephone appointments, and they're not on my days off, they're in work time. And having to actually have 20 minutes privately anywhere was very difficult."* [Emma]

Most found phone consultations acceptable; for instance, Lee understood the need for phone appointments to reduce the risk of COVID-19 transmission and felt comfortable where well-established relationships existed with clinicians already,

> *"...it's a fairly natural phone conversation and I understand why they're doing it. I think it's sensible that fewer people are invited into a central hub to cross-contaminate each other. So it hasn't bothered me in the slightest."* [Lee]

Claire felt her consultant had more time to dedicate to her care by phone,

> *"My care wasn't interrupted at all. In fact, the phone call that I had from my consultant, because she was working from home, she kind of had more time and it was just me and her. There was no nurse specialist there. I felt that she was asking me more personal questions because she had more time. So I actually enjoyed that. You know? It was nice."* [Claire]

However, there was also an appreciation that some interactions are missed by teleconsultations rather than face-to-face consultations,

> *"I miss that (face-to-face). Because it's like there are some emotions I can feel. When you are remote, like this, you cannot pick up on them easily. But when you are face-to-face in person, you actually pick up on those things. And my consultant is very good at that. He will just look at me and say, "Hmmhmm, what is on your mind today?" Because he has seen that I am worrying about something. But when you are virtual, like this, the virtual one is a tool which can be used because of circumstances..."* [Julie]

> *"I feel like they can actually see how well you are if you go in. This is to do with anything not just HIV, but I just feel face-to-face is better because they can get more of a picture of how you're feeling. I think that's mentally just as well as physically."* [Susan]

During the pandemic, most participants experienced a "blended" approach, in which a telephone conversation would then be followed by a minimal in-person visit to take blood (to monitor viral load and CD4 counts). Although some were initially worried about attending in person, the COVID-19 safety protocols in place helped alleviate any concerns including reduced numbers which made visiting times quicker,

> *"I didn't really worry about it too much. I've been fairly sanguine, the whole time. I didn't feel particularly vulnerable. I had very strict guidelines. So, you had to put antibacterial on your hands as soon as you entered the hospital. You had to have proof that you had an appointment. When you got to the clinic, they took your temperature before you were allowed in. And obviously, we are still wearing masks throughout. So, no. I didn't feel particularly worried."* [Stephen]

An in-person visit was reassuring for Andrew,

> *"To be honest, you know, I'm glad to see people. I'm glad to see the people who are responsible for my HIV care because, again, the nurses are familiar and having that familiarity and reassurance that everything's okay, it's a million times more powerful than somebody saying that to you on a telephone."* [Andrew]

Medication

For most, their HIV medication delivery method had remained the same (either home delivery or pharmacy/clinic collection). Anthony was not aware of home deliveries as an option but would have preferred this to collecting it from the clinic. Paul raised some concerns around privacy of home deliveries,

> *"I didn't really like having to have all my medications delivered by somebody who lives up the road (...) I found that a bit intrusive, but on the other hand, I was very grateful that that was happening."* [Paul]

Participants spoke of their access to medications and supplies during the pandemic. Nobody experienced any shortages of medication although some had reached low levels during the pandemic; most were prescribed several months (four to six months) worth at a time,

> *"There was a point when I, because I think, obviously... What did I say? I ran out in June. We were still quite early on then and I think I was like, "How am I going to get my meds?" but I think, once I'd phoned them up, it was all quite straightforward."* [Anthony]

> *"I did have one stage when I didn't have enough, so I phoned them up and they sorted it out really easily, so it wasn't an issue. I think what's really nice is they know their patients, so when you phone up and you speak to the nurse. The nurse has been there the longest is a lady called [name] and she's lovely and she knows who everybody is. They just sort it out and it's very easy to sort out, you don't have to jump through anything like you might have to in another clinic."* [Susan]

Only one person interviewed described some adherence issues with their ART during COVID-19; Emma shared that they sometimes forgot to take their HIV medication,

> *"Sometimes I forget. I think bipolar is- I am more worried about having a breakdown than getting sick from HIV. Because one of the worst things is to be really mentally unwell, that is more of a worry for me, so adherence with my medication is that much higher."* [Emma]

Some participants spoke of side effects of their ART during the pandemic. However, Adam explained that he was uncertain whether the pandemic or a change in medication had affected his mental health,

> *"Because I think predominantly the problem for me was that the last batch of medication I took that matched, really, the kind of COVID and psychologically unhinged me in a way that I was just like, "What's going on here? What's happening?" My thinking had changed and I was beginning to stay at home more. I think it cut me off from a whole year of life I would have normally lived."* [Adam]

Some participants tried to switch or adapt HIV medication regimens during the pandemic; for Adam, this was a complicated process which he found challenging to describe by phone,

> *"And if I had trouble with this medication now and we were still doing phone calls I don't think they'd get it really. I think it's, in some sense, the way that I present the information to them doesn't fit with kind of how they might expect it to be presented. So, I just present it as real to me and I'm like, "You know, I feel psychologically unhinged and this is what it's doing to me." I represent it matter of fact, but there's no elements of emotional distress from me and there's no elements of emotional pain expressed, that's just me."* [Adam]

Susan switched from dolutegravir (Tivicay) and emtricitabine/tenofovir (Truvada) to dolutegravir/lamivudine (Dovato) (one pill a day) during the remote lockdown which *"went fine."* However, Ronald also switched medication during the pandemic by phone, after he experienced side-effects (specifically *"nonsense dreams"*), but did not prefer this format of consultation,

> *"Well, I had the conversation over the phone, which is the one which I didn't care for. That was not a nice experience. I would rather be in the clinic to be more reassured, talking face to face. Because I have known [Name] for a long time. We are on first name terms, because he has been there since 1993, the same doctor (...) When I had to change the medication it was over the phone. That I found difficult."* [Ronald]

Charity and peer support

Kenneth sought support from HIV charities during the pandemic – mostly, this was done by phone for emotional and practical support although as restrictions had begun to ease he had begun attending in-person which had helped ease feelings of loneliness,

> *"...It has kept me going. That peer support is very important for HIV-positive people like ourselves, particularly during this COVID (...) Because it breaks down loneliness and isolation, you are able to socialise a little bit, meet your peers, talk to them, have something to eat, have some tea, have some coffee, have some food from this peer support. It can be more important than just taking the medication (...) Particularly if you live alone, like myself. It gives you hope. (...) It makes a person like me keep going. It gives some positive- Out there, the peer support group, you get emotional support as well. Good for the mental health."* [Kenneth]

However, Claire expressed concerns about the long-term implications of COVID-19 on the finances of HIV charities,

> *"Peer support, community, because I think there are going to be more people my kind of age diagnosed and stuff like that, so there has to be support groups and peer... Because that money is not ring-fenced anymore, and obviously, because of the pandemic, there are no facilities or no money for... It's all peer led, so there has to be more peer support, more groups, more social networks for people so they're not isolated, because that's a killer, an absolute killer."* [Claire]

Quality of care

We asked participants whether they felt they had experienced any changes in relation to the quality of their HIV care during COVID-19, compared to before the pandemic, which opened up conversations about care preferences, as well as relationships with their HIV clinical team.

Adam felt that the quality of the HIV service had been reduced during the pandemic,

> *"I think it (quality) dropped really, the phone calls. I think there was some element of speed of just rushing through the calls. And, "Let's kind of just see if we can keep things going and just rush through this call and end it." So I didn't think the stuff that I was saying was resonating with them, personally, when they phoned. I don't know that it entirely does face-to-face, but I think it's a bit better face-to-face. You almost feel that there's still a pressure to kind of get you out of the room as quick as possible."* [Adam]

Although Stephen did not experience specific problems, he raised concerns for others who may require more support, which is now missed due to the quality of care provided.

> *"Manageable. I think, unless you've got a specific problem, then the support is there on telephone. Whether there would be an issue about going in and actually having practical support, that might be another issue but, as I say, I haven't needed to do that. That might be an issue for other people."* [Stephen]

This was highlighted further by Julie,

> *"I think before COVID, we had better care, because you could go in and have a chat. You know, there is that connection when you are doing it face-to-face, not remotely, like we are doing now. In person, it is more- What can I say? It's more personal. (...) I miss that."* [Julie]

However, others were satisfied with the service provided given all of the challenges of the pandemic,

> *"With what they had available, I must say at least the clinic that I belong to in [location], they've done great. Because they were still trying, and they will still, "Okay guys, we can't see you, but we'll still allow you an hour for a doctor appointment for a chat." Not much to talk about during that appointment, but still there is that opportunity at least."* [Mark]

> *"I think it's the same. It's the same, the same quality, absolutely, but I feel because of that phone call and the consultant asking me kind of... I feel a bit closer to her, like I feel more of a personal connection with her. And I think, maybe, a lot of people as well after COVID, we appreciate the connection and the time that we can spend with people when we haven't been able to."* [Claire]

Social determinants

Participants broadly spoke of social determinants of health with respect to life before the pandemic, although some also reflected on the changes since then. This included education, employment (or work situation), finances, home environment (or living situation), migration, social support and technology.

Education

Education was referred to in relation to life before the pandemic although some participants were studying during the pandemic and reflected on their experiences of online learning.

Employment

Many participants who were working spoke of their work set-up including their relationships with colleagues during the pandemic. For example, the introduction and use of technology to remain connected, as well as colleagues on sick leave or anxiety due to COVID-19 and struggles with isolation and demanding workloads,

> *"But, I mean, for me, my team struggled, because they ended up been isolated themselves and there was a disconnect. I didn't know much what they were doing. There were lots of different projects being invented while COVID was happening and then it was hard to kind of keep track of all those really."* [Adam]

Anxieties specific to COVID-19 had directly impacted some relationships,

> *"One staff member just- it was very, very difficult to handle because she was absolutely... I'm not being critical. I don't mean paranoid, that she's a paranoid person. But she*

> *was just so worried about the whole of COVID that it was difficult to even have a sensible conversation with her. (...) I mean, like... demanding that we had weekly risk assessments."* [Lee]

A specific issue raised about working situations was sharing of HIV statuses – for some (Adam, Lee), having their HIV status shared in the workplace was no longer a concern, although shielding letters had raised some issues,

> *"...I did say to work I'd got the shielding letter, which then they wanted to know the reasons why and I didn't want to disclose the reasons why for that."* [Adam]

Issues around sharing reasons why people were being asked to shield were raised by others,

> *"At work, somebody asked the question, "Do we have any vulnerable staff members?" and I said, "That's a really, really dangerous question to ask," because you can't expect people, legally, to disclose any of their health issues. So, you can't say, "Yes, we've got three," because the natural question is, "Who are they, and why?" And whether it's HIV or whether it's diabetes, you do not go down that road, because people have a right to their privacy (...) And there is an additional issue with HIV because it still has the stigma. It's not viewed in the same way as I have diabetes or I have long-term arthritic whatever, it really isn't. So, I understand people's sensitivity and not wanting to disclose that."* [Thomas]

Mark shared specific examples from work where he had experienced stigma, including during COVID-19,

> *"Stigma is still there. (...) It was like, I spotted that one time when I just used a cup. Straight away someone grabbed it with a glove. I'm like, "[Are you fucking crazy]?" It's the 21st century. So, it's like, "Okay. I'm not sure I want to be here again."* [Mark]

Claire decided against sharing her HIV status with her employer from fear of stigma,

> *"The only thing where the HIV became an issue was, at work, they sent out a thingy: "Are you at risk?" You know, to do a risk assessment? HIV was on that list, but there was no way I was telling my immediate line managers of my condition. There was no way I was trusting them with that information."* [Claire]

After speaking to their consultant, Claire decided to not declare their HIV status to their employer,

> *"I weighed up the situation, the information from my consultant. She was aware of my working situation, and not telling my immediate line managers. Yes. I signed the*

> *document that said, "I have none of those conditions," and I just thought I was going to have to take that risk if I'm going to be held liable at some point. I'm going to have to take that risk, and I will explain and I will defend it, but I'm not telling those people. (...) Where I live is a small place (...) So they're aware, but my line managers for my company aren't. I have not told them because I can't trust them that they won't gossip and they won't tell. I can't trust that they will keep confidentiality."* [Claire]

Those working in healthcare settings were particularly worried about their risk of acquiring COVID-19; Emma sought advice from her employer about her risks,

> *"Occupational Health were absolutely useless. (...) It still came out as zero on the actual information, to say what my risk factors are."* [Emma]

Emma also described feeling guilty about shielding and the impact this may have on colleagues,

> *"Then I actually realised that I would be letting down my colleagues and this, that and the other and I didn't want to let them down, so I chose not to shield."* [Emma]

Financial security

Participants talked of saving money during the pandemic or having savings to support them during the pandemic. One participant (Kenneth) spoke about issues accessing welfare benefits and immigration challenges that have had an impact on their mental health,

> *"I am on Personal Independence Payment. The immigration people said, "You don't have income, your wife cannot come here," they don't any other support that I would have got from my wife, being together. It's very depressing. I'm very depressed. Because if we were together- Because it's painful (...) It is as worrying as you can think about anything. And I live alone. You try to ask for care from Social Services, they say, "No, we are short of funds. If we are supposed to send a carer to you, you will have to pay some costs." I don't have the money. This is about care from Social Services."* [Kenneth]

Others spoke of financial issues raised by people living with HIV that they support,

> *"So, I had problems, I could not do Skyping or anything because they don't have airtime on their phones (...) And somebody is telling you they don't have money for bus fare. It is just heart-breaking."* [Julie]

Living situation

Participants spoke of changes in their living situations during the pandemic; for instance, adapting to

working from home, reduced socialisation with people outside the household, and how their physical environment impacted their mental health. Adam described restricted household space and access to green space leaving him feeling like he was *"living in a prison"*,

> *"I probably would have coped better, actually, on my own. (Laughter) You know, if it was just me, but having somebody else around you and the feeling I mentioned, the way I'm feeling, kind of, hemmed in. I think it just almost, for me, like prison cells your life off into a little kind of cube. Because I think if we'd have had a garden and we've had a house with different floors."* [Adam]

Some of those who lived alone during the pandemic spoke of feelings of loneliness and isolation,

> *"And other networks of support are not there, because of COVID as well. (...) All the support they can do is give you phone calls, or come and leave something by your door. That's it. The house, everything, you have to fend for yourself. Inside, alone, by yourself"* [Kenneth]

Others spoke of tensions with housemates relating to COVID-19 rules,

> *"And I had anxieties about the housemates as well, because they weren't adhering to the lockdown rules (...) the landlord was coming around, they were having their friends around. It is no point being shielded when the landlord comes around when she wants, the other housemates were going out and everything. It wouldn't be shielding."* [Emma]

Migration

Five people interviewed were born outside the UK, including Africa, Europe, and Oceania.

Julie was supporting a person living with HIV from Africa who is facing immigration issues and unstable housing situations which was impacting on their mental health whilst also dealing with the risk of acquiring COVID-19,

> *"And the regime that she is on does not exist in her country. But the political system in this country is so determined to send her back, even though she has got a child. Her mental health issue is just there. So, it is some things like this, which are never looked at (...) So, this is our community. And we have people like that, who are facing that. Not everyone is privileged to have their own accommodation. Not everyone is privileged to have their own documentation. But they are our community. So, it is all these people who are being affected, and I don't see hope for them."* [Julie]

Kenneth spoke of challenges related to immigration that also affected his mental health,

> *"It's just the immigration rules can't allow us to be together all these years. And my wife now is fed-up. And she is also positive. She is threatening to separate. There are lots of family problems, family issues. Which is depressing me. I am doing counselling now."* [Kenneth]

Social support, relationships and caring responsibilities

Participants described relationships with family, friends and partners, including caring responsibilities. This related to both life before (e.g. their HIV diagnosis) and during the pandemic (e.g. social distancing). For instance, Andrew spoke of how social support was key to improving his mood,

> *"...I've got friends who live not too far away. And they really understand my domestic situation and what I've been through. So they were very good ports of call and they were open to me visiting if I wasn't in a great head space..."* [Andrew]

Participants with elderly relatives or friends often spoke of caregiving responsibilities such as delivering shopping or avoiding visits to minimise any risks,

> *"Family was more difficult. Although, my family live in (UK region), so we have to travel to get there. (...) Obviously, my parents are quite elderly, very elderly now. So, didn't want to put them at risk but we did go up and stay in a hotel last year, between lockdowns."* [Stephen]

Paul's partner required intensive care during the pandemic following an operation which proved difficult,

> *"I found that difficult and I found that the district nurses didn't want to come out, which I found really hard. We needed them and they weren't there."* [Paul]

Claire spoke of her fears of falling ill when she was first diagnosed with HIV and the impact on her caregiving duties for her children,

> *"I wouldn't exert myself because I felt, "Oh, if I get too tired, I'm going to lower my immune system, I'm going to get ill and I'm going to die, and no one is going to look after the children" (...) And also, because I'm a single mum, I can't get ill and I can't die or anything like that because I've got to look after the kids, so it's a strong motivator."* [Claire]

Technology and digital platforms

Technology played a significant role in the lives of those interviewed – from attending support groups and remaining connected with friends and family to accessing HIV and other clinical care appointments. Some issues about familiarity with technology, privacy concerns, and safety issues using Zoom were raised in the earlier days of the pandemic, although these had decreased over time. One person (Paul) found that the system of booking GP appointments had improved during the pandemic,

> *"That's one good thing because you don't have to speak to, you know, the receptionist who seems to think it's his or her job to keep you out of the system, you can just book yourself in and then the GP phones (...) And I prefer doing it like that because I don't have to, you know, sit on the phone for hours. It doesn't work brilliantly yet, but I mean, my surgery is getting to grips with it, certainly."* [Paul]

Claire was able to connect with HIV support groups that they would otherwise have been unable to because of geographical distance,

> *"The only thing that's been really good about the pandemic is the explosion of Zoom, and so I've been able to access so many more things, like to do with other women that have HIV. I've joined a few groups that like online because of Zoom, where, normally, I wouldn't be able to access that because it would be based in London (...) it's enabled me to have further connections with other people, particularly other women with HIV. It's been so empowering, actually."* [Claire]

However, digital exclusion and poverty were also considerable issues for some people living with HIV, particularly among for instance, materially deprived people living with HIV who were being mentored and were unable to afford to pay for technology. Another specific issue raised by a participant was 'Zoom fatigue' and access issues,

> *"Zoom, Teams and Skype, Google Meet more recently. I think it was a very fragmented experience. I don't think anybody knew what to do with it or how to, kind of, sit on a Zoom. There was constant, you know, the video wasn't working, the sound was working. (...) I think very much myself and other members kind of felt Zoom fatigue."* [Adam]

> *"Clocks do not go backwards, time does not go backwards. We are not going back anywhere, we are going forward into a new environment. Whatever that new environment is, we have got to be able to be prepared for it."*
>
> Alan

4.4.6 Perception of the future

We asked participants what they viewed for the future of life beyond COVID-19 at an individual, community and societal level and what they plan to do for what may happen next.

At the individual level, many spoke of returning to work (or working more flexibly from home and the office), socialising more, and travelling. At the community level, there was hope that COVID-19 had increased people's health awareness and hygiene but also concerns of long COVID and how this may impact people living with HIV specifically. At a societal level, participants anticipated future lockdowns in the winter months and the continuation of restrictions and guidelines,

> *"...I think the things like we will probably manage to integrate into our daily lives some aspects of social distancing and mask wearing indoors and things like that."* [Michael]

Participants were also concerned about exacerbated inequalities in providing and receiving HIV care both globally but also within a local context, as well as social and economic inequalities,

> *"And it is difficult. Because when they are in government housing, you know how much they have? £37 a week (...) So, it was very difficult for me and, at times, I would feel overwhelmed by what they would be saying."* [Julie]

Future of HIV care

Format of consultation

It was expected that HIV care would change to a blended or hybrid model of face-to-face and online/telephone-based appointments, which was acceptable for most, although some speculated that perhaps HIV care would never return face-to-face,

> *"...I would be happier with electronic consultation and less face-to-face time. I think it's important for care to be delivered face-to-face, at any level. If it's more convenient to be electronic, and it allows you to attend more appointments, because of cost or convenience or it's more efficient for that service, then that's not a bad trend to gently head towards. But the care world needs to be face-to-face. That's the key to humanity and care should have that flavour because it's kind, because it's complete (...) And so what I mean by complete is you miss things over a telephone call or a video call that you pick up when you're sat in front of a professional or a professional is sat in front of a patient, you can see from body language and you can read so much, and treatment should be complete."* [Nick]

Others speculated that telephone or online consultations may continue as it is *"more cost effective"* [Mark]. Emma anticipated that they would never see a consultant in person again and it would only be by phone from now on.

Frequency of monitoring appointments

Participants also spoke of the possibility of switching from 6-monthly monitoring appointments to yearly, which had mixed levels of acceptability,

> *"I guess they will, because I guess they'll see it works, and I guess they can see more people in a year. It saves them money, so I understand that. I just imagine that will become normal."* [Anthony]

Monitoring appointments provided participants with reassurance on their health status,

> *"So, once you're in the system, I feel like when you're monitored every six months nothing too bad can go wrong."* [Susan]

> *"I've always felt very, sort of, comforted by the care that I've had. So I would prefer to go back to having an appointment every six months, which is what I'm on, where I'd go along, see the nurse, have my bloods, get checked out and then go back two weeks later to see the consultant."* [Paul]

Andrew described how COVID-19 caused more anxieties and that monitoring appointments were able to resolve those concerns,

> *"I suppose a couple of years back that would have been a real anxiety for me. Because I've had such a stable experience as far as my viral load is concerned, then if COVID wasn't around, then I would be okay with, say, a yearly appointment. The fact that COVID is around, my concern is if I got COVID, would my viral load be affected? And*

> *my ability to take the medication (...) Things like long COVID, would that cause damage to my immune system (...) if I think about 12 months appointments for HIV, would not be appropriate (...) But at the moment, again, it's that insecurity, it's about the anxiety, you know, the world just feels a less safe place."* [Andrew]

Future advancements in treatments

Julie speculated on the possible introduction of injectables[19] that had left them feeling *"hopeful."*

Shift to primary care and loss of HIV specialisation

Some participants also spoke about the shift in HIV care from specialised services to primary care; as expected, the acceptability of this was driven by context. For instance, for individuals with good relationships with their GPs and confidence in their GP practices services this did not cause any concern. However, for others, this was problematic as they felt the specialist service provided by HIV clinics was no match with GP practices,

> *"...I think there were plans for that to happen. Which I would not feel comfortable with. Because I think it's no different to moving cancer care to GPs. GPs, they don't have the specialist knowledge (...) we must continue to have direct specialist care..."* [Thomas]

Some were, however, concerned about the potential loss of the specialist roles in HIV clinics – specifically consultants and nurses as HIV is now a manageable, lifelong condition,

> *"Obviously, I do chat to the nurses when I go there and they say that they used to be booked up all day long, with appointments and, now, there are many fewer people going to the clinic because fewer people needing to go to the clinic. Obviously, I think they have had a reduction in staff, at the clinic that I go to. In a way, that's a measure of success, isn't it? In the treatment of the condition. So, from the point of view of services, they are contracting. Necessarily, because they're not having to do that kind of intensive work."* [Stephen]

[19] Injectable HIV treatment (cabotegravir with rilpivirine) was, in fact, formally approved in November 2021 by NICE to be introduced into HIV clinics in England by April 2022 for adults living with HIV who are virologically suppressed (VL<50 copies/mL) (444).

"...the training is really helpful, you get to realise the amount of work and people that are involved in a research project."

Co-researcher

4.5 Reflections of impact of using a co-production approach in a doctoral research project

The average interview time length was 71.3 minutes; this was similar among interviews conducted by academic researchers (72.4) and peer researchers (68.4). Both peer researchers spoke about their experience of being involved in the project at both the start and end of one of their interviews, including the training they received and how they heard about the opportunity.

There was no difference (p=0.788) in the types of questions asked by academic or peer interviewers **(Figure 4.5)**. In four of five interviews completed by peer researchers, the peer researcher provided advice to participants; for example, names of community-based HIV organisations for further practical support[20] as well as general advice for seeking social support.

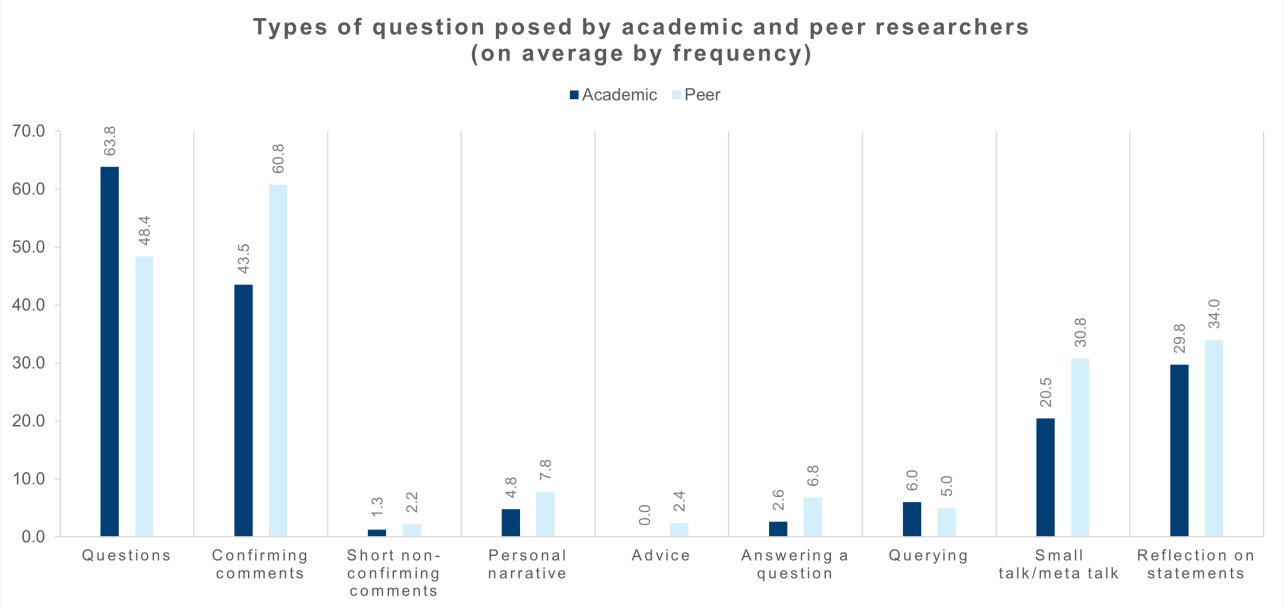


Figure 4.5: Graph of average question type asked by academic researchers and peer researchers during interviews

[20] This was also included as a reference point at the end of the interview topic guide **(Appendix D)**.

Originally, I had scheduled for each peer researcher to interview three people each; however, one participant did not attend their interview date and so this had to be rescheduled later with a member of the academic research team. This left a peer researcher feeling disappointed; therefore, managing expectations, for instance, highlighting the possibilities of "no shows" or participants withdrawing from the study during training, is essential.

Additionally, during the study, some co-researchers experienced life events (e.g. bereavements, work commitments) that impacted their level of involvement at various stages. There were some issues with accessing documents by Microsoft One Drive which had to be troubleshooted.

4.5.1 Evaluation and feedback of involvement

Ultimately, the peer researchers grew in confidence over time, and other co-researchers expressed their positive engagement throughout the process at meetings, by phone or email,

> *"I don't know about the others but I am enjoying my involvement in the project so far and (...) the training is really helpful, you get to realise the amount of work and people that are involved in a research project"* [Advisory Group Member]

> *"Thanks for your efficiency – I love the "Action points" at the end of the emails, it makes it super easy to know what my next steps should be. I think I might steal that technique and use it in my professional work too!"* [Advisory Group Member]

> *"I truly appreciate your kindness"* [Peer Researcher]

> *"I really do enjoy being part of the team"* [Peer Researcher]

> *"It has been such a pleasure to collaborate with you and the team. I have learned a lot! It has really helped me when I had to quickly analyse our submission to APPG based on the survey and gave me more confidence. I do feel that the analysis and reflections last night were really enriched by looking through the lenses of our lived experiences. Thank you to all involved for the commitment and generosity of sharing ideas and experiences."* [Advisory Group Member]

I asked all participants to complete a 'Rose, Thorn, Bud' activity[21] to reflect on their experiences of involvement in the project before data collection had taken place; however, this was met with limited engagement **(Figure 4.6)**.

[21] Taken from human-centred design, this method identifies the successes (roses), negatives (thorns) and opportunities (buds) of a project (445).



Figure 4.6: Anonymous reflections on involvement by co-researchers in March 2022 hosted on Google Jamboard

The relationship built between the interviewer and interviewee is essential in the research process. I asked all those interviewed by a peer researcher to provide feedback after the call. Two participants shared feedback on being interviewed by a peer researcher which were both positive of the interaction and also approach,

> *"Karl made an excellent interviewer by the way – really attentive, a good listener and easy to talk to"* [Paul]

> *"I found the interview with Karl excellent and very supportive from start to end, and indeed it is mainly through these kind of interviews to gauge service users'/patients' experiences that services and support can be better tailored to needs that comes up."* [Kenneth]

One participant gave positive feedback to the other peer researcher during the interview itself,

> *"It's been great. You've been so receptive and listened and fed back to me about how I've responded to the questions. So I feel kind of empowered. I feel listened to, and it's been a really good experience..."* [Claire]

4.5.2 Research impact and dissemination

Since October 2021, we have worked as a group to share findings of our research project as well as reflections from co-producing research (**Table 4.3**). This has included conference presentations, an infographic, sharing training resources developed, a podcast and a co-produced event.

Feedback event for participants and key stakeholders

From March to July 2022, I organised and led an event (that took place in July) which was co-designed with four co-researchers; one was unavailable to participate due to conflicting workloads. The event was attended by 25 stakeholders including some who were interviewed in either of the qualitative studies. We produced two public-facing blogs on the event; one focussed on how the event was designed, and the other on reflections and outputs – the latter I co-authored with HJ (448, 449).

We co-designed the half-day showcase event to be participatory in nature to give participants insights for the type of work we had completed as a group. This included three participatory activities **(Appendix D)** in the form of a:

1. 'Drawing Concepts' exercise: asking participants to present 'what co-research means to them'
2. Discussion and priority setting exercise: to explore which research findings should be prioritised, how, and with whom
3. Group collage exercise on principles of co-production co-created with a group of co-researchers

The event was recorded and a short video was produced by a filmmaker to highlight why co-production is important for HIV research **(Figure 4.7)**. Notes from the event were also visually recorded by an illustrator **(Figure 4.8)**.

Table 4.3: Dissemination activity and impact to date

Date	Activity (type)	Involvement[1]	Audience	Reach/Impact[2]
Oct 2021	Conference (reflective **workshop**) on 'Building and Sustaining Relationships in Participatory Action Research' at online NCRM Research Methods conference alongside Imperial researchers	Co-produced	Academics, NGOs, community organisations, charities	39 participants
Nov 2021	Summary **infographic** of preliminary results from the study	Co-designed	People living with HIV (e.g. study participants); Positively UK supporters	19 participants
Feb 2022	Development and open access deposit of **training resource** (436)[3]	Informed	Academics, NGOs, community organisations, charities	Over 370 downloads[4] and over 7,700 impressions[5]
Mar 2022	**Podcast** episode with Positive Effect's 'Pozcast' to share reflections and experiences featuring academic researcher and peer researcher (446)	Engaged	International	-
Apr 2022	**Workshop** on 'Exploring the depths of peer research: building relationships, challenging power dynamics and the role of effective training' at Imperial College London's Engagement Day	Co-produced	Academics (staff/students)	Approx. 20 participants
Jul 2022	HIV co-production showcase **event** on research findings to key stakeholders[6]	Co-produced	People living with HIV (including study participants); clinicians; researchers; policymakers; charities	25 stakeholders
Jul 2022	**Conference ePoster** at AIDS 2022 (331)	Co-designed	International	-
Jul 2022	Development of a short **video** sharing our experiences of working together and why we selected a co-production approach to the project	Co-designed	International	-

[1] According to "ladder of co-production" (447).
[2] Correct as of 22 November 2022.
[3] I have since deposited an additional document to Spiral on supporting co-researchers (433).
[4] Statistics from Spiral deposit.
[5] Promotional Twitter post.
[6] Included a participatory activity to prioritise research findings with reflective blogs published on the event (448, 449).



Figure 4.7: Screenshot from video filmed at showcase event in July 2022. Film-maker: Ed Rolfe. Patient Experience Research Centre, Imperial College London Copyright © 2022 (450).

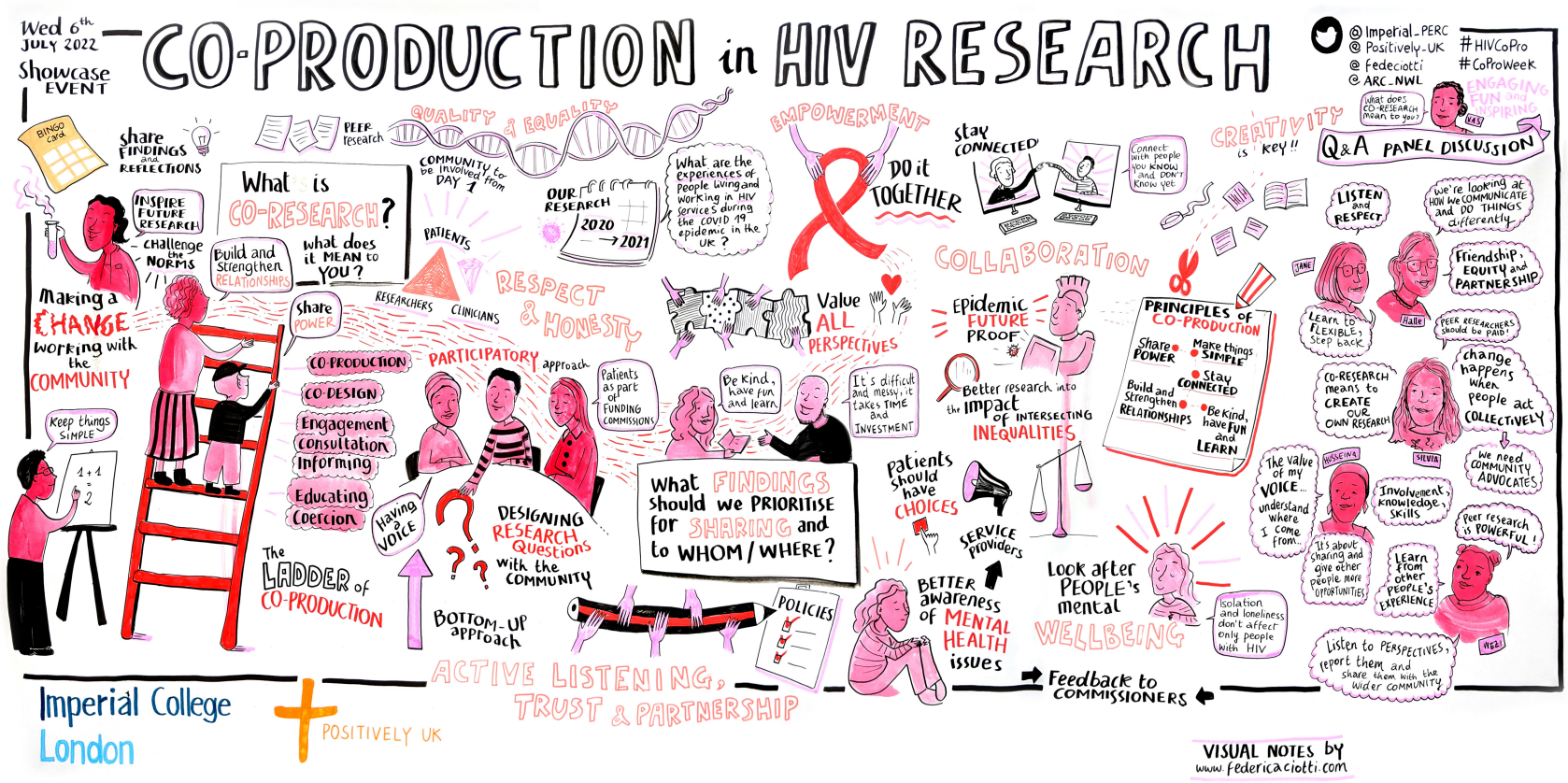


Figure 4.8: Visual notes from showcase event. Illustrator: Federica Ciotti. Patient Experience Research Centre, Imperial College London Copyright © 2022 (449).

4.6 Discussion

The persistent nature of health inequalities during the COVID-19 pandemic, relating to chronic conditions and social determinants, has been described by Bambra et al. (1) and builds on syndemic theory which was first proposed by Singer (427). COVID-19 and inequalities are a 'syndemic pandemic' that has been referred to as the "perfect storm" as it is based on a cumulative effect of several negative factors (1, 451). Bambra (260) describes pathways to inequalities in emerging infectious disease pandemics, such as COVID-19, as inequalities in treatment, exposure, susceptibility, and transmission.

4.6.1 Key findings

Our study showed that COVID-19 posed challenges for people living with HIV and like the work of Bambra et al. (1, 260, 451), the pandemic highlighted inequalities in the personal lives of the participants, including their experiences of accessing adapted HIV services. Some inequalities had existed before the pandemic; however, most were exacerbated by the pandemic itself.

First, before the pandemic, there were issues around the stigma of living with HIV, concerns around mental health and positive and negative experiences of accessing HIV care and relationships with clinicians (including HIV team and GP). However, social support, including support groups, could offer both practical advice and emotional support to help overcome the challenges of living with HIV.

Secondly, participants emphasised how the pandemic affected their daily lives, their sense of self, and their feelings of connection with others. Although most of the people interviewed did not require specific support to meet needs (e.g. food, housing, finances), clear examples of more vulnerable and marginalised people living with HIV who had been disproportionately impacted were identified. Specific examples were given of negative experiences of navigating their HIV status within the workplace but also in the embodiment of SARS-CoV-2. Participants were frustrated with the government's pandemic response but were overall positive about the progress made in developing a COVID-19 vaccine. However, several participants shared negative experiences accessing NHS services during the pandemic and/or were concerned about the risk of acquiring SARS-CoV-2 in healthcare

settings; the latter has been described in studies in other NHS settings (452).

Thirdly, as described by some of our participants, it has been argued that people living with HIV are now experiencing their "second pandemic" (255, 453). Nuanced comparisons were made on stigma and discrimination experienced in the early days of the HIV epidemic and COVID-19, and uncertainties of transmission during the early phases. However, overwhelmingly, participants highlighted mental health and the intricacies of navigating the pandemic whilst living with HIV; for instance, being mistakenly added to the NHS shielding list and seeking COVID-19 guidance specific to living with HIV from their clinic or HIV care team. Additionally, adaptations made to HIV services (e.g. postponed appointments, shifting from face-to-face to teleconsultations, and receiving longer length prescriptions) were generally well accepted. However, this was not the perception of all – some felt that the quality of their care had decreased and felt less connected to their HIV care team. Several were concerned that some of these approaches may continue in the future, although most would accept a blended approach of face-to-face and online/teleconsultations. Concerns were raised about the "loss of the HIV specialism" and the possibility of HIV care moving from specialist services to primary care.

4.6.2 Strengths, limitations and reflections

To conduct a meaningful study of people living with HIV, I proposed working closely with HIV community groups with strong relationships with people in the community to ensure that this work facilitated a dialogue for change (454). This was evident through the extensive opportunities that have arisen since collaborating with co-researchers; I have worked with them since the start of amending documents for ethics to sharing our findings and learning of working together through traditional academic channels and non-academic media (e.g. podcasts and events) (446). As detailed above, I provided co-researchers with the opportunity to reflect on their experiences early on during the project; however, I did not receive as much engagement with the reflection process towards the end. Therefore, embedding specific milestones for reflection (e.g. specific reflective meetings) would be helpful in future projects.

The initial recruitment to the study was slow, which meant that there were some time delays between our peer researchers being trained to interview and conducting their first interview. Therefore,

I suggested that peer researchers shadow two interviews with experienced qualitative researchers (VP, JB) and be shadowed during their first interview and given feedback. This helped to give peer researchers the confidence needed to then do an interview alone. I also amended our ethics application to provide an honorarium payment to interview participants, which significantly helped with study recruitment. In addition, participatory approaches require an academic researcher to have extensive experience but also time and resources to allocate training and supporting of co-researchers (410, 418, 421, 422). Finally, previous research has shown that some ethical dilemmas may arise when peer researchers share emotions or experiences with research participants (418, 455). I found that providing time to debrief after interviews, first a short email immediately afterwards, and then scheduling a call if specific issues arose, and/or giving space at research team meetings, allowed peer researchers to reflect on these concerns.

All interviews and co-researcher meetings were conducted online due to the COVID-19 pandemic. Similarly to previous reports in the literature, some experienced technical issues although these were mostly resolved (e.g. connectivity difficulties, quality/reliability of calls) (360). Using established features of Zoom including 'locking rooms' and enabling the 'waiting room' helped to protect the privacy of participants (456). Additionally, it was important to ensure that co-researchers were aware of features to change their background (either blur or select a virtual background) to protect their own privacy (456). We reflected, as a group, on the choice of online interviews which could expand the issue of digital exclusion; however, we also provided the option for telephone interviews and renumeration for time and Wi-Fi/data costs according to the NIHR guidelines (432) to reduce barriers to participation. There is, however, the possibility that some people did not decide to participate due to not having access to technology. Digital engagement generally helped to increase the diversity of those interviewed as we were not restricted to London. Overall, our co-researchers had access to the technology required however, working with Positively UK we were able to source further equipment for one of our peer researcher's before conducting interviews. We also developed guides where tasks required technology to be used (e.g. Zoom for interviews) (433). During the project, we used several different platforms (Kahoot, Padlet and Google Jamboard), although the success of these varied.

Some elements of the project lent themselves more easily to participatory approaches than others; for instance, training and support for interviewing skills and techniques were easy to manage as

both peer researchers had experiences in professional or personal settings (e.g. through work or volunteering as peer mentors). However, conducting a truly participatory qualitative data analysis was more challenging, which may be partly due to the timing of the analysis, as it clashed with summer holidays (July-August 2021), where co-researchers had less time to participate, but also we provided only one session on coding and developing a coding framework for individuals new to thematic analysis. Only one peer researcher (KD) actively coded their assigned transcripts from interviews they conducted, and I met with him to discuss the process, codes he had generated, and compared them to my own coding framework. The other co-researchers (HH, WT) met with an academic researcher (JB) after they had read one transcript and one co-researcher (JA) was unable to participate in the coding exercise. Training was based on the DEPICT model (438), however, most of the knowledge and insights were gained from one-on-one meetings as well as a group meeting held in September 2021. This was because the transcripts were lengthy due to the nature of the interview times. Therefore, our approach combined elements from both the DEPICT model as well as participatory theme elicitation whereby a sorting card method is used (457). Our team tended to work well with the first few steps of the DEPICT model, however, became less engaged with later steps, which involved more engagement; in other words, the group responded to "dynamic reading" but became less engaged with the "participatory coding" (438). I also found that KD had conducted 'descriptive' and 'holistic' coding (458) rather than categorising them into a framework (or shifting to an axial coding approach); this happened instead during our one-to-one meeting. Upon reflection, next time coding together in a group setting first may help to alleviate any issues that arise at this stage, as the DEPICT model is dependent on good facilitation and coordination, yet it was a new methodology for me and the research team (438). On the other hand, the group worked well with the "collaborative analysing" stage of the DEPICT model that helps to make sense of the data and engaged with the stage of "translating" (438).

Conducting participatory approaches in doctoral research projects has been shown to improve the self-esteem of the researcher as well as the well-being of students by alleviating experiences of isolation (459). On a personal level, the project was very motivating for me as a doctoral researcher; working with others during the pandemic and engaging the community helped to keep me motivated and engaged with the topic particularly when social distancing measures were lawfully mandated. I was

also interested in developing more meaningful research for people living with HIV and disseminating research findings and learning using creative approaches (446). Building genuine connections with the co-researchers was essential; I tried to navigate this by organising activities to get to know each other on a personal level (e.g. icebreakers at the beginning of meetings to share stories and experiences), organising a virtual film screening, and sending gifts to everyone at the start and end of the project to recognise their contributions.[22] I learnt a great deal from the co-researchers; particularly the importance of being flexible to adapting to their situations, needs/requirements but also in keeping open channels of communication. For instance, setting expectations at the start for how long ethics might take and the need to submit amendments to ethics when required. This aligns with the concept of "participatory impact" whereby a researcher experiences a "change in the thinking, emotions and practice" (461). It was incredibly fulfilling to see peer researchers grow in confidence over the 6 months, particularly after their first interview. Their overwhelmingly positive feedback has allowed us to think about how we can continue to develop these relationships after the project funding ended.

4.6.3 Significance of research, study implications and future research

This study provided the opportunity to build new relationships, and strengthen existing ones, with individuals living with HIV a major component of which involved upskilling community members as co-researchers. Our co-researchers represented a diverse group; they included two cisgender men and three cisgender women of African, Indian, Italian and White British backgrounds living in London, the Northeast and Southwest of England.

Using a qualitative study design, we were able to record a richer, contextual understanding of the experiences of people living with HIV during the COVID-19 pandemic, as well as their support system. For example, the study highlighted growing concerns about mental health, loneliness, and isolation experienced by some people living with HIV, including both new experiences and pre-existing mental health conditions worsened by the pandemic. Social support, including personal relationships (e.g. family, friends, partners) as well as HIV support groups have helped to address some of these issues; this aligns with research findings on mental health during the pandemic (462, 463).

[22] I sent all co-researchers a tea gift set so we could virtually enjoy a tea together at our first meeting and sent them a copy of a research handbook for co-researchers (460) at the end of the project which had informed much of our training.

The findings indicate how people living with HIV have perceived changes to their HIV care during the pandemic and their hopes for future service delivery and design. Furthermore, we were able to gain a deeper insight into the various social factors impacted by the pandemic and the role of the Third Sector in helping to support the most vulnerable groups living with HIV. Integrated, person-centred HIV services with non-statutory organisations appeared to be the preferred approach by those accessing services and could help to tackle the wider determinants of health which may be impacting on engagement in HIV care. These services will ultimately help to address the needs of people living with HIV more holistically to improve health-related quality of life and health outcomes (92, 464).

We support several of the future co-production recommendations first highlighted by Dewa et al. (417); although this study involved young people in mental health research, there are transferable recommendations for working with people living with HIV. Specifically, we also recommend advocating for flexibility in budgeting by both funders and governing bodies, as well as recognising the contribution of co-researchers through the provision of formal accreditation or a personalised certificate to support their personal development (417). Similarly, research funders should continue to mandate how communities have been involved in developing grant applications, including prior engagement activities (465). Finally a need remains for standardised guidelines for HIV researchers and clinicians interested in and/or currently utilising participatory approaches in their practice specifically around tools to evaluate impact and to be more explicit and transparent about their engagement (465). This would help to address issues of evaluating the impact of participatory approaches (patient/public involvement) which are frequently referenced in the literature (466, 467).

4.7 Conclusion

In this Chapter, I have described how COVID-19 has impacted the lives of a sub-sample of people living with HIV who participated in the 2017 Positive Voices study. I identified how a 'syndemic' of HIV and COVID-19 has highlighted poorer mental health, which was exacerbated by government restrictions and perceptions of the pandemic. Involving people living with HIV as co-researchers helped record richer and more meaningful accounts while simultaneously training people in the community

to conduct qualitative research projects in the future. The pandemic led to rapid adjustments to HIV services, with some of those adaptations likely to continue in the future. However, this study emphasises the need to implement any long-term changes to HIV care in conversation with service users to ensure these do not widen inequalities in accessing care nor HIV outcomes. These conclusions complement those identified in **Chapter 3**.

5

A quantitative exploration of the social determinants and health inequities that exist among people living with HIV using 2017 Positive Voices survey data

In **Chapter 2**, I presented the findings of a systematic review and meta-analysis that identified associations between social determinants and clinical outcomes.

In **Chapter 4**, I presented the findings of an interview-based study of people living with HIV in the UK who were sampled from the 2017 Positive Voices study who shared experiences during the COVID-19 pandemic. Mental health was a key theme that underpinned much of the interviews.

In **Chapter 5**, I will investigate the association between self-reported mental health and social determinants of health measured in the 2017 Positive Voices study.

BD and HW provided comments on this chapter.

5.1 Abstract

It is well established that people living with HIV report poorer mental health than the general population. I aimed to identify the associations between social determinants and mental health outcomes among participants in the 2017 Positive Voices study. I identified probable mental ill health using a 12-item General Health Questionnaire (GHQ-12) score≥4. Multivariate logistic regression was used to assess associations with demographic characteristics (age, gender, ethnicity, sexuality), social determinants (education, employment, housing, receiving welfare benefits, keeping up with bills/credit payments and having enough money to meet basic needs), and clinical measures (year of diagnosis and CD4 count) with models built using purposeful selection. Over 29% (n=1,261) of eligible study participants self-reported symptoms of probable mental ill health (GHQ-12≥4). I found that people who were unemployed, economically inactive, receiving welfare benefits, and behind with bill/credit commitments were more likely to self-report GHQ-12≥4. The greatest difference was amongst those who were unemployed compared to those who were employed (aOR 2.43, 95% CI 1.62, 3.64), after adjusting for demographics, all other social determinants and clinical measures. There were also significant associations with age, gender, ethnicity, and socioeconomic disadvantage with an increased likelihood of GHQ-12≥4 among younger (aged 18-34) than older (aged 65+) adults, cisgender women than cisgender men, individuals of White British compared to Black African ethnicity and those with less compared to more financial stability.

5.2 Introduction

In 2018, London became the first city worldwide to exceed the UNAIDS 95:95:95 targets for diagnosis, treatment, and viral suppression (16, 468). Although improvements have been made in relation to clinical outcomes, concerns remain for those diagnosed late, retaining people in care and health-related quality of life which has been further tested by the COVID-19 pandemic (17). These disparities are challenging the UK's ambitions for no new HIV transmissions by 2030 (16).

Sir Michael Marmot's seminal works on social determinants describe a social gradient of health with poorer health outcomes visible among those at increasing social disadvantage (165–167). A similar health gradient has been described among people living with HIV, particularly amongst those who "face economic adversity", and is visible by persisting health disparities (175–177). A dose-dependent relationship has been described between socioeconomic determinants and HIV care outcomes of retention in care, ART adherence and durable viral suppression (VL<200 copies/mL in past year) among people living with HIV in the US Centers for Disease Control and Prevention (CDC) Medical Monitoring Project (178). Here, the authors generated the 10-item Oregon Social Determinants of HIV Health Index across five domains of social determinants as defined by the CDC's Healthy People 2020 national objectives (education; economic stability; health; neighbourhood/built environment; social and community context) to explore the cumulative effects of social factors, rather than their individual influence (178, 469).

It is important to consider the health and well-being of people living with HIV, now a long-term condition with good life expectancy for people in care; there have been calls for a fourth UNAIDS target addressing good health-related quality of life (12, 41, 91, 470, 471). People living with HIV have been shown to have poorer mental health (e.g. clinical diagnoses) and health-related quality of life outcomes (e.g. EQ-5D) compared to people without HIV and/or scores than the average of the general population (97, 106, 472, 473). For example, the prevalence of mental illness among people living with HIV in the UK has been reported to be between 22-49% and 27-47%, in relation to anxiety and depression, respectively (473, 474). A recent cohort analysis (473) using nationally representative primary care electronic health records in the UK found that people living with HIV had higher rates of depression (aHR 1.94; 95% CI 1.68, 2.24), anxiety (aHR 1.38; 95% CI 1.15, 1.66) and

severe mental illness (aHR 2.18; 95% CI 1.41, 3.39) compared to people without HIV after adjusting for age, sex, ethnicity, geographical region, deprivation and health status (including smoking status).

A bi-directional relationship has been described between HIV and mental health due to biological, psychosocial, and economic factors (105, 473, 475, 476). Factors relating to poverty (e.g. ability to meet basic needs), physical symptom burden (or pain), HIV-related stigma and discrimination and social support have been associated with poorer self-reported health status and depressive symptoms among people living with HIV in the UK (208, 477, 478). For instance, the Positive Voices study found that MSM who were unemployed were 87% more likely (aOR 1.87; 95% CI 1.13, 3.11; p=0.022) to self-report depression (GHQ-12 score$\geq$4) after adjusting for age, financial security, smoking, binge drinking, co-morbidities, and self-reported pain than women (p=0.288) or heterosexual men (p=0.651) (477). Gooden et al. (473) found that those who were the most deprived had higher rates of depression than those least deprived; this association did not hold for composite mental illness, anxiety, or depression.[1] A linear, dose-response relationship has been described between duration of depression and HIV outcomes including risk of missing a HIV primary care appointment and treatment failure (VL$\geq$75 copies/mL) (476, 479). A threshold, rather than dose-response, association has been described between duration of depression (measured as percentage of days with depression) and rate of all-cause mortality among adults living with HIV accessing six primary care facilities across the US (479). These co-occurring diseases are likely embodied[2] and influence biological mechanisms that affect the immune system, such as oxidative stress and chronic inflammatory responses (476).

Some marginalised groups living with HIV are known to experience poorer health outcomes than others. For example, minority stress theory[3] has been proposed to explain the associations of poorer HIV outcomes found among sexual minority (non-heterosexual) populations, including immunological response (CD4+ cell count) and virological suppression (237). Ferlatte et al. (480) applied an intersectionality framework[4] to their stratified analysis of sexuality and partnership status and found that single Canadian gay men were 46% more likely (aOR 1.46; 95% CI 1.23, 1.72) to report a

[1] Social deprivation was measured according to employment status, household overcrowding and house/car ownership (473).
[2] Embodiment is a core concept in ecosocial theory which is further explained in **subsection 1.3.1**.
[3] Minority stress theory is further explained in **subsection 1.3.1**.
[4] Intersectionality is further explained in **subsection 1.3.1**.

syndemic[5] of two or more pyschosocial issues after adjusting for demographic factors compared to bisexual men and female-partnered MSM.[6]

There are concerns that the COVID-19 epidemic will have worsened the mental health of people living with HIV and may have compounded existing issues related to HIV prevention and care outcomes (105). Therefore, it remains necessary to characterise which social determinants may be associated with some of the trends seen to inform the design of appropriate and effective interventions to improve the health and well-being of people living with HIV. In addition, identifying vulnerable subgroups who display poorer health outcomes would assist with developing more targeted interventions which could be co-created with the HIV community.

My aim was to investigate the relationships between social determinants and mental health outcomes among Positive Voices study participants. I hypothesised that socioeconomically disadvantaged individuals, or those "less privileged", would display poorer outcomes than those "more privileged" which may be explained by racism, sexism, heterosexism, gender binarism and classism (161, 481).

5.2.1 Research questions

1. What is the contribution of social determinants to inequalities in HIV outcomes?

2. What is the relationship between social determinants of health and self-reported mental health outcomes among people living with HIV in the UK?

5.2.2 Aim and objectives

Aim

To identify the demographic, social and clinical determinants that influence the health and well-being of adults ($\geq$18 years old) living with HIV in the UK who participated in the 2017 Positive Voices survey.

[5] The authors (480) confirmed the presence of a syndemic by exploring the association between the outcome (psychosocial issues) and condomless sex including the reinforcing effect of one on the other (calculated by percentages, crude odds ratios and multivariable logistic regression).

[6] One of the subcategories in this study was "men partnered or married to a woman (whether gay, bisexual or straight identified)" which were coded as "female-partnered MSM" (480).

Objectives

1. To explore the relationship between determinants and self-reported mental health (GHQ-12 score) using logistic regression.

2. To build a multivariate logistic regression model and explore interactions between and across variable groups (demographic, social, and clinical) and the mental health outcome.

3. To build these models by using both a theoretical and data driven approach.

4. To identify the social determinants that are associated with self-reported mental health among groups identified to experience historical and current health inequalities through stratified analysis, according to gender identity, ethnicity and sexuality.

5.3 Methods

5.3.1 Data source

2017 Positive Voices Study

The Positive Voices cross-sectional study is conducted every four years, with the first version was completed between January and September 2017 at 73 clinical sites in England and Wales (208, 482). The study was first piloted in 2014 and expanded in 2017, with data linked to the HIV and AIDS Reporting System (HARS) of clinical and epidemiological data (483–487).

To be eligible, study participants had to be 18 years or older, living with HIV, a resident of and accessing outpatient NHS HIV clinics in England and Wales and reported to the national surveillance system (Survey of Prevalent HIV Infections Diagnosed, SOPHID) in 2015 (488). Participants were sampled by two stages: first, by inviting any clinic in England and Wales with five or more patients in 2015, and secondly, taking a random sample from those who presented at participating clinics in 2015 (208). Surveys were distributed either in person (at HIV clinics), by post or by email and were completed either online or by paper (208). Approximately 20% (n=12,144) from each clinic were eligible, with 8,463 successfully invited to take part and 4,422 respondents completing the survey (52.3% response rate); this represents about 5.3% of people living with diagnosed HIV in England and Wales (208).

5.3.2 Recoding variables

I received a dataset that had already been cleaned and processed by the Positive Voices team; however, not all variables were in the format required. Therefore, I recoded the variables, the details of which are outlined below and in **Appendix E**. Continuous data were transformed into categorical variables.

Exposure variables

Independent variables were demographic characteristics, social determinants, and those related to HIV care. Demographic characteristics were age, gender identity, country of birth[7], ethnicity, and sexuality.

Social determinants were highest educational attainment[8], current work situation[9], current living situation[10], source of income in the past year[11], ability to keep up with household bill and credit commitments in the past year (Likert scale: up to date, behind with some, behind with all), enough money to meet basic needs including food, rent, gas, electricity, and water (Likert scale: yes – always; yes – most of the time; yes – sometimes; no), and annual total household income before tax.

I considered factors related to HIV care which were virological suppression (copies/mL), CD4 count (cells/mm^3) and year of HIV diagnosis. Viral load counts were dichotomised (detectability at 50 copies/mL) and CD4 counts were categorised, according to BHIVA guidelines (46, 489).[12] Due to the high proportions of missing data, I asked the Positive Voices team at the UKHSA for updated clinical measures (specifically CD4 and viral load counts) when conducting this analysis in May 2022. As a result, I received an additional 11 observations (five CD4 and six viral load counts) which were extracted from the HARS database on 9 May 2022. I combined these with the existing dataset using the merge function in Stata. I used this dataset for subsequent analyses.

Outcome variable

Mental health was determined using the 12-item General Health Questionnaire (GHQ-12) screening instrument (490). The GHQ-12 is a well-validated tool across multiple populations and countries (including England), which has been developed to be used in GP settings to screen for probable mental ill health (490–492). GHQ-12 identifies the likelihood of psychiatric disturbance across 12 domains including sleep, concentration, and self-worth (490, 493). Each domain asks the respondent

[7] I categorised this variable according to 2019 World Bank classifications (278).
[8] This was recoded by the Positive Voices team according to the ISCED (194).
[9] This was recoded by the Positive Voices team to match UK ONS statistics whereby there are three categories: employed, unemployed and economically inactive.
[10] I recoded the data based on home ownership status.
[11] I recoded data to indicate whether individuals received welfare benefits or not (see **Appendix E** for further details).
[12] Categories used for CD4 counts (cells/mm^3) were <200 (very advanced disease), 200-349 (recommended 3-monthly monitoring), 350-499 (recommended 6-monthly monitoring) and 500+ (recommended annual monitoring) (46).

to rate on a Likert scale how they have felt in relation to their symptoms (from worse to better than usual), with six questions positively phrased and six negatively (493). Research has shown that GHQ is able to detect "functional psychoses such as schizophrenia or psychotic depression" despite this not being the specific purpose of the design, and ultimately can be viewed as a "pure state measure"; the measure reports "how much a subject feels that their present state is unlike their usual state" (490, 494, 495).

I then used the GHQ coding method '0-0-1-1' to score the responses (total possible: 12) and the individuals were classified into 3 groups: 0 (no evidence of probable mental ill health), 1-3 (<optimal mental health) and 4+ (probable psychological disturbance or mental ill health) (490). This coding method is considered preferable to eliminate response bias (490, 496).[13] A threshold of 4 has been selected in accordance with previous surveys conducted in England (493) and among people living with HIV (496).

5.3.3 Statistical analysis

Analyses were performed using Stata / SE 15.1 (College Station, TX: StataCorp LLC) (497).[14]

I have presented the frequencies of independent and dependent variables and the results of the chi-square tests for the association between categorical independent variables in **Appendix E**; in other words, I explore how closely related these variables are to one another. I tested for associations between most recent CD4 count and viral load measurement using Spearman's rank-order correlation and visually presented using a scatterplot (**Appendix E**). I also cross-tabulated self-reported pre-existing mental health conditions (including anxiety, depression and bipolar disorder) and GHQ-12 score to explore longstanding and acute changes to mental health. Prefer not to say and "don't know" responses were coded as missing and missing data were handled by complete case analysis whereby each analysis was limited to people with complete data for the necessary variables (500).

I performed logistic regression to assess the unadjusted and adjusted associations between exposure and outcome variables. Individual covariates significant at $p<0.20$ were included in multivariate

[13] The GHQ scoring method "eliminates any errors due to 'end-users' and 'middle-users' since they will score the same irrespective of whether they tend to prefer columns 1 and 4 or columns 3 and 3"; for example, GHQ scoring (0011) vs. simple Likert scoring (0123) (490).

[14] The following additional packages used to create the plots presented: grc1leg, grstyle (498) and palettes (499).

models (501). The baseline categories were the most observed or the category of lowest/highest socioeconomic advantage. Model building was driven by both the data (i.e. goodness of fit tests) and theory (see **Appendix E**) with my approach guided by Gomez et al. (502) and based on purposeful selection (501). This model building process helps identify possible causal and confounding associations (502); I controlled for three groups of determinants which may fall on the causal pathway (demographic characteristics, social factors, and clinical measures). I present the most parsimonious model in the Results.

First, I added the selected demographic variables one at a time. Secondly, I built a model with all social determinant variables. Thirdly, I added all the HIV measures to be included one at a time. I then tested for relationships between the three groups of covariates and created a final model with all covariates. I assessed each model using the Hosmer-Lemeshow goodness-of-fit as well as the Likelihood Ratio Test (503) using the estat gof command and the lrtest command whereby each model was compared to the full model using estimate store memory in Stata. I tested model fit by using an adapted stepwise regression approach (504) whereby I purposively removed a variable from models 1 (demographics only), 2 (social determinants only) and 3 (clinical variables) based on where collinearity may exist according to theory; for instance, country of birth and ethnicity. Statistical significance of the Hosmer-Lemeshow test output indicates that the full model (i.e. where all variables are included) is preferred[15] – see **Appendix E** for further details. I then used these results to build models combining the groups of variables (excluding any variables that were significantly affecting model fit): demographic and social determinants (model 4); clinical and demographic (model 5); clinical and social determinants (model 6) and all variables (model 7).

I ran a sensitivity analysis *(post-hoc)* of the full multivariate model which excluded a variable with high number of missing observations (CD4 count). I then tested for interactions between groups of categorical variables by attempting to build a fully saturated, multiplicative model with interaction terms for each variable within each independent group type (demographics, social determinants and clinical measures).[16] I also ran post-estimation tests for collinearity (including variance inflation factor) between independent variables using the *collin* package (507) whereby cases were only analysed

[15] In other words, a statistically significant Hosmer-Lemeshow test indicates poor model fit (505).

[16] This method was suggested by Tsai and Venkatarami (506) as a way to investigate interactions based on syndemic theory.

where the dependent variable (GHQ-12 score) was not missing.

Finally, I performed *post-hoc* stratified analysis of various subgroups according to demographics (gender, sexuality, ethnicity), based on the findings from initial model building, using the bysort command in Stata (outlined in **subsubsection 5.4.4** and **Appendix E)**. I generated combinations of stratified groups based on the most common sub-categories; specifically, in relation to gender and ethnicity[17] (White British cisgender men and Black African cisgender women) and sexuality and ethnicity (White British gay or lesbian/homosexual and Black African straight/heterosexual).

5.3.4 Ethical and institutional permissions

The Positive Voices study received ethical approval from the Health Research Authority and the London Harrow NHS Research Ethics Committee (Project ID 13/LO/0279). To access this data as part of my PhD, I signed a Collaborative (CASE) Student Agreement between Imperial College London and Public Health England. I also hold an Honorary Contract with Public Health England.

[17] The second most common subgroup was any other White cisgender men (n=253) however, I chose to run the model based on the third most common group as Black heterosexual women (n=241) are identified as a population disproportionately affected by HIV in the UK (508).

5.4 Results

Figure 5.1 outlines the study cohort at each stage of analysis.

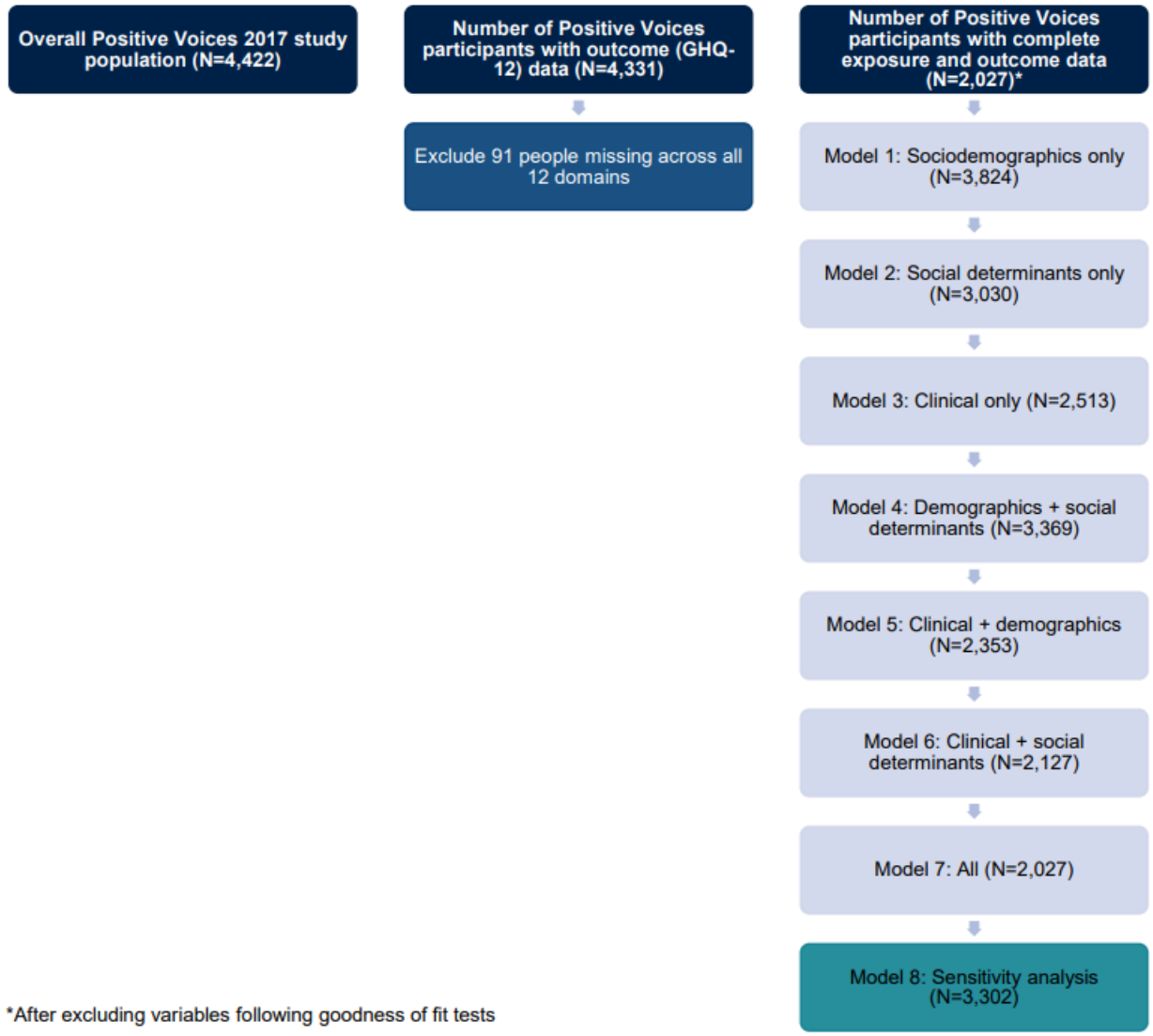


Figure 5.1: Sample size at each stage of analysis based on complete case analysis.

5.4.1 Summary statistics

Here, I present initial descriptive statistics of the study population.

Demographics

Overall, when excluding missing/prefer not to say data, respondents were predominantly: cisgender men (n=3083, 72.1%), aged 45-54 years (n=1539, 35.7%; mean age of 48 years (SD=11.1, range

18 to 85) with most born in a high-income country according to World Bank classifications (n=2754, 64.7%) – over half were born in the UK (n=2197, 51.6%). Most participants identified as being of White ethnicity (n=2625, 60.3%) and gay or lesbian/homosexual (n=2141, 51.9%).

Table 5.1: Demographic characteristics of Positive Voices survey participants

Demographics	**Overall (N=4,422)**		**Excluding missing**		**Complete cases**	
Age group (N=4,316)	**n or mean**	**% (SD)**	**n**	**%**	**n or mean**	**% (SD)**
18-34	490	11.1	490	11.4	471	11.2
35-44	1,125	25.4	1,125	26.1	1,086	25.8
45-54	1,539	34.8	1,539	35.7	1,508	35.9
55-64	839	19.0	839	19.4	821	19.5
65+	323	7.3	323	7.5	316	7.5
Missing	106	2.4	-	-	-	-
Age at time of survey	48.1	11.1	-	-	-	-
Gender identity (N=4,276)	**n**	**%**	**n**	**%**	**n**	**%**
Cisgender man	3,083	69.7	3,083	72.1	3,041	72.8
Cisgender woman	1,165	26.4	1,165	27.3	1,134	27.2
Transgender woman, non-binary or in another way	28	0.6	28	0.7	-	-
Prefer not to say	5	0.1	-	-	-	-
Missing	141	3.2	-	-	-	-
Country of birth (N=4,262)	**n**	**%**	**n**	**%**	**n**	**%**
High-income country – UK	2,197	49.7	2,197	51.6	2,155	51.9
High-income country – Other	557	12.6	557	13.1	545	13.1
Low/middle income country	1,508	34.1	1,508	35.4	1,455	35.0
Missing/Unclassified	160	3.6	-	-	-	-
Ethnicity (N=4,357)	**n**	**%**	**n**	**%**	**n**	**%**
White British	2,116	47.9	2,116	48.6	2,076	48.9
Any other White background	509	11.5	509	11.7	502	11.8
Black African	1,156	26.1	1,156	26.5	1,113	26.2
Any other Black background	180	4.1	180	4.1	171	4.0
Mixed background	149	3.4	149	3.4	144	3.4
Asian background	140	3.2	140	3.2	133	3.1
Any other ethnic background	107	2.4	107	2.5	106	2.5
Missing	65	1.5	-	-	-	-
Sexuality (N=4,123)	**n**	**%**	**n**	**%**	**n**	**%**
Straight/heterosexual	1,740	39.4	1,740	42.2	1,709	42.0
Gay or lesbian/homosexual	2,141	48.4	2,141	51.9	2,130	52.3
Bisexual	181	4.1	181	4.4	177	4.3
Asexual/other	61	1.4	61	1.5	55	1.4
Prefer not to say	76	1.7	-	-	-	-
Missing	223	5.0	-	-	-	-

Social determinants

When excluding missing and prefer not to say data, over 90% (n=3,842) of people had a formal educational qualification (ISCED classification$\geq$3), almost two-thirds were employed (n=2736, 65.0%) and nearly all had stable housing (n=3896, 92.8%). Alternatively, 6.5% (n=267) of participants achieved an educational level of primary school or less (ISCED classification 1/2), over one-third (35.1%, n=1476) were either unemployed or economically inactive and 7.2% (n=303) were in unstable/other housing. Most were financially secure; they were able to keep up with household bills and credit commitments in the past year (n=2850, 72.8%), had enough money to meet basic needs at least most of the time (n=3087, 75%). Over half (n=1938, 57.5%) had an annual household income more than or equal to the median UK household income in 2017 of £27,300 according to the ONS Household Finances Survey (509). However, over one-quarter (27.1%, n=1063) were behind with some/all household bills and credit commitments in the past 12 months, 11.6% (n=474) did not have enough money to meet basic needs and 42.5% (n=1430) had a total annual household income before tax in the past year of $<$£20,000.

Table 5.2: Social determinants of Positive Voices survey participants

Social determinants of health	Overall (N=4,422)		Excluding missing		Complete cases	
Highest educational level (N=4,109)	**n**	**%**	**n**	**%**	**n**	**%**
ISCED1/2: Primary or less	267	6.0	267	6.5	263	6.5
ISCED3: Upper secondary education (to age 18)	1,603	36.3	1,603	39.0	1,581	38.9
ISCED4/5: Technical and vocational education and training	410	9.3	410	10.0	404	9.9
ISCED6: Bachelors or equivalent level	1,167	26.4	1,167	28.4	1,157	28.5
ISCED 7/8: Postgraduate degree	662	15.0	662	16.1	658	16.2
Missing	313	7.1	-	-	-	-
Current work situation (N=4,212)	**n**	**%**	**n**	**%**	**n**	**%**
Employed	2,736	61.9	2,736	65.0	2,705	65.1
Unemployed	421	9.5	421	10.0	406	9.8
Economically inactive	1,055	23.9	1,055	25.1	1041	25.1
Missing	210	4.8	-	-	-	-
Current living situation (N=4,199)	**n**	**%**	**n**	**%**	**n**	**%**
Own or purchasing house or flat	1,625	36.8	1,625	38.7	1,608	38.8
Renting – privately owned	1,063	24.0	1,063	25.3	1,051	25.4
Renting – council/housing association	1,208	27.3	1,208	28.8	1,189	28.7
Unstable or other	303	6.9	303	7.2	292	7.1
Missing	223	5.0	-	-	-	-
Sources of income, past year (N=4,009)	**n**	**%**	**n**	**%**	**n**	**%**
Welfare or other state benefits	1,254	28.4	1,254	31.3	1,231	31.1
Any other income source	2,755	62.3	2,755	68.7	2,728	68.9
Prefer not to say	98	2.2	-	-	-	-
Missing	315	7.1	-	-	-	-
Keeping up with household bills and credit commitments, past 12 months (N=3,913)	**n**	**%**	**n**	**%**	**n**	**%**
Yes, up to date	2,850	64.5	2,850	72.8	2,826	73.0
No, behind with some	917	20.7	917	23.4	901	23.3
No, behind with all	146	3.3	146	3.7	143	3.7
Prefer not to say	144	3.3	-	-	-	-
Missing	365	8.3	-	-	-	-
Enough money to meet basic needs (N=4,094)	**n**	**%**	**n**	**%**	**n**	**%**
Yes, always	2,019	45.7	2,019	49.3	1,999	49.5
Yes, most of the time	1,068	24.2	1,068	26.1	1,057	26.2
Yes, some of the time	533	12.1	533	13.0	526	13.0
No	474	10.7	474	11.6	460	11.4
Missing	328	7.4	-	-	-	-
Total annual household income before tax, last year (N=3,368)	**n**	**%**	**n**	**%**	**n**	**%**
<median (£20,000)	1,430	32.3	1,430	42.5	1,410	42.3
≥median (£20,000+)	1,938	43.8	1,938	57.5	1,921	57.7
Don't know	314	7.1	-	-	-	-
Prefer not to say	314	7.1	-	-	-	-
Missing	426	9.6	-	-	-	-

HIV diagnosis and clinical monitoring

The mean duration of living with HIV at the time of the survey was 12.5 years (SD=7.4); in other words, they had been diagnosed in the early 2000s. A good immune response and virological suppression were common amongst the survey respondents. When excluding missing and prefer not to say data, overall, almost all participants had an undetectable viral load (n=3387, 93.0%); however, there was a high amount of variation with the data positively skewed (kurtosis=392.1; skewness=17.8) with a large amount of missing data (n=780, 17.6%). I also treated one measurement as an outlier and recoded it as missing (VL=634,531 copies/mL). Additionally, median CD4 count was 627 (IQR 464-809) indicating that most people had CD4 counts considered to be in the 'normal' range and would therefore, only be required to be monitored annually in clinic (if their viral load was suppressed)[18] according to BHIVA guidelines (46). However, more than one-third of the participants had missing CD4 count data (n=1,722, 38.9%).

Table 5.3: HIV diagnosis and clinical monitoring of Positive Voices survey participants

HIV diagnosis and clinical monitoring	**Overall (N=4,422)**		**Excluding missing**		**Complete cases**	
Year of diagnosis (N=4,287)	**n or mean**	**% (SD)**	**n**	**%**	**n or mean**	**% (SD)**
1981-1995	545	12.3	545	12.7	535	12.8
1996-2005	1,593	36.0	1,593	37.2	1,553	37.1
2006-2015	2,149	48.6	2,149	50.1	2,096	50.1
Missing	135	3.1	-	-	-	-
Years living with HIV	12.5	7.4	-	-	-	-
CD4 cell count (cells/mm^3) (N=2,700)	**n or mean**	**% (SD)**	**n**	**%**	**n or mean**	**% (SD)**
<200	69	1.6	69	2.6	67	2.5
200-349	224	5.1	224	8.3	219	8.3
350-499	519	11.7	519	19.2	503	19.1
≥500	1,888	42.7	1,888	69.9	1,845	70.0
Missing	1,722	38.9	-	-	-	-
Mean CD4 count (SD)	655.6	282.3	-	-	-	-
Median CD4 count (IQR)	627	464-809	-	-	-	-
Viral load count (copies/mL) (N=3,642)	**n or mean**	**% (SD)**	**n**	**%**	**n or mean**	**% (SD)**
Undetectable (VL<50)	3,387	76.6	3,387	93.0	3,301	93.0
Detectable (VL≥50)	255	5.8	255	7.0	248	7.0
Missing	780	17.6	-	-	-	-
Mean VL count (SD)	406.5	4428.5	-	-	-	-
Median VL count (IQR)	31.5	19-39	-	-	-	-

[18] In total, 66.9% (n=1,764/2,637) of eligible participants for analysis had CD4 counts over 500 cells/mm^3 and an undetectable viral load (VL<50 copies/mL).

Mental health

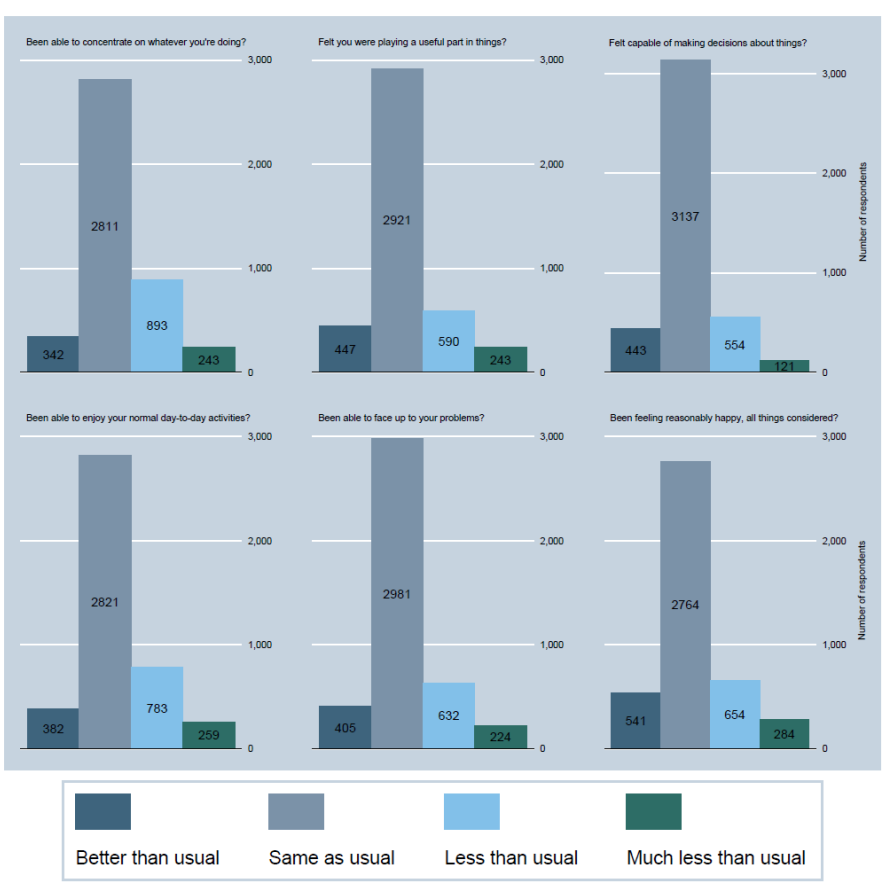
In this study, I was interested in a self-reported indicator of mental health, the GHQ-12 score (**Table 5.4**). I found that almost half (n=2155, 49.8%) indicated less than optimal mental health or probable psychological disturbance or mental ill health. Overall, the mean GHQ-12 score was 2.8 (SD=3.9). However, it is important to note that there is no universal threshold score, and these categories (particularly a score of 4+) are known to result in false positives (490, 493).[19] I also explored the frequency of pre-existing mental health conditions and found that the most frequently self-reported diagnoses were for anxiety (n=1064, 26.2%) and depression (n=1409, 33.9%). The frequency of responses in each GHQ-12 domain is reported in **Figures 5.2a and 5.2b**.

[19] The GHQ-12 survey authors have previously suggested that the average GHQ score of the survey population provides the best threshold to "achieve an optimal trade-off between sensitivity and specificity"; however, they also specify that research in primary care settings with a mean above 2.7 (such as the case in this survey population) works best using a 3/4 threshold (510).

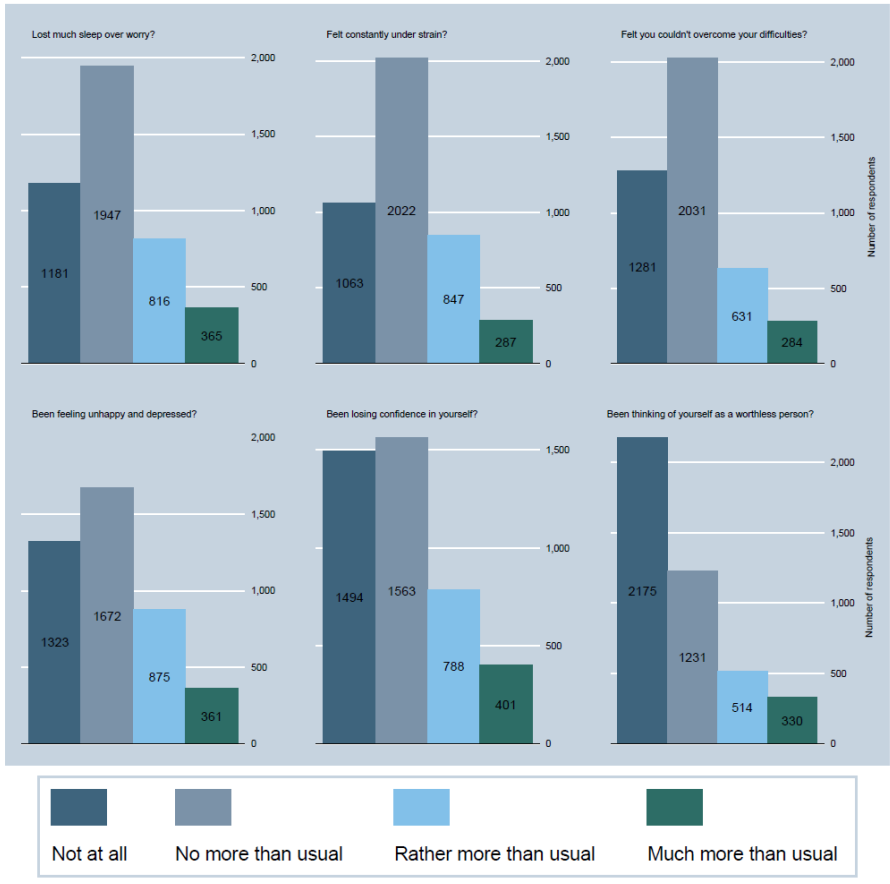
Table 5.4: Mental health and well-being of Positive Voices survey participants

Mental health and well-being	Overall (N=4,422)		Excluding missing		Complete cases	
GHQ-12 score (out of 12) (N=4,331)	**n**	**%**	**n**	**%**	**n**	**%**
No evidence of probable mental ill health (0)	2,176	49.2	2,176	50.2	2,167	50.4
Less than optimal mental health (1-3)	884	20.0	884	20.4	876	20.4
Probable psychological disturbance or mental ill health (4+)	1,271	28.7	1,271	29.4	1,261	29.3
Missing	91	2.1	-	-	-	-
Mental health conditions						
Anxiety (N=4,061)						
Yes	1,064	24.1	1,064	26.2	1,041	26.2
No	2,997	67.8	2,997	73.8	2,939	73.8
Don't know	77	1.7	-	-	-	-
Missing	284	6.4	-	-	-	-
Depression (N=4,152)[1]						
Yes	1,409	31.9	1,409	33.9	1,380	33.9
No	2,743	62	2,743	66.1	2,693	66.1
Don't know	58	1.3	-	-	-	-
Missing	212	4.8	-	-	-	-
Personality disorder (N=3,843)						
Yes	93	2.1	93	2.4	88	2.3
No	3,750	84.8	3,750	97.6	3,683	97.7
Don't know	43	1	-	-	-	-
Missing	536	12.1	-	-	-	-
Bipolar disorder (N=3,854)						
Yes	69	1.6	69	1.8	67	1.8
No	3,785	85.6	3,785	98.2	3,715	98.2
Don't know	39	0.9	-	-	-	-
Missing	529	12	-	-	-	-
Eating disorder (N=3,869)						
Yes	128	2.9	128	3.3	123	3.2
No	3,741	84.6	3,741	96.7	3,673	96.8
Don't know	36	0.8	-	-	-	-
Missing	517	11.7	-	-	-	-
Sleep disorder/insomnia (N=3,974)						
Yes	609	13.8	609	15.3	596	15.3
No	3,365	76.1	3,365	84.7	3,305	84.7
Don't know	56	1.3	-	-	-	-
Missing	392	8.9	-	-	-	-
Post-traumatic stress disorder (PTSD) (N=3,856)						
Yes	187	4.2	187	4.9	180	4.8
No	3,669	83	3,669	95.2	3,605	95.2
Don't know	54	1.2	-	-	-	-
Missing	512	11.6	-	-	-	-
Psychosis or schizophrenia (N=3,844)						
Yes	90	2	90	2.3	82	2.2
No	3,754	84.9	3,754	97.7	3,689	97.8
Don't know	41	0.9	-	-	-	-
Missing	537	12.1	-	-	-	-
Any other mental health conditions (N=3728)						
Yes	90	2	90	2.4	83	2.3
No	3,638	82.3	3,638	97.6	3,573	97.7
Don't know	15	0.3	-	-	-	-
Missing	679	15.4	-	-	-	-

[1] Including post-natal depression.



(a) Positively phrased questions



(b) Negatively phrased questions

Figure 5.2: Frequency of GHQ-12 domain responses

Missing data

Missingness varied across variables in the entire Positive Voices dataset **(Appendix E)**. For example, among social determinants, a large proportion of missing data/prefer not to say were recorded in annual household income (n=1054, 23.8%). Interestingly, a pattern emerges among some participants (n=267) who are missing any data relating to finances or income.[20] A substantial proportion (n=1722, 38.9%) were missing CD4 count data. 730 people were missing data on both CD4 and VL count. Among the GHQ domains, missingness remained low and ranged from 2.6% (domain 2: sleep loss) to 5.0% (domain 3: playing useful part) with a higher range of self-reports of mental health diagnoses (6.1%, depression to 15.7%, other mental health condition). The total proportion of missingness in the outcome variable was 2.1% (n=91); therefore, those eligible to be included in our analysis were 4,331.

5.4.2 Univariate analyses

Exploring collinearity between independent variables

I tested the associations between demographics, social determinants, and clinical measures to see how closely related they were by running chi-squared tests. I explored all independent variables including those excluded from the subsequent multivariate models **(Appendix E)**. All associations were significant at $p<0.05$ apart from:

- Age x viral load (p=0.089)
- Age x income (p=0.161)
- Gender x CD4 count (p=0.550)
- Gender x viral load (p=0.065)

I found no association between social determinants (particularly educational attainment) and clinical variables:

- Education x year of diagnosis (p=0.259)

[20] Financial/income variables: source of income, keeping up with bill/credit commitments, enough money for basic needs and annual household income.

- Education x CD4 count (p=0.078)
- Education x viral load (p=0.538)
- Ability to keep up with bill payments x CD4 count (p=0.077)
- Income x viral load (p=0.132)
- Year of diagnosis x viral load (p=0.582)

I also tested for associations within each group of variable "type", the detail of which are presented in **Appendix E**. Therefore, I proposed further investigation by means of logistic and multivariate regression to help unpack how determinants cluster with one another and are related to outcomes, whilst accounting for potential confounders.

Unadjusted logistic regression

Table 5.5 presents the findings of unadjusted logistic regressions for each exposure variable against the binary outcome (GHQ-12 score$\geq$4), excluding missing/prefer not to say observations.[21] Variables with any associations significant at p$<$0.20 or considered significant based on expert opinion were carried forward for multivariate analysis (502, 503).

Demographic characteristics

People living with HIV who were aged 65 or older were approximately 40% less likely (OR 0.61; 95% CI 0.43, 0.85) to self-report a GHQ-12 score$\geq$4 compared to those aged 18-34. Significantly lower odds were also found among those born in low/middle-income countries (OR 0.75; 95% CI 0.65, 0.87), of Black African ethnicity (OR 0.66; 95% CI 0.56, 0.78) and who identified as straight/heterosexual (OR 0.74; 95% CI 0.64, 0.85) compared to those born in the UK, of White ethnicity and who identified as gay or lesbian/homosexual.

[21] N.B. I dropped transgender women, non-binary or in another way category from the model due to low sample size (n=27).

Social determinants

Higher educational attainment was associated with a reduced likelihood of poorer mental health; those with either a Bachelors (or equivalent level) or postgraduate degree were 33% and 35% less likely, respectively, to report a GHQ-12 score$\geq$4 compared to those with primary level education or less (OR 0.67; 95% CI 0.50, 0.89 and OR 0.65; 95% CI 0.48, 0.88). However, being unemployed or economically inactive were 3-times more likely to report poorer mental health, compared with those employed (OR 2.99; 95% CI 2.41, 3.72 and OR 3.03; 95% CI 2.60, 3.53). Similarly, those living in council/housing association accommodation or unstable housing were over 2-times more likely (OR 2.13; 95% CI 1.80, 2.51 and OR 2.07; 95% CI 1.59, 2.70, respectively) to report GHQ-12 score$\geq$4 compared to homeowners. Similar directions of associations were found among those who received welfare benefits (OR 3.04; 95% CI 2.63, 3.51), were behind with some (OR 2.33; 95% CI 1.98, 2.73) or all (OR 5.22; 95% CI 3.69, 7.39) bill and credit commitments or who had an annual household income $<$£19,999 (OR 2.29; 95% CI 1.97, 2.67) compared to their counterparts. Individuals who reported having enough money to meet basic needs always (OR 0.20; 95% CI 0.16, 0.24), most (OR 0.42; 95% CI 0.33, 0.52), or some of the time (OR 0.65; 95% CI 0.51, 0.84), were less likely to report poorer mental health compared to those who did not.

Clinical

I also explored how factors related to HIV were associated with self-reported mental health; for example, those diagnosed more recently (since 1996) were less likely to report GHQ-12 score$\geq$4, compared to those diagnosed in the 'early days' of HIV. For instance, those diagnosed in 1996-2005 were 37% less likely (OR 0.63; 95% CI 0.51, 0.77) to have a GHQ-12 score$\geq$4, compared to those diagnosed in 1981-1995. Additionally, participants with higher CD4 counts (350-499 cells/mm^3) were 57% less likely (OR 0.43; 95% CI 0.25, 0.73) to report probable mental ill health compared to individuals with CD4$<$200.

Table 5.5: Unadjusted associations between independent and dependent variables (N=4,304)

		Probable mental ill health (GHQ12≥4)	
	n/N (%)[1]	OR (95% CI)[2]	p-values
Age (N=4,202)			
18-34	143/471	Ref	Ref
35-44	307/1086	0.90 (0.71, 1.15)	p=0.403
45-54	445/1508	0.96 (0.77, 1.20)	p=0.724
55-64	271/821	1.13 (0.89, 1.44)	p=0.326
65+	66/316	**0.61 (0.43, 0.85) *****	**p=0.003**
Gender identity (N=4,175)			
Cisgender man	917/3041	Ref	Ref
Cisgender woman	312/1134	0.88 (0.76, 1.02) *	p=0.096
Country of birth (N=4,155)			
High-income (UK)	684/2155	Ref	Ref
High-income (Other)	174/545	1.01 (0.82, 1.23)	p=0.933
Low/middle-income	377/1455	**0.75 (0.65, 0.87) *****	**p<0.001**
Ethnic group (N=4,245)			
White British	663/2076	Ref	Ref
Any other White background	163/502	1.02 (0.83, 1.26)	p=0.818
Black African	263/1113	**0.66 (0.56, 0.78) *****	**p<0.001**
Any other Black background	45/171	**0.76 (0.53, 1.08)**	**p=0.129**
Mixed background	47/144	1.03 (0.72, 1.48)	p=0.861
Asian background	34/133	**0.73 (0.49, 1.09)**	**p=0.127**
Any other ethnic group	34/106	1.01 (0.66, 1.53)	p=0.976
Sexuality (N=4,071)			
Gay or lesbian/homosexual	678/2130	Ref	Ref
Straight/heterosexual	438/1709	**0.74 (0.64, 0.85) *****	**p<0.001**
Bisexual	57/177	1.02 (0.73, 1.41)	p=0.919
Asexual/other	21/55	1.32 (0.76, 2.30)	p=0.320
Education (N=4,063)			
ISCED1/2: Primary or less	92/263	Ref	Ref
ISCED3: Upper secondary education (to age 18)	495/1581	0.85 (0.64, 1.12)	p=0.237
ISCED4/5: Technical and vocational education training	128/404	0.86 (0.62, 1.20)	p=0.376
ISCED6: Bachelors or equivalent level	306/1157	**0.67 (0.50, 0.89) *****	**p=0.006**
ISCED7/8: Postgraduate degree	170/658	**0.65 (0.48, 0.88) *****	**p=0.006**
Work (N=4,152)			
Employed	573/2705	Ref	Ref
Unemployed	181/406	**2.99 (2.41, 3.72) *****	**p<0.001**
Economically inactive	467/1041	**3.03 (2.60, 3.53) *****	**p<0.001**
Housing (N=4,140)			
Homeowner (own or purchasing house)	355/1608	Ref	Ref
Renting (privately)	307/1051	**1.46 (1.22, 1.74) *****	**p<0.001**
Renting (council/housing association)	447/1189	**2.13 (1.80, 2.51) *****	**p<0.001**
Unstable or other	108/292	**2.07 (1.59, 2.70) *****	**p<0.001**
Sources of income, past year (N=3,959)			
All other income sources	598/2728	Ref	Ref
Received welfare benefits	567/1231	**3.04 (2.63, 3.51) *****	**p<0.001**
Keep up with bill and credit commitments (N=3,870)			
Up to date	663/2826	Ref	Ref
Behind with some	375/901	**2.33 (1.98, 2.73) *****	**p<0.001**
Behind with all	88/143	**5.22 (3.69, 7.39) *****	**p<0.001**
Enough money to meet basic needs (N=4,042)			
No	247/460	Ref	Ref
Yes, always	370/1999	**0.20 (0.16, 0.24) *****	**p<0.001**
Yes, most of the time	345/1057	**0.42 (0.33, 0.52) *****	**p<0.001**
Yes, some of the time	226/526	**0.65 (0.51, 0.84) *****	**p=0.001**
Annual household income (N=3,331)			
≥median (£20,000)	410/1921	Ref	Ref
<median (£19,999)	541/1410	**2.29 (1.97, 2.67) *****	**p<0.001**
Year of diagnosis (N=4,184)			
1981-1995	204/535	Ref	Ref
1996-2005	434/1553	**0.63 (0.51, 0.77) *****	**p<0.001**
2006-2015	597/2096	**0.65 (0.53, 0.79) *****	**p<0.001**
CD4 count (cells/mm^3) (N=2,634)			
<200	28/67	Ref	Ref
200-350	78/219	0.77 (0.44, 1.35)	p=0.360
350-499	119/503	**0.43 (0.25, 0.73) *****	**p=0.002**
≥500	547/1845	**0.59 (0.36, 0.96) ****	**p=0.035**
Viral load count (copies/mL) (N=3,549)			
Undetectable (VL<50)	934/3301	Ref	Ref
Detectable (VL≥50)	79/248	1.18 (0.89, 1.56)	p=0.232

[1] Number of individuals within each category with GHQ-12≥4 / total number of individuals within each category.
[2] **Bold** indicates values significant at p<0.20. ***p<0.01, **p<0.05, *p<0.1.

Pre-existing mental health conditions

Additionally, I conducted a preliminary analysis of pre-existing mental health conditions[22] against GHQ-12 score which is detailed in **Appendix E**.

Overall, I found that individuals were more likely to report GHQ-12 score$\geq$4 if they were diagnosed with any mental health condition, compared to individuals who were not; for example, participants ever diagnosed with anxiety or depression were over 6.3 (OR 6.26; 95% CI 5.36, 7.32) and 6.6 (OR 6.61; 95% CI 5.69, 7.67) times more likely, respectively, to report a GHQ-12 score of 4 or more than those who were not previously diagnosed.

5.4.3 Multivariate models

In the following sub-section, I will present summarised outputs from models where variable group types are combined; however, **Appendix E** includes each intermediary model for the groups of variables included (demographics, social determinants and clinical). I created each multivariate model by grouping various categories of variables, specifically:

- Model 1: Demographic only (n=3,824)
- Model 2: Social determinants only (n=3,030)
- Model 3: Clinical only (n=2,513)
- Model 4: Demographic and social determinants (n=3,369)
- Model 5: Demographic and clinical (n=2,353)
- Model 6: Social and clinical (n=2,127)
- Model 7: Full model (n=2,027)
- Model 8: Sensitivity analysis – excluding CD4 (n=3,302)

Here, I will present a summary for each individual model, focussing on the associations which changed in relation to direction or significance compared with the univariate model **(see Table 5.6)**.

[22] Pre-existing mental health conditions were anxiety, depression, personality disorder, bipolar, eating disorder, insomnia, post-traumatic stress disorder (PTSD), psychosis and other mental health conditions.

Model 1: Demographic only

Compared to the univariate model, variables with significant associations remained the same; older adults (65+ years) were 40% less likely (aOR 0.60; 95% CI 0.42, 0.85) to self-report poor mental health, after adjusting for gender, country of birth, ethnicity and sexuality compared to younger people (18-34 years). Additionally, people who identified as Black African were 37% less likely (aOR 0.63; 95% CI 0.50, 0.79) than those of White British ethnicity to report a high GHQ-12 score, after adjusting for all other demographic factors. However, associations between GHQ-12 and sexuality were no longer significant compared to the univariate model.

Model 2: Social determinants only

Having received education to age 18 (ISCED3), having a postgraduate degree, being unemployed or economically inactive, receiving welfare benefits, being behind with some/all bill and credit commitments were associated with poorer mental health. For instance, the largest magnitude was reported among those who were economically inactive who were over 2-times more likely (aOR 2.37; 95% CI 1.95, 2.88) to report GHQ-12 score$\geq$4 after adjusting for all other social determinants. However, not having enough money to meet basic needs all/most of the time was associated with being less likely to report poor mental health. Compared to the univariate model, there was a new significant relationship between GHQ-12 score and having an upper secondary education; however, associations were no longer significant according to housing type nor having enough money to meet basic needs some of the time.

Model 3: Clinical measures only

Being diagnosed in more recent years was associated with reduced odds of poorer mental health; being diagnosed in 1996-2005 with being 41% less likely (aOR 0.59; 95% CI 0.45, 0.77) and being diagnosed in 2006-2015 with being 41% less likely (aOR 0.59; 95% CI 0.46, 0.76) compared to being diagnosed in 1981-1995, after adjusting for CD4 and viral load count. Furthermore, those with a 'mid-range' CD4 count (350-499 cells/mm^3) were 57% less likely to report a GHQ-12 score$\geq$4, compared to those with a CD4$<$200 after adjusting for viral load and year of diagnosis (aOR 0.43; 95% CI 0.25, 0.73). A similar relationship was also found among those with higher CD4 counts

($\geq$500) who were 41% less likely (aOR 0.59; 95% CI 0.36, 0.98) to report a high GHQ-12 score.

Model 4: Demographic characteristics and social determinants

The direction of associations between age, ethnicity, sexuality, employment status, receiving welfare benefits, keeping up with bill/credit commitments and having enough money to meet basic needs and poorer mental health remained the same. Significant associations (at $p<0.05$) were no longer present for housing ownership status and having enough money to meet basic needs some of the time, compared to the univariate model.

Model 5: Clinical measures and demographic characteristic

A reduced likelihood of probable mental ill health remained for those aged 65+, diagnosed in more recent years and with a CD4 count between 350-499 cells/mm^3 or $\geq$500 cells/mm^3. Significant associations were no longer present in relation to sexuality (identifying as straight/heterosexual) nor ethnicity (identifying as being Black African), compared to the univariate model.

Model 6: Clinical measures and social determinants

Being unemployed or economically inactive, receiving welfare benefits and being behind with all bill/credit commitments remained associated with a GHQ-12 score$\geq$4. Having enough money to meet basic needs all/most/some of the time and being diagnosed in 1996-2005 remained significantly negatively associated with probable mental ill health. Significant associations were no longer present in relation to higher educational attainment (ISCED6 and ISCED7/8), housing status (renting or having an unstable living situation), being behind with some bill/credit commitments, being diagnosed in 2006-2015 nor a 'mid-range' CD4 (350-499 cells/mm^3) or $\geq$500 cells/mm^3 and self-reported GHQ-12$\geq$4.

Model 7: All

Age, gender, ethnicity, sexuality, employment status, income source, and measures of financial security were associated with GHQ-12 score$\geq$4. Specifically, older adults (65+ years) of Black African ethnicity, who identified as straight/heterosexual and had enough money to meet basic needs

always some/most/all of the time were less likely to report probable mental ill health. However, adults who identified as cisgender women, of any other ethnic background, who were unemployed or economically inactive, receiving welfare benefits and being behind with some/all bill and credit commitments were more likely to report a GHQ-12$\geq$4. The largest magnitude was found among those who were unemployed who were almost 2.5 times more likely to report poor mental health (aOR 2.43; 95% CI 1.62, 3.64) than those employed, after adjusting for all other determinants. Educational attainment, housing status, year of diagnosis and CD4 count were not associated with probable mental ill health.

Table 5.6: Determinants of GHQ-12≥4: adjusted OR and 95% CI from multivariate analyses

	Univariate	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6	Model 7
Age (ref: 18-34)								
35-44	0.90 (0.71, 1.14)	1.01 (0.79, 1.29)			1.00 (0.75, 1.35)	1.06 (0.77, 1.46)		1.21 (0.83, 1.76)
45-54	0.96 (0.77, 1.20)	1.01 (0.80, 1.28)			0.91 (0.69, 1.21)	1.00 (0.73, 1.37)		1.12 (0.76, 1.63)
55-64	1.13 (0.89, 1.44)	1.13 (0.87, 1.46)			0.88 (0.63, 1.21)	1.14 (0.80, 1.62)		1.18 (0.77, 1.82)
65+	**0.61 (0.43, 0.85)** ***	**0.60 (0.42, 0.85)** ***			**0.40 (0.26, 0.63)** ***	**0.60 (0.37, 0.96)** **		**0.53 (0.29, 0.96)** **
Gender identity (ref: cisgender man)								
Cisgender woman	0.88 (0.76, 1.02) *	1.23 (0.98, 1.55) *			1.16 (0.88, 1.54)	1.32 (0.98, 1.78) *		**1.50 (1.03, 2.18)** **
Ethnic group (ref: White British)								
Any other White background	1.02 (0.83, 1.26)	1.04 (0.84, 1.30)			1.12 (0.87, 1.44)	1.19 (0.91, 1.56)		1.22 (0.88, 1.67)
Black African	**0.66 (0.56, 0.78)** ***	**0.63 (0.50, 0.79)** ***			**0.39 (0.29, 0.53)** ***	0.74 (0.54, 1.00) *		**0.42 (0.28, 0.63)** ***
Any other Black background	0.76 (0.53, 1.08)	0.80 (0.55, 1.17)			0.65 (0.41, 1.02) *	0.89 (0.55, 1.44)		0.67 (0.37, 1.19)
Mixed background	1.03 (0.72, 1.48)	1.03 (0.69, 1.52)			1.06 (0.66, 1.70)	1.15 (0.68, 1.94)		1.22 (0.66, 2.26)
Asian background	0.73 (0.49, 1.09)	0.76 (0.50, 1.17)			0.75 (0.44, 1.28)	0.71 (0.39, 1.27)		0.64 (0.31, 1.33)
Any other ethnic background	1.00 (0.66, 1.53)	1.11 (0.72, 1.70)			1.14 (0.69, 1.89)	1.58 (0.93, 2.66) *		**1.89 (1.03, 3.46)** **
Sexuality (ref: gay or lesbian/homosexual)								
Straight/heterosexual	**0.74 (0.64, 0.85)** ***	0.85 (0.67, 1.06)			**0.61 (0.46, 0.80)** ***	0.80 (0.60, 1.07)		**0.56 (0.39, 0.80)** ***
Bisexual	1.02 (0.73, 1.41)	1.07 (0.76, 1.50)			0.92 (0.61, 1.39)	1.16 (0.74, 1.81)		1.11 (0.65, 1.91)
Asexual/other	1.32 (0.76, 2.30)	1.36 (0.73, 2.57)			0.63 (0.26, 1.50)	1.02 (0.41, 2.55)		0.39 (0.09, 1.64)
Education (ref: ISCED1/2 primary or less)								
ISCED3: Upper secondary education (to age 18)	0.85 (0.64, 1.12)		**1.46 (1.04, 2.05)** **		1.21 (0.83, 1.76)		1.52 (0.97, 2.38) *	1.33 (0.82, 2.16)
ISCED4/5: Technical and vocational training	0.86 (0.62, 1.20)		1.41 (0.95, 2.09) *		1.28 (0.83, 1.97)		1.35 (0.81, 2.25)	1.18 (0.67, 2.06)
ISCED6: Bachelors or equivalent level	**0.67 (0.50, 0.89)** ***		1.42 (1.00, 2.01) *		1.27 (0.86, 1.87)		1.47 (0.93, 2.34)	1.31 (0.79, 2.19)
ISCED7/8: Postgraduate degree	**0.65 (0.48, 0.88)** ***		**1.60 (1.09, 2.33)** **		1.42 (0.93, 2.15)		1.58 (0.96, 2.61) *	1.40 (0.81, 2.42)
Work (ref: employed)								
Unemployed	**2.99 (2.41, 3.72)** ***		**1.98 (1.50, 2.62)** ***		**2.11 (1.56, 2.85)** ***		**2.36 (1.62, 3.44)** ***	**2.43 (1.62, 3.64)** ***
Economically inactive	**3.03 (2.60, 3.53)** ***		**2.37 (1.95, 2.88)** ***		**2.56 (2.03, 3.24)** ***		**2.19 (1.69, 2.83)** ***	**2.33 (1.72, 3.16)** ***
Housing (ref: homeowner)								
Renting (privately)	**1.46 (1.22, 1.74)** ***		1.18 (0.96, 1.45)		1.19 (0.95, 1.50)		1.18 (0.90, 1.55)	1.18 (0.88, 1.59)
Renting (council/housing association)	**2.13 (1.80, 2.51)** ***		0.91 (0.73, 1.14)		1.09 (0.86, 1.39)		0.97 (0.73, 1.30)	1.08 (0.79, 1.49)
Unstable or other	**2.07 (1.59, 2.70)** ***		1.02 (0.72, 1.46)		1.06 (0.72, 1.57)		1.03 (0.65, 1.63)	1.05 (0.63, 1.74)
Sources of income, past year (ref: all other)								
Received welfare benefits	**3.04 (2.63, 3.51)** ***		**1.66 (1.37, 2.02)** ***		**1.61 (1.29, 1.99)** ***		**1.52 (1.17, 1.97)** ***	**1.45 (1.09, 1.92)** **
Keep up with bill and credit commitments (ref: up to date)								
Behind with some	**2.33 (1.99, 2.73)** ***		**1.29 (1.04, 1.59)** **		**1.38 (1.10, 1.73)** ***		1.32 (0.99, 1.75) *	**1.45 (1.07, 1.97)** **
Behind with all	**5.22 (3.69, 7.39)** ***		**1.81 (1.16, 2.84)** ***		**1.81 (1.09, 3.01)** ***		**1.96 (1.11, 3.48)** **	**2.07 (1.09, 3.93)** **
Enough money to meet basic needs (ref: no)								
Yes, always	**0.20 (0.16, 0.24)** ***		**0.33 (0.24, 0.46)** ***		**0.22 (0.15, 0.32)** ***		**0.30 (0.20, 0.46)** ***	**0.20 (0.12, 0.32)** ***
Yes, most of the time	**0.42 (0.33, 0.52)** ***		**0.60 (0.44, 0.81)** ***		**0.43 (0.31, 0.60)** ***		**0.59 (0.40, 0.87)** ***	**0.41 (0.26, 0.63)** ***
Yes, some of the time	**0.65 (0.51, 0.84)** ***		0.79 (0.58, 1.08)		0.76 (0.54, 1.08)		**0.63 (0.41, 0.95)** **	**0.55 (0.35, 0.86)** **
Year of diagnosis (ref: 1981-1995)								
1996-2005	**0.63 (0.51, 0.77)** ***			**0.59 (0.45, 0.77)** ***		**0.64 (0.48, 0.85)** ***	**0.60 (0.44, 0.83)** ***	0.75 (0.53, 1.05) *
2006-2015	**0.65 (0.53, 0.79)** ***			**0.59 (0.46, 0.76)** ***		**0.58 (0.44, 0.78)** ***	0.78 (0.57, 1.06)	0.83 (0.59, 1.18)
CD4 count (cells/mm^3) (ref: <200)								
200-350	0.77 (0.44, 1.35)			0.77 (0.44, 1.37)		0.72 (0.40, 1.32)	0.96 (0.47, 1.96)	0.90 (0.43, 1.90)
350-499	**0.43 (0.25, 0.73)** ***			**0.43 (0.25, 0.73)** ***		**0.38 (0.22, 0.67)** ***	0.60 (0.31, 1.17)	0.55 (0.27, 1.10) *
≥500	**0.59 (0.36, 0.96)** **			**0.59 (0.36, 0.98)** **		**0.51 (0.30, 0.86)** ***	0.88 (0.47, 1.66)	0.73 (0.38, 1.42)

Coloured text indicates change in significance compared with univariate model — blue: NS to S; green: S to NS at p<0.05.
Statistical significance at ***p<0.01, **p<0.05 and *p<0.1.

Goodness of fit

I ran goodness-of-fit tests to check model fit – see **Appendix E**. I found that country of birth, education, income, and viral load were affecting the model fit (measured by likelihood ratios, AIC and BIC values, and Hosmer-Lemeshow test) of models 1, 2, and 3, respectively. I decided to keep education, as it is a significant variable that is not captured by any other measurements. Therefore, subsequent combined models (models 4 to 6) and the final model excluded the variables that significantly affected model fit (country of birth, income, and viral load) **(Table 5.7)**. These tests are limited because they do not test for interacting factors; therefore, I attempted to build a saturated model to look at interactions between variables (see **subsection 5.4.4**).

Table 5.7: Goodness of fit output for mixed models

Model	AIC	BIC	LR χ^2 (df); p-value[1]	H-L χ^2 (df); p-value
4. Demographics x social determinants	1.056	-23560.75	589.35 (29) ***	9.93 (8); p=0.2699
5. Demographics x clinical	1.206	-15280.90	64.39 (19) ***	5.04 (8); p=0.7534
6. Social determinants x clinical	1.099	-13797.01	239.67 (20) ***	5.23 (8); p=0.7323
7. Full model	1.073	-12996.25	366.69 (34) ***	5.10 (8); p=0.7467

Abbreviations: AIC, Akaike's Information Criterion; BIC, Bayesian Information Criterion; H-L, Hosmer-Lemeshow test; LR, Likelihood Ratio test.
[1] ***p<0.001

5.4.4 Post-hoc analysis

I also performed a sensitivity analysis **(Appendix E)** where I reran the full multivariate model but excluded CD4 count which had a high number of missing values. The Hosmer-Lemeshow output ($\chi^2(8)$=7.16; p=0.5192) indicated that the full (original) model was preferred to the sensitivity analysis.

Testing for interaction effects

I attempted to build three fully saturated models of each variable group type to test for interactions based on syndemic theory. Several variables across the models were omitted due to collinearity or because no observations were found in the sample; this tended to occur as more interaction terms were added. Therefore, no further results are reported in the thesis.

Testing for collinearity

The outputs (variance inflation factor and condition number) from testing for collinearity across the three model groups (models 1, 2 and 3), combined model groups (models 4, 5 and 6) and full model (model 7) did not indicate any instability or collinearity as being a major issue in the model as both of these were less than 10 in value (511). However, some of the eigenvalues imply item multicollinearity (values are close to 0) (512). Outputs are listed in **Appendix E**.

Stratified analysis

Here, I present stratified analysis according to combined demographic factors (ethnicity/gender and ethnicity/sexuality). A full breakdown of all types of stratified analysis according to each distinct demographic factor (gender identity, ethnicity and sexuality) are given in **Appendix E**.

Ethnicity and gender

Stratified analyses for White British cisgender men and Black African cisgender women were undertaken **(Table 5.8)**.

I found that straight/heterosexual identifying White British cisgender men were over half as likely (aOR 0.48; 95% CI 0.28, 0.82) to report GHQ-12$\geq$4 compared to those identifying as gay/homosexual, after adjusting for all other demographics, social determinants and clinical variables. Being unemployed or economically inactive among White British cisgender men was associated with more than 2-times increased likelihood of higher GHQ-12 scores (aOR 3.77; 95% CI 1.87, 7.63 and aOR 2.94; 95% CI 1.85, 4.69, respectively). However, men who always have enough money to meet basic needs were 84% less likely (aOR 0.16; 95% CI 0.07, 0.39) to report GHQ-12$\geq$4 .

Black African cisgender women whose highest educational attainment was a postgraduate degree were 97% less likely (aOR 0.03; 95% CI 0.002, 0.56) to self-report a GHQ-12 score indicating probable psychological disturbance compared to those with the lowest educational attainment. A similar direction of association was seen among Black African cisgender women diagnosed more recently (from 1996 onwards); however, among this subgroup, women who were behind with some bill and credit commitments were almost 3-times more likely (aOR 2.83; 95% CI 1.01, 7.90) to report a higher GHQ-12 score.

Table 5.8: Stratified analysis by ethnicity and gender

	White British, cisgender man (n=1,006)		**Black African, cisgender woman (n=241)**	
	OR (95% CI)	p-values	OR (95% CI)	p-values
Age				
18-34	Ref	Ref	Ref	Ref
35-44	1.76 (0.92, 3.37)	p=0.085	1.47 (0.40, 5.38)	p=0.561
45-54	1.46 (0.78, 2.72)	p=0.235	0.98 (0.27, 3.64)	p=0.981
55-64	1.40 (0.70, 2.79)	p=0.340	2.72 (0.53, 13.90)	p=0.230
65+	0.57 (0.24, 1.35)	p=0.200	1.00 (0.05, 20.51)	p=0.999
Sexuality				
Gay or lesbian/homosexual	Ref	Ref	Ref	Ref
Straight/heterosexual	**0.48 (0.28, 0.82) ****	**p=0.007**	1.15 (0.07, 18.49)	p=0.922
Bisexual	1.06 (0.49, 2.26)	p=0.889	-	-
Asexual/other	0.66 (0.10, 4.35)	p=0.667	-	-
Education				
ISCED1/2: Primary or less	Ref	Ref	Ref	Ref
ISCED3: Upper secondary education	1.52 (0.79, 2.94)	p=0.210	0.60 (0.11, 3.39)	p=0.562
ISCED4/5: Technical and vocational education training	0.92 (0.43, 1.97)	p=0.833	0.41 (0.06, 3.06)	p=0.384
ISCED6: Bachelors or equivalent level	1.56 (0.77, 3.17)	p=0.218	0.35 (0.06, 2.15)	p=0.258
ISCED7/8: Postgraduate degree	1.41 (0.66, 3.03)	p=0.376	**0.03 (0.002, 0.56) ****	**p=0.018**
Work				
Employed	Ref	Ref	Ref	Ref
Unemployed	**3.77 (1.87, 7.63) *****	**p<0.001**	1.48 (0.51, 4.31)	p=0.467
Economically inactive	**2.94 (1.85, 4.69) *****	**p<0.001**	1.71 (0.66, 4.41)	p=0.269
Housing				
Homeowner (own or purchasing house)	Ref	Ref	Ref	Ref
Renting (privately)	1.25 (0.82, 1.91)	p=0.302	3.13 (0.71, 13.76)	p=0.131
Renting (council/housing association)	0.95 (0.58, 1.53)	p=0.827	1.73 (0.49, 7.38)	p=0.457
Unstable or other	0.86 (0.37, 2.00)	p=0.728	2.00 (0.31, 12.42)	p=0.458
Sources of income, past year				
All other income sources	Ref	Ref	Ref	Ref
Received welfare benefits	1.47 (0.92, 2.35)	p=0.106	1.22 (0.56, 2.70)	p=0.615
Keep up with bill and credit commitments				
Up to date	Ref	Ref	Ref	Ref
Behind with some	1.14 (0.70, 1.83)	p=0.603	**2.83 (1.01, 7.90) ****	**p=0.048**
Behind with all	1.57 (0.40, 6.09)	p=0.515	3.35 (0.70, 16.1)	p=0.131
Enough money to meet basic needs				
No	Ref	Ref	Ref	Ref
Yes, always	**0.16 (0.07, 0.39) *****	**p<0.001**	0.43 (0.11, 1.67)	p=0.226
Yes, most of the time	0.51 (0.22, 1.18)	p=0.115	0.47 (0.16, 1.40)	p=0.176
Yes, some of the time	0.96 (0.37, 2.46)	p=0.930	0.43 (0.16, 1.09) *	p=0.076
Year of diagnosis				
1981-1995	Ref	Ref	Ref	Ref
1996-2005	1.04 (0.65, 1.66)	p=0.873	**0.17 (0.03, 0.97) ****	**p=0.046**
2006-2015	1.06 (0.65, 1.73)	p=0.826	**0.13 (0.02, 0.69) ****	**p=0.017**
CD4 count (cells/mm^3)				
<200	Ref	Ref	Ref	Ref
200-350	0.87 (0.28, 2.70)	p=0.805	3.05 (0.16, 56.93)	p=0.455
350-499	0.53 (0.18, 1.57)	p=0.254	1.49 (0.10, 23.00)	p=0.775
≥500	0.65 (0.23, 1.82)	p=0.416	2.16 (0.15, 30.93)	p=0.570

Ethnicity and sexuality

A stratified analysis of White British gay or lesbian/homosexual and Black African straight/heterosexual adults living with HIV **(Table 5.9)** found that having an upper secondary education, being unemployed or economically inactive, and receiving welfare benefits were associated with an increased likelihood of self-reporting GHQ-12$\geq$4 after adjusting for all other demographics, social determinants, and clinical variables among White British gay adults. The greatest magnitude of association was reported among White British, gay adults who were unemployed (aOR 4.17; 95% CI 1.75, 9.92). Alternatively, White British gay adults who always had enough money to meet basic needs were 87% less likely (aOR 0.13; 95% CI 0.04, 0.39) to report GHQ-12$\geq$4.

I also found that Black African heterosexual populations privately renting were over three times more likely (aOR 3.20; 95% CI 1.05, 9.77) to report a high GHQ-12 score. A reverse relationship was found among this subgroup and those diagnosed in 2006-2015 (aOR 0.25; 95% CI 0.08, 0.82), who have enough money to meet basic needs always/most of the time (aOR 0.27; 95% CI 0.09, 0.81 and aOR 0.31; 95% CI 0.13, 0.76, respectively).

Table 5.9: Stratified analysis by ethnicity and sexuality

	White British, gay or lesbian/homosexual (n=829)		**Black African, straight/heterosexual (n=373)**	
	OR (95% CI)	p-values	OR (95% CI)	p-values
Age				
18-34	Ref	Ref	Ref	Ref
35-44	1.63 (0.83, 3.23)	p=0.159	1.91 (0.57, 6.33)	p=0.292
45-54	1.34 (0.70, 2.57)	p=0.380	1.19 (0.36, 3.93)	p=0.773
55-64	1.56 (0.75, 3.26)	p=0.232	3.14 (0.79, 12.53)	p=0.105
65+	0.75 (0.29, 1.91)	p=0.542	0.84 (0.06, 11.90)	p=0.895
Gender identity				
Cisgender man	Ref	Ref	Ref	Ref
Cisgender woman	-	-	1.32 (0.70, 2.50)	p=0.394
Education				
ISCED1/2: Primary or less	Ref	Ref	Ref	Ref
ISCED3: Upper secondary education	**2.46 (1.04, 5.79) ****	**p=0.040**	1.42 (0.33, 6.00)	p=0.637
ISCED4/5: Technical and vocational education training	1.33 (0.51, 3.50)	p=0.558	1.06 (0.21, 5.38)	p=0.940
ISCED6: Bachelors or equivalent level	2.42 (0.99, 5.90) *	p=0.053	0.84 (0.19, 3.67)	p=0.821
ISCED7/8: Postgraduate degree	2.19 (0.85, 5.63)	p=0.105	0.50 (0.09, 2.65)	p=0.415
Work				
Employed	Ref	Ref	Ref	Ref
Unemployed	**4.17 (1.75, 9.92) *****	**p=0.001**	2.10 (0.90, 4.93) *	p=0.087
Economically inactive	**2.35 (1.41, 3.92) *****	**p=0.001**	1.98 (0.90, 4.37) *	p=0.091
Housing				
Homeowner (own or purchasing house)	Ref	Ref	Ref	Ref
Renting (privately)	1.11 (0.70, 1.76)	p=0.658	**3.20 (1.05, 9.77) ****	**p=0.041**
Renting (council/housing association)	0.80 (0.46, 1.40)	p=0.442	1.82 (0.61, 5.46)	p=0.286
Unstable or other	1.06 (0.41, 2.76)	p=0.897	1.44 (0.34, 6.12)	p=0.623
Sources of income, past year				
All other income sources	Ref	Ref	Ref	Ref
Received welfare benefits	**1.90 (1.11, 3.24) ****	**p=0.018**	1.23 (0.64, 2.37)	p=0.539
Keep up with bill and credit commitments				
Up to date	Ref	Ref	Ref	Ref
Behind with some	1.24 (0.72, 2.12)	p=0.434	1.94 (0.90, 4.21)*	p=0.092
Behind with all	1.03 (0.20, 5.16)	p=0.973	2.26 (0.67, 7.61)	p=0.188
Enough money to meet basic needs				
No	Ref	Ref	Ref	Ref
Yes, always	**0.13 (0.04, 0.39) *****	**p<0.001**	**0.27 (0.09, 0.81) ****	**p=0.020**
Yes, most of the time	0.36 (0.12, 1.08) *	p=0.069	**0.31 (0.13, 0.76) ****	**p=0.010**
Yes, some of the time	0.94 (0.28, 3.15)	p=0.920	0.50 (0.24, 1.07) *	p=0.075
Year of diagnosis				
1981-1995	Ref	Ref	Ref	Ref
1996-2005	1.05 (0.63, 1.76)	p=0.853	0.37 (0.12, 1.21) *	p=0.100
2006-2015	1.21 (0.70, 2.09)	p=0.496	**0.25 (0.08, 0.82) ****	**p=0.022**
CD4 count (cells/mm^3)				
<200	Ref	Ref	Ref	Ref
200-350	1.41 (0.36, 5.43)	p=0.620	1.97 (0.33, 11.81)	p=0.460
350-499	0.85 (0.24, 3.04)	p=0.805	0.75 (0.13, 4.20)	p=0.744
≥500	0.99 (0.29, 3.36)	p=0.984	1.47 (0.28, 7.67)	p=0.650

5.5 Discussion

5.5.1 Key findings

In this Chapter, I build on initial analyses of Positive Voices data (208, 477) and provide an in-depth understanding of the relationships between social determinants and mental health. The multiple analyses suggest possible mechanisms between mental health outcomes and determinants *via* the interrelatedness between some social (e.g. income and financial security) as well as demographic factors (e.g. gender, ethnicity, sexuality).

The prevalence of probable mental health problems was high among participants in the Positive Voices study, with more than a quarter (n=1271, 29.4%) having a GHQ-12 score$\geq$4. This proportion is an absolute increase of 10.4% (95% CI 9.4, 12.4) compared to adults in the 2016 Health Survey for England study of 19% (95% CI 17, 20) (491). Furthermore, the proportion of people with probable mental ill health was higher than estimates for the English population as a whole by gender and age group (208, 491). My multivariate analysis identified significant associations between the GHQ-12 score, demographic characteristics (age, gender, ethnicity, sexuality) and social determinants (employment status, receiving welfare benefits, keeping up with bill/credit commitments and having enough money to meet basic needs). I found no significant associations with education, housing, and factors relating to HIV (year of diagnosis and CD4 count).

As hypothesised, individuals with poorer socioeconomic circumstances, including being unemployed, were significantly more likely to self-report poorer mental health. The greatest magnitude of the association was observed among those who were unemployed (aOR 2.43; 95% CI 1.62, 3.64) compared to the employed reference group and was even greater in the stratified analysis of White British adults who identified as gay or lesbian/homosexual (aOR 4.17; 95% CI 1.75, 9.92) and White British cisgender men (aOR 3.77; 95% CI 1.87, 7.63), respectively. It is well established that mental health and employment status have a bidirectional relationship; in other words, being employed can improve emotional and mental health through material/social advantages and self-esteem, but also that good mental health is essential for job seeking and retention (198, 200, 513). For people living with HIV, concerns relating to occupational justice and social inclusion have been identified which largely focus on issues relating to poverty, stigma and discrimination (514). Associations have also been

identified between employment status and HIV outcomes, including adherence to ART; for example, a meta-analysis of 28 studies across 14 countries found that people who were employed were 27% more likely (pooled OR 1.27; 95% CI 1.04, 1.55) to be ART adherent, than those unemployed (203).

Alternatively, in the stratified analysis **(Appendix E)**, I found that those who identified as straight/heterosexual and had enough money to meet basic needs always, most or some of the time, were less likely to have a GHQ-12 score≥4 than adults who identified as gay or lesbian/homosexual or did not have enough money to meet their basic needs, after adjusting for all other determinants (aOR 0.21; 95% CI 0.11, 0.43 and aOR 0.34; 95% CI 0.18, 0.64 and aOR 0.42; 95% CI 0.23, 0.77, respectively). This corroborates research that has identified an increased likelihood of poorer mental health among sexual minority adults (236, 515, 516). For example, a meta-analysis of 12 UK population health surveys found that adults 55 years and older and identified as lesbian/gay were more than two times more likely to have a GHQ-12 score≥4 compared to heterosexuals after adjustment for age and sex (aOR 2.25; 95% CI 1.43, 3.52) (516). Researchers anticipate that these associations may be explained by minority stress theory, whereby experiences of discrimination, stigma and prejudice, working together with community and individual coping/social support mechanisms, can exacerbate mental health outcomes (236, 515).

An unexpected finding was that individuals of Black African ethnicity were significantly less likely to report signs of mental ill health than individuals of White British ethnicity, as previous research indicated otherwise (242, 517). For instance, the PRIME study found that older women living with HIV in England of Black African or Black Caribbean ethnicity were significantly more likely to report current psychological distress than White British women (aOR 3.34; 95% CI 1.38, 8.13 and aOR 4.81; 95% CI 1.61, 14.41, respectively) (242). Respondents may have misreported or under-reported their mental health status due to perceived social stigma (518, 519). However, after conducting a stratified analysis by ethnicity and gender, I found that Black African cisgender women who were behind with some bills/credit commitments were nearly 3-times more likely (aOR 2.83; 95% CI 1.01, 7.90) to report a GHQ-12 score≥4 or more compared to those up to date. Additionally, Black African adults living with HIV who identified as straight/heterosexual and were privately renting housing reported higher odds (aOR 3.20; 95% CI 1.05, 9.77) of mental ill health than homeowners.

5.5.2 Strengths and limitations

A strength of my analysis is the use of the first nationally representative survey of people living with HIV in England and Wales, Positive Voices (208). The survey methodology and questionnaire were designed through a multi-stakeholder partnership that included people living with HIV to ensure that the questions asked were meaningful to those with lived experience (208). My approach to model building used "clusters" of variables in each domain that had significant χ^2 associations with the outcome. I was also able to identify some inequalities in poorer outcomes among subgroups of the study population. However, some of the greatest magnitudes of associations were seen among White British adults who identified as gay or lesbian/homosexual (n=829) and had an upper secondary education (aOR 2.46; 95% CI 1.04, 5.79), were unemployed (aOR 4.17; 95% CI 1.75, 9.92) or economically inactive (aOR 2.35; 95% CI 1.41, 3.92) and/or received welfare benefits (aOR 1.90; 95% CI 1.11, 3.24).

However, I recognise limitations in the survey instrument and study design. First, I anticipate some issues with the use of GHQ-12 as a measurement tool for general psychiatric morbidity (490). For example, the applicability of GHQ-12 as a clinical psychometric measurement remains contested due to concerns of misclassification and response biases (520). This may result in a poor predictive value of the GHQ (520, 521); for example, respondents may not recognise a change in the format of responses (520, 522, 523). However, a recent confirmatory factor analysis found that GHQ-12 provides valid comparisons between ethnic groups in the UK (524). Secondly, I am limited by the cross-sectional nature of the survey in that it is indicative of a single point in time, particularly in relation to the outcome measure which records symptoms of mental health in recent weeks. Significant time has passed since data collection (almost five years ago) and clinical data (viral load and CD4) depended on participants opting in for data linkage, which may be influenced by selection bias. Additionally, due to the survey being a cross-section in time (on date of completion) any changes in social determinants will not be captured therefore, I am unable to comment on the temporal nature of determinants. I also did not have an external comparison group, therefore, I am unable to definitively determine the causal pathways by which social determinants, HIV clinical measures, demographics and mental health are organised. Thirdly, the 2017 Positive Voices survey is not specifically designed to collect social determinant data; for example, I have no data on food

security/sufficiency, social support, coping style, and have limited data on HIV-related stigma, which are all understood to be significant predictors and mediators of mental health-related quality of life (100, 215, 525). Finally, I had a large amount of missing data across some variables, noticeably CD4 count, annual household income and virological suppression which could be due to intentional missing, or respondent refusal.

5.5.3 Study implications and future research

More research is needed to explore other outcomes measured in the Positive Voices study to provide a fuller picture of the mental health and well-being of this study population; for example, EQ-5D-5L, life satisfaction and health rating data. This could also include the use of more recent health data from participants who have opted to link their HIV outpatient clinic data with their study record; for example, the HARS dataset also records indicators of receiving psychiatric care as well as the care professional most recently seen at HIV clinic (e.g. psychologist, social worker etc.) (281).

Additionally, using a survey measure of a specific mental health condition would enable a more in-depth analysis of relationships with social determinants; for example, the 2022 Positive Voices survey replaces the GHQ-12 instrument with an instrument measuring the severity of depression (PHQ-9: Patient Health Questionnaire-9) which has greater specificity than GHQ-12 and therefore results in fewer false positive cases (526). Imputation, with support from a statistician may help to overcome some of the missingness with data. Structural equation modelling, such as mediation analysis, may help to unpick the causal mechanisms underpinning the associations found; for instance, the unexpected finding between ethnicity and how other social determinants may be mediating this association (527, 528).

Furthermore, if further biological data were collected or linked, it may be possible to explore relationships with physiological functioning and hypotheses based on embodiment. I have recommended the inclusion of additional social determinant data for the upcoming Positive Voices 2022 study (482); specifically, measures of food security and social support, loneliness/social isolation. I also recommend the addition of measures of determinants at contextual levels such as neighbourhood/community level; for example, environmental exposure (access to green space, noise/air pollution) through linkage to postcode of residence and structural determinants of health to look beyond individual

attributes (529). Structural components could include measures of racism and gender binarism, as highlighted by Krieger (161).

5.6 Conclusion

Social factors are a key influencer of self-reported mental health among people living with HIV. More research is required to understand how these determinants can 'cluster' or interact with each other and can magnify or weaken the associations observed with health and well-being outcomes to identify possible causal pathways of social and health inequities. Qualitative research would allow exploration of 'how' certain groups experience living with HIV and could reveal why mental health remains a key challenge. In the following Chapter, I will triangulate these findings with the qualitative components of the thesis to determine converging, diverging and complementary findings.

6

Applying and adapting a theoretical framework to a mixed-methods study

In **Chapter 2**, I presented the findings of my quantitative synthesis of published data and identified social determinants that appear to be associated with clinical outcomes of HIV in the literature (specifically housing, employment, deprivation, or income). This indicated that there is a persistent social gradient of health related to viral suppression and adherence to ART in high-income countries, despite significant advances in HIV treatment and care.

In **Chapter 3** and **Chapter 4**, I presented my qualitative research which focused on experiences of the COVID-19 pandemic (including daily life and adaptations to HIV services) among people living with HIV and service providers in the UK. I highlighted the challenges to mental health and well-being, adaptations made to HIV services (and their acceptability among service participants) and perceptions on the future of HIV services.

In **Chapter 5**, I presented my secondary data analysis of the 2017 Positive Voices study and focussed on a self-reported measure of mental health (GHQ-12). I found that individuals with poorer socioeconomic circumstances, including being unemployed and those who identified as sexual minorities, were significantly more likely to self-report poorer mental health compared to their counterparts (who were employed or identified as heterosexual). However, adults of Black African ethnicity were less likely to self-report GHQ-12$\geq$4, which contradicts minority stress theory.

In **Chapter 6**, I will triangulate data from my systematic review, qualitative research and secondary data analysis and apply these findings to syndemic theory, while using an intersectional approach, to help uncover how social determinants are associated with clinical and mental health outcomes among people living with HIV. This will help to propose recommendations for clinical care and policy.

I presented a proposed framework to interpret my mixed-methods findings using syndemic theory at the UKHSA PhD student event in July 2022.

HW and BD provided comments on this Chapter.

6.1 Abstract

Syndemic theory aims to explain how diseases and social factors interact to widen inequalities. COVID-19 has presented a further challenge to the HIV response and has highlighted inequalities, including in mental health. In my thesis, I have explored how social determinants impact the health and well-being of people living with HIV in the UK. I converged my qualitative data and compared this with the data collected from my systematic review and quantitative analysis. I then drew on syndemic theory to identify how social determinants may interact with the outcomes explored – specifically, clinical (virological suppression/ART adherence) and mental health and well-being while interpreting my findings using an intersectional approach. As my data are collected at different time points (2017, 2020 and 2021), I have attempted to consider how the COVID-19 pandemic may be influencing the reported outcomes. For instance, social distancing and other COVID-19 regulations posed significant challenges to mental health and well-being for many people with HIV, creating anxiety in what some described as experiencing their "second pandemic". Issues around stigma, confidentiality and social support were evident; however, peer support and other community-based initiatives may have helped to alleviate some challenges experienced. Significantly, this work found that concerns for the mental health of people living with HIV persist. For people already engaged with their HIV care, integrated services provide opportunities to address multiple determinants of health in the HIV clinic, including psychological services and welfare support. However, additional investment in resources (time, staff, and finances) for smaller rural clinics is required to eliminate disparities in HIV care currently experienced across the UK.

6.2 Introduction

6.2.1 Theoretical and conceptual frameworks

Theoretical frameworks allow researchers to structure and design their research; therefore, they can be likened to a "blueprint" and are sometimes synonymously termed conceptual frameworks (530). However, as recommended by Crawford (531), I delineate the two by using the adapted definition from Ravitch and Riggan (532) of a theoretical framework as "...an element of a conceptual framework that situates the relationships explored in the study into the context of developing or testing formal theories." Conceptual frameworks depend on three sources: experience, literature, and the theoretical framework (531). Therefore, the research questions we ask are influenced by the conceptual frameworks we use (533).

Historical frameworks, including the WHO CSDH, have been critiqued for their linguistic determinism[1] which likely overlooks variations within groups as well as their tendency to look at structural determinants individually and not how these interact nor how the social context (e.g, power, privilege and oppression) operate with this (535–537). As a result, I was interested in exploring theories that align with intersectional approaches, specifically ecosocial theory and syndemic theory.

Intersectionality

As briefly detailed in **subsection 1.3.1**, intersectionality stems from Black feminism as well as Third World Liberation movements and is a "broad-based knowledge project" or "...simultaneously a field of study, an analytical strategy, and a critical praxis" rather than a theory itself (153, 535, 538). This is because intersectionality does not have "core elements or variables to be operationalised and empirically tested" (156). Specifically, Kimberlé Crenshaw (152) coined the term intersectionality to acknowledge multiple identities that co-exist and interact (134). A Marxist feminist approach extends intersectionality by considering "how these categories are created, how they exploit and not simply oppress, and why they intersect" (538). Therefore, it looks at relationships between "capitalism, gender, race and other social categories" and how "forms of power and oppression drive

[1] Defined as a theory "that language determines the way people perceive the world and think, rather than vice versa" (534).

health inequities" (156, 538, 539).

Ecosocial theory

In **subsection 1.3.1**, I describe ecosocial theory, first proposed by Nancy Krieger in 1994 (127), as an approach for understanding how and why diseases are distributed at the population level. Ecosocial theory is based on a critique of traditional individualistic and biomedical approaches to the causation of health and disease and is a cross-cutting integration of biological and social determinants (128, 161, 533, 535). Although elements of ecosocial theory draw similarities to intersectionality, the former differs by its form of a "self-contained theory" rather than an "analytical perspective" or research paradigm and ecosocial theory can be viewed as an extension of this school of thought (535).

Ecosocial theory emphasises the importance of the social context in which disease distributions, dynamics and powers operate (533). As Krieger (533) states,

> *"Ultimately, our challenge as epidemiologists — no matter what level our research — is for us all to grapple conceptually with the simultaneity of "macro" to "micro" "levels" and their embodied expression in current and changing population distributions of disease, disability, and death."*

Embodiment is one of the key constructs and processes of ecosocial theory whereby we aim to study people in their context (163). Krieger likens embodiment to our "bodies telling stories" about our histories and accounts which people may or may not decide to share or "as clue to life histories, hidden and revealed" (163). For example, when exploring relationships between racial discrimination and health, Krieger (540) postulates the biological embodiment of discrimination according to "6 discrete (yet entangled) multi-level pathways" including economic and social deprivation, socially inflicted trauma and inadequate healthcare.

Therefore, ecosocial theory explores research questions that investigate patterns of health, disease, and well-being in populations, while considering the historical context in relation to social inequalities and the intersections of "gender, race/ethnicity, sexuality, and other social categories reflecting inequitable social relations" (541). Finally, ecosocial theory aligns with a "practice of reflexive epidemiology" of the investigator's research as well as considering politics, polities and social movements (128, 540).

Syndemic theory

As described in **subsection 1.5.1**, a syndemic model of health emphasises how diseases can cluster and interact with one another to enhance overall disease burden (transmission, progression and/or negative health outcomes); this relationship is classically referred to as a "co-morbidity or multi-morbidity" (426, 542). According to Mendenhall and Singer (542), the second rule of syndemic theory considers "biological, social and/or psychological interactions". Finally, syndemic theory also considers the contribution of "large-scale social forces that precipitate disease clustering", particularly structural and political adversity (e.g. poverty, systemic oppression, social trauma, environmental threat) to this pathway (426, 542–544). Therefore, syndemic theory is often "amplified in populations that face extreme structural, political, and social vulnerabilities" (e.g. undocumented migrants) (543–545). As a result, syndemic theory is supported by evidence and literature from multiple disciplines including anthropology, biology and epidemiology (542).

In 2020, Bambra et al. (1) described how COVID-19 is affecting health inequalities, arguing that we are experiencing a "syndemic pandemic" of COVID-19, NCDs, and social inequalities,

> *"...for the most disadvantaged communities, COVID-19 is experienced as a syndemic – a co-occurring, synergistic pandemic that interacts with and exacerbates their existing NCDs and social conditions."* (1)

The authors adapted this theoretical perspective from the classical social determinants of health "rainbow" first stipulated by Dahlgren and Whitehead[2], which they combined with Singer's syndemic theory **Figure 6.1)**.

[2] See **subsection 1.3.1** for further details.

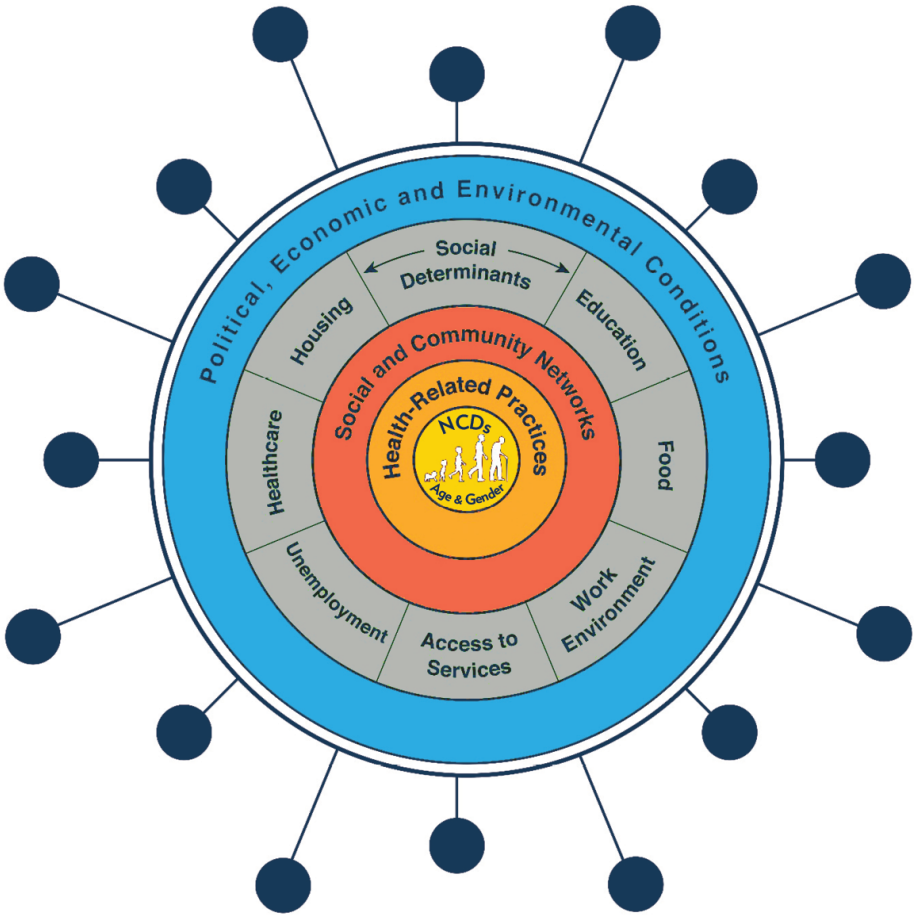


Figure 6.1: Diagrammatic representation of COVID-19 and health inequalities syndemic. Reproduced in colour from The COVID-19 pandemic and health inequalities, Bambra et al, 74:964-968 (1), with permission from BMJ Publishing Group Ltd. Copyright © 2020

6.2.2 HIV-specific frameworks

Social epidemiology frameworks specific to HIV tend to focus on the risk of acquiring HIV as well as the 'context' of epidemics to inform HIV prevention strategies; for example, a modified social ecological model proposed by Baral et al. (546) focuses on "vulnerable populations" (e.g. sex workers), according to their sociocultural context. The dimensions used in their model are: (1) intrapersonal, (2) interpersonal/network, (3) community and (4) public policy; in other words, from biological/behavioural factors to laws and policies (546). Other researchers (547) have recommended that interventions addressing social and structural drivers of HIV prevention should also hypothesise causal pathways, levels of influence as well as embed implementation, monitoring and evaluation mechanisms to feedback on outcomes and impact. Poundstone, Strathdee and Celentano (548)

present a heuristic framework of the social epidemiology of HIV which identifies similar categories to Baral et al. (546). Specifically, in relation to social-level factors: social capital, cultural context, neighbourhood effects (e.g. socioeconomic factors) and social networks (e.g. dynamics); and for structural-level factors: war and militarisation (e.g. displacement), demographic change (e.g. migration), structural violence and discrimination (e.g. racism, sexism and stigma), legal structures (e.g. criminalisation) and the policy environment (e.g. relating to health, the economy or social welfare) (548).

6.2.3 Conceptualising interactions and causal pathways

Directed acyclic graphs (DAGs) are used to present potential causal pathways from an exposure to outcome whilst simultaneously displaying hypothesised relationships between variables, including mediators (549). DAGs go beyond simplistic definitions of potential confounders to provide a more sophisticated depiction of relationships among covariates which may be confounding true associations; a confounder is a covariate associated with both the exposure and outcome of interest but not caused by the exposure itself (550).

DAGs are based on a series of qualitative and non-parametric assumptions which may be untestable, have unknown validity or be restricted in terms of their statistical power (549). They are limited by the potential exclusion of significant but unmeasured variables and their inability to eliminate all sources of bias such as measurement bias (550, 551). Therefore, data presented do not represent relative distributions or specific functions among variables including the sign, magnitude, shape or form of the relationship (549, 552). For example, some unobserved (or 'latent') variables may be included within a DAG either because they were not measured in the original study or because the concept is difficult to define theoretically (e.g. social status) (551). DAGs are also limited by their inability to fully capture directions of influence; DAGs are acyclic in nature (in other words, they do not form a cycle) however, in reality, multiple pathways or bi-directional interactions may exist (553). Despite these limitations, DAGs may be used to identify covariate adjustments to reduce the likelihood of structural confounding bias (otherwise known as selection or collider bias) which may be introduced by traditional methods such as adjusting for a covariate in a multiple regression model or by stratification (550, 551).

However, causal inference continues to be an area of disagreement among epidemiologists. For example, Krieger and Davey Smith (554) argue for a broadening of the approach to causal inference towards a "flexible framework of inference to the best explanation", a concept adopted from the philosopher Peter Lipton (555). In other words, to be driven by a causal rather than logical approach which is underpinned by theory and knowledge that explains the evidence presented whilst remaining attuned to the context (including histories or historical periods) by which knowledge is generated (554). Inference to the best explanation supports an approach of "evidential or causal pluralism" through which several methods, data sources, and investigations are triangulated to test for different assumptions and biases (554).

6.2.4 Mental health and HIV

As people living with HIV continue to age, mental health is an increasing challenge. Before COVID-19, people living with HIV were disproportionately affected by mental ill health compared to people who did not live with HIV (105, 474). For example, a systematic review (474) found that the prevalence of mental health conditions among people living with HIV in the UK was much higher than the general population.[3] Specifically, the study found high prevalence across multiple conditions including depression (27-47% vs. 2-5%), anxiety (22-49% vs. 4-5%), depression or anxiety (33-58% vs. 27%), sleep disturbance (61% vs. 10%) and suicidal ideation (31% vs. 1%) (474).

Internalised HIV-stigma, loneliness, social isolation and mental ill health following a HIV diagnosis can manifest into physical symptoms (e.g. problems sleeping and/or effects on the immune system) through chronic immune activation (or inflammation) (105). Therefore, mental health, in and of itself, is important, as even if a person has few or no associated physical symptoms, this can still have an impact on their daily life and reduce their overall quality of life.

Operario et al. (556) recently reviewed evidence of HIV and mental health interventions among MSM where they mapped determinants to multiple conceptual frameworks including syndemic theory, intersectionality, and minority stress theory on personal, interpersonal, community, and structural ecological levels. The authors argue that integrated interventions are necessary to end the global HIV epidemic with structural interventions to address human rights issues (e.g. HIV criminalisation

[3] The study (474) compared population-based surveys, including the 2007 Adult Psychiatric Morbidity Survey in England, 2012 Health Survey for England, and an epidemiological database ('PatientBase').

among sexual and gender minorities); the authors conclude that the prioritisation of psychological care and mental health is a "basic need for all individuals" (556).

A shift from acute mental health to chronic conditions has increased demand for mental health services and is likely to have worsened during the COVID-19 pandemic (251). Therefore, by combining findings from qualitative and quantitative studies, I aim to explore changes in health and well-being as a result of the pandemic with comparisons of data collected pre-pandemic (2017) and during the pandemic (2020 and 2021).

6.3 Research questions

1. How do social determinants of health impact the health and well-being of people living with HIV in the UK and how this is affected by the COVID-19 pandemic?

6.4 Aim and objectives

6.4.1 Aim

To develop a multifaceted conceptual framework of the relationship between structural and social determinants, mental health, and well-being among people living with HIV by applying findings to existing theory.

6.4.2 Objectives

1. To triangulate data across all studies included in the thesis and present findings according to the social and structural determinants identified.

2. To identify the social conditions and historical background which may be influencing any inequalities seen (relating to socioeconomic position, ethnicity, gender and sexual identity).

3. To develop a conceptual framework based on existing theories and approaches; specifically, ecosocial theory, syndemic theory and intersectionality.

4. To propose a causal pathway between an exposure (deprivation) and outcome (mental health) and explore possible explanations for these associations through the development of a provisional directed acyclic graph (DAG) and applications to existing theories.

6.5 Methods

I initially proposed to apply my research findings to ecosocial theory only. However, as my project explored the emerging COVID-19 pandemic, syndemic theory was another appropriate framework which I used to interpret my findings. Both theories are centred on disease concentration (and disease interaction in the case of syndemic theory) (557). Therefore, in this Chapter, I propose using a combined framework to uncover the interactions between HIV, COVID-19 and mental health in studies using data collected before and during the pandemic. I have defined mental health using self-reported data rather than confirmed diagnoses.

6.5.1 Triangulation

Norman Denzin's first call for triangulation (558) focused on mixing data from multiple qualitative methods; however, the approach has since evolved to apply to mixed-methods research also (559, 560). In his original conception of triangulation, Denzin (558) described four applications of triangulation including (a) data[4], (b) methodological[5], (c) theory[6] and (d) researchers' (or investigators')[7] background (562). Since then, debates and criticisms have emerged around the philosophical grounding of triangulation with Denzin explaining that the goal of multiple triangulation is "... a fully grounded interpretive research approach" that focusses on in-depth understanding rather than validity (563, 564). The revised concepts have defined triangulation as a way to "extend knowledge potential" (562).

Qualitative and quantitative results can converge (agree), diverge (contradict), and/or complement each other (supplement) (560). Torrance (563) also relates a less commonly described element of triangulation in the literature of 'respondent validation' (or 'member checking'). During my data collection, a participant in the qualitative study of service providers (**Chapter 3)** asked to see his transcript for quality checking. However, no other participants asked to see their transcripts. Interview transcripts were shared with co-researchers as part of the participatory approach in **Chapter 4**

[4] Includes time, space and person and levels of aggregate, interactive and collectivity for the "person" type (558). In other words, "each data point represents different data of the same event; discovering commonalities within dissimilar settings" (561).
[5] This can be "within-method" and "between-method" (558).
[6] This could be single or multiple perspective(s) "in relation to the same set of objects" (558).
[7] Denzin (558) clarified that this could be a single or multiple observer(s) of the "same object".

– I would argue this is a type of "respondent validation" of sense-checking made by community members. Finally, as part of a community-led research dissemination event hosted in July 2022 **(subsection 4.5.2)**, I shared findings from both qualitative studies with key stakeholders (including study participants) and asked for feedback on how these should be interpreted and shared more widely, which could also be viewed as 'respondent validation.'

In my thesis, I triangulate different perspectives, study data, methods and theoretical perspectives. First, to uncover the relationships between social determinants and clinical outcomes, I conducted a systematic review and meta-analysis **(Chapter 2)**. Secondly, to uncover how HIV services were adapted during the COVID-19 pandemic, I used a qualitative method of semi-structured interviews, as well as co-production, to explore the experiences of people living with HIV and those providing services, applying ecosocial and syndemic theories **(Chapter 3 and Chapter 4)**. These qualitative investigations include the exploration of the impact of COVID-19 on mental health and well-being. These three independent studies included multiple observers (e.g. independent screener in the systematic review and multiple interviewers and coders in the qualitative studies), which Denzin argues removes bias from the research process and "insures a greater reliability in observations" (558).

In this Chapter, I triangulated data from the qualitative studies by merging both NVivo project files and reducing the codes and themes by combining any duplicates. I used ecosocial theory as the main framework.

6.5.2 Application and adaptation of theoretical framework

I was unable to apply the findings from all empirical strands of work to ecosocial theory due to limitations related to the data captured from the methods used. For example, I am unable to explicitly refer to embodiment due to limited clinical (including biological) data and unclear pathways. Therefore, I have considered the interactions between HIV, COVID-19 and mental health using syndemic theory and guided by an intersectional approach. As described by Smith et al. (565), integrating intersectional and syndemic frameworks can uncover the interconnectedness between multiple health inequities and corresponding syndemic exposures across "interlocking social positions." This interrelatedness is demonstrated by one study (566) which qualitatively explores the syndemic

conditions (e.g. mental health, substance use) experienced by young Black gay, bisexual, and other MSM exacerbated by personal and structural conditions including homonegativity and racism.

6.5.3 Development of a DAG

I used the online programme DAGitty v3.0 (551) to present a provisional causal pathway between deprivation/poverty and mental health. I designed this diagram, including the direction of pathways, according to the findings from each Chapter of the thesis as well as well-established theories of associations and definitions in the literature. Specifically, I map interactions between social determinants only based on the literature, including those relating to socioeconomic position (191), socioeconomic status (190), social class (133) and deprivation (183, 567). For example, the English indices of deprivation 2019 (183, 567) identifies seven domains of deprivation which are combined to generate an index of multiple deprivation: (1) income, (2) employment, (3) education, (4) health, (5) crime, (6) barriers to housing and services and (7) living environment.

I re-labelled any social determinants that were not observed in the Chapters as "unobserved" (crime and social capital) and grouped exposures from the quantitative analysis, which measured similar determinants, together; specifically, financial security (income, having enough money to meet basic needs, income source and keeping up with household bills/credit commitments).

6.6 Results

Overall, across all studies, measures of deprivation were associated with poorer outcomes including clinical measures and mental health. However, associations between some outcomes and determinants were less clear or displayed no evidence; specifically, education (GHQ-12 score and ART adherence), employment (virological suppression and ART adherence), housing (GHQ-12 score) and social class (CD4 counts).

6.6.1 Triangulated qualitative findings

Both qualitative studies identified social determinants of health as a theme at the individual and interpersonal level. This included reflections of daily life before the pandemic and changes to social circumstances as a result of COVID-19 and government restrictions. For example, when discussing social support, participants shared how this related to their mental health and coping mechanisms in past histories (e.g. HIV diagnosis) and present day (e.g. COVID-19 virtual peer support, restrictions on seeing family members and the formation of "support bubbles"). **Figure 6.2** presents a combined framework of themes and sub-themes identified from merging the NVivo codebooks from both qualitative studies and have been mapped to key concepts of ecosocial theory (accountability, agency and inequalities). Here, I present both individual and interpersonal ecological levels together as several of the themes identified fall under both.

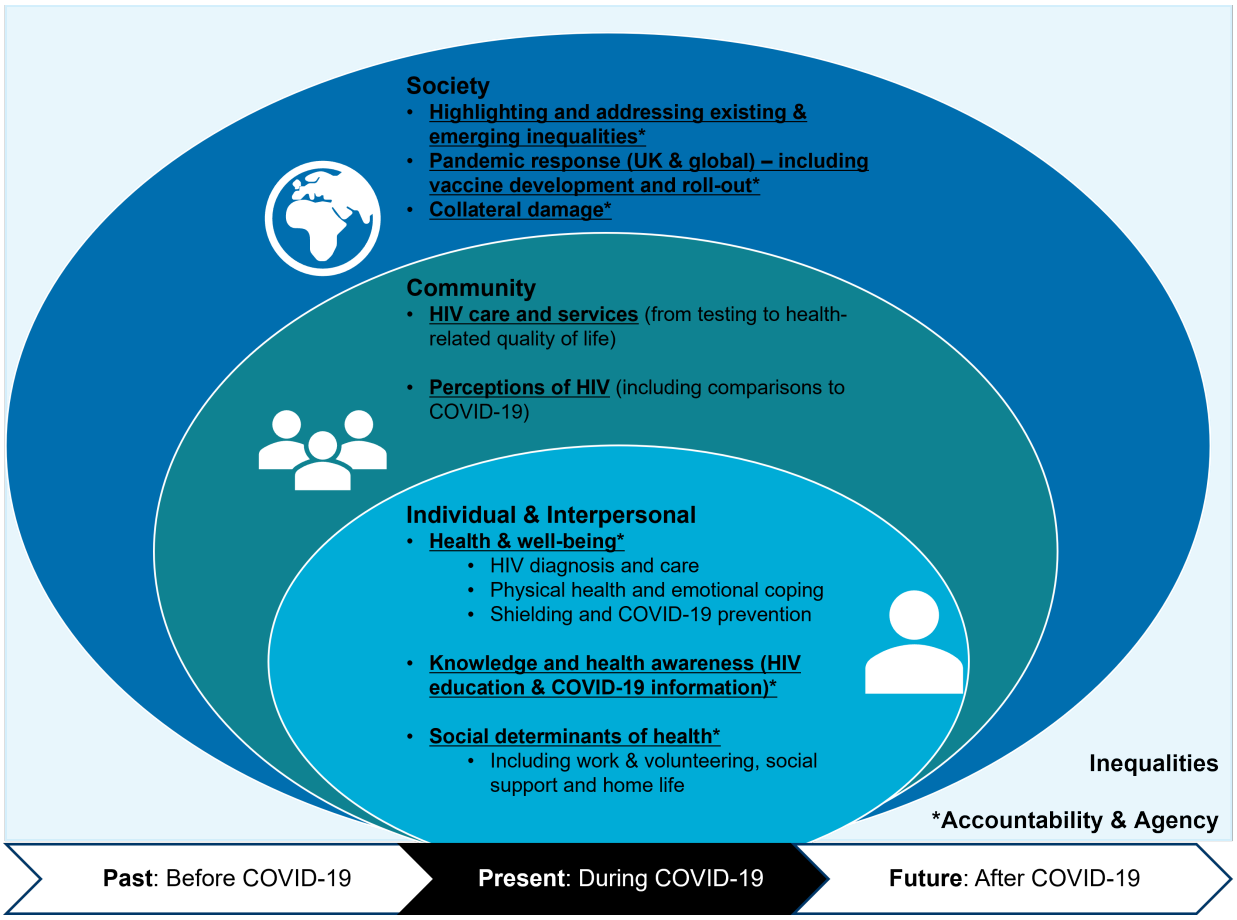


Figure 6.2: Concept map of **themes** and sub-themes identified from triangulating qualitative data and mapped to key concepts of ecosocial theory (see light blue Box), according to ecological level and COVID-19 timeline. Adapted from Enane et al. (369, 370).

6.6.2 Mixed-methods results

I mapped the results of each study to an individual social determinant which is presented in **Table 6.1** according to the study type. Here, I present an overall summary of results from the systematic review, overall findings from both qualitative studies (including illustrative quotes) as well as adjusted effect estimates (where possible) from the quantitative study.

Table 6.1: Mixed-methods results

Social determinant	Systematic review (Chapter 2)	Qualitative (Chapters 3 and 4)	Quantitative (Chapter 5)	Overall associations
Deprivation/ poverty	Included in 9/83 (10.8%) of studies (neighbourhood level). Two studies found significant **negative** associations between deprivation and virological suppression and one study found a **negative** association between deprivation and medication adherence.	"*...my healthcare team are in [location]. It's a deprived, northern city with a lot of social challenges and complexities."* [Nick]	*Determinant not measured in the Positive Voices survey; however, several measures of deprivation are detailed below.*	Higher levels of deprivation/poverty associated with **poorer** virological suppression; adherence (individual level) and availability of HIV care (area-level)
Education	Included in 9/83 (10.8%) of studies reporting associations with virological suppression. Five **positive** associations with higher education, four **negative** associations with lower education. **Less clear** relationship with medication adherence (mostly **negative** with lower education).	Three participants, including one service provider, were current students. Some reported increasing isolation, "*The lessons from university for me went online, which I was happy with, so I didn't have to travel. So, all that kind of thing about the isolation, I was isolated anyway, so it made no difference for me."* [Claire]	No significant associations were found between educational level and GHQ-12 score after adjusting for demographics, social determinants, and clinical measures.	Higher educational attainment **improved** virological suppression (individual level) **Poorer** mental health/ isolation during COVID-19 (individual level) **Unclear** relationship with adherence and **no evidence** with mental health (GHQ-12) (individual level)
Employment	Included in 33/83 (39.8%) of studies – mostly **negative** for unemployed compared to employed, although largely **unclear**.	Some participants shared how their employment status or role changed after they were diagnosed, "*...I couldn't continue doing the work as well as I could, because my health was then deteriorating..."* [Kenneth] The pandemic resulted in some people being made redundant or furloughed; for example, one person's partner had been furloughed and another spoke of friends made unemployed. Participants spoke of work-related stress due to increased workloads during the pandemic which impacted mental health, "*...it was very difficult to separate because I think everything at work was COVID and then at home (…)*	Unemployed or economically inactive participants were over 2-times more likely to self-report GHQ-12≥4 compared to those employed, after adjusting for all other demographics, social determinants, and clinical measures (aOR 2.43; 95% CI 1.62, 3.64 and aOR 2.33; 95% CI 1.72, 3.16, respectively).	Unemployment associated with **poorer** mental health (GHQ-12 and during COVID-19) and physical health at HIV diagnosis (individual level) **Unclear** relationship between employment and virological suppression and adherence (individual level)

Social determinant	Systematic review (Chapter 2)	Qualitative (Chapters 3 and 4)	Quantitative (Chapter 5)	Overall associations
		hearing and reading about COVID so there was no sort of distinction in those two." [Jack, Charity Worker]		
Financial security and/or income	Included in 33/83 (39.8%) of studies. Overall, studies suggest an association between lower income and poorer virological suppression and adherence. Of the five studies finding an association with virological suppression; three studies found a **negative** association with lower income and two studies a **positive** association with middle/higher income.	Two people living with HIV shared that they were receiving welfare benefits before the pandemic; others shared how their (or other peoples') income was affected by the pandemic. However, for most interviewed, their financial situation had remained the same.	Participants who received welfare benefits (aOR 1.45; 95% CI 1.09, 1.92) or were behind with some (aOR 1.45; 95% CI 1.07, 1.97) or all (aOR 2.07; 95% CI 1.09, 3.93) bill/credit commitments were around twice as likely to report poorer mental health (GHQ-12≥4) than participants who had another source of income in the past year or were up to date with their bill/credit commitments, after adjusting for demographics, social determinants and clinical measures. Conversely, participants who had enough money to meet basic needs always, most and some of the time were 80% (aOR 0.20; 95% CI 0.12, 0.32), 59% (aOR 0.41; 95% CI 0.26, 0.63) and 45% (aOR 0.55; 95% CI 0.0.35, 0.86) less likely, respectively, to report a high GHQ-12 score compared to those who did not, after adjusting for demographics, social determinants and clinical measures.	Financial insecurity/lower income associated with **poorer** virological suppression, adherence and mental health (GHQ-12) (individual level)
Food security	7/83 (8.4%) studies measured food security (e.g. number of meals per day) at the individual/household level with one study reporting a **negative** association with virological suppression and six studies reporting the same direction of association with ART adherence.	Mostly discussed in relation to food availability and sufficiency during the pandemic, with two sharing that they had received food parcels either from community groups or the government, "*When the lockdown first started I was categorised as being extremely vulnerable and I received Government food packages and things like that for some months..."* [Michael] One service provider described a need to supply food services to vulnerable people during the pandemic, "*...if they were in a vulnerable group clinically, it was about accessing food banks to deliver stuff to their property so that they could sustain isolation."* [Nick]	*Determinant not measured in Positive Voices survey although captured by "enough money to meet basic needs" - see financial security.*	Food insecurity associated with **poorer** virological suppression, adherence, COVID-19 experience (individual/ interpersonal levels)

Social determinant	Systematic review (Chapter 2)	Qualitative (Chapters 3 and 4)	Quantitative (Chapter 5)	Overall associations
HIV-related stigma	*Not explored in systematic review.*	HIV-related stigma was often referred to in relation to sharing HIV statuses. Some discussed the challenges of friends and family not knowing their status, whereas others shared that they had come to terms with their diagnosis and were happy to share their status, "*I will never tell my sister (...) Now I feel there is not as much of a stigma as it used to be, and I am quite happy to tell people if they- No-one has asked me. Sometimes I have told them by myself. Most of my friends know. It is no biggie now."* [Ronald] Most people discussed stigma across society, particularly when navigating new relationships. This narrative was shared among people living with HIV in remote areas where HIV is still stigmatised, "*But still, for me at least, it's on a need-to-know basis. (…) maybe living in a small village, and working in the care sector, it's not the best place to say because first, it's a really small world."* [Mark] Additionally, Julie shared challenging experiences navigating her HIV status in her community, both as a Christian but also Black African woman living with HIV, "…I *could not even tell them (…) because it's like they will never understand, they preach against it. But amongst themselves, they don't go for testing. (…) To them, I am somebody else, and I have to maintain that face to them, so that's a challenge on its own. And at times it takes its toll on you as well, because you have got to maintain all these different faces to different people..."* [Julie] Susan described how the intersections of gender, ethnicity and sexuality can prevent people from sharing their HIV status and perpetuate stigma in communities, "*There are so many different stigmas depending on what culture you're from (…) for certain cultures women will be too afraid to say anything because they're worried about breastfeeding and then straight men have a problem because it's associated with gay men. For some reason white straight men never come out, it's always gay men or African men, which I find really strange. (...) I think it's important, so it shows that anybody can get HIV."* [Susan]	*Not explored in quantitative analysis.*	HIV-related stigma associated with **poorer** mental health during diagnosis and navigating relationships (individual/ interpersonal levels)

Social determinant	Systematic review (Chapter 2)	Qualitative (Chapters 3 and 4)	Quantitative (Chapter 5)	Overall associations
Housing	Included in 39/83 (47.0%) of studies. 8 studies reported significant **negative** associations between unstable housing and virological suppression and eight studies finding the same direction of association with medication adherence. Overall, people living in unstable housing were 52% less likely (pooled AOR 0.48, 95% 0.33, 0.70) to be virologically suppressed (VL<200 copies/mL).	Conversations often focussed on relationships with family members (including caring responsibilities) and the physical space. Participants shared how they navigated living with family members who they had not shared their HIV status or issues of isolation/loneliness if they lived alone (n=6). People working in services tended to focus on their experiences of working from home, "*Colleagues of mine that live in like one-bedroom flats, have no garden, no balcony and their office their dining table if they have one becomes their office and they hated it. (...) so I was really lucky."* [Phil, Peer Support Worker]	No significant associations were found between housing and GHQ-12 score after adjusting for demographics, social determinants, and clinical measures.	Housing stability associated with **improved** virological suppression, adherence (individual level) **Poorer** mental health among those living alone during pandemic (individual/ interpersonal levels) **No evidence** of relationship with mental health (GHQ-12) (individual level)
Migration	*Not explored in systematic review.*	Issues relating to migration were raised; for instance, some people born outside of the UK shared difficulties of being unable to travel home or experiences of new migrants negotiating overcrowded home environments during the pandemic, "*During the pandemic, she was still living with so many people. I don't know how they live, because I never visited her, we always meet somewhere neutral. I don't know how they live, but I think there are so many people in the same house or whatever. And there is no observation of COVID regulations or rules."* [Julie]	*Country of birth not explored in full multivariate model.*	**Poorer** social support among those experiencing challenges relating to migration during COVID-19 (individual/ interpersonal levels)
SES/SEP	Included in 4/83 (4.8%) of studies. Two reported a **positive** association between virological suppression and mid/higher-range SES/SEP.	*Determinant not explored in qualitative studies.*	*Determinant not measured in Positive Voice survey; however, several measures of SES/SEP were investigated.*	Higher level SES/SEP associated with **improved** virological suppression (individual level)
Social class	Included in 1/83 (1.2%) of studies and found **no difference** in CD4 counts across defined social class groups.	*Determinant not explored in qualitative studies.*	*Not measured in Positive Voices survey.*	**No evidence** of relationship with CD4 counts (individual level)
Social support	*Not explored in systematic review.*	Participants shared the support they, or others they support, accessed to cope with the pandemic (e.g. online peer support groups).	*Not measured in Positive Voice survey although questions added to 2022 version.*	Social support associated with **improved** mental health/coping during

Social determinant	Systematic review (Chapter 2)	Qualitative (Chapters 3 and 4)	Quantitative (Chapter 5)	Overall associations
		Nearly all of those interviewed shared a sense of loss at the ability to see, or physically touch, friends or family members, particularly during the peak of the pandemic and lockdown periods. People shared how they formed "support bubbles" to cope during the pandemic as well as the importance of social support when they were newly diagnosed.		COVID-19 and with HIV diagnosis (individual/ interpersonal levels)
Substance use	Two studies reported a **negative** association between drug use and retention in care. One study reported an association between severity of alcohol use and having a detectable viral load.	Some of those interviewed shared their previous struggles with alcohol and substance use, often linked to poor mental health, with one participant sharing how they have recovered through the help of established services, "*I'm a recovered drug addict (...) I have definitely benefited from integrated care systems, peer support and mutual aid, compassionate organisations giving me chances (…) multidisciplinary kind of support network."* [Nick]	*Not explored in quantitative analysis.*	Substance used associated with **poorer** virological suppression, retention in care, mental health (individual/ interpersonal levels)
Technology and digital platforms	*Not explored in systematic review.*	Interviewees shared how they continued to access peer support groups virtually during the pandemic, with some having to adapt quickly to online environments, "*To be able to communicate and get support, you need some extra phone skills, smartphone skills, and laptop or IT skills, Zoom skills, which I didn't have."* [Kenneth] Online environments made peer support more accessible for people living with HIV in remote locations, "*The only thing that's been really good about the pandemic is the explosion of Zoom, and so I've been able to access so many more things, like to do with other women that have HIV (…) where, normally, I wouldn't be able to access that because it would be based in London."* [Claire] Others described accessing healthcare through online environments – either related to HIV or other services through teleconsultations.	*Not measured in Positive Voices survey.*	Technology access associated with **improved** mental health – increased connection with peer support (individual/ interpersonal levels) Lack of access may be a **negative** barrier to healthcare access (individual level)

In the following sub-section, I focus on one social determinant (deprivation/poverty) to illustrate possible causal pathways. Deprivation/poverty may be a composite measure of multiple determinants (e.g. financial security, food security and housing status) at various ecological levels (e.g. individual, neighbourhood).

Deprivation and poverty

My preliminary DAG **(Figure 6.3)** shows causal paths identified by each Chapter relating to deprivation/poverty (exposure) and mental health (outcome). The relationships between social determinants are complex; several putative causal pathways centre around SES and SEP.

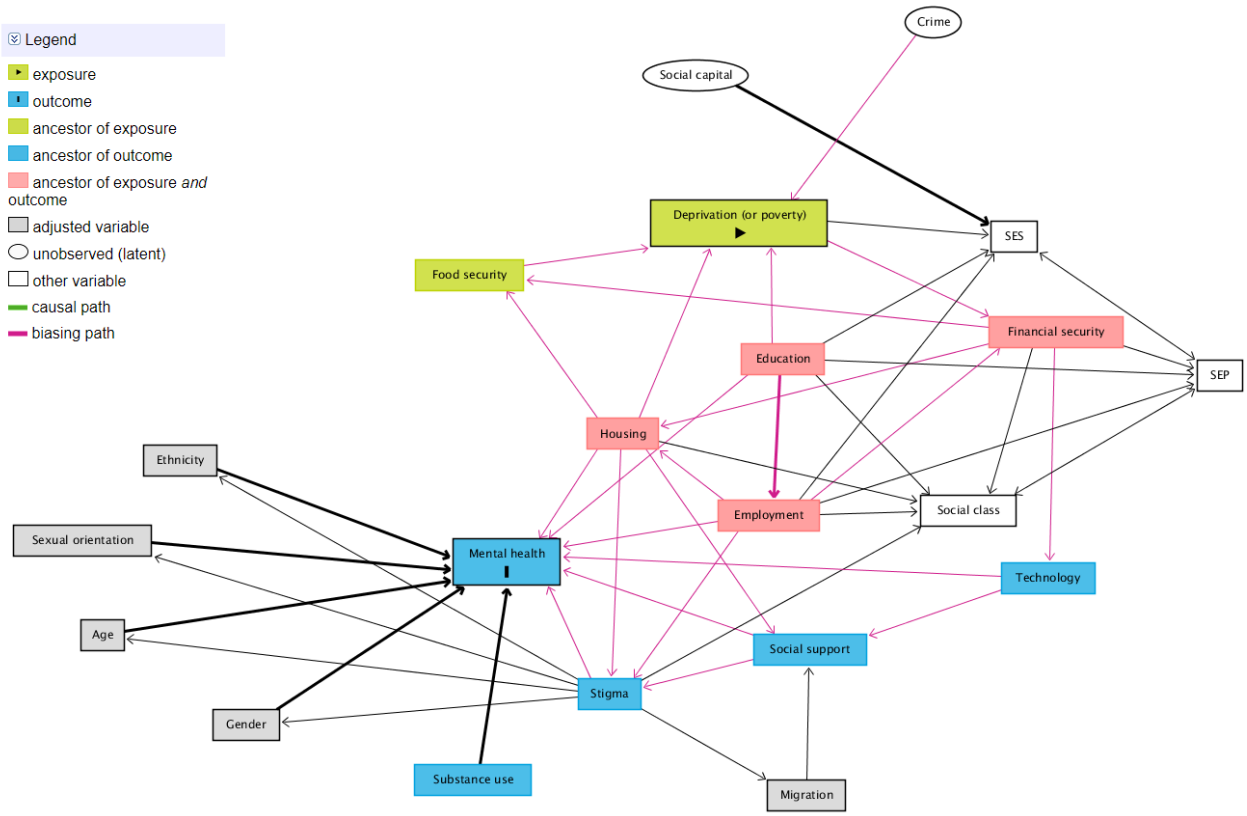


Figure 6.3: Proposed DAG between deprivation/poverty and mental health created using DAGitty (568).

The DAG identifies several atomic direct effects (indicated by bold arrows); these are pathways by which there is no corresponding indirect path.[8] Additionally, the model contains a cycle between deprivation (or poverty) → financial security → food security → deprivation (or poverty). DAGitty.net

[8] In other words, if we removed one of these arrows, "there will no longer be any causal effect between the corresponding variables" (569).

determined that the minimal sufficient adjustment sets containing age, ethnicity, gender, migration, sexual orientation for estimating the direct effect of deprivation (or poverty) on mental health are:

- **Age**, education, employment, **ethnicity**, **gender**, housing, **migration**, **sexual orientation**, (access/use of) technology
- **Age**, education, employment, **ethnicity**, financial security, **gender**, housing, **migration**, **sexual orientation**

We can begin to postulate the various mechanisms between this determinant and study outcomes by applying the selected theories. People who are materially deprived have access to fewer and/or poorer resources. For example, people facing financial insecurity may need to negotiate food availability according to their low income alongside paying rent, bills and other expenditure (experiences of food security). According to syndemic theory, these social determinants may interact with one another, as well as interact with poverty to "precipitate disease clustering" (542) of stress and mental ill health. Other factors may worsen the magnitude of this effect; for example, people with caregiving responsibilities (i.e. children to feed, costs of childcare) as well as structural factors such as the political landscape, the economic climate and policies.[9] COVID-19 is an additional communicable disease which intersects with these relationships. Intersectionality may begin to explain why some groups are more disproportionately affected than others; for example, Black and racially minoritised women living with HIV in England reporting a high prevalence of socioeconomic disadvantage and poor mental health and "live with the consequences of structural racism" (242).

[9] For example, since late 2021, the UK has been experiencing a 'cost-of-living crisis' demonstrated by a loss of real income and increasing costs (e.g. food and energy) (570–572).

6.7 Discussion

In this Chapter, I proposed a conceptual framework from the convergence of data from all four studies included in the thesis which I applied to syndemic theory. I demonstrated how COVID-19 has a 'synergistic' relationship with other diseases including HIV and mental health. As people living with HIV continue to grow older, I argue that the HIV/mental health syndemic would fall into the centre of Bambra's proposed model **(Figure 6.1)** which also highlights the inequalities exacerbated by the COVID-19 pandemic. Additionally, I found that there appears to be an abundance of literature on some social determinants which are slightly easier (or less subjective) to measure than others (e.g. housing versus social class).

Using a convergent mixed-methods design allowed me to analyse each study using their traditional methods which is a more intuitive and efficient process (268). I was also able to compare findings from the second qualitative study with the survey data as this was a sub-sample from the original Positive Voices study. However, some limitations exist. For example, each study contained different sample sizes and looked at different outcomes, which made some comparisons difficult particularly when merging text and numbers. Additionally, Krieger and Cruskin (541) emphasise the importance of frameworks for how and when analyses are performed across levels, the scale(s) and level(s) of analyses need to be explained, including the strengths and limitations of these. In this Chapter, I was limited by the data collected and analysed which was largely at an individual level. Therefore, data collected at the community and population levels may help to provide a more complete view of the dynamics and interactions present between social determinants.

Although embodiment (or social-to-biological transition) is evident in other areas of health research, such as research on inflammatory markers and educational attainment (573),[10] I was unable to speculate nor develop a clear biological mechanism in my research. Gathering evidence of mechanisms of disease pathways may be possible at the biological level but difficult to unpick at

[10] Maurel et al. (573) analysed six European cohort studies (including three British, two Swiss and one Finnish cohort). The authors reported that inflammation (measured by C-Reactive Protein which is a marker for coronary heart disease and atherosclerosis) was the most "socially patterned" biomarker and was associated with educational attainment in adulthood (573). For example, in the analysis of the Whitehall II cohort (574), the study authors (573) found that participants with lower educational attainment were more likely (β=0.22; 95% CI 0.15, 0.29) to have higher levels of CRP, compared to those with higher education which remained after adjusting for intermediate factors (β=0.10; 95% CI 0.03, 0.17).

the social level; researchers may be able to speculate how social determinants operate and try to "control" for these, however fundamental aspects have yet to be addressed. Syndemic theory and intersectionality provide an opportunity to investigate what researchers are observing; for example, Smith et al. (565) describe how "policing and immigration systems reinforce interlocking inequities by chronically destabilizing family, social, economic, and housing environments along axes of race, class, and gender."

Future research could consider ecosocial theory, particularly the concepts of embodiment, accountability and agency to unpack other pathways and mechanisms through which social and structural determinants operate, and ultimately how and why health inequities persist at the population level. Investigating embodiment enables the exploration of both the biological and social factors to hypothesise how diseases manifest and operate within the social world, including histories, powers and pathways. Additionally, research using an intersectional lens can address issues of power and hierarchies. Poteat and Logie (575) argue that intersectionality research (specifically relating to HIV-related stigma) should shift from a predominantly deficit approach (leading to pathologisation) to a strengths-based approach to re-enforce that the system, rather than communities, are "the problem" (576, 577). Community-based participatory research (CBPR) is one example of a strength-based approach as this focusses on asset-based outcomes including empowerment, resistance and flourishing (577). Similarly, a shift of interventions, policies and service delivery that target focussed, upstream goals (e.g, culture, policies and laws) and how these connect to individual outcomes, rather than a purely siloed approach that medicalises HIV, is needed (539, 577).

6.8 Conclusion

By mapping the results from each distinct Chapter in the thesis, I was able to summarise the effect of social determinants on various outcomes including clinical measures (ART adherence, virological suppression) and mental health. However, the relationship between some determinants and outcomes displayed unclear or no evidence; for example, social class (virological suppression), housing/education (self-reported mental health), employment (treatment outcomes) and education (adherence). However, this Chapter demonstrates the complexity, interconnectivity, and collinearity between social determinants. Future research using more advanced statistical methods (e.g. multi-

level modelling) would help to further clarify the pathways through which social determinants operate and would help to propose causal pathways that could be targeted by public health and policy interventions.

7

Discussion

"Societies, no matter how stable they may appear, are ongoing things. The world is in a state of continuous flux, and as life conditions change, knowledge must be kept pace. In this sense all knowledge is social."

Shibutani (558, 578)

7.1 Aim of thesis

This thesis aimed to identify the contribution of social and structural determinants on clinical outcomes and self-reported health and well-being among adults (aged 18 years and over) living with HIV in the UK. This included an exploration of the impact of COVID-19 on people living with HIV in the UK and the development of a conceptual framework. I wanted to determine whether social determinants explain variations in outcomes as well as the role of structural determinants on influencing outcomes.

As recommended by Galea and Link (553), this thesis also engages with theory from other disciplines (including anthropology and sociology), which help us to understand the importance and significance of social determinants, therefore, broadening the scope of epidemiology beyond the "black-box" discipline.

7.2 Summary of findings

Social epidemiology straddles the epistemological positions of empiricism and pragmatism, but favours the former (e.g. observations over social factors) (125). Therefore, as a discipline, social epidemiology advocates for the shift of understanding disease causation from a biomedical[1] to a social perspective, with scholars advocating for a shift in focus within the discipline towards mechanisms (127, 553). The Bradford Hill criteria is a classical approach to establishing whether there is a causal relationship between factors (579).[2] However, as outlined in Krieger's seminal paper on "the web of causation" (127), the spider web metaphorises the complexity of disease causation; interconnected risk factors or outcomes intersect with 'strands' of "diverse causal pathways."

In my thesis, I am unable to determine definitive causal pathways between the social determinants and outcomes investigated, however, I begin to uncover some of the evidence. For example, a clear, strong association is established between housing status and treatment outcomes (e.g. unstable housing $\rightarrow$ poorer virological suppression) as well as financial security and mental health outcomes (e.g. unable to keep up with bill payments $\rightarrow$ higher self-reported GHQ-12 score). These relationships

[1] Biomedical individualism often considers social determinants as secondary (or irrelevant) to biological factors (127).
[2] The nine criteria are strength of association, consistency (or repeated observation), specificity, temporality, biological gradient, plausibility, coherence, experiment and analogy (579).

appear to also intersect with other social factors (e.g. gender and ethnicity) which I believe, by applying Krieger's work on ecosocial theory (161, 481), can be explained by structural factors (e.g. sexism and racism).

7.2.1 Key findings by chapter

Overall, the thesis suggests that a social gradient of health persists among people living with HIV and associations between various health and well-being outcomes and social determinants; however, these relationships appear to be clearer among some determinants (e.g. measures of deprivation) than others (e.g. education).

First, **Chapter 2** highlighted the difficulties of 'detangling' social determinants of health, how determinants are interconnected, intersect and interwoven at the individual, community and population level. I was able to determine the relative contributions of some determinants more than others (specifically where consistent definitions are used in the literature). This largely aligned with previous studies in the UK examining similar social determinants and outcomes (20, 293).

Secondly, **Chapter 3** and **Chapter 4** provided novel insights to the experiences of HIV service providers and people living with HIV during the COVID-19 epidemic in the UK during 2020 and 2021. I was able to explore how services adapted, how these adaptations have been perceived by service users as well as to speculate on the long-term impacts to HIV care pathways. I also uncovered perspectives on how social and health inequalities have widened during the pandemic and used existing theory (ecosocial theory and syndemic theory) to help interpret these findings. This aligned with broader research on inequalities during the pandemic as well as preliminary qualitative findings emerging from the UK (174, 255, 258, 377). Finally, I provided a detailed description of a co-produced qualitative study and reflections of where this worked well during a doctoral research project as well as areas for improvement.

Thirdly, **Chapter 5** outlined results from the analysis of the 2017 Positive Voices survey and identified how some social determinants (e.g. measures of financial insecurity and unemployment) were associated with poorer self-reported mental health (GHQ-12 scores). These associations appeared to be greater in magnitude among marginalised groups which could be explained by existing theory (e.g. minority stress theory) (236, 515). However, associations between ethnicity and mental

health did not appear in the direction I expected.

Finally, in **Chapter 6**, I triangulated my data and proposed a causal pathway between deprivation and mental health which I interpreted through an intersectional lens and by applying syndemic theory. I also reflected on being unable to fully utilise ecosocial theory due to limitations in study design and data collected. Additionally, comparing chapters was difficult due to the numerous types of outcomes explored, different time points in which data were collected and/or analysed and heterogeneity in social determinants investigated.

7.3 Reflections and study implications

Conducting the thesis during the COVID-19 pandemic required rapid adaptations to be made in the ordering of the mixed-methods study (from a proposed explanatory study to a convergent, parallel design). I was also fortunate to acquire further funding to embed a CBPR project within the thesis which transformed the study and my own approach to research.[3] Largely, CBPR provides an opportunity for academic researchers to work directly with community members to design and implement solutions to challenges generated by community members themselves. On reflection, I would have engaged with people living with HIV before beginning my PhD and during every project in the thesis; however, I was limited by time to establish meaningful relationships and adhere to research milestones and resources in terms of funding and support. Additionally, I acknowledge that CBPR within academia is limited by the constraints of power traditionally held by academic institutions. However, it is motivating to learn of how co-researchers are now applying the qualitative research skills gained in other projects in settings within and outside of academia.

The findings of the thesis have implications for clinical practice and policy, particularly to the design and delivery of HIV services. The thesis suggests how services need to adapt to address the unmet needs of people living with HIV including those relating to their social conditions (e.g. housing, finances and employment status). Services that provide advice and practical support continue to be well received by people living with HIV but they face uncertainty due to the current economic climate. Virtual and online services provide a solution to geographical access but may also be widening inequalities (e.g. digital poverty and confidentiality). Mental health continues to be a growing

[3] The peer research project appears to have had the most research impact – see **subsection 4.5.2**.

challenge to progress in HIV and has been amplified by the COVID-19 pandemic. Marginalised populations who were already displaying poorer outcomes have been disproportionately affected by COVID-19, with these outcomes likely to have worsened over time.

7.4 Future research

It is well established that inequalities are driven by social and structural determinants of health, therefore, a social determinants approach to mental health should address multiple determinants, including recognition of past histories, and structural factors (e.g. racism and discrimination). Galea and Link (553) recommend that social epidemiologists explore how "all disease is biologic" as well as the implications of the "social, cultural, political and economic context" on pathways which they believe will provide a more holistic understanding of health and "the intersection of factors that matter inside and outside of the skin." Therefore, future research should focus on how marginalised populations living with HIV, who have experienced "enforced marginalisation from positions of power", experience health inequities rather than viewing them as "key" or "special" populations (127). By focussing on distinct populations, for instance, by using structural equation modelling (e.g. latent class analysis), we would be able to further unpick the health inequalities that exist and explore how these cluster depending on sociodemographic characteristics. These statistical models should be designed in line with the "rich theoretical foundation of research" that exists in the association between social determinants of health, disease processes and outcomes (580).

Multivariate analyses and multicausal frameworks would also enable the exploration of how factors are interconnected (127). Specifically, multilevel models will help to further investigate the interactions and relationships between upstream determinants (social factors) and the wider (and broader) social context at both the individual (disease pathologies) and population level (disease clustering); the latter remains unaddressed in the literature (243, 244, 428, 544, 581). Kelly and colleagues (582) propose a more integrated approach to disease causation which considers interactions between individuals and populations alongside disease temporality (583).

However, as advanced by Muntaner (125), the common approach of applying mathematical models to answer research questions can draw unrealistic conclusions as these do not typically consider "theory-informed social mechanisms". Therefore, Munataner (125) argues for a more

theoretical-driven approach to consider how concepts are 'conceptualised', how they can be related to other concepts and how these relationships can be tested/explored. Multi-level analyses will not be able to answer all the 'unknowns' as they remain limited in their ability to "understand how social mechanisms at the country level affect individual health outcomes" (125). Therefore, I also recommend the reconceptualisation of composite social determinants (e.g. measures of SES) beyond their indicators (e.g. income, education, employment) to also include social mechanisms in their analysis (125). By looking at each determinant separately, and then as a composite measure, we would be able to further clarify causal mechanisms and pathways. For example, developing a measure or index of SES specifically in relation to HIV, which could use age, gender and geography (deprivation) as proxies and is therefore guided by an intersectional lens.

As proposed in **Chapter 5**, an extension of the thesis would be to utilise HIV care data from the HARS dataset in the analysis of the 2022 Positive Voices survey. Additionally, a comparison of data from the 2017 and 2022 surveys would be interesting, however, this would be challenging as the populations sampled are different in each, therefore a longitudinal analysis or cross-sectional analysis of the same people from the two time periods is not possible. However, it may be possible to compare the cohorts according to specific health and well-being data collected in both studies including those relating to mental health symptoms (e.g. happiness, depression, anxiety, sleep disturbance and self-confidence) as well as pre-existing mental health diagnoses.

Finally, future research should continue to involve communities and acknowledge syndemic theory and human rights approaches to help to ultimately drive change:

> *"The next challenge, of course, is to mobilise the political will needed to work collaboratively towards meaningful changes in law, policy, and practice. At each step, the voices of those most affected will need to be part of the conversation."* (543)

8

Conclusion

"All scientific work is incomplete – whether it be observational or experimental. All scientific work is liable to be upset or modified by advancing knowledge. That does not confer upon us a freedom to ignore the knowledge we already have, or to postpone the action that it appears to demand at a given time."

Bradford Hill (579)

In the thesis, I have developed a body of evidence which contributes to the knowledge of how social determinants of health are associated with the health and well-being of people living with HIV in the UK.

The thesis found that generally, people living with HIV who are the most socioeconomically disadvantaged display poorer outcomes than those who are more advantaged; however, the strength and significance of these associations varies depending on the specific social determinant observed and measured. These findings complement those of previous studies of other health research areas, notably the prominent work of Sir Michael Marmot (UK) and Nancy Krieger (USA). Therefore, the thesis would be of interest to service providers and policymakers supporting people living with HIV who reside in the margins of society experiencing various systems of oppression and discrimination. The findings would also be relevant to people living with HIV in the UK who are currently experiencing the present transient nature of fiscal policies, austerity and government-imposed regulations since the COVID-19 pandemic leading to a cost-of-living crisis that is now being experienced across all sections of society.

A limitation of this research is that much of the data presented have been collected at specific points in time (they are cross-sectional) and are limited by the data that are collected, measured and observed. There are inevitably data which will be of significance but have not been presented (e.g. social class). Although the thesis is based on a small number of people living with HIV in the UK, it utilises the first nationally representative survey sample (2017 Positive Voices data) and also presents case studies of experiences of people sampled from the aforementioned survey.

Several questions remain unanswered, particularly relating to how determinants interact with one another to amplify, or reduce, associations with health and well-being outcomes. Other questions of interest would include:

1. How social determinants of health interact with structural systems of power and oppression among people living with HIV and how these intersect with their health and well-being?

2. How people living with HIV are experiencing the effects of the COVID-19 pandemic currently, specifically relating to the energy crisis and forecasted recession?

3. How data presented on social determinants from the 2017 Positive Voices study compare with

the 2022 study?

4. How social factors experienced at the individual and area level cluster at the population level and are associated with people living with HIV?

However, future research questions should be designed and prioritised by people living with HIV to ensure their relevance and importance to those with lived experience.

9

Outputs

Outputs relevant to thesis

I have published a number of outputs through traditional academic formats (e.g. peer-reviewed journal articles and conference posters) as well as formats for the general public (e.g. podcasts) which are detailed below.

Journal articles

- Appleby G & **Papageorgiou V** et al. Caregiver perceptions and experiences of paediatric emergency department attendance during the COVID-19 pandemic: A mixed-methods study. *PLoS One* (2022);**17**(11):e0276055. doi:10.1371/journal.pone.0276055

  This article discusses similar themes to those in Chapters 3 and 4 such as concerns about accessing services during the pandemic.

- **Papageorgiou V**, Crittendon E, Coukan F et al. Impact of daily, oral pre-exposure prophylaxis on the risk of bacterial sexually transmitted infections among cisgender women: a systematic review and narrative synthesis [version 2; peer review: 2 approved]. *Wellcome Open Research* (2022), **7**:108. doi: 10.12688/wellcomeopenres.17457.2

  The search strategy from this article was used to design that used in Chapter 2.

- **Papageorgiou V**, Davies B, Cooper E et al. Influence of material deprivation on clinical outcomes among people living with HIV in high-income countries: a systematic review and meta-analysis. *AIDS and Behavior* (2022), **26**, 2026-2054. doi:10.1007/s10461-021-03551-y

  This article informed Chapter 2.

Reports

- Pristerà P, **Papageorgiou V**, Kaur M, Atchison C, Redd R, Bowman L, et al. Report 14: Online community involvement in COVID-19 research & outbreak response: early insights from a UK perspective. *Imperial College London* (2020). doi:10.25561/77842

  This report was used to design the community involvement in Chapters 3 and 4.

- **Papageorgiou V**, Cooper E, Bruton J, Petretti S, Pristerà P, Ward H. Insight Report: "Let's Talk About... HIV Care". Imperial College London (in collaboration with Positively UK). *COVID-19 Community Involvement Insight Reports.* 15 July 2020. doi: 10.25561/93710

  This report informed the interview topic guide of Chapters 3 and 4 and was used to inform the overall study design of Chapter 3. Some participants from this event were recruited to the study in Chapter 3.

Conferences and events

- **ePoster:** Papageorgiou V, Bruton J, Dsouza K, Hamza H, Thamm W, Anderson J, Petretti S, Cooper E, Johnson H, Ward H. *Experiences of the COVID-19 epidemic: a participatory qualitative study with people living and/or working with HIV in the UK*, 24th International AIDS Conference 2022.

  This output includes preliminary triangulated findings from Chapters 3 and 4.

- **Reflective Workshop:** *Building & Sustaining Relationships in Participatory Action Research* (speaker and lead facilitator) at 2021 Research Methods eFestival hosted by the National Centre for Research Methods and methods@Manchester.

  This event reflected on the relationships built when co-producing the study in Chapter 4 and was attended by one of the co-researchers from the project alongside co-researchers from other co-produced projects.

- **ePoster:** Papageorgiou V, Bruton J, Petretti S, Shah A, Kall M, Cooper E, Day S, Delpech V, Ward H. *PED460 Impact of COVID-19 on the HIV care continuum in the United Kingdom*, 11th IAS Conference on HIV Science 2021

  This output included the preliminary findings from Chapter 3.

Other outputs

- **Papageorgiou V**, Bruton J, Johnson H, Ward H. *Supporting material for co-researchers.* Patient Experience Research Centre: Imperial College London (2022). doi: 10.25561/100339

This resource includes supporting material used to induct co-researchers, support peer interviews and useful resources for participants of the study described in Chapter 4.

- **Papageorgiou V**, Bruton J, Johnson H, Ward H. *Peer Research Training Resource*. Patient Experience Research Centre: Imperial College London (2022). doi: 10.25561/94819

  This training resource is a slide deck of all the training delivered as part of the project in Chapter 4.

- **Audio podcast:** Pozcast (March 2022). *Peer Research across the pond: a fascinating UK study exposes barriers and bias bolstered by the pandemic.*

  This podcast episode reports the preliminary findings from Chapter 4 as well as reflections of co-producing the project from a co-researcher.

Outputs not related to thesis

This section outlines other outputs which do not directly relate to the thesis.

Journal articles

- **Papageorgiou V**, Jones K, Halliday BP et al. A qualitative exploration of participant and investigator perspectives from the TRED-HF trial. *ESC Heart Failure* (2021);**8**(5). doi: 10.1002/ehf2.13524

- Atchison C, Pristerà P, Cooper E, **Papageorgiou V** et al. Usability and acceptability of home-based self- testing for SARS-CoV-2 antibodies for population surveillance. *Clinical Infectious Diseases* (2020);**72**(9). doi: 10.1093/cid/ciaa1178

- **Papageorgiou V**, Wharton-Smith A, Campos-Matos I, Ward H. Patient data-sharing for immigration enforcement: a qualitative study of healthcare providers in England. *BMJ Open* (2020);**10**(2). doi:10.1136/bmjopen-2019-033202

Conferences and events

- **Oral presentation:** Papageorgiou V, Jones K, Mindham R, et al., *'Do I really want to do this for the rest of my life?': a qualitative exploration of participant and study staff perspectives from the Therapy withdrawal in Recovered Dilated cardiomyopathy - Heart Failure (TRED-HF) study*, Chronic Living Conference 2020 [postponed to April 2021 due to COVID-19]

- **Oral presentation:** Papageorgiou V, Crittendon E, Davies B, Ward H. *Impact of pre-exposure prophylaxis on the risk of bacterial sexually transmitted infections among cisgender women: systematic review*, AIDS Impact 2019

- **ePoster:** Papageorgiou V, Wharton-Smith A, Campos-Matos I, Ward H. *Patient data sharing for immigration enforcement purposes: a qualitative study of healthcare providers in England.* Public Health England Annual Conference 2019

Other outputs

- **Papageorgiou V**, Kendall W, Puerta LL. COVID-19 Stories: How PhD Students Are Experiencing Disruption and Uncertainty during the Pandemic. *Consciously Quarantined: A COVID-19 Response from the Social Sciences (Ed. Irons, R. & Gibbon, S.), UCL Medical Anthropology Blog*, May 2020. Medanthucl.com

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A

Thesis Appendix

This Appendix includes:

- **Copyright permissions**
- **Data access statements**

Copyright permissions to include third party material

Item	Format	Reference	Copyright holder (year)	Permission to re-use	Notes from publisher website
Figure 1.2	Figure from published report	Baylis A, Buck D, Anderson J, Jabbal J, Ross S. The future of HIV services in England. London: *The King's Fund* (2017). Available from: https://www.kingsfund.org.uk/publications/future-hiv-services-england [Accessed 18 November 2022]	© The King's Fund (2017)	Yes, see notes	"We are happy for visitors to download, save, share, copy and distribute content from kingsfund.org.uk for non-commercial purposes free of charge as long as it is appropriately attributed to The King's Fund with a link to the relevant page on our website. Unless otherwise stated, the copyright and other rights on all material published on kingsfund.org.uk belong to The King's Fund under a Creative Commons Attribution-NonCommercial-NoDerivs 4.0 licence."
Figure 1.3	Figure from published paper	World Health Organization. A conceptual framework for action on the social determinants of health. *World Health Organization* (2010). Available from: https://apps.who.int/iris/handle/10665/44489 [Accessed 18 November 2022]	© World Health Organization (2010)	Yes, see notes	"Subject to the terms and Conditions of this Agreement, WHO grants to you a worldwide, royalty free, non-transferable, non-sublicensable, non-exclusive licence to use, reproduce, publish, and display the Licensed Materials in the manner and using the media indicated in the Permissions Request Form you submitted to WHO (the "Licensed Use"). This licence is limited to the current edition of your publication. Future editions or a different use of the Licensed Materials will require additional permission from WHO. If your request includes translation into different languages, then non-exclusive permission is hereby granted to translate the Licensed Materials into the languages indicated (…) Mandatory Acknowledgement. In every instance of the Licensed Use, you must make suitable acknowledgement of WHO, either as a footnote or in a reference list at the end of your publication, as follows: "Reprinted from Publication title, Vol /edition number, Author(s), Title of article / title of chapter, Pages No., Copyright (Year)"."
Figure 1.4	Figure from published paper	Krieger N. Measures of Racism, Sexism, Heterosexism, and Gender Binarism for Health Equity Research: From Structural Injustice to Embodied Harm—An Ecosocial Analysis. *Annual Review of Public Health.* (2020);41(1):37-62.	© Annual Reviews (2020)	Yes, see notes	"Copyright © 2020 by Annual Reviews. This work is licensed under a Creative Commons Attribution 4.0 International License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See credit lines of images or other third party material in this article for license information."

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Figure 1.5	Figure from published paper	Galobardes B, Shaw M, Lawlor DA, Lynch JW, Davey Smith G. Indicators of socioeconomic position (part 1). *Journal of Epidemiology and Community Health.* (2006);60(1):7-12	© BMJ Publishing Group Ltd (2007)	Yes, see notes	"Subject to the terms set out herein, BMJ hereby grants to you (the Licensee) a non-exclusive, non-transferable licence to re-use material as detailed in your request for this/those purpose(s) only and in accordance with the following conditions… Acknowledgement: In all cases, due acknowledgement to the original publication with permission from BMJ should be stated adjacent to the reproduced Licensed Material. The format of such acknowledgement should read as follows: "Reproduced from [publication title, author(s), volume number, page numbers, copyright notice year] with permission from BMJ Publishing Group Ltd"."
Figure 4.6	Background image from Unsplash	Photo by Josi Ribeiro on Unsplash	N/A	N/A, see notes	"Unsplash grants you an irrevocable, nonexclusive, worldwide copyright license to download, copy, modify, distribute, perform, and use photos from Unsplash for free, including for commercial purposes, without permission from or attributing the photographer or Unsplash, but this license does not include the right to compile photos from Unsplash to replicate a similar or competing service."
Figure 4.7	Screenshot from video	Imperial Medicine. Why Co-Production? Reflections from an HIV Research Study. *YouTube* (2022). Available from: https://www.youtube.com/watch?v=MvyKA3k5J9o. [Accessed 18 November 2022]	© Patient Experience Research Centre, Imperial College London (2022)	Yes, see notes	The Patient Experience Research Centre contracted Edward Rolfe to develop this video and have agreed for its inclusion in the thesis.
Figure 4.8; Appendix D	Illustration and photographs from blog	Johnson H. HIV Co-Production Showcase: Sharing learnings from a participatory research project (Part 2). *Imperial blog: Patient Experience Research Centre* (2022). Available from: https://blogs.imperial.ac.uk/perc/2022/08/05/hiv-co-production-showcase-sharing-learnings-from-a-participatory-research-project-part-2/ [Accessed 18 November 2022]	© Patient Experience Research Centre, Imperial College London (2022)		"The College reserves all copyright in all content (both text and graphics) created by College employees. You may not re-purpose, re-publish, or re-present this content in any medium or format without the prior written consent of the College." The Patient Experience Research Centre contracted Federica Ciotti to develop the illustration and have agreed for its inclusion in the thesis. The photographs included in the Appendix were taken by members of the team who have agreed for them to be included in the thesis.

Item	Format	Reference	Copyright holder (year)	Permission to re-use	Notes from publisher website
Figure 6.1	Figure from published paper	Bambra C, Riordan R, Ford J, Matthews F. The COVID-19 pandemic and health inequalities. *Journal of Epidemiology and Community Health*. (2020);74(11):964	© BMJ Publishing Group Ltd (2020)	Yes, see notes	"Subject to the terms set out herein, BMJ hereby grants to you (the Licensee) a non-exclusive, non-transferable licence to re-use material as detailed in your request for this/those purpose(s) only and in accordance with the following conditions… Acknowledgement: In all cases, due acknowledgement to the original publication with permission from BMJ should be stated adjacent to the reproduced Licensed Material. The format of such acknowledgement should read as follows: "Reproduced from [publication title, author(s), volume number, page numbers, copyright notice year] with permission from BMJ Publishing Group Ltd"."
Appendix B	Published paper	Papageorgiou, V., Davies, B., Cooper, E. *et al.* Influence of Material Deprivation on Clinical Outcomes Among People Living with HIV in High-Income Countries: A Systematic Review and Meta-analysis. *AIDS & Behavior* (2022); **26**, 2026–2054.	© The Author(s) (2021)	Yes, see notes	"This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by/4.0/."
Appendix C	Published report	Papageorgiou V, Cooper E, Bruton J, Petretti S, Pristerà P, Ward H. Insight Report: "Let's Talk About… HIV Care". Imperial College London (in collaboration with Positively UK). *COVID-19 Community Involvement Insight Reports.* 15 July 2020. doi: https://doi.org/10.25561/93710	© The Author(s) (2022)	Yes, see notes	This work is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License.

Data access statements

- **Chapters 1, 6, 7 and 8**: No new data were generated or analysed.
- **Chapter 2**: Data supporting this study are included within the published article and supporting materials. The full data extraction table is available upon request by email to vasiliki.papageorgiou17@imperial.ac.uk
- **Chapters 3 and 4**: Data supporting this study cannot be made available due to ethical restrictions (participants did not agree for their data to be shared). Participants were designated a non-identifiable code to ensure anonymity. Anonymised transcripts are stored in an encrypted and password-protected environment at Imperial College London.
- **Chapter 5**: This study used third party data made available under licence that the author does not have permission to share. Requests to access the data should be directed to the Positive Voices team at positive.voices@phe.gov.uk

B

Chapter 2 Appendix

This Appendix includes:

- **Peer-reviewed publication**

AIDS and Behavior (2022) 26:2026–2054
https://doi.org/10.1007/s10461-021-03551-y

SUBSTANTIVE REVIEW

Influence of Material Deprivation on Clinical Outcomes Among People Living with HIV in High-Income Countries: A Systematic Review and Meta-analysis

Vasiliki Papageorgiou[1] · Bethan Davies[2] · Emily Cooper[1] · Ariana Singer[3] · Helen Ward[1]

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Abstract
Despite developments in HIV treatment and care, disparities persist with some not fully benefiting from improvements in the HIV care continuum. We conducted a systematic review to explore associations between social determinants and HIV treatment outcomes (viral suppression and treatment adherence) in high-income countries. A random effects meta-analysis was performed where there were consistent measurements of exposures. We identified 83 observational studies eligible for inclusion. Social determinants linked to material deprivation were identified as education, employment, food security, housing, income, poverty/deprivation, socioeconomic status/position, and social class; however, their measurement and definition varied across studies. Our review suggests a social gradient of health persists in the HIV care continuum; people living with HIV who reported material deprivation were less likely to be virologically suppressed or adherent to antiretrovirals. Future research should use an ecosocial approach to explore these interactions across the lifecourse to help propose a causal pathway.

Keywords Antiretroviral therapy · HIV · Meta-analysis · Social determinants of health · Socioeconomic factors · Systematic review · Viral suppression

Resumen
A pesar de los avances en el tratamiento y la atención al VIH, ciertas desigualdades persisten en estas áreas. Como resultado, algunas personas que viven con el VIH no se benefician plenamente de las mejoras en la atención del VIH a todos los niveles. Realizamos una revisión sistemática para explorar las asociaciones entre los determinantes sociales de la salud y los resultados del tratamiento del VIH (supresión viral y tratamiento de adherencia) en países de ingresos altos. Completamos un metaanálisis siguiendo un modelo de efectos aleatorios e incluyendo medidas consistentes de exposiciones. Identificamos 83 estudios observacionales elegibles para inclusión. Los determinantes sociales vinculados a las circunstancias materiales (privación) se identificaron como educación, empleo, seguridad alimentaria, vivienda, ingresos, pobreza / privación, situación / posición socioeconómica y clase social; sin embargo, su medición y definición variaron entre los estudios. Nuestro estudio sugiere que un gradiente de salud social persiste en la atención sanitaria del VIH a todos los niveles; las personas que viven con el VIH que declaran privación material tenían menos probabilidades de alcanzar la supresión viral o de ser adherente a los antirretrovirales. Futuras investigaciones deberían utilizar un enfoque ecosocial para explorar estas interacciones a lo largo del curso de la vida para ayudar a proponer una vía causal.

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Abbreviations

aHR	Adjusted Hazard Ratio
aOR	Adjusted Odds Ratio
aPR	Adjusted Prevalence Ratio
aRR	Adjusted Relative Risk
ART	Antiretroviral therapy/treatment
cART	Combination antiretroviral therapy
CI	Confidence interval
CSDH	WHO Commission on Social Determinants of Health
EPICES	Evaluation of Deprivation and Inequalities in Health Examination Centres
FPL	Federal Poverty Level
HAART	Highly active antiretroviral therapy
HFSSM	Household Food Security Survey Module
MEMS	Medication Event Monitoring Systems
NICE	National Institute for Health and Care Excellence (UK)
OECD	Organisation for Economic Co-operation and Development
SEP/SES	Socioeconomic position/status
VL	Viral load

Introduction

The social determinants of health describe the conditions in which a person is "born, grows, lives, works and ages" and operate alongside social hierarchy, socioeconomic position, power differentials and the wider socioeconomic and political context [1]. Less privileged and marginalised individuals experience poorer health outcomes than the general population which can, in part, be attributed to current and historical struggles with structural racism, discrimination, recurring inequalities and social exclusion [1–4]. Recent evidence suggests that a decade of government austerity has led to widening health, social and economic inequalities in countries, such as England, that have resulted in stalling life expectancy, declining social mobility and increased food insecurity [5, 6].

Inequalities persist among people living with HIV globally despite advancements in life expectancy, treatment and care. Some groups are disproportionately affected including migrants, the homeless and sex workers [7–11]. These disparities are underpinned by social and structural factors including gender, sexual orientation, ethnicity, racism and socioeconomic position which influence an individual's agency and power within a specific context [12, 13]. A literature review by Burch et al. [14] reported that people living with HIV who had poorer socioeconomic status (SES) were more likely to have poorer virological and immunological responses to antiretroviral therapy (ART). The authors defined SES according to material factors (e.g., education, neighbourhood socioeconomic position) and the health system (e.g., health insurance) itself [1, 14]. In countries without universal healthcare systems, such as the US, publicly funded systems of care exist to support individuals who are uninsured access healthcare; for instance, the Ryan White HIV/AIDS Program [15, 16]. However, the funding, accessibility and eligibility requirements of these services are influenced by structural determinants including the political systems, structures, policies and leadership in which they exist and operate.

For people living with HIV, adhering to prescribed antiretrovirals is essential to maintain virological suppression and to reduce the risk of drug resistance [17, 18]. Early research [19] estimated that HIV-1 viral load (VL) can be reduced by approximately 99% within two weeks of treatment initiation (using protease inhibitors and reverse transcriptase inhibitors). The level of ART adherence required to reach viral suppression is now considered to be regimen-dependent and could be as low as 75% for some [20]. Successful treatment and viral suppression are the second and third UNAIDS 90:90:90 targets; several high-income countries including the UK, Denmark and the Netherlands met these targets before the deadline of 2020 [21, 22]. Referral to, and retention in, HIV care services is therefore critical. However, this is dependent on early diagnosis which is not always achieved; in the UK in 2019, it was estimated that approximately 42% of people living with HIV were diagnosed late, defined by a CD4 count at diagnosis of < 350 cells/mm^3 [23, 24]. The percentage of late diagnoses varied according to age, ethnicity and mode of transmission, with the highest proportion (52%) among heterosexual men [23, 24].

Social determinants exist within complex, intersectoral systems, can be highly correlated and are driven by the context in which they are created and manifest [1, 25]. We build on the definition of social determinants by the WHO Commission on Social Determinants of Health (CSDH) framework to include the "intermediary determinants" of living circumstances, working conditions and food availability [1]. We frame our findings in relation to Krieger's ecosocial theory which aims to understand how "health inequities constitute biological expressions of injustice" across societal and ecosystem levels, pathways and power differentials [13, 26–28]. Ecosocial theory attempts to unpick the complexity of interactions across ecologies; for instance, the scale of phenomena (including measured and unmeasured factors), how these are organised (hierarchies) and spatiotemporal dynamics which means they are restricted by the extent to which these have been previously theorised, conceptualised, inferred and explored [27]. Much like ecosocial theory, the social production of disease and/or political economy of health as well as psychosocial theory can help elucidate how and why diseases are unevenly distributed across societies as well as implications for action [27]. We focus on factors of material deprivation, which could be targeted by social and public health policies.

Our aim is to synthesise the evidence and identify the social determinants that have an impact on HIV treatment outcomes (specifically viral suppression, ART adherence) among people living with HIV in high-income countries.

Methods

We conducted a systematic review using the PRISMA 2020 checklist (Additional file 1); a full protocol is published on PROSPERO (identification number: CRD42020171850) [29, 30]. We adapted the approach of Burch et al.[14] to provide a more recent examination of the association between social determinants and HIV treatment outcomes; however, we focus on observational studies (cohorts and cross-sectional studies), rather than randomised controlled trials, as these replicate real-world settings.

Search Strategy and Selection Criteria

We searched MEDLINE, EMBASE, Global Health, HMIC, Cochrane Library, CINAHL, Web of Science, ProQuest and Scopus databases from date of creation (or first stored record) to 13 January 2020 using a search strategy developed with a University librarian. We also hand searched conference databases until March 2020 and searched the reference lists of relevant review articles and editorials. Further detail, including search strategies, are provided in Additional file 2.

Studies were assessed for eligibility using the criteria detailed in Additional file 3. To be included, study populations had to comprise adults (aged 18 or older) living with HIV in high-income countries. We defined high-income countries using the 2019 World Bank classification and Organisation for Economic Co-operation and Development (OECD) country membership [31, 32]. Social determinants focussed on measures of material deprivation and were broadly defined as education, employment, food security, housing, income, poverty (or deprivation), socioeconomic status (or position) and social class. They had to be compared across levels and recorded at either the individual, household, or neighbourhood level. The primary outcomes of interest were HIV treatment-related, specifically medication adherence and viral suppression, measured by VL or CD4 cell counts. We also extracted data of other social factors which may act as confounders, specifically age, gender, sexual orientation, ethnicity and migration status.

Screening, Data Collection and Analysis

Two authors (VP, AS) screened title and abstracts, followed by full-text, using Covidence [33] and original study authors were contacted by VP to provide any unavailable full-text articles. If the search identified a non-peer-reviewed and peer-reviewed publication for the same study, the most recently published was included. Selected studies were then exported and managed using Excel with a data extraction table initially piloted among 10 studies and subsequently refined. VP extracted data items (Additional file 4) which were cross-checked by EC.

Forest plots were created using Revman 5 [34] for each social determinant and used to present relative effect sizes of comparable associations [adjusted odds ratios (aOR) with 95% confidence intervals (CIs)]. Data are mainly presented using a narrative synthesis as there were large amounts of heterogeneity between included studies. A random-effects meta-analysis was performed for studies where definitions and measurements across studies were consistent; we present the associated I^2 value for heterogeneity (proportion of variation in effect estimates due to heterogeneity rather than chance) [35]. Data presented in forest plots compare poorer social determinants (e.g., unstable housing) to improved determinants (e.g., stable housing).

Quality Assessment

VP and BD assess the risk of bias of included studies using the Newcastle–Ottawa scale and an adapted version for cross-sectional studies (Additional file 5) [36, 37]. Studies categorised as 'other' study design, such as secondary data analysis, are assessed using the most appropriate quality assessment tool. We define the most important confounders for studies to adjust for as gender, sexual orientation, age, race/ethnicity and social class, based on the literature [38]. We define adequate follow-up for outcomes based on WHO guidelines of routine VL monitoring of 6 months following ART initiation and measuring ART adherence at 30 days [39, 40]. No data from 'low quality' studies are included in the meta-analysis; therefore, a sensitivity analysis was not conducted.

Results

We screened 4031 records, following the removal of duplicates, of which 83 observational studies were eligible (Fig. 1).

Most included studies explored the social determinants of education (n = 52, 62.7%); followed by housing (n = 39, 47.0%), employment (n = 33, 39.8%) and income (n = 33, 39.8%) (Table 1). The studies included a total of 1,445,150 people living with HIV. Almost three-quarters (n = 61, 73.5%) of the included studies were based in North America. Some studies focussed on specific sub-populations of people living with HIV such as transgender women (n = 5, 6.0%), people who formerly/currently use drugs (n = 3, 3.6%), people in prison (n = 1, 1.2%), migrants (n = 1, 1.2%), people living with HIV and hepatitis C (n = 1, 1.2%), homeless/marginally housed individuals (n = 1, 1.2%) as well as individuals who hold multiple identities; for instance, being in

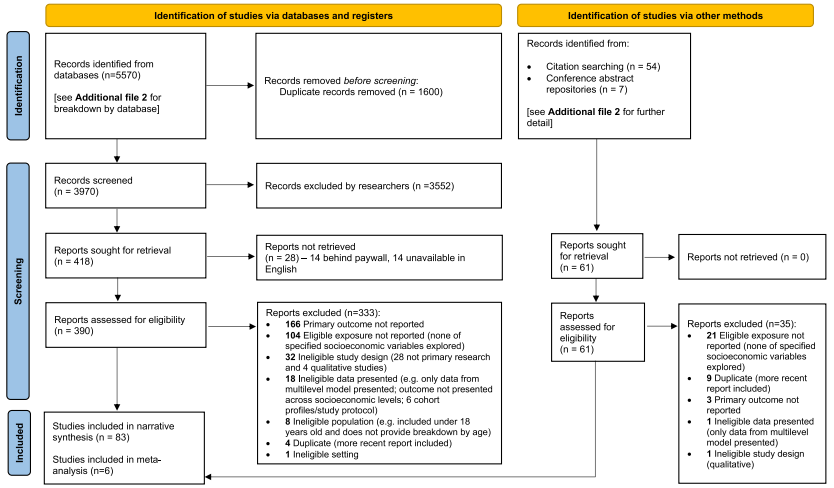


Fig. 1 PRISMA 2020 flow diagram. Adapted from Page et al. [29]

prison and homeless (n = 1, 1.2%) or being socioeconomically disadvantaged and using drugs (n = 1, 1.2%).

We identified 38 studies that explored the association between social determinants and virological suppression (or non-suppression); 35 that investigated adherence (or non-adherence) to ART including combination ART (cART) and highly active ART (HAART); and 10 that explored both primary outcomes. Study characteristics are detailed in Table 2.

Most studies measuring viral suppression predominantly recorded VL, although some also reported the immunological response of CD4 cell count. The VL thresholds to meet viral suppression varied across studies from 20 to 400 VL copies/mL or defined as 'detectable' or 'undetectable'. Adherence had more varied measurements; some studies asked how often participants had missed medication in a specific time frame or used medication event monitoring systems (MEMS) to record the number of times a pill cap was opened which was sometimes also verified by an unannounced pill count by phone. One study [41] used an index of the "number of days out of medication" (MED-OUT) using pharmacy-refill based measures.

Social determinants primarily focussed on measures of material deprivation. This included education (e.g., level, attainment, student status); employment (e.g., status, grade, type); housing (e.g., status, stability, homelessness, living situation, condition, ownership); measures of food security; income (e.g., annual household, financial stability, receiving benefits, financial hardship/concerns, economic situation); socioeconomic status/position (individual/neighbourhood); and measures of deprivation and social class.

We present data under the following headings: education, employment, housing, and material deprivation (which includes measures of deprivation, food security, income, and socioeconomic status/position). For some studies, we present the inverse of the data reported in the original manuscript as we were interested in the outcomes of virological suppression and ART adherence. A full summary of findings, including the confounders adjusted for and reference categories, is provided in Additional file 6.

Education

Education was typically defined by the highest educational level of attainment; from primary school in the UK (or elementary school in the US) to university qualifications.

Of 83 studies, 52 focussed on education with nine studies reporting a significant adjusted association with virological suppression [43, 84, 88, 97, 103, 106, 107, 116, 119]; four reported negative associations (lower education) and five positive (higher education). Overall, people who had lower educational levels were less likely to be virologically suppressed (Fig. 2a; Additional file 6) than individuals who had

Table 1 Summary of key characteristics of included studies

Characteristic	Total studies (%)
Publication type	
Peer-reviewed (e.g., journal article, short/brief report, short/concise communication)	77 (92.8)
Not peer-reviewed (e.g., conference abstract, editorial letter, thesis)	6 (7.2)
Setting	
North America	61 (73.5)
Europe	20 (24.1)
Asia	1 (1.2)
Australia	1 (1.2)
Study design	
Cohort/longitudinal	31 (37.3)
Cross-sectional[b]	30 (36.1)
Other[c]	22 (26.5)
Social determinants[a]	
Education	52 (62.7)
Employment	33 (39.8)
Food security	7 (8.4)
Housing	39 (47.0)
Income	33 (39.8)
Poverty/deprivation	9 (10.8)
Socioeconomic status/position	4 (4.8)
Social class	1 (1.2)
Primary outcome(s)	
Viral (non-)suppression[d]	38 (45.8)
Medication (non-)adherence[e]	35 (42.2)
Both	10 (12.0)
Secondary outcome(s)[a]	
Diagnosis-related	1 (1.2)
Medication-related (e.g., initiation, use, coverage, response)	8 (9.6)
HIV care-related (e.g., engagement, retention, missed visits)	13 (15.7)

[a]More than 1 option possible

[b]Includes cross-sectional surveys of cohort studies

[c]Mixed methods (observational data extracted), programme evaluations, needs assessment, cross-sectional surveys/analysis of cohort studies and chart/record/baseline intervention reviews

[d]CD4 cell count, HIV viral load

[e]ART, cART, HAART

higher educational attainment after adjusting for confounders [53, 88, 106]. For instance, in a cohort of 1246 people living with HIV attending healthcare in France, D'Almeida et al. [106] found individuals whose highest educational attainment was elementary school were 60% less likely (aOR 0.40; 95% CI 0.18, 0.90) to have a VL < 50 copies/mL, compared to those with more than 2 years of a university degree. Shacham et al.[88] found that individuals presenting at an urban HIV clinic in the US, with a high school diploma or less were over 2-times more likely (aOR 2.32; 95% CI 1.08, 5.00) to be virologically non-suppressed; this study used a higher threshold (VL < 400 copies/mL).

The direction of the association between education and medication adherence was less clear. Four studies reported a significant adjusted negative association with medication adherence and lower educational attainment [57, 93, 103, 118]; one [93] also reported positive associations among some sub-groups (Fig. 2b; Additional file 6). Sunil and McGehee [93] found different patterns across educational levels when stratifying by race/ethnicity. White Americans (n = 992) who had completed high school, some College or had an undergraduate qualification were 30% (aOR 1.30; 95% CI 1.24, 1.37), 41% (aOR 1.41; 95% CI 1.34, 1.48) and 58% (aOR 1.58; 95% CI 1.51, 1.66) more likely, respectively, to be adherent to ART compared to individuals who completed some high school only [93]. The same general trend was seen for African American participants (n = 581): individuals who completed high school and some College

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Creasy et al. 2019 [49] (article)	Atlanta; Detroit; Houston; Memphis; Philadelphia; and Washington, DC (USA)	5143 male and Black/African American adults recruited from Black Pride events; part of Promoting Our Worth, Equality, and Resilience (POWER) study (cross-sectional)	Housing	–	Missed doses (4–7/week, 2–3/week, 1/week, < 1/week, never) Last missed dose (never, > 3 months, 1–3 months, 3–4 weeks, 1–2 weeks, or within the week)
Doshi et al. 2017 [50] (article)	USA	1,296,248 adults accessing > 800 medical care providers, 2010–2014; part of Health Resources and Services Administration (HRSA) and served by Ryan White program (surveillance records review)	Housing	VL < 200 copies/mL	–
Dowshen et al. 2016 [51] (short report)	USA (including Puerto Rico), 15 cities	1584 "behaviourally-infected youth" (including 66 young transgender women) from a multisite study conducted at 20 Adolescent Medicine Trials Units; part of Adolescent Trials Network (ATN) (secondary data analysis—cross-sectional)	Housing	Detectable viral load	–
Fadul et al. 2017 [52] (conference abstract)	North Carolina, USA	184 newly diagnosed people living with HIV treated in East Carolina Universityclinic; part of Ryan White program (retrospective chart review)	Education; housing; poverty	VL < 200 copies/mL	-
Feldman et al. 2015 [53] (article)	Greater New York metropolitan area (USA)	2896 MSM; part of Ryan White Part A program (programme evaluation)	Education; housing	VL > 200 copies/mL CD4 < 350 cells/mm^3	–
Feller and Agins 2016 [54] (article)	New York State (USA)	11,252 adults receiving treatment across 186 HIV clinics (classification and regression tree analysis algorithm—cohort)	Housing	VL < 200 copies/mL % virally suppressed	–

Table 2 Characteristics of included studies

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
North America (n = 61)					
Almeida-Brasil et al. 2018 [42] (article)	Canada	566 adults with hepatitis C, receiving cART; part of Food Security & HIV-HCV Study (FS) of the Canadian Co-infection Cohort (CCC) (prospective cohort)	Education; employment; food security; income	VL > 50 copies/mL	Missed ≥ 1 cART dose, past 4 days
Anderson et al. 2018 [43] (article)	USA	239 women at an urban HIV specialty clinic (cross-sectional)	Education; employment	CD4 < 200 cells/mm^3 VL > 20 copies/mL	–
Baguso et al. 2019 [44] (article)	San Francisco (USA)	123 self-identified transgender women; part of Transwomen Empowered to Advance Community Health 3 (TEACH 3) study (cross-sectional)	Education; housing	Detectable and unknown viral load	–
Berg et al. 2004 [45] (article)	Bronx, New York (USA)	113 people who currently/formerly use opioids; part of HIV Epidemiologic Research on Outcomes (HERO) study (prospective cohort)	Housing	–	MEMS caps openings divided by number of prescribed doses
Blank et al. 2015 [46] (article)	Brooklyn; Chicago; Los Angeles; Miami; San Antonio; Longview; Anniston; and Chapel Hill (USA)	944 women of colour; part of Special Projects of National Significance (SPNS) Enhancing Access to and Retention in Quality HIV Care for Women of Color initiative (prospective cohort)	Education; employment; housing	VL < 200 copies/mL	–
Chitsaz et al. 2013 [47] (article)	Connecticut; Georgia; Illinois; Massachusetts; New York; Ohio; Pennsylvania; Rhode Island; South Carolina (USA)	1166 adults with a diagnosis of HIV before being jailed in 10 jails in US across 9 states; part of Enhance Link initiative (cross-sectional)	Education; employment; food security; housing	–	≥ 95% ART adherence
Clemenzi-Allen et al. 2018 [48] (brief report)	San Francisco, USA	1222 adults at HIV clinic ("Ward 86") (cross-sectional)	Housing	VL < 200 copies/mL	–

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Kacanek et al. 2019 [62] (article)	USA (including Puerto Rico)	122 18–22-year olds based across 15 clinical sites; part of Pediatric HIV/AIDS Cohort Study (longitudinal)	Income	VL > 400 copies/mL	Self-reported missed ≥ 1 ART dose, past week
Kalichman and Grebler 2010 [63] (article)	Atlanta, Georgia (USA)	188 people living with HIV/AIDS who demonstrated poor health literacy (cross-sectional)	Education; employment; income; poverty	–	85% ART adherence 75% ART adherence
Kalichman et al. 2010 [64] (article)	Atlanta, Georgia (USA)	344 people living with HIV/AIDS (cross-sectional)	Education; employment; food security; housing; income	Undetectable viral load Change in most recent viral load Change in most recent T cells Most recent CD4 cell count	80% ART adherence 90% ART adherence Self-report adherence rating Unannounced pill count adherence
Kalichman et al. 2014 [65] (article)	Atlanta, Georgia (USA)	364 men and 157 women living with HIV (cross-sectional)	Food security	CD4 < 500 Detectable viral load	85% ART adherence
Keith McInnes et al. 2013 [41] (article)	Atlanta; Baltimore; Bronx; Brooklyn/Manhattan; Houston; Los Angeles; Pittsburgh; and Washington, DC (USA)	1871 veterans living with HIV; part of Veterans AgingCohort Study (VACS) and completed 5th follow-up survey in 2010–2011 (cross-sectional analysis of longitudinal cohort)	Education; employment; housing; income	–	ART adherence (1-MEDOUT ≥ 0.90)
Kleeberger et al. 2004 [66] (concise communication)	USA	597 men living with HIV reporting use of HAART; part of Multicenter AIDS Cohort Study (prospective cohort)	Education; income	–	Negative change (%): visit-pairs with 100% adherence Positive change (%): visit-pairs with < 100% adherence
Koehn et al. 2020 [67] (short communication)	Vancouver (Canada)	99 Dr Peter Centre clients who completed a 12-month follow-up interview (longitudinal cohort)	Education; employment; food security; housing; income	–	≥ 95% cART adherence

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Gardner et al. 2015 [55] (conference abstract)	Ontario (Canada)	3322 people living with HIV receiving clinical care; part of Ontario HIV Treatment Network Cohort Study (OCS) (cohort)	Income	VL < 200 copies/mL	–
Gebo et al. 2003 [56] (article)	USA	196 people living with HIV taking at least 1 ART in an urban hospital clinic (John Hopkins University HIV Clinic) (cross-sectional)	Deprivation	–	< 90% ART adherence (stratified by injecting drug use and gender)
Golin et al. 2002 [57] (article)	Southern California (USA)	117 people living with HIV in a county hospital HIV clinic with newly initiated HAART; part of Adherence and Efficacy to Protease inhibitor Therapy (ADEPT) study (prospective cohort)	Education; employment; income	–	Number of PI/NNRTI/HAART doses taken divided by prescribed over 4-weeks
Haider et al. 2019 [58] (article)	South Carolina (USA)	342 people living with HIV receiving HIV care in immunology centre; part of Ryan White Program (cross-sectional)	Education; employment; income	VL < 100 copies/mL	–
Hussen et al. 2018 [59] (article)	Southeastern city, USA	81 young Black gay, bisexual and other MSM aged 18–24 years old in a paediatric/adolescent clinic (cross-sectional)	Education; employment; housing	VL ≤ 40 copies/mL	–
Iralu et al. 2010 [60] (article)	Navajo Nation (USA)	36 American Indians under Navajo AIDS Network (NAN) case management; part of Four Corners American Indian Circle of Services Collaborative (4CC) (cross-sectional)	Education; employment; housing; income	CD4 < 200 cells/mm^3 Viral load (log)	–
Johnson et al. 2003 [61] (article)	San Francisco; Los Angeles; New York City; Milwaukee, (USA)	2765 adults taking ART; part of Healthy Living Project (baseline pre-intervention—cross-sectional)	Education; employment; housing	–	90% ART adherence, past 3 days

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Mimiaga et al. 2019 [75] (article)	Rhode Island (USA)	296 adults; part of Ryan White Part B HRSA (needs assessment)	Education; employment; housing; income	Virological non-suppression	Sometimes/never take ART as prescribed, past 12 months
Mohammed et al. 2004 [76] (article)	Louisiana (USA)	273 adults from 8 areas in non-urban Louisiana (cross-sectional)	Education; employment	–	Self-report missed any HAART doses, previous week
Moore et al. 2016 [77] (article)	Vancouver (Canada)	719 MSM; part of Momentum Health study (cross-sectional)	Education; income	VL ≥ 200 copies/mL	–
Nyaku, Beer and Shu 2019 [78] (article)	USA (including Puerto Rico)	18,423 adults who self-reported taking ART: part of Medical Monitoring Project (MMP) (secondary data analysis—surveillance records review from cross-sectional sample)	Education; housing; poverty	–	ART non-persistence
O'Neil et al. 2012 [79] (article)	British Columbia (Canada)	566 people living with HIV who have accessed ART; part of Longitudinal Investigations into Supportive and Ancillary health services (LISA) cohort study (cross-sectional analysis of cohort)	Education; housing; income	–	≥95% HAARTadherence
Oliver et al. 2019 [80] (article)	Nashville, Tennessee(USA)	248 women living with HIV with ≥ 1 prenatal visit; part of Vanderbilt Obstetrics Comprehensive Care Clinic (VCCC) (observational cohort)	Education	VL ≥ 200 copies/mL	–
Phillips 2011 [81] (article)	USA	160 Black men living with HIV/AIDS who use illicit drugs (cross-sectional)	Housing	–	Self-reported mean number of ART doses missed, past 4 days
Phillips et al. 2013 [82] (article)	Canada; USA (including Puerto Rico)	1873 adults; part of International Nursing Network for HIV Research Study V (cross-sectional)	Education	–	≥99% ART adherence (self-reported visual analogue scale for 30 days)
Rebeiro et al. 2018 [83] (article)	Southern USA	2541 adults in viral suppression analysis; part of VCCC (observational cohort)	Socioeconomic status/position	VL < 200 copies/mL among those with ≥ 1 clinic visit	–

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Kyser et al. 2011 [68] (article)	Denver; Minneapolis; Providence; and St. Louis (USA)	528 people living with HIV taking cART; part of study to understand the natural history of HIV/AIDS in the era of effective therapy (SUN) (cross-sectional analysis of longitudinal, prospective cohort)	Education; employment	–	cART adherence, past 3 days (missed ≥ 1 ART doses)
Lacombe-Duncan et al. 2019 [69] (article)	British Columbia, Ontario, and Quebec (Canada)	50 transgender women; part of Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) (cross-sectional / mixed methods)	Education; housing; income	VL < 50 copies/mL	≥95% ART adherence
Lim et al. 2015 [70] (article)	New York City (USA)	1698 people living with HIV /AIDS with both jail incarceration and homelessness (retrospective cohort)	Housing	VL < 400 copies/mL	–
Ludema et al. 2016 [71] (article)	Bronx; Brooklyn; Washington DC; Los Angeles; San Francisco; Chicago (USA)	1481 women; part of Women's Interagency HIV Study (WIHS) (prospective cohort)	Income	VL > 200 copies/mL	–
Marshall et al. 2016 [72] (article)	Vancouver (Canada)	706 people who use drugs; part of AIDS Care Cohort to Evaluate Exposure to Survival Services (ACCESS) (prospective cohort)	Education; employment; housing	Undetectable VL or VL < 50 copies/mL	–
McCoy et al. 2016 [73] (article)	Arizona, California, Illinois, Massachusetts, Michigan, Pennsylvania, Texas, Washington, and Wisconsin (USA)	426 people living with HIV aged 50 years and older; part of PRIME baseline study (baseline pre-intervention—cross-sectional)	Education; employment; income	–	≥95% ART adherence
Miller et al. 2006 [74] (article)	British Columbia (Canada)	892 people living with HIV; part of HIV/AIDS Drug Treatment Program of the British Columbia Centre for Excellence in HIV/AIDS (programme evaluation)	Housing; income	VL < 500 copies/mL	–

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Storholm et al. 2019 [92] (article)	Los Angeles, California (USA)	239 African American adults living with HIV recruited in community settings (246: Project Mednet and 108 from Project Rise) (longitudinal)	Education; employment; housing; income	–	ART adherence trajectory group: high-stable (mean > 90%), moderately low-stable (> 60%), low-decreasing (< 27%) at 2, 4, 6 months or 1.5, 4.5, 6 months
Sunil and McGehee 2007 [93] (article)	USA	1910 people living with HIV taking ART; part of HIV Cost and Services Utilization Study (HCSUS) (cross-sectional survey of cohort)	Education	–	ART adherence, past 7 days (non-adherent: ≥ 1 medication missed)
Surratt et al. 2015 [94] (article)	Miami; Fort Lauderdale (USA)	503 socioeconomically disadvantaged substance users (cross- sectional—structured interviews)	Housing; income; poverty	–	Missed ARTs because of diversion, past 90 days
Tymejczyk et al. 2018 [95] (article)	New York City (USA)	1045 people living with HIV (sexual health clinic electronic medical records matched with longitudinal data from NYC HIV Surveillance Registry in 12 months before and after clinic visits) (secondary data analysis—linked surveillance and medical records review)	Poverty	VL ≤ 200 copies/mL	–
Vyas et al. 2014 [96] (article)	San Diego, California (USA)	350 adults attending a HIV clinic (prospective longitudinal)	Income	–	≥ 90% ART adherence
Wagoner et al. 2016 [97] (article)	Birmingham, Alabama (USA)	382 people living with HIV at University of Alabama clinic (1917 Clinic) with a HIV viral load available; part of Project Client-Oriented New Patient Navigation to Encourage Connection to Treatment (CONNECT) (cohort)	Education	VL ≥ 200 copies/mL	–

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Robinson and Knowlton 2016 [84] (article)	Baltimore (USA)	383 people who inject drugs formerly/currently (secondary data analysis—cross-sectional)	Education	VL ≤ 40 copies/mL	-
Santos et al. 2014 [85] (short report)	San Francisco (USA)	314 transgender women; part of San Francisco Transfemale Respondent Driven Sampling Study (secondary data analysis—cross-sectional)	Housing	VL ≤ 200 copies/mL	–
Sayles et al. 2012 [86] (article)	Los Angeles county (USA)	11,397 people living with HIV who were uninsured; part of Ryan White program (cohort)	Housing; income	VL > 200 copies/mL	–
Schafer et al. 2012 [87] (article)	Virginia (USA)	251 men and women; part of UVa Ryan White clinic (RWC) (cross-sectional cohort)	Education; socioeconomic status	CD4 < 200 Detectable HIV viral load	–
Shacham et al. 2010 [88] (article)	St Louis, Missouri (USA)	514 people living with HIV presenting at Washington University HIV Clinic in 2007 (cross-sectional)	Education; employment; housing	VL ≥ 400 copies/mL	–
Shacham et al. 2013 [89] (article)	St Louis, Missouri (USA)	762 people living with HIV presenting at Washington University HIV Clinic in 2008 (cross-sectional)	Employment; poverty	CD4 < 200 cells/µl VL < 400 copies/mL	–
Singh et al. 1999 [90] (article)	USA	123 people who completed refill-methodology assessment of adherence (prospective cohort)	Education; employment; income	–	< 90% ART adherence
Stone et al. 2001 [91] (article)	Rhode Island; Maryland; New York State; Michigan (USA)	289 women living with HIV/AIDS; part of HIV Epidemiologic Research (HER) longitudinal cohort study (cross-sectional survey of cohort)	Education	–	Missed ≥ 1 HAART doses, past 3 days

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Burch 2018 [103] (thesis)	UK	2704 adults recruited from eight HIV outpatient clinics; part of Antiretrovirals Sexual Transmission Risk and Attitudes (ASTRA) study (cross-sectional)	Education; employment; housing; income	VL > 50 copies/mL VL > 200 copies/mL	≥ 2 ART consecutive missed days, past 3 months or ≥ 1 missed, past 2 weeks
Carrieri et al. 2003 [104] (article)	Marseilles; Avignon; Nice; Paris suburbs (France)	96 people who inject drugs (30 women, 66 men) living with HIV initially adherent to HAART in hospital clinics; part of French MANIF 2000 cohort (cohort)	Education; employment; housing	–	< 80% HAART adherence, past 18-months
Collazos et al. 2009 [105] (article)	Spain	1352 people living with HIV from 69 hospitals; part of Grupo Español para el Estudio Multifactorial de la Adherencia (GEEMA) cohort (prospective cohort)	Education	CD4 + cell count (cells/μl) at baseline Undetectable VL (baseline and 12 months) VL (log copies/mL) at baseline	HAART adherence rates
D'Almeida et al. 2016 [106] (article)	France	1246 people living with HIV who were HIV treatment-naïve at cART initiation and on cART for at least 12 months across 73 hospital departments; part of ANRS VESPA-2 study (cross-sectional)	Education; employment; deprivation	Sustained viral suppression (or undetectable VL < 50 copies/mL) for at least 6 months	–
Del Amo et al. 2017 [107] (article)	Austria, France, Germany, Greece, Italy, Spain, Switzerland, and the Netherlands	24,069 people living with HIV with data on education from 15 cohorts of patients initiating cART; part of Collaboration of Observational HIV Epidemiological Europe (COHERE) within EuroCoord Network of Excellence (multi-site cohort)	Education	VL < 400 copies/mL (1 year after cART initiation) Immunological response (change in CD4 + count) at baseline, first 6 months and after 6 months	–
Dorz et al. 2003 [108] (article)	Italy	88 male and 21 female adults living with HIV undergoing protease inhibitor treatment (cross-sectional)	Education; employment; income	–	< 80% adherence, past 7 days

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Weiser et al. 2013 [98] (concise communication)	San Francisco (USA)	284 homeless and marginally housed individuals; part of San Francisco Research on Access to Care in the Homeless cohort (observational cohort)	Education; food security; housing; income	VL > 100 copies/mL CD4 < 200 cells/mm^3	< 90% ART adherence
Whelan et al. 2019 [99] (article)	King County, Washington (USA)	549 newly diagnosed people living with HIV who received a partner services interview (retrospective cohort)	Housing	VL ≥ 200 copies/mL	–
Wilson et al. 2018 [100] (article)	San Francisco Bay Area (USA)	159 transgender women of colour (55 participated at TransAccess, 46 at Brandy Martell Project, and 58 at Butterfly Project) as part of the Special Projects of National Significance (SPNS) Program, "Enhancing Engagement in Retention and Quality of Care for Transgender Women of Color" initiative (programme evaluation)	Food security; housing; income	CD4 < 500, past 6 months Undetectable VL, past 6 months	–
Yehia et al. 2014 [101] (article)	Philadelphia, Pennsylvania (USA)	12,759 adults using multiple clinics for primary HIV care; part of Ryan White program (retrospective cohort)	Income	VL ≤ 200 copies/mL	–
Europe (n = 20)					
Abgrall et al. 2014 [102] (letter)	France	200 individuals from Sub-Saharan Africa adherent to cART at enrollment; part of Agence Nationale de Recherche sur le SIDA et les hépatites virales (ANRS)-VIHVO study (cross-sectional)	Housing	–	< 80% cART adherence

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Sherr et al. 2012 [118] (article)	London (UK); South East (UK)	259 adults living with HIV attending 5 HIV clinics (cross-sectional)	Education	–	All HAART doses taken at correct time and under correct conditions
Sobrino-Vegas et al. 2012 [119] (article)	Spain	4549 people living with HIV from 27 public health centres; part of CoRIS (AIDS Research Network Cohort) (prospective cohort)	Education	Immunological response to treatment (CD4 + T-cell count) at 6 months and 1 year VL < 50 copies/mL (6 months and 1 year)	–
Spire et al. 2002 [120] (article)	France	445 people living with HIV in 47 hospital departments; part of APROCO cohort (prospective cohort)	Housing; income	–	HAART non-adherence at 4 months follow up
Uusküla et al. 2012 [121] (article)	Kohtla-Järve (Estonia)	144 people living with HIV receiving outpatient HIV care (cross-sectional)	Education; income	–	< 100% ART adherence
Asia and Australia (n = 2)					
Siefried et al. 2017 [122] (article)	Australia	522 adults on ART at 7 clinics; part of Parameters Associated with Adherence to Antiretroviral Therapy (PAART) study (cross-sectional analysis of cohort)	Employment; housing; income	–	Self-reported missed ≥ 3 ART, past 3 months
Yang and Bang 2017 [123] (article)	South Korea	300 people living with HIV from 6 hospitals; part of Nationwide Specialized Counseling Program (cross-sectional)	Education; employment; income	–	≥ 95% ART adherence

ART antiretroviral therapy, *cART* combination antiretroviral therapy, *HAART* highly active antiretroviral therapy, *MEMS* medication event monitoring system, *MSM* men who have sex with men, *PI* protease inhibitor, *VL* viral load

[a]Measures of social determinants vary across studies and may be compared at individual, household, or neighbourhood level

[b]Measures of viral suppression include CD4 cell count and viral load. [c]Medication includes ART, cART, and HAART

Table 2 (continued)

Study (publication type)	Population: Setting (city/state, country)	Population: Population of people living with HIV; project name (study design)	Exposure: Social determinant(s)[a]	Outcomes: Virological (non-) suppression measure[b]	Outcomes: Medication[c] (non-) adherence measure
Gordillo et al. 1999 [109] (article)	Madrid (Spain)	366 people living with HIV on ART treatment (cross-sectional)	Education; employment	–	> 90% ART adherence ('good')
Gueler et al. 2015 [110] (article)	Switzerland	2694 ART-naïve for virologic response at six months; part of Swiss HIV Cohort Study (prospective cohort)	Socioeconomic position	Virological response to cART or viral suppression (VL < 50 copies/mL) at 6 months	–
Jansen et al. 2009 [111] (conference abstract)	Germany	2045 people living with HIV; part of Competence Network for HIV/AIDS (KompNet) cohort (cohort)	Income	VL < detection limit CD4 + cell count	–
Papadopoulou 2000 [112] (thesis)	Enfield/Haringey, London (England)	56 people living with HIV taking cART (cross-sectional)	Education	–	cART adherence (4 categories—"adhering to correct dose", "taking drugs at right time", "following dietary instructions" and "overall adherence")
Parruti et al. 2006 [113] (article)	Abruzzo Region (Italy)	171 people living with HIV clinically monitored for at least 24 weeks (cohort)	Employment; housing; SES	–	90% HAART adherence
Persson et al. 1994 [114] (article)	Malmö (Sweden)	47 MSM living with HIV (cross-sectional)	Social class	Low CD4 cell count (< median)	–
Raho-Moussa et al. 2019 [115] (article)	Paris (France)	475 people living with HIV attending two hospital outpatient clinics on ART for at least 6 months (cross-sectional)	Education; employment; deprivation	VL > 50 copies/mL	–
Saracino et al. 2018 [116] (article)	Italy	8023 ART naïve people living with HIV with Italian nationality; part of Italian Cohort Naïve Antiretrovirals (ICONA) cohort (observational cohort)	Education; employment	VL < 50 copies/mL	ART discontinuation
Sellier et al. 2006 [117] (brief report)	Paris (France)	61 adults born in Sub-Saharan Africa and living in France attending 3 infectious diseases departments (cross-sectional)	Education; employment	–	Never missed ART doses compared to frequently or rarely

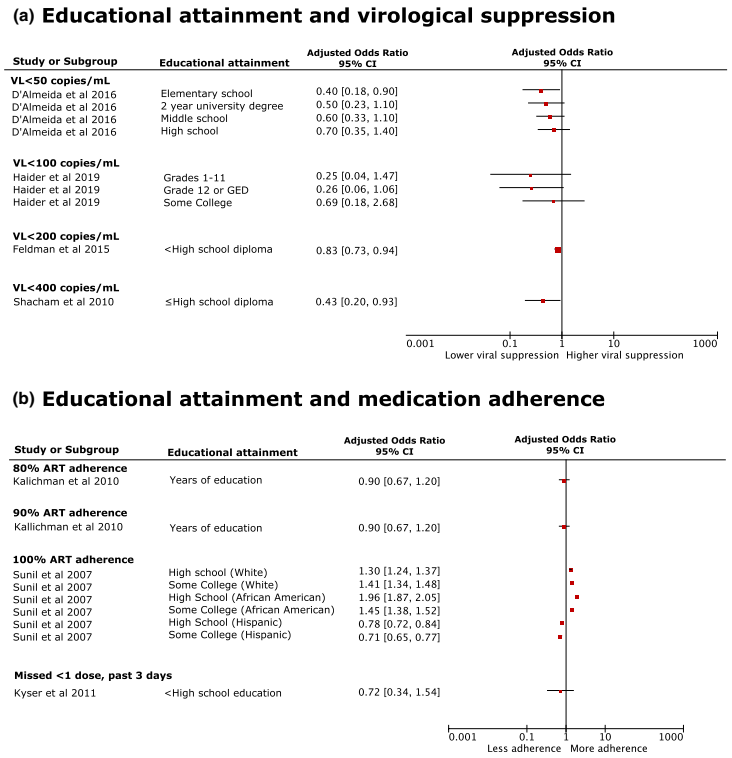


Fig. 2 Forest plots of likelihood (aOR) of **a** virological suppression and **b** medication adherence among people living with HIV with low, compared to high, educational attainment after adjusting for sociodemographic factors. *ART* antiretroviral therapy, *GED* general educational diploma, *VL* viral load

were 96% (aOR 1.96; 95% CI 1.87, 2.05) and 45% (aOR 1.45; 95% CI 1.38, 1.52) more likely to be adherent to ART than those who only completed some high school, however those with an undergraduate qualification were 12% less likely (aOR 0.88; 95% CI 0.82, 0.95) to be adherent [93]. For Hispanic American participants (n = 272), the direction of association was less sequential; individuals who had completed high school or some College were 22% (aOR 0.78; 95% CI 0.72, 0.84) and 29% (aOR 0.71; 95% CI 0.66, 0.77) less likely, respectively, to be adherent whereas university graduates were 40% more likely (aOR 1.40; 95% CI 1.27, 1.55) to be adherent compared to those who only completed some high school [93].

Employment

Employment was defined either by status, occupation type or whether work was paid.

Of 83 studies, 33 looked at employment with only three studies reporting a significant association with virological suppression after adjustment for confounders [58, 103, 116]; two associations were negative (those unemployed), one was

positive (those employed) (Fig. 3a; Additional file 6). Overall, there was an inconsistent association between employment and virological suppression. For instance, D'Almeida et al.[106] reported no difference in viral suppression between people living with HIV of a lower employment grade or unemployed working status compared with executive occupational grades or employed. However, Saracino et al. 2018 [116] found that unemployed people living with HIV had lower rates (adjusted Hazard Ratio [aHR] 0.87; 95% CI 0.79, 0.96) of virological suppression, compared to full-time workers. Similarly, Burch [103] reported that the prevalence of virological non-suppression (VL > 50 copies/mL) was almost 2-times greater among the unemployed, compared to employed (adjusted Prevalence Ratio [aPR] 1.98; 95% CI 1.51, 2.61).

Similarly, the association between medication adherence and employment varied. Four studies reported a significant adjusted association with medication adherence [47, 68, 103, 116]; three reported a negative association (those unemployed) and one a positive association (those employed) (Fig. 3b; Additional file 6). Saracino et al.[116] found unemployed people living with HIV were more at risk of discontinuing ART (aHR 1.18; 95% CI 1.04, 1.34) and when they looked at specific job types, "housewives" were found to be less at risk of ART discontinuation (aHR 0.73; 95% CI 0.59, 0.90), after adjusting for CD4 count, VL, pregnancy status and smoking. Kyser et al.[68] reported that people living with HIV who were unemployed or looking for work were over 2-times more likely (aOR 2.03; 95% CI 1.14, 3.61) to report having missed cART doses in the past 3 days.

Housing

Some studies described housing as the physical environment; some grouped individuals into categories of 'unstable'

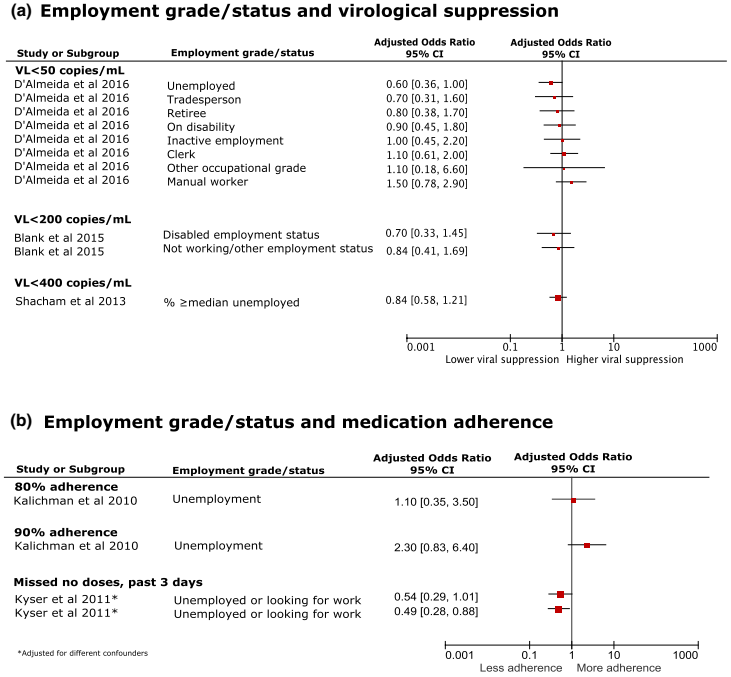


Fig. 3 Forest plots of likelihood (aOR) of **a** virological suppression and **b** medication adherence among people living with HIV with lower employment grade or unemployed status, compared to high, after adjusting for sociodemographic factors. *VL* viral load

and 'stable' housing; some used time of residence and others used home ownership. We grouped studies which explored the association between people living with HIV in unstable compared to stable housing and differing VL thresholds. Housing 'stability' was either explicitly described by the authors or was defined in relation to the type of housing (e.g., living in subsidised housing or in a shelter).

Of 83 studies, 39 looked at housing with eight studies reporting a significant adjusted association with virological suppression, all of which were a negative association, i.e., more unstable housing was associated with lower viral suppression [44, 48, 50, 53, 72, 85, 98, 103] (Fig. 4a; Additional file 6). As measurements and definitions of housing status and virological suppression were consistent, we conducted a random-effects meta-analysis of this determinant and outcome. Most included studies in the meta-analysis used a VL threshold < 200 copies/mL [46, 48, 53, 85, 86] however, one used < 100 copies/mL [98]. The pooled aOR of studies that used a VL threshold of < 200 copies/mL was 0.48 (95% CI 0.33, 0.70) with high heterogeneity between the studies ($I^2 = 90\%$). All but 5 reported subgroups found unstable housing to be significantly associated with lower

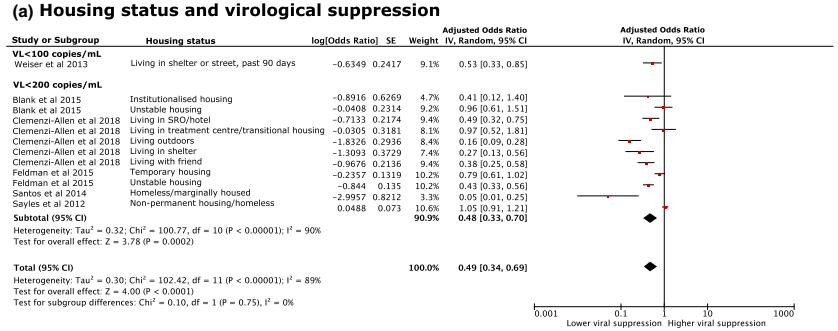


Fig. 4 Forest plots of likelihood (aOR) of **a** virological suppression and **b** medication adherence among people living with HIV living in unstable, compared to stable, housing after adjusting for sociodemographic factors. A meta-analysis is presented for virological suppression. *M0* month 0, *M4* month 4, *SRO* single room occupancy, *VL* viral load

viral suppression with the strongest relative effect reported by Santos et al. [85]. Santos et al. [85] found that homeless or marginally, compared to stably, housed transgender women living with HIV were 95% less likely (aOR 0.05; 95% CI 0.01, 0.25) to be virally suppressed after adjusting for social factors including age and race/ethnicity. Overall, the pooled aOR was 0.49 (95% CI 0.34, 0.69) with the random-effects model for meta-analysis displaying considerable heterogeneity across studies ($I^2 = 89\%$) [35].

Nine of 39 studies looking at housing found a significant adjusted association with medication adherence [45, 81, 94, 98, 102, 103, 113, 120, 122]; eight reported a negative association (unstable housing or homelessness) and one positive (long-term housing) (Fig. 4b; Additional file 6). Individuals living in unstable housing across a range of settings, including subsidised housing [122], living with others [102], being recently homeless [81, 94, 98, 113] or renting [103], were at greater risk of experiencing medication adherence failure, compared to those with more stable living situations. Spire et al. [120] looked at housing quality and found individuals living in stable, but poor housing or unstable housing at baseline have a greater likelihood of being non-adherent to HAART following 4-months of follow-up after adjusting for age, marital status and other intermediary determinants [120].

Other Measures of Material Deprivation

Some studies grouped social determinants to report one overall deprivation measure; for instance, Kalichman and Grebler [63] grouped social determinants of housing, food and financial security as "poverty-related experiences" or "stressors." We present comparable aORs exploring the association between measures of material deprivation, including food security, with virological suppression and medication adherence (Fig. 5; Additional file 6) and a narrative synthesis provided for each factor. Of 83 studies, 53 explored a measure of deprivation: specifically, food security (n = 7), poverty/deprivation explicitly (n = 9), income (n = 33) and socioeconomic status/position (n = 4).

Food Security

Food security is measured at the individual level using specific measurement tools such as the Household Food Security Survey Module (HFSSM). Food security was sometimes reported as a combined measure with income. One of seven food security studies reported a significant negative adjusted association with viral suppression [98]. Weiser et al.[98] found that individuals who reported any food insecurity were 29% more likely to be virologically non-suppressed (aOR 1.29; 95% CI 1.04, 1.61); however, the same study [98] found no difference in virological suppression among food insecure individuals after adjusting for adherence. Six studies investigating food security and adherence found a significant negative adjusted association [42, 56, 64, 65, 67, 98]. For instance, Almeida-Brasil et al.[42] examined a cohort of adults in Canada living with HIV and hepatitis C and established that there was no difference in virological suppression (VL > 50 copies/mL) among individuals reporting income-related food insecurity (aOR 1.44; 95% CI 0.95, 2.19) but were more likely to be non-adherent to medication (aOR 1.77; 95% CI 1.26, 2.48).

Poverty and Deprivation

Poverty and deprivation are reported as fundamentally neighbourhood or area level factors and based on context-specific measurement tools, including the Evaluation of Deprivation and Inequalities in Health Examination Centres (EPICES). Two of nine studies reported a significant adjusted negative association with virological suppression and deprivation [95, 115]. For instance, Raho-Moussa et al. [115] found that individuals who reported either individual determinants of deprivation (specifically financial difficulties in past month) or had an EPICES score indicating residence in a deprived state were 66% (aOR 0.34; 95% CI 0.16, 0.72) and 65% (aOR 0.35; 95% CI 0.14, 0.85) less likely, respectively, to achieve a VL < 50 copies/mL, compared to people living with HIV who did not meet these measures of deprivation, after adjusting for age and medication-, and clinically-related factors. Only one study reported a significant adjusted association with medication adherence which was in a negative direction [63]. Kalichman and Grebler [63] report that individuals reporting poverty-related stress are 28% (aOR 0.72; 95% CI 0.59, 0.89) and 26% (aOR 0.74; 95% CI 0.62, 0.88) less likely to report 85% and 75% ART adherence, respectively, after adjusting for social stressors, depression, internalised AIDS stigma and drug use.

Income

Income included components of temporality (e.g., annual), ecological level (e.g., household), sources (e.g., social benefits) and quantities (e.g., < $15,000). Four of 33 studies looking at income found a significant adjusted association with virological suppression [58, 77, 86, 101, 103]; three reported a negative association (lower income) and the other two a positive association (higher/mid-range income). For instance, the likelihood of virological non-suppression among Canadian men who have sex with men earning < $15,000 annually were 6-times greater (aOR 6.43; 95% CI 2.08, 19.89), than those earning more, after adjusting for age, ethnicity, sexual orientation, country of birth and other characteristics [77]. However, one study [58] found people living with HIV with an annual household

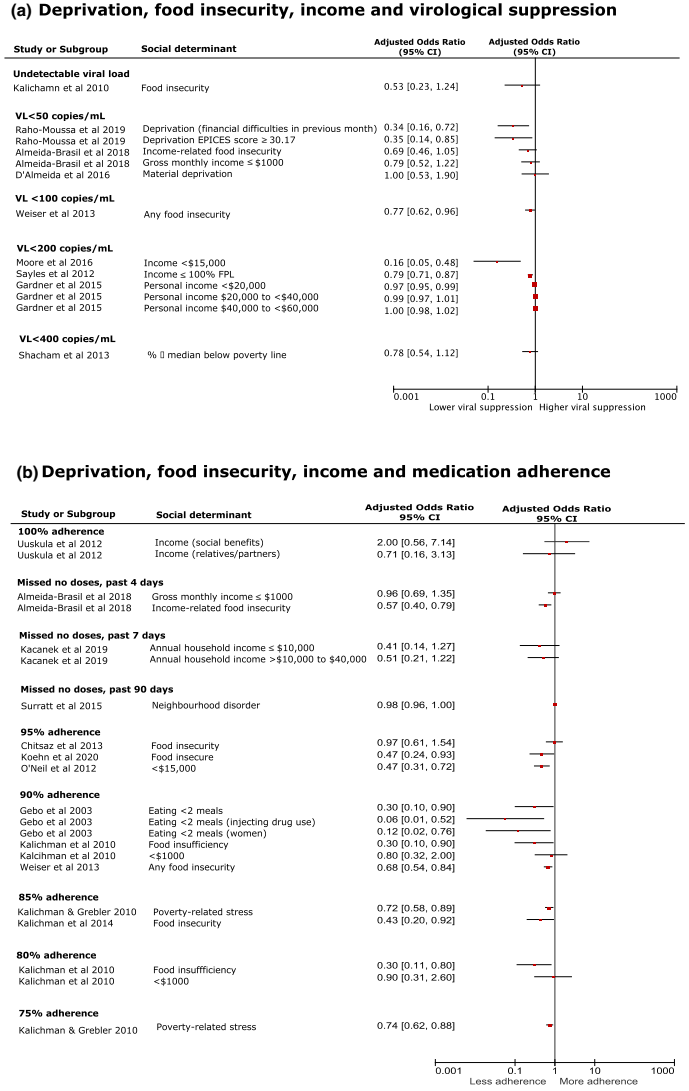


Fig. 5 Forest plots of likelihood (aOR) of **a** virological suppression and **b** medication adherence among people living with HIV who were disadvantaged, compared to more advantaged after adjusting for sociodemographic factors. *EPICES* Evaluation of Deprivation and Inequalities in Health Examination Centres, *FPL* federal poverty level, *VL* viral load

income of < $10,000 were significantly more likely to report virological suppression, compared to those earning $10,000–$24,999 (aOR 0.21; 95% CI 0.06, 0.73) and $25,000-$49,999 (aOR 0.11; 95% CI 0.03, 0.52) [58]. The authors suggest that this may be due to those with lower annual household incomes being more likely to be receiving support linked to the Ryan White Program [58]. Sayles et al.[86] used federal poverty level (FPL) as a measure of income and found that uninsured people living with HIV in Los Angeles, who were receiving publicly funded healthcare through the Ryan White program, and had an income ≤ 100% FPL were 27% more likely (aOR 1.27; 95% CI 1.15, 1.41) to be virologically non-suppressed than those with an income greater than the FPL. Five studies reported a significant adjusted association between income and medication adherence [41, 57, 79, 96, 103]; negative associations were found among low income individuals [57, 79, 103] whilst, comparatively, mid-level/higher income were found to be positively associated [41, 96]. Vyas et al.[96] found individuals with a higher annual household income (≥ $10,000) were significantly more likely to be ≥ 90% ART adherent. The situation is less clear within the Veterans Aging Cohort Study whereby only individuals earning a mid-range annual household income ($25,000–$49,999) were significantly more likely to be adherent to medication, compared to those earning < $6000 [41]. A significant association was not found among the other 3 income categories [41]. Finally, Burch [103] reported whether individuals in the UK had financial stability through a proxy of having "enough money for basic needs"; they found that those who reported mostly, sometimes or not having enough were more likely to be non-adherent, compared to always having enough money.

Socioeconomic Status/Position (SES/SEP)

SES/SEP were reported across ecological levels. Two of four studies reported a significant positive adjusted association with higher/mid-range SES/SEP and viral suppression [87, 110]. Interestingly, a US study [87] found that individuals who had a "mid-range" SES which was defined by their payscale and whether they received support with healthcare costs (5–70% co-pay) were less likely (adjusted Relative Risk [aRR] 0.39; 95% CI 0.16, 0.94) to have a detectable HIV viral load, although this did not remain significant when considering CD4 counts < 200. Only one study looked at adjusted associations between SES and medication adherence; Parruti et al.[113] report no significant difference (OR 0.76; 95% CI 0.30, 2.00) in HAART adherence between people living with HIV in Italy with very low or low SES, compared to those with medium or high SES.

Social Class

One study [114] explored the association between social class and treatment outcomes. Persson et al.[114] found no difference in the likelihood of having CD4 counts lower than the median value among skilled and unskilled workers (defined as social class III) compared to middle range civil servants (social class II) (OR 1.5; 95% CI 0.5, 4.9).

Marginalised Sub-groups

Some studies followed specific subgroups of individuals who are often disproportionately affected by HIV; including, the homeless, people in prisons, people who use drugs and transgender women. Oftentimes, people will identify with multiple identities (intersectionality). For instance, Marshall et al. [72] reported that homeless people living with HIV who use drugs were almost half as likely (aPR 0.55; 95% CI 0.42, 0.71) to have an undetectable VL compared to those with housing, even after adjusting for sociodemographic factors and factors related to their substance use including addiction treatment. Berg et al. [45] found ART adherence rate was greater among individuals who were current or former opioid users who had lived in long-term housing even after adjusting for gender and intermediary determinants including alcohol and substance use. Finally, a small cross-section of transgender women living with HIV (n = 123) living in unstable housing had one of poorest virological outcomes, specifically their risk of having a detectable VL was over 7-times (aRR 7.37; 95% CI 1.07, 50.88) that of transgender women living in stable housing [44].

Risk of Bias

Overall, 8 (9.6%) studies [51, 60, 69, 81, 102, 111, 117, 123] included in the review were scored 'low quality' or had a high risk of bias. Notably, several of the cross-sectional studies were possibly affected by selection bias; for instance, investigating a small sample size or not stating the frequency of non-respondents (Additional file 7). There was heterogeneous reporting within and between studies with no standardised approach for measuring and classifying social factors (exposures), outcomes or associations which limited possible study comparisons.

Discussion

A small proportion (10–20%) of studies observed significant associations between material deprivation and poorer clinical outcomes. Overall, they suggest that people living with HIV who are the most materially deprived (housing, employment, deprivation, or income) display poorer viral suppression and medication adherence compared to those more advantaged. The strongest evidence is present for housing whereby 1 in 5 studies found unstable housing status was associated with poorer viral suppression; however, we found that 89% of the variability in the ORs could be explained by heterogeneity between the studies. An inconsistent association was observed for studies measuring education and adherence outcomes. A higher proportion of included studies observed significant, consistent associations between SES/SEP and virological suppression (50%) and food security and adherence (86%). We also found evidence that intersectionality worsens outcomes. The magnitude of associations were compounded within specific subgroups; for example, US transgender women who were homeless or marginally housed were 20-times more likely to be virologically non-suppressed than transgender women living in stable housing, after adjusting for age, race/ethnicity, history of injection drug use and health insurance status [85].

Our findings are in line with other studies including reviews which have found worsening outcomes associated with material deprivation, including unstable housing status, food insecurity and lower socioeconomic status [14, 124–126]. We find that these associations persist in high-income countries even as advanced generations of antiretrovirals become widely available, HIV prevention programmes continue to be scaled-up and HIV care evolves significantly through the digital age. For instance, in line with Krieger's ecosocial theory [27, 28], issues of agency for HIV care exacerbate inequities among US women living with HIV [127]. This may be explained by the context-specific and interrelated nature of social determinants. For instance, school leavers ages vary across countries (from 15 to 18 years old) as does minimum wage, entitlements to welfare and state benefits and other support services available. In other words, social and cultural capital go beyond the measures of "relative deprivation" but can be more difficult to measure [128, 129]. Unlike Burch et al. [14], we did not explore health insurance as this is not a considerable barrier in countries with a universal healthcare system, such as the UK. Rather, factors such as social class drive health inequalities seen in the UK which were first described in the 1980 Black Report and later by Marmot's Reports [3, 5, 130]. Associations between structural factors (HIV-related laws), interpersonal factors (perceived social capital) and individual outcomes (ART adherence) have also been identified across ecosocial context levels in North America which highlights the potential mechanisms of relationships between social and structural determinants [82]. Additionally, some determinants may be more directly associated with outcomes than others; for instance, some medication should be taken with food which may not be possible for somebody who is food insecure/insufficient, in turn influencing ART adherence [126].

The review had several strengths including a comprehensive search strategy and the inclusion of independent reviewers at screening, data extraction and quality assessment stages. We also grouped duplicate reports at the final stage of screening as one study and included the most recent report in the review to avoid possible publication bias. The majority of included studies were scored as low or uncertain risk of bias; however, the modified Newcastle–Ottawa scale used for cross-sectional studies has not been validated [37, 131]. Additionally, no grey literature was included, nor publications not published in English, which may have inadvertently excluded relevant studies, particularly from HIV community groups and charities. We only included observational studies, limiting the ability to make any causal inferences and potentially introducing social desirability bias of studies reliant on self-reported data only. Our review contributes to this field of knowledge but is unable to determine how determinants may or may not be causally linked but begins to suggest which determinants may interact with treatment outcomes of people living with HIV. We also recognise that social determinants are heavily interlinked, with collinearity between variables; however, we do not attempt to develop a causal pathway in this paper.

These findings re-emphasise the need for well-designed measures of social determinants in studies with evidence-based, context-specific definitions; for instance, higher-income countries (e.g., in Europe) use a 'class structural' approach to define occupation compared to low- and middle-income countries whereby occupation is highly dependent on working conditions (e.g., formal/informal sectors or environmental factors) [132]. As previously suggested by Krieger et al.[38] studies should be collecting socioeconomic data across all ecological levels and the lifecourse, treat income and poverty as dynamic, consider types of assets and wealth but also not conflate between SES and social class. We found that these recommendations were not met in most included studies and rather studies measured determinants at single timepoints or only at one ecological level. There is a clear gap for well-designed research looking at the impact of social class on treatment outcomes of people living with HIV. For instance, research into using subjective social class has found that individuals often use measures of socioeconomic position to assign status however, also take into account their current and future material and economic

prospects which may be a more suitable, composite socioeconomic indicator [133].

Additionally, to develop a more conclusive understanding, a need remains to standardise thresholds of viral suppression across studies to allow for more detailed analyses of the direction of reported effect sizes. This would enable more robust random effects meta-analyses, and subsequent meta-synthesis, to be conducted despite issues relating to the generalisability of results and heterogeneous nature of studies. As a result, this would support the design of more appropriate, system-wide interventions and clinics to identify and support the most socioeconomically disadvantaged, and marginalised, people living with HIV. For instance, interventions focussing on the provision of stable and secure housing, rather than limiting this to adherence support for people continuing to live in precarious housing conditions which could have significant implications for HIV outcomes as well as wider mental health and wellbeing outcomes [134]. The Housing and Health Study for rental assistance found that HIV-related housing services were cost-effective as a HIV prevention intervention but also in relation to quality of life; a cost-per-QALY-saved estimated to be $62,493 for homeless and unstably housed people living with HIV across three US cities [135, 136]. At today's exchange rate, this exceeds the UK National Institute for Health and Care Excellence (NICE) evidence-based guidelines for public health and social care services in for which as a cost-effectiveness threshold between £20,000-£30,000 per QALY gained [137].

Further research is required to determine to what extent person-centred and holistic HIV care improves the health and wellbeing outcomes among people living with HIV. For instance, the provision of social support services including housing, welfare and benefits advice, food and transport vouchers, alongside routine clinical monitoring to help address stigma, reduce health inequalities and ensure equitable access to HIV treatment and care.

Conclusions

Our study has shown that the contribution of measures of material deprivation on HIV treatment outcomes remains complex. There is a need to propose a causal pathway of the relationship between these factors. An ecosocial analysis would help to establish the impact of social determinants between and across ecological levels (e.g., individual, household, neighbourhood) and how these are 'embodied' by individuals across the lifecourse. Further research might then be able to disentangle how social determinants are driven by inequalities in gender, sexual orientation, social class, and race/ethnicity allowing us to build a deeper understanding of how, when, and to what extent, these determinants interact with one another. Subsequently, this would ensure the support systems and services in places for the most marginalised groups living with HIV are acceptable and have the greatest impact on service users.

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Data Availability Supporting data are available from the corresponding author upon request.

Code Availability Not applicable.

Declarations

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C

Chapter 3 Appendix

This Appendix includes:

- **Reporting guidelines:** Standards for Reporting Qualitative Research (SRQR)
- **Insight Report:** COVID-19 Community Involvement Event
- **Study documents:** Participant Information Sheet, Online Consent Form, Optional Demographics Survey, Interview Topic Guide and Resource List
- **NVivo map**
- **Summary report for participants**

Standards for reporting qualitative research (SRQR) checklist[a]

Adapted from O'Brien *et al* (2014).[1]

No.	Topic	Item	Section/page number
Title and abstract			
S1	Title	Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 76
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Section 3.1
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Section 3.2
S4	Purpose or research question	Purpose of the study and specific objectives or questions	Section 3.2; Section 3.2.2 and 3.2.3
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale[b]	Section 3.3
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Section 1.8
S7	Context	Setting/site and salient contextual factors; rationale[b]	Section 3.3.3
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	Section 3.3.2
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Section 3.3.5 and Appendix C
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	Section 3.3.3 and 3.3.4
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Section 3.3.3
S12	Unit of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Section 3.4; Section 3.4.1
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Section 3.3.3 and 3.3.4
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale[b]	Section 3.3.4
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	Section 3.3.4
Results/findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Section 3.4
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Section 3.4
Discussion			
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Section 3.5.1 and 3.5.3
S19	Limitations	Trustworthiness and limitations of findings	Section 3.5.2
Other			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	N/A
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	N/A

[a] The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

[b] The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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In collaboration with Positively UK

17 January 2022, v2.1

Insight Report: COVID-19 Community Involvement- "Let's Talk About…HIV Care"

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Executive Summary

Background



This informal session led by the Patient Experience Research Centre (PERC), in collaboration with Positively UK, invited people living with, affected by, or working in HIV to share their experience, views, questions and concerns on accessing HIV care during COVID-19. The aim of the call was to gather feedback on specific areas to help guide a proposed qualitative (interview-based study) looking to explore experiences, specifically on:

1. **Challenges and concerns in managing HIV care during COVID-19**
2. **Challenges in the provision of HIV care during COVID-19**
3. **Opportunities presented for HIV care during COVID-19**

We also wished to inspire new ways to rapidly engage and involve communities remotely during a public health emergency, through strengthening partnerships with existing groups (in this case, Positively UK).

Impact of COVID-19 on HIV Care

COVID-19 has had an impact on HIV services across the UK, including testing, treatment and care provided. Before the pandemic, some HIV services in the UK had already begun to transition towards a self-care (or 'collaborative care' model) through community-based nursing and e-consultations. However, for some people living with HIV this will be a new and unfamiliar experience. At the start of the outbreak, people living with HIV were included in government shielding recommendations despite the fact that the majority are healthy with an undetectable viral load.

Researchers at PERC are setting up a study to explore the experiences of people living with, affected by, and working in HIV during COVID-19. We collaborated with Positively UK, a peer-led organisation that offers a holistic approach and specialised services to improve the health and wellbeing of people living with HIV. We carried out community involvement to gather early evidence of the impact of COVID-19 on HIV care to inform our interview topic guide as well as any other feedback on our approach. This work will feed into a larger doctoral research project (using the 2017 Positive Voices survey data) looking to explore the impact of social determinants (e.g. housing, employment, income etc.) on the health and wellbeing of people living with HIV. This doctoral research project is in collaboration with colleagues based in the HIV Section at Public Health England.

Call overview and agenda

We ran a community involvement Zoom call on Tuesday 23 June 2020, 5pm-6.30pm which was attended by 25 people from across the UK– see **Appendix 1** for demographics. Those who we received feedback from had been living with HIV or working in HIV services/charities for several decades, although we are unable to comment on the wider group.

The agenda included (1) introduction to PERC and Positively UK; (2) background to the project; (3) our plans for research; (4) Q&A (although no questions were asked during the session) and pre-discussion anonymous polls; (5) breakout room discussions facilitated by one member of Positively UK and co-facilitated by a PERC staff member (5 rooms; 4-7 community members per room); (6) next steps.

The breakout room discussions primarily focussed conversations on the challenges, concerns and opportunities presented in HIV care during the COVID-19 outbreak.

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Attendee recruitment

We recruited through our personal networks, social media and an email invite was sent to over 250 people who Positively UK engage with. See **Appendix 2** for further details on recruitment, event registration and technical requirements of the Zoom call.

Key Insights Summary

Overall, we identified 8 key themes with summarised comments from breakout room discussions given below. Further detail of these can be found in the next section.

1. **Misinformation, conflicting/delayed messaging and shielding advice**
- This primarily focussed on conflicting government advice regarding people living with HIV being sent text messages and receiving letters informing them that they need to shield.
- However, there were also some discussions around conspiracy theories, the UK government response and rumours within the HIV community.

2. **Avoiding, delaying or being prevented access to healthcare (including GP, hospital appointments, sexual health/HIV services)**
- This was predominantly centred around a fear of acquiring COVID-19.
- Some health professionals also described how many people living with HIV assumed services were not open during COVID-19, when they in fact were.

3. **Maintaining an adequate supply of medication, managing regimens and adhering to therapy were conflicted by issues around privacy and confidentiality**
- People described some challenges around maintaining adequate supplies of medication, being unable to adapt their regimen, and continuing adherence to antiretroviral therapy during lockdown.
- Lockdown has resulted in a re-emergence of concerns regarding privacy and confidentiality, particularly among people living with HIV who have not shared their HIV status with members of their household.
- There were some concerns that people may have to share their HIV status in situations that made them feel uncomfortable; for instance, when ensuring an adequate supply of medications.

4. **Adapting HIV services to a new model of self-care, and digital exclusion**
- Despite a shift towards virtual support groups and telemedicine which functioned for some people, digital exclusion was considered to be a real barrier for those who do not have easy access to the internet, phone or computer.

5. **Re-deployment of HIV staff during COVID-19**
- Some health professionals who had joined the call reflected on their personal experiences, and that of colleagues, who had been re-deployed to intensive care units during COVID-19.

6. **Impact on self and feelings of isolation when shielding/during lockdown**
- Lockdown resulted in people being isolated from their usual support systems which will have negative consequences to mental health.

7. **Wider negative impact on finances, food security and housing and the disproportionate impact on the most vulnerable and marginalised groups living with HIV**

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- This was a widely discussed concern across the breakout rooms and was often linked to conversations around the most vulnerable and marginalised people living with HIV and equally, difficulties for people accessing services.
- Breakout rooms discussed concerns for the most vulnerable (e.g. homeless, newly diagnosed, experiencing domestic violence, migrants, racially minoritized communities, people living below the poverty line etc.).

8. **Longer-term health and economic consequences of COVID-19**
- This was discussed in relation to those having had COVID-19 (e.g. long-term side effects) but also in relation to the provision of care and services by charities and other methods of support.

Poll 1: How would you say your life has changed during COVID-19?

Nineteen of 25 call participants took part in this anonymous poll and were almost equally divided between saying life had changed somewhat negatively (n=10), and somewhat positively (n=9).

Poll 2: In your experience, how much has HIV care been impacted by COVID-19?

Twenty one of 25 call participants took part in this poll; 10 said extremely or very, 10 somewhat or slightly, and one said not at all.

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Breakout Room Discussion Themes

We have performed a rapid analysis of the key themes that came through during the breakout room discussions and summarised below the main points that were raised. The discussions focussed on new challenges and concerns, but also potential opportunities for HIV care as a result of COVID-19.

People who were unable to join the call but wanted to share their views were invited to do so by email. Their insights can be found in **Appendix 3.**

Please note: *the following insights came from an* ***involvement***[1] *exercise and should not be interpreted as research results. In other words, the insights reported below will be used to help refine our research question and to influence the design and delivery of a future research study (including the interview topic guide).*

1. **Misinformation, conflicting / delayed messaging and shielding advice**
   - Mixed messaging from government about who should and shouldn't shield led to confusion and anxiety among people living with HIV (particularly those who did not receive one). Some attendees reported receiving letters themselves and some working in clinics explained that they did not know who had and hadn't received a letter. Some attendees were themselves shielding.
   - The language used in shielding letters left some feeling traumatised, vulnerable and fearful.
   - One group discussed the belief held by some people that antiretrovirals are protective, which is not known. This was given as an example of misinformation and panic.
   - Conflicting information given in different regions in the UK and internationally has left people feeling confused about whether or not to follow the shielding advice.
   - In addition, the delay of UK government action has resulted in a lack of trust or feeling conflicted about the accuracy of the guidance provided.
   - However, it was also recognised that there are several resources available to the HIV community and wider public to remain well-informed. Two attendees specifically spoke about completing the open-access course on COVID-19 produced by the London School of Hygiene & Tropical Medicine.

2. **Avoiding, delaying or being prevented access to healthcare**
   - Some felt that the negative media/government messaging (e.g. stay at home, do not travel if non-essential) may have resulted in people being too scared to access services, or to people assuming that services were not open during COVID-19. This was seen as particularly the case for certain more vulnerable groups, for example there was a feeling that poorer outcomes from COVID-19 among racially minoritised communities has led to fear around accessing services. There is a real concern that some people may have completely disengaged in care.
   - Some were anxious about their experience of intensive care if they had a severe response to COVID-19.
   - One person living with HIV described previously being able to see HIV consultants if they needed to urgently attend A&E or walk-in clinics.

[1] Defined by the NIHR as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them": https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-to-help-with-research/ [Accessed 13 July 2020]

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   - Another group discussed how the COVID-19 crisis may have a long-term impact on primary care services as people may now be *"put off"* engaging with GP practices after experiences during the pandemic. They discussed the *"disappearance"* of some GP practices with reception staff left to do triage and feeling that there was no or little access to doctors. This resulted in some not wanting to call their GP or HIV clinic when they had experienced symptoms.
   - People described a lack of access to routine blood tests (e.g. every 4-6 months) potentially posing a risk to health, with regular tests being reassuring for some. Some noted that they felt some people living with HIV seemed to prefer to stay at home but were now beginning to come for blood tests. It was not felt that lack of PPE was a barrier.
   - In contrast, one group also discussed how at the start of COVID-19 they saw a re-engagement by people who had previously been disengaged with their care who were now worried about their HIV.

3. **Maintaining an adequate supply of medication, managing regimens and adhering to therapy were conflicted by issues around privacy and confidentiality**
   - Several groups discussed how adherence to medication became a new challenge for many, particularly for those who had not shared their HIV status with those they were living with (e.g. family members) and no longer had access to a private space to take medication. Some spoke of reports from people living with HIV missing doses or pills due to this.
   - Before lockdown, people living with HIV were able to adapt or 'personalise' their doses however, this was no longer possible as this required a consultation and were told to keep their prescribed regimen. One person described visiting hospital to take medication for the first time and, despite seeing a different clinician, they found the consultation went well.
   - There were fears that medical supplies would be interrupted or affected due to COVID-19; for instance, some people living with HIV asked for 6-month supplies to avoid frequent visits to maintain supply. This seemed to be a concern for some doctors and pharmacists.
   - It was felt that being able to access pharmacies or clinics to collect medications would not be possible for some people based in more remote, or rural, locations. Two people living with HIV described visiting the hospital in order to access extra supplies of medication; one found the experience unnerving, another felt scared and returned home *"feeling contaminated"* after having to use public transport to get there as their local pharmacy could not give the prescription.
   - Some described a lack of privacy and confidentiality when 'isolating' or being in lockdown with others in the household (e.g. young people living with HIV).
   - Issues of having private phone calls/online and taking medication as there is no access to a quiet or confidential space; this would normally be provided by the clinic or support groups.

4. **Adapting HIV services to a new model of self-care, and digital exclusion**
   - It was felt that changes would be good for people who do not want as much contact and would prefer self-care.
   - However, concerns of managing poor mental health, confidentiality, accessibility/language barriers and the benefits of face-to-face interactions were raised; one group spoke of the 'doorknob' moment as people leave the office and someone raises something that had not come up during the consultation. Some people are fearful of using technology or do not want to speak to someone they do not know by phone.

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- There were concerns about digital exclusion and a recognition that there is no "one size fits all" model. A shift to remote and online services (e.g. support groups, appointments) would work for some, but people raised concerns about inequalities in accessibility. For instance, where English is not a first language or where people do not have access to the appropriate technology.
- People living with HIV based in rural rather than urban areas expressed concerns about a lack of follow-up, support network and difficulties if they preferred face-to-face consultations.
- A telephone consultation was felt to be more of a "check-in" rather than holistic; a physical meeting provides communication which is non-verbal.
- Others considered that the rapid digitisation of services has encouraged people living with HIV to become more 'digitally savvy' but recognised that the NHS would need to invest more in digital capacity. For instance, many NHS staff do not have the equipment required for online services (e.g. old computers, no or limited number of webcams).
- Referrals for other services (e.g. mental health) have been delayed; one person felt their mental health telephone appointment was brief, rather than a holistic conversation they were expecting and leaving them feeling disappointed by a lack of follow-up.
- Regular peer support and social support within HIV clinics provides a safe space for people to share; people valued interacting in this way physically and expressed worries about where or how their peer support group members are. Tea and coffee stations which used to play an important role have been removed.
- People living with HIV expressed worries about what would happen between appointments during lockdown and what was happening at their clinic; for instance, some had appointments/consultations delayed after hearing from their Clinical Nurse Specialists while others had no contact from their clinic at all. One felt that this may affect when and how they present to the clinic if needed to do so.
- One group discussed how COVID-19 provided the opportunity for more community-based care through building on the notion of keyworkers. They felt a triage system is needed for telemedicine, with continued need for some face-to-face consultations, for example for test results. It was reflected that it is important to have others around to support newly diagnosed and for clinics and charities to run digital audits to reveal certain vulnerable groups.

5. Re-deployment of HIV staff during COVID-19

- People working in HIV services spoke about their experiences of being re-deployed to intensive care during COVID-19 with issues of "not feeling part of the team" and then facing challenges when re-integrating back into a team (HIV/sexual health) that had changed its ways of working during their absence.
- Attendees felt that re-deploying staff was manageable in well-resourced areas (e.g. London) but more difficult for future planning in smaller, more rural areas with the pandemic highlighting the disparity of services across the UK. For instance, rural clinics running on lower staffing levels which would potentially leave people without a service if staff were re-deployed or a reduction in services being offered.
- Some colleagues had experienced trauma when being re-deployed to COVID-19 wards and expressed feelings of vulnerability intruding into their daily lives.
- One healthcare professional described staff being re-deployed at short notice, leaving few to arrange prescriptions.

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6. Impact on self and feelings of isolation when shielding/during lockdown

- Several spoke of an increase in mental health problems related to social isolation and, for example, an inability to access support groups. People were particularly concerned for people who had never engaged with HIV organisations prior to lockdown. Despite this, peer mentors were able to link people to one another and peer navigators were also able to provide phone calls.
- However, it was felt that virtual support groups now provided an opportunity for a support network for some who would not normally be able to access them such as those based in more remote locations.
- Peer support had mostly stopped, leaving a gap for people who are newly diagnosed who may not be receiving the support they need. One person living with HIV described not wanting one-to-one video meetings when offered; some felt emotions communicated in person are lost when meetings are not conducted in person.
- For some, lockdown was an emotional reminder (or 'triggering') of their initial HIV diagnosis experience; one person described a 14-day quarantine *as "…another thing to add to what I am."* Another person felt described being *"locked down within myself"* whilst someone described feeling more "aware of their infectiousness again" in a non-traumatic sense, but rather as a strong memory.
- However, some felt lockdown gave them the opportunity to spend more time taking up new hobbies, studying and exploring support beyond HIV groups, or building links with HIV support groups based internationally. Others described taking up new (mindfulness) classes or attending weekly meetings which were now at a time and a place convenient for them as they have moved online, as well as the adaptation of other peer support groups to online which provides some continuity (e.g. Positively UK Seeds Project).
- There are anxieties with the easing of lockdown when COVID-19 is still circulating. Life is now different to before; life has a *"new normal."*
- However, others viewed COVID-19 as a positive catalyst for conversations with people feeling more comfortable to ask for support and less embarrassed to ask for help. Some felt able to talk about COVID-19 with friends and family who are unaware of their status to determine how they talk about viruses and *"involving people in conversations gay men have been having for years, kind of feels like welcome to conversation."*

7. Wider negative impact on finances, food security and housing and the disproportionate impact on the most vulnerable and marginalised groups living with HIV

- We heard of concerns for the homeless who had been re-housed during lockdown and were not guaranteed housing security now restrictions were being lifted.
- Financial hardship was a key area of concern, particularly for those submitting/accessing benefit claims who now needed to complete this online. Stories were shared of people not receiving financial support they required or waiting for personal independence payment (PIP) assessments. One attendee spoke of having to use their savings as they are self-employed and have yet to receive anything through the furlough scheme.
- Food security was a challenge for people on low incomes, the homeless and the most vulnerable people living with HIV. One person based at a charity providing nutritional support services discussed people being lost during referrals and therefore being missed, and some people with HIV unable to access food when shielding.

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- Some struggled to go to the shops during lockdown and were generally fearful about leaving their homes. Some made face coverings but are fearful of others not wearing face masks*; "I protect myself, but they don't."*
- One group discussed how community initiatives were much faster at responding to COVID-19 than 'more traditional' organisations due to their agile set-up (e.g. food banks knew who to support and already had links established).
- One attendee described being put on local council list and having volunteers to provide support with COVID-19; another visits shops once a week and finds the protective measures in supermarkets reassuring.
- Concerns were raised for the most vulnerable being missed, lost or dying without any support and who we aren't hearing from. *"People can easily slip through the net"; "Their voices aren't heard."* People also spoke about this in relation to the Zoom conversation itself who they felt were not in the room for this session.
- Some discussions focussed on the disparities of poorer outcomes being reported Black, Asian and minority ethnic (BAME) and more deprived communities resulting in people being worried about accessing services with the media amplifying these anxieties. Some spoke of BAME staff living with HIV feeling even more frightened to engage with care. Again, this was linked to past 'triggering' experiences during their diagnosis and the AIDS epidemic; however, some did not agree that there were similarities between COVID-19 and the early days of HIV in relation to multiple deaths and fear.
- Concerns were raised for people living with co-morbidities such as cancer who assumed that no treatments or services were available.

8. Longer-term health and economic consequences of COVID-19

- One group discussed concerns long-term consequences of people living with HIV who had COVID-19; for instance, lung damage, follow-up with GPs or specialists.
- Charity workers and community support staff expressed concerns of the long-term effects of an economic downturn and austerity on their services and funds. Specifically, there were worries for smaller charities who may not have secured funding and rely on fundraising resulting in a disruption and closure of HIV services with the voluntary sector being heavily disrupted.

During the call, some people also explained why they had joined the call. For instance, a clinician joined to see whether the method (Zoom conversation) would be a good way to get patients involved in service change. Another described wanting to hear from people living with HIV due to only having contact with clinicians to date.

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Post-call feedback from attendees (n=11/25)

When asked to rate their experience of taking part in the Community Involvement Zoom call, all of the eleven respondents gave the call a 6/10 or above with three rating it 10/10.

Over half of respondents (n=6) reported that they would be extremely likely to join another Zoom call like it to hear about and discuss important topics relevant to COVID-19 and HIV. The remaining respondents reported they would be somewhat likely to join another call.

When asked what they liked most about the session respondents selected an average of 2.4 elements each with 'Discussions around the impact of COVID-19 on HIV care' being the most popular, chosen by ten out of eleven people. The 'Anonymous polls' were liked by four out of the eleven as was the 'Background information to the project'.

Four respondents provided other reasons they liked the session, this included a good mix of people who had a positive HIV diagnosis with those who are not living with HIV, the sharing of first-hand personal thoughts feelings and experiences of both patients and frontline staff. They enjoyed exploring the commonalities and differences.

Four out of eleven respondents heard about the call by email from either the National HIV Nurses Association (NHIVNA), Positively UK, UK Community Advisory Board (UK-CAB) or another HIV organisation. However, a further two stated they heard from other sources, again citing UK-CAB and Positively UK, and another cited a website which they reported as the Positively UK site. One participant mentioned a WhatsApp group and another Twitter, the remaining two heard through word of mouth.

When asked how strongly they agreed that that they had made an impact on research none of the respondents 'strongly agreed' or 'strongly disagreed'. The majority (n=6) 'agreed' or 'somewhat agreed'.

When asked for recommendation about how the call could be improved the suggestions included the following ideas:

- More Zoom training and technical support (e.g. person on the call for technical issues)
- More introductions to people at start of call
- More people living with HIV rather than just Positively UK/ PERC /Clinicians
- WhatsApp involvement for those who can't access online

The preferred method of remote involvement that was chosen as one of the respondent's top two choices was 'Group conference (Zoom) calls' as used in the session. Other popular choices included 'Anonymous online surveys/ forms' and 'Online discussion forums.' When asked their preference for online involvement opportunities rather than in person there was no clear answer, of the ten that answered half said 'maybe' while two said 'yes' and three said 'no'.

The topics suggested by respondents for future Zoom call included:

- Anxiety caused by COVID-19 (related to peoples understanding of risk and the information available)
- Specific, known HIV-related conditions
- Supporting those who are living with HIV to connect online for peer support
- Ageing and HIV

See **Appendix 4** for full table of feedback responses and **Appendix 5** for feedback from a de-brief call with all facilitators.

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Conclusion and next steps

Our report highlights some of the key areas of HIV care that people living with, affected by and working in HIV feel have been affected by COVID-19.

The insights from this activity will be used to help focus the design of the qualitative study, particularly the interview topic guide. The community involvement call has emphasised some key areas regarding the longer-term health and economic consequences of COVID-19, impact of lockdown on self-identity and vulnerable groups living with HIV which we plan to explore further with our research. Feedback received from the call is also useful for planning how and where to recruit participants and will be used to inform the ethics application we are currently preparing for submission. We will also remain mindful that our topic guide and methodology remain open to new ideas and experiences as the project progresses. The involvement activity has emphasised the need to ensure the research remains accessible to all (e.g. people with no internet access).

We will continue to work with Positively UK during the next planning stage (and eventual undertaking) of this study to ensure our work remains meaningful and relevant to people living with HIV.

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Acknowledgements

We would like to thank all those who attended and the breakout room facilitators: Joyce (Positively UK), Mina (Positively UK), Helen (Positively UK), Meerat Kaur (PERC), Julie (Positively UK), Will Viney (PERC) and Mel (Positively UK).

Appendices

Appendix 1: Demographic of public attendees

As event registration was hosted on Eventbrite, which is a US-based company we were unable to ask some sociodemographic questions at this stage in order to adhere to GDPR regulations. We decided to ask these following the event through a feedback form hosted on Qualtrics which meets GDPR requirements.

Table 1: Demographic details provided during event registration (n=23/25)

Characteristic	n (%)
Age (in years)	
Mean (range)	65 (25-78)
Approx. age group	
18–24	0 (0.0)
25–34	2 (8.7)
35–44	6 (26.1)
45–54	4 (17.4)
55–64	5 (21.7)
65–74	4 (17.4)
75–84	1 (4.3)
No response	1 (4.3)
Gender	
Female (including transwomen)	13 (78.3)
Male (including transmen)	9 (39.1)
In another way	0 (0.0)
Prefer not to say	0 (0.0)
No response	1 (4.3)
Location	
Yorkshire and the Humber	1 (4.3)
West Midlands	1 (4.3)
East of England	1 (4.3)
Greater London	13 (78.3)
South East England	2 (8.7)
South West England	2 (8.7)
Northern Ireland	1 (4.3)
Prefer not to say	2 (8.7)

Table 2: Additional demographic details provided during feedback (n=10/25; data not available for 15 attendees; 1 attendee gave no demographic details but gave feedback and so is included in Table 3)

Characteristic	n (%)
Ethnicity	
White (English/Welsh/Scottish/Northern Irish/British)	7 (70.0)
Mixed / Multiple ethnic groups	0 (0.0)

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Asian / Asian British	0 (0.0)
Black / African / Caribbean / Black British	0 (0.0)
Any other ethnic group	1 (10.0)
Prefer not to say	0 (0.0)
No response	2 (20.0)
Experience of HIV (could select multiple options)	
Currently living with HIV	7 (70.0)
Friend or loved one of someone living with HIV	1 (10.0)
HIV advocate supporting people living with HIV	3 (30.0)
Healthcare worker supporting people living with HIV	4 (40.0)
Advanced Nurse Practitioner	1 *(10.0)*
Consultant Physician	*1 (10.0)*
Health Advisor	*1 (10.0)*
Peer Mentor	*1 (10.0)*
Charity worker supporting people living with HIV	2 (20.0)
Community worker supporting people living with HIV	1 (10.0)
Approx. years living, supporting or working in HIV	
Mean (range)	21 (5-36)

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Appendix 2: Event registration and Zoom call set-up

Attendee recruitment

We invited attendees through a number of existing channels / contacts and asked that the information was shared with anyone who might be interested in joining. Specifically, an email invite was sent to a Positively UK mailing list, but we also contacted other charities, community support groups and professional networks by email and/or social media (full list below). We also shared a link to the Eventbrite page on social media (Twitter) and asked key stakeholders to share/retweet.

- **Charities/community groups:** Positively UK, National AIDS Trust, Positive East, SWIFT, Terrence Higgins Trust, Sophia Forum, CHIVA, Naz Project, HIV Scotland, The Sussex Beacon
- **Professional networks/contacts:** BHIVA, HIV section at PHE, BASHH, NHIVNA, DHIVA, HIV Prevention England,
- **Information/advice:** UK-CAB, HIV iBase, NAM/Aidsmap

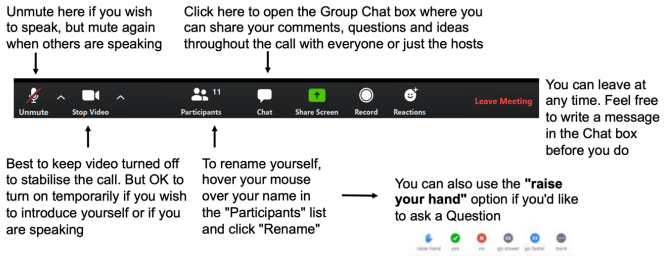
Event registration

Attendees were asked to register for the call via Eventbrite, which included providing some basic demographic details (gender, geographic location); these were restricted to meet GDPR requirements. We therefore asked more sociodemographic information in the feedback form which is hosted on Qualtrics (a service recommended by Imperial College London for hosting data).

44 individuals registered for the call via Eventbrite of which 24 joined on the day. An additional 1 person was given direct access to the Zoom call by PERC (see **Appendix 1** for demographics).

Zoom call technical requirements and troubleshooting

The team allowed for people to join in the first 10 minutes before the session began and shared a holding slide that provide attendees with tips on how to navigate and use Zoom. The team also did a quick run through of these once the meeting began.



All facilitators (PERC/Positively UK) were set up as co-hosts, which supported attendee management as well as troubleshooting. We asked Positively UK staff to lead facilitation of breakout rooms (if they felt comfortable doing so) and had a second facilitator (PERC staff member) to notetake and manage attendees who may be struggling. This was the set-up in all but one breakout room; the other breakout room had a PERC staff member leading, Positively UK member taking notes and second PERC staff member taking notes/troubleshooting. PERC staff recorded breakout rooms to their computers and shared the notes and audio recordings via Box after the call.

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Appendix 3: Further insights following the Zoom call

We invited anyone who did not want to, or were not able to, join the Zoom call to share their insights by email with Vas. Their comments (in relation to the 3 breakout room questions) are below. We have only added those that did not otherwise arise during the discussions on the day.

1. **What new challenges have emerged during COVID-19?**

   - A person living with HIV spoke of issues queuing for shopping for basic items (e.g. milk, bread) due to living with several chronic health conditions. They found online shopping was otherwise OK.

   - A peer support worker added after the call that people living with HIV who are also diabetic/had high blood pressure have complained of getting food they are told not to eat (e.g. high in sugar, salt etc.)

2. **What are your key concerns regarding HIV care during COVID-19?**

   - A person living with HIV felt that people living with HIV will be "added to the bottom of the list" by those involved in managing their care.

3. **What changes have there been in the provision of HIV care? Any opportunities?**

   - A person living with HIV described changes to ordering medications online.

   - They also suggest that there was an opportunity to learn from COVID-19 in relation to HIV care, in particular by listening to patients.

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Appendix 4: Post-call feedback

Table 3: Responses to post-call online feedback form (11/25)

Characteristic	n (%)
On a scale of 1–10, how would you rate the call?	
<5	0 (0.0)
6	1 (9.1)
7	2 (18.2)
8	4 (36.4)
9	1 (9.1)
10	3 (27.3)
How likely are you to join another Zoom call like it?	
Extremely likely	6 (54.6)
Somewhat likely	5 (45.5)
Neither likely nor unlikely	0 (0.0)
Somewhat unlikely	0 (0.0)
Extremely unlikely	0 (0.0)
What did you like most about the session, if anything? (multiple select allowed)	4 (14.8)
Introduction to the Patient Experience Research Centre and Positively UK	4 (14.8)
Background to the project	4 (14.8)
Anonymous poll (s)	10 (37.0)
Breakout room discussions	0 (0.0)
None of it	4 (14.8)
Other: • I was very impressed with the mix of non +ves and +ves and with the mix of frontline and clients - though it would have been nice to have had more clients on there. And also what I really found very interesting was hearing first hand from frontline staff and the challenges they had and how open they were and they care and concern shown. • It was very important to contribute in the breakout rooms as a patient. • Personal experiences. In the breakout group, people were very open and willing to share their thoughts, feelings and experiences • It was interesting and useful to hear the experiences of others. Exploring commonality and differences. Reason why: • It's important to get an assessment of how covid is impacting the HIV community. This is a good start...but I do worry that there will be 'selection bias"...not sure how to overcome that, though! And the sample size might be a bit small, too...the discussion was OK, but maybe could hav been more foucussed and structured, to get clearer inputs...some of the feedback was a bit "rambling" and unfocussed (sorry to be blunt...no offence intended!). Maybe a clearer definition of personal experience versus experience seen as part of our volunteering or other work might have been useful, too	
How strongly do you agree that you have made an impact on research?	
Strongly agree	0 (0.0)
Agree	4 (36.4)
Somewhat agree	2 (18.2)
Neither agree nor disagree	4 (36.4)

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Somewhat disagree	0 (0.0)
Disagree	1 (9.1)
Strongly disagree	0 (0.0)
Do you have any thoughts on how we could improve these calls, the process of taking part or make it more accessible?	5 (55.6)
Yes: • Some WhatsApp and phone calls surveys. The most deprived people otherwise do not have the chance to participate. • Arrange for team including breakout room facilitators to meet before the start of the call...so that everyone is on hand to assist people struggling to get in and the meeting begins on time. Having a Zoom expert on standby might also be useful. Our breakout group sorted out technical problems amongs ourselves. Turning of video makes a huge difference to participation when bandwith is low or poor connection causes image and sound to break up • Facilitate group introductions when everyone has joined - ask each person in turn to quickly introduce themselves. • Was good to have Positively UK & PERC plus all the clinicians. But there were only a few PLHIV such as myself. I did also worry if I spoke too much. • I need more training re Zoom	
No	2 (22.2)
Don't know	2 (22.2)
In general, what would be your preferred method of remote involvement? Select top 2 choices	1 (5.0)
Anonymous online polls	4 (20.0)
Anonymous online surveys/forms	8 (40.0)
Group conference calls (e.g. via Zoom)	4 (20.0)
Online discussion forums	0 (0.0)
Directly by email	1 (5.0)
Via WhatsApp chats or equivalent	0 (0.0)
Other – please specify and/or share your thoughts on other ways we could engage and involve people, e.g. reviewing materials and in influencing research	2 (10.0)
Phone calls	2 (10.0)
Would you prefer to attend online involvement opportunities, rather than in-person, particularly once social distancing measures have lifted?	
Yes	2 (20.0)
Maybe	5 (50.0)
No	3 (30.0)
How did you hear about the call? Select all that apply	
By email, please specify: • Regular positing from HIV organisation • NHIVNA • Positively UK • ...hmmm...not sure where now...UK-CAB probably	4 (36.4)
On a website, please specify: • Eventbrite and Positively UK	1 (9.1)
Social media, please specify: • Twitter	1 (9.1)
Word of mouth (friend or colleague)	2 (18.2)
Other, please specify:	3 (27.3)

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• Uk cab • Through our all ladies WhatsApp group here in Ireland • Positively UK	
Any final comments, including any suggestions for future topics that you would like to see discussed with people living with, affected by, or working in HIV?	
Yes: • We need to address the anxiety caused by covid...in many cases, OVERanxiety...we need to rebuild confidence as we come out of lockdown and social distancing...finding ways to assess our own personal risk may not be easy for everyone, but this will be the way forward...Government cannot be expected to provide "rules" to cover every eventuality...rather, there will be guidelines and advice for us to make our own decisions...but not everyone will be comfortable with that, and people's views of 'risk" are often poor or ill-informed... • Specific, known, HIV related health conditions • How can we, those who are +, connect online, in a safe way, with others to be there just for a chat, peer support etc • Ageing and HIV	4 (66.7) 2 (33.3)
No	

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Appendix 5: De-brief with facilitators

Vas hosted a 1hr de-briefing meeting with all facilitators (all but one attended). Before the meeting, a Padlet board was created for facilitators to anonymously leave their feedback of their experiences specifically: (1) what did we learn, (2) what went well, (3) what could be improved and (4) what next. During the call, Vas shared this Padlet and added notes – the Padlet remained open afterwards for anyone to add any additional comments.

The key things we found that worked well were:

1. **Positively UK facilitating –** having community members who were part of the process and shared their experience whilst facilitating helped participants to open up. All Positively UK staff members were women from a range of backgrounds, which differs to normal activity run by the charity and seemed to work well.

2. **Having a mixed group of participants –** allowed the group to hear from all perspectives (e.g. clinicians explaining how things are working in practice on the ground; PLHIV explaining first-hand experience with HIV care; charities/voluntary sector describing changes in service use). In particular, one group found that discussions around the economic impact of COVID-19 was particularly helpful to hear from different perspectives.

3. **Open and honest discussions –** people were open to sharing their experiences from a clinical and personal level. This is likely to have been guided by the points above.

The key things we thought could be improved:

1. **Digital exclusion –** are there other ways we could involve people who do not use Zoom?

2. **Gender balance of facilitators –** all but one facilitator were women.

3. **Timing –** although we gave 40 minutes for discussions, it was felt that perhaps this could have been extended.

4. **Issues joining breakout rooms –** one person emailed to say they had issues joining the breakout room and then were not able to join the call. Vas emailed them to say they can share feedback if they wish by email. We also found that 2 participants left the call accidentally during breakout room discussions but were able to join after. For future – perhaps instructions should be circulated or said about how to re-join if people accidentally leave or their internet connection drops.

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Imperial College London

School of Public Health
Imperial College London
ICREC Reference: 20IC5893

Experiences of COVID-19 Epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

Participant Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study aims to explore the experiences of people living with, affected by, or working in HIV during the COVID-19 epidemic and to use this to inform current policy.

Why have I been invited?

You are being invited to take part in this study because you are someone who supports people living with HIV (either as a health, social care, charity or community worker), are aged 18 or older and has experiences of the COVID-19 pandemic. We hope to conduct between 10-15 interviews initially and then interview people living with, and affected by, HIV in a larger study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form online. You are free to withdraw at any time and without giving a reason.

What would I have to do?

This study involves filling out a short questionnaire and being interviewed at two time points (once at the start of the study, and a second time 3-months after the first interview). Because of the pandemic, the study is being conducted digitally using Microsoft Teams or by telephone.

The confidential online questionnaire asks basic demographic information. This data will be aggregated to describe the sample of participants and will be used to ensure that we have reached a diverse group of people.

We will use the interviews to conduct research focused on understanding how people living with HIV, and HIV services, are currently being impacted by the pandemic, and we will use this information to inform research design and policy development. We will ask you to consent to participating in the study through Qualtrics, an online platform used for surveys by Imperial College. Where not possible, we will ask for consent verbally.

If you agree to be interviewed, you will be contacted by email or telephone to discuss the study further and arrange your participation. We expect interviews will last between 60 and 90 minutes and will be informal. We will ask you to reflect on a series of questions about the COVID-19 epidemic. The interview will be conducted on Microsoft Teams and will be recorded. For participants who do not have digital access to Microsoft Teams, we will conduct and record interviews over the phone, and where not possible to consent via Qualtrics, we will ask for verbal consent from participants at the beginning of the interviews. Over the course of the interview, you may refuse to answer any question at any time. You may also retract your consent during the research process and any time after this research is completed.

We will also give you the opportunity to be re-contacted, so that we can keep you updated with the progress we make, should you consent to this.

What will happen to me if I take part in the interview?

You will sign an electronic consent form via a link in the invitation email via ticking a box on the form.

Participants will be invited to contribute to one or more of these procedures:

1) Participants will be asked to fill out a confidential online questionnaire with basic demographic information. This data will be aggregated to describe the sample of participants and help us to select a diverse group to be invited to be interviewed.
2) Some participants will be invited for a video-chat interview with one of the researchers. Over the course of the interview, you may refuse to answer any question at any time. You may also retract your consent during the research process and any time after this research is completed.

The interview will be a little like a conversation, in which I will help you talk about yourself in your own words. Issues we would like to discuss include work life, family life, friendships and social connections and the impact of COVID-19 on HIV care. We will also be inviting living with HIV (and their carers) to take part in a separate study.

What are the possible disadvantages and risks of taking part?

There are no particular disadvantages to taking part in the interview. You may be asked about sensitive information, such as your health status. If you feel uncomfortable with any part of the interview conversation, you can refuse to answer any question or ask for part of the conversation to be removed from the transcript. You may feel inconvenienced by the time required as the entire interview process will require approximately 60 to 90 minutes. Finally, given the general public anxiety surrounding the outbreak, answering some of the questions may cause distress. A list of useful resources are given in an attached PDF handout.

What are the benefits of taking part in the interview?
You will not derive a particular benefit from participating in the interview, though many interview participants find the opportunity to discuss their experience to be satisfying or therapeutic. As researchers, we hope that your participation offers an opportunity for reflection. We expect that your perspective, alongside that of others in this study, will be of great value in developing public health policy now and in the future.

What does taking part in the interview involve?
Taking part involves an interview with a qualified interviewer. It takes approximately 60-90 minutes to complete. If, when doing the interview, a topic of conversation arises that makes you feel uncomfortable, you can let the interviewer know that you wish to move on to another subject or terminate the session altogether. It is important for you to understand that you are not required to discuss anything that you do not want to.

What if I decide to withdraw after the interview has taken place?
You are free to leave the study at any time. If you decide to leave after an interview has taken place, all recordings, transcripts and typing of your interview would be destroyed. You can request to leave the study by emailing or telephoning the research team.

What would happen after the interview?
The interviews are recorded and transcribed using an automated, in-built Microsoft Teams transcription service. We will record the interviews to ensure we do not forget or miss important information that you tell us. No identifying information, such as your name, would be kept with the interview transcripts and the interview recordings, and only people in the research team would have access to them subject to participant's agreement. The digital recording and the digital typed up record (transcript), identified only by the code number, would be kept on secure servers at the Patient Experience Research Centre at Imperial College London.

How would the researcher use the interview recording and transcript?
If you do decide to allow your interview to be used for the research study, they would be used along with interviews from between 10-15 other people working in areas supporting people living with HIV. We will use these in two ways. First, we will use the interviews to conduct research focused on understanding how people living with HIV are currently being impacted by the pandemic, and we will use this information to inform research design and policy development.

All data use is strictly within the terms of the General Data Protection Regulation [GDPR] which came into effect on 25 May 2018, and its implementing legislation, the Data Protection Act 2018. The study data may be looked at by individuals from Imperial College London, for the purpose of audit and monitoring.

What if something goes wrong?
If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator Professor Helen Ward, email: h.ward@imperial.ac.uk, telephone: +44 (0)20 7594 3303.

If you are still not satisfied with the response, you may contact the Imperial Joint Research Compliance Office.

Who is funding and organising this research?
Imperial College London School of Public Health is funding and leading the research.

Who has reviewed the study?
The Principal Investigator has obtained approval from the Head of Department and Joint Research Compliance Office (JRCO). The day-to-day management of the study will be co-ordinated by Vasiliki (Vas) Papageorgiou.

Contact for Further Information
If you have would like more information about the study or have any concerns or questions, you can contact Vas Papageorgiou (email: vasiliki.papageorgiou17@imperial.ac.uk) who will do her best to help.

HOW WILL WE USE INFORMATION ABOUT YOU?

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

We will need to use information from you for this research project.
This information will include your

-Name
- Contact Details, including your email address and telephone number

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.
We will keep all information about you safe and secure.

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.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.
Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that

incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

- Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.
- The following Research Collaborators / Partners in the study;
  - Positive Voices Study team (HIV Section, Public Health England; Positively UK): we are partnering with them on the larger study interviewing people living with, and affected by, HIV.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, and normally we will keep information about you that we already have. If a participant decides to leave the study after an interview has taken place, all audio recordings, transcripts and typing of your interview would be destroyed if requested.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information

- by asking one of the research team
- by sending an email to vasiliki.papageorgiou17@imperial.ac.uk

COMPLAINT

If you wish to raise a complaint on how we have handled your personal data, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO

does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

Thank you very much for taking the time to consider taking part in this study.

Yours faithfully,

Vas Papageorgiou

Imperial College London

School of Public Health
Imperial College London

Experiences of COVID-19 epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

Online Consent form

Chief Investigator
Prof Helen Ward

Researchers
Vasiliki Papageorgiou
Jane Bruton
Emily Cooper

Taking part is voluntary. If you agree, you will be invited to take part in an interview. You can withdraw from the study at any time and only anonymised data will be shared with the research team. More details on the project and how we process your data can be found in the participant information sheet [dated 16/09/2020, version 1.4].

Please read the following statements and confirm your agreement. At the end of the survey, you will be redirected to a second survey to share your contact details so that a member of the research team can contact you about your participation. Please ensure that your name on the consent form matches that provided in the second survey.

1. I confirm that I have read and understand the participant information sheet dated 16/09/2020 version 1.4 for the above study and have had the opportunity to ask questions which have been answered fully.	☐ Yes ☐ No
2. I understand that my participation is voluntary, and I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	☐ Yes ☐ No
3. I give consent for information collected about me to be used to support other research in the future, including those outside of the EEA.	☐ Yes ☐ No
4. I consent to take part in the above study.	☐ Yes ☐ No
5. I give consent to being contacted to potentially taking part in other research studies.	☐ Yes ☐ No
6. I understand that, with my permission, anonymised quotes from my interview may be used in reports, publications and presentations as part of publicising the study findings.	☐ Yes ☐ No
7. I understand the options for confidentiality and anonymity in participation. Please check off the options that reflect your consent:	☐ Yes ☐ No

SURVEY	
a) I agree to participate in the confidential survey.	☐ Yes ☐ No
INTERVIEW	
b) If invited to participate in an interview, I agree to do so and to contribute an anonymised transcript of my interview to the research project.	☐ Yes ☐ No

_____ _____ _____

Name of participant Date Signature

SECOND SURVEY (CONTACT DETAILS)
Thank you for your interest in our study ("Experiences of COVID-19 epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK").

Details about the study and how we will process your data can be found in the Participant Information Sheet [version 1.4, dated 16/09/2020]. Please provide us with your contact details so a member of the study team can contact you about your participation.

- Name (mandatory):
- Email address (mandatory):
- Contact number (optional):

Imperial College London

School of Public Health
Imperial College London

Experiences of COVID-19 epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

Thank you for your willingness to participate in this research project. This confidential questionnaire covers some basic topics that are important for us to make sure we're reaching people with varied perspectives. If you do not feel like answering a question, you do not need to answer it. You can always just click the "prefer not to answer" box. It should take you no longer than 15 minutes to complete this questionnaire.

None of the information you give in this questionnaire will be publicly linked to your interview materials. When you fill out the questionnaire, you will be assigned a "random identification number" and your personal contact information will be separated from your answers to these questions. That means we can guarantee that all of your answers will be confidential and only the research coordinators for this project will have access to individual responses.

If you have any questions about confidentiality or concerns while filling out the questionnaire, feel free to reach out with questions to Vas Papageorgiou at vasiliki.papageorgiou17@imperial.ac.uk

1) What is your age?
2) What gender do you identify with?(Please select the option that best applies. If your answer is not provided in the list shown, please type it in the 'in another way' box)

<1> Male (including transman)
<2> Female (including transwoman)
<3> Non-binary
<4> In another way, please specify
<5> Prefer not to say

3) Is this the same gender you were assigned at birth?

<1> Yes
<2> No
<3> Prefer not to say

4) Which of the following best describes how you think of yourself?

<1> Straight/Heterosexual
<2> Gay or Lesbian/Homosexual
<3> Bisexual
<4> Asexual
<5> Other sexual orientation (please specify)
<6> Prefer not to say

5) Which ethnic group do you identify with? Choose one option that best describes your ethnic group or background. (We ask the question in this way so that it is consistent with updated Census 2021 categories.)

White	a) English / Welsh / Scottish / Northern Irish / British b) Irish c) Gypsy or Irish Traveller d) Roma e) Any other White background
Mixed/Multiple ethnic groups	a) White and Black Caribbean b) White and Black African c) White and Asian d) Any other Mixed / Multiple ethnic background
Asian/Asian British	a) Indian b) Pakistani c) Bangladeshi d) Chinese e) Any other Asian background
Black/African/Caribbean/Black British	a) African background, please describe b) Caribbean c) Any other Black/Black British or Caribbean background
Other ethnic group	a) Arab b) Hispanic/Latino c) Any other ethnic group
Prefer not to say	

Questionnaire form - v1.2 16/09/2020

6) Which of the following statements do you identify with? You can select multiple options

<1>	Currently living with HIV
<2>	Currently caring for someone living with HIV
<3>	Loved one of someone living with HIV
<4>	Health professional supporting people living with HIV
<5>	Social care worker supporting people living with HIV
<6>	Charity worker supporting people living with HIV Long-term
<7>	Community worker supporting people living with HIV
<8>	HIV advocate supporting people living with HIV
<9>	Other, please specify

If <1>, <2>, <3>: how long have you/your loved one been living with HIV? Did you/they receive a letter/message to shield?

If <4>, <5>, <6>, <7>, <8>: how long have you been working in HIV? What is your job title?

7) What is the highest educational or work-related qualification you have?

<1>	No formal qualifications	<11>	GCE A level or Higher Certificate
<2>	Youth training certificate/skillseekers	<12>	Scottish Higher Certificate
<3>	Recognised trade apprenticeship completed	<13>	Nursing qualification (e.g. SEN, SRN, SCM, RGN)
<4>	Clerical and commercial	<14>	Teaching qualification (not degree)
<5>	City & Guilds certificate	<15>	University diploma
<6>	City & Guilds certificate - advanced	<16>	University or CNAA first degree (e.g. BA, B.Sc, B.Ed)
<7>	ONC	<17>	University or CNAA higher degree (e.g. M.Sc, Ph.D)
<8>	CSE grades 2-5	<18>	Other technical, professional or higher qualification
<9>	CSE grade 1, GCE O level, GCSE, School Certificate	<19>	Don't know
<10>	Scottish Ordinary/ Lower Certificate	<20>	Prefer not to say

8) What is your current work situation?

<1>	Working full time (30 or more hours per week)
<2>	Working part time (8-29 hours a week)
<3>	Working part time (Less than 8 hours a week)
<4>	Temporary employment (fixed period contract, agency temping, casual work, seasonal work, other temporary work)
<5>	Full-time student
<6>	Retired
<7>	Long-term sick/disabled (for 3 months or more)
<8>	Temporarily sick/disabled (for 3 months or more)
<9>	Carer
<10>	Unemployed
<11>	Not working
<12>	Other, please specify

If <1>, <2>, <3>, <4>, <5>, <12>: do you have 'key worker' status? as defined by government 'critical workers': https://www.gov.uk/government/publications/coronavirus-covid-19-maintaining-educational-provision/guidance-for-schools-colleges-and-local-authorities-on-maintaining-educational-provision)

a. Yes
b. No
c. Unsure
d. Not applicable (not currently working)
e. Prefer not to answer

9) Where do you currently live?

<1>	Own or purchasing house or flat
<2>	Renting (privately owned)
<3>	Renting (council or housing association owned)
<4>	Rent free (provided by friends, family, etc
<5>	Sheltered accommodation/retirement housing
<6>	Residential care home
<7>	Temporary accommodation (housing, shelter, bed and breakfast)
<8>	Homeless
<9>	Other, please specify

10) Gross HOUSEHOLD income is the combined income of all those earners in a household from all sources, including wages, salaries, or rents and before tax deductions. What is your gross household income?

<1>	under £5,000 per year	<10>	£45,000 to £49,999 per year
<2>	£5,000 to £9,999 per year	<11>	£50,000 to £59,999 per year
<3>	£10,000 to £14,999 per year	<12>	£60,000 to £69,999 per year
<4>	£15,000 to £19,999 per year	<13>	£70,000 to £99,999 per year

Questionnaire form - v1.2 16/09/2020

<5>	£20,000 to £24,999 per year	<14>	£100,000 to £149,999 per year
<6>	£25,000 to £29,999 per year	<15>	£150,000 and over
<7>	£30,000 to £34,999 per year	<16>	Don't know
<8>	£35,000 to £39,999 per year	<17>	Prefer not to answer
<9>	£40,000 to £44,999 per year		

11) How many people live in your household?

a. Please choose a number between 1 and 10
b. 10+

Display question 8 if question 7 answer is 2 or more:

12) Is everyone in your household related to you in some way?

a. Yes
b. No
c. Prefer not to answer

13) What is your postcode?

14) In what country were you born?

15) If you were born outside of the UK, how long have you lived here for?

a. Less than 1 year
b. 1-2 years
c. 3-4 years
d. 5-10 years
e. 11+ years
f. Not applicable
g. Prefer not to answer

Thank you for completing our survey. If you have any comments, questions or concerns please contact Vas at vasiliki.papageorgiou17@imperial.ac.uk

Notes to send to interviewee

Thank you for taking part in this interview which we are conducting as part of our coronavirus research.

We are designing research to explore the experience of the COVID-19 outbreak for people living, or supporting those living, with HIV – whether directly or indirectly affected – and how it has impacted HIV care.

We would really value hearing about your experience, your thoughts and recommendations.

If it is OK with you, we will record the interview so that it can be transcribed and shared with colleagues to inform our research and education activities.

The areas I would like to ask about are:

- *Your experiences of life during COVID-19 as someone [**living with/caring for/working in**] HIV*
- *Where you have sought information from*
- *How you are communicating with others*
- *Practical challenges for you:*
    - ***If living/caring for someone with HIV**: seeking/receiving HIV services, your work/social life; following government advice*
    - ***If working in HIV**: providing HIV services, supporting people living with HIV; following government advice whilst supporting people living with HIV*

As the interview will touch on a number of personal areas of your life, which may be particularly difficult, please do let me know if you'd like to pause, take a break or would prefer not to answer a particular question. You are also free to end the interview at any time and withdraw your consent to take part, without giving a reason why.

The interview will take up to 1 hour.

TOPIC GUIDE

*N.B. items in **bold** to be edited depending on who is being interviewed*

Background

1. Can you tell me a little bit about yourself and your background? Whatever you think is important to share about your life up until now, before we get into questions about your recent experiences.
    a. Prompts: work, family, time living with/working in HIV

Personal experience

2. Are you working?
    a. Prompt: How has that changed?
    b. Prompt: Has your job impacted your ability to manage your day-to-day during the outbreak?
    c. Prompt: Is anyone else you know having their work impacted?
    d. Prompt: Do you know what the situation is with people with other employers? (also people with manual / insecure jobs).

3. What new things are you doing because of this?
    a. Prompt: habits, skills, hobbies; why? What do these offer?

4. Tell me about some practical challenges that you are facing because of the outbreak?
    a. Prompt: at home (family/relationships);
    b. Prompt: daily life (friends/neighbours/relationships), housing, food and finances, feeling safe/at risk
    c. Prompt: work (work life, co-workers, people you manage, boss, income), feeling safe/at risk

5. **[if working in health/social care]:** were you re-deployed during COVID-19? How did you find that?
    a. Prompt: relationships with colleagues, dealing with trauma(?), feeling safe (e.g. PPE), risk management by their employer

6. [**If living with HIV/carer]:** you mentioned earlier that you **are living alone/with/support your [relationship]**. What is your plan if **you/they** get sick?

7. Have you had symptoms of COVID-19?
    a. Prompt: Were you tested?
    b. Prompt: have you noticed any longer-term impacts (e.g. to your health, wellbeing, living/working/financial situation? Tell me more about this

8. Can you please tell me about how you have found the experience emotionally?

a. Prompt: isolation/loneliness, support, mental health

Information and guidance

9. **[If living with HIV]:** Did you receive any information from the government about shielding? Tell me more about this.
    a. Prompt: letter, text, contact from GP - the language used, frequency of messaging

10. OR **[If working in HIV]:** are you aware of anyone you support (e.g. people living with HIV) receiving information from the government about shielding? Tell me more about this. Prompt: letter, text, contact from GP - the language used, frequency of messaging
    a. Did you agree with the decision and why?
    b. What is the most recent message that specifically affects people living with HIV that you recall from the government, other government officials or agencies? Prompt: shielding; being "clinically vulnerable"; ART prescriptions

11. **[If living with HIV]:** What guidelines are you following from the government? Prompt: shielding (if living with HIV and has been advised to); social distancing; hand washing; wearing a face mask in enclosed spaces
    a. Have any of the changes been particularly difficult to make?
    b. How do you think the government is doing so far handling it? Are they doing enough? What has been most helpful so far?
    c. Do you see other people following those guidelines?

12. Where have you been looking for information about COVID-19?
    a. Prompt: HIV charities, community groups, clinician, internet
    b. Prompt: What sources of information do you trust?

HIV treatment and care

13. **[If living with HIV]:** Have you experienced any changes to your HIV treatment and care? Tell me more about this
    a. Prompt (medication): ART prescriptions, maintain adequate ART supply, ability to adapt ART regimen, continuing adherence to ART
    b. Prompt (services): face-to-face versus online/phone consultations, delayed/cancelled appointments
    c. Prompt (peer support): virtual support groups

14. **[If living with HIV]:** Did you have any concerns about attending appointments during the pandemic?
    a. Prompt: fear of acquiring COVID-19, lack of personal protective equipment

15. **[If providing services]:** In your experience, what has been the impact of COVID-19 on the services you provide? Please tell me more about the potential risks and opportunities

    a. Prompt (practicalities): providing medication/prescriptions, arranging check-ups, logistics, personal protective equipment
    b. Prompt (service users): missing/vulnerable groups
    c. Prompt (communication): remote services rather than face-to face

Society and social support

16. What changes have you noticed in the HIV community? How about wider society? Prompt: discrimination, stigma

17. How have you changed how you interact socially? Prompt: peer support groups

18. Have you ever experienced anything like this before? Prompt: early days of HIV

19. What are you planning or doing to be ready for what you think will happen next?

Future/long-term

20. What long-term changes do you think this situation will have for

[If living with HIV]

    b. You/your HIV care (prompt: social life, job, housing)
    c. Your family
    d. Your community/HIV services
    e. Your country
    f. The world

[If working in HIV]

    a. People living with HIV that you currently support
    b. HIV community
    c. Your field/job/profession
    d. HIV services

21. Is there anything you would like to ask me?

Thank you for your time.

The interviewer will share information about resources in a follow-up email (listed below) thanking the interviewee for taking the time to participate and share their experiences. These are provided in the PDF handout titled app_9(…)

Advice and support

- Positively UK – provide support for people living with HIV remotely
- Body & Soul - "Share the Love" campaign during COVID-19 including MindSET Livestream sessions and crisis counselling for NHS frontline staff
- NAZ – BAME-led sexual health agency with information on services available during COVID-19
- CHIVA – support for children, young people and their families living with HIV
- HIV Scotland – advice for people living with HIV in Scotland during COVID-19
- UK-CAB – a network for community HIV treatment advocates
- National AIDS Trust – includes advice on shielding, workers' rights and other resources
- PrEPster – advice for people using PrEP, including COVID-19 'tips and tricks'
- Terrence Higgins Trust – blogpost with FAQ on HIV and COVID-19

News/clinical guidelines

- British HIV Association – latest guidelines by the leading national advisory body on HIV care
- NAM Aidsmap – latest news on HIV and COVID-19
- HIV i-Base – HIV treatment information and advocacy with specific information on COVID-19

USEFUL COVID-19 RESOURCES FOR PEOPLE LIVING WITH HIV



Advice and support

- **Positively UK** - provide remote peer support
- **Body & Soul** - "Share the Love" campaign during COVID-19 includes crisis counselling for NHS staff
- **Naz** - BAME-led sexual health agency with information on services available during COVID-19
- **CHIVA** - support for children, young people and their families living with HIV
- **HIV Scotland** - advice for people living with HIV in Scotland during COVID-19, including a coronavirus helpline (Monday-Friday, 10am-6pm)
- **UK-CAB** - network for community HIV treatment advocates
- **National AIDS Trust** - includes advice on shielding, workers' rights and other resources
- **PrEPster** - advice for people using PrEP, including COVID-19 'tips and tricks'
- **Terrence Higgins Trust -** blogpost with FAQ on HIV and COVID-19

News and clinical guidelines



- **British HIV Association** - latest guidelines by the leading national advisory body on HIV care
- **NAM Aidsmap** - latest news on HIV and COVID-19
- **HIV i-Base -** HIV treatment information and advocacy including specific content on COVID-19

Health and travel guidance

- **World Health Organization** - for answers to most frequently asked questions about COVID-19
- **NHS.UK** - for information about the virus and how to protect yourself
- **GOV.UK** - for the latest information about the situation in the UK and what to do if you think you're at risk

Other support



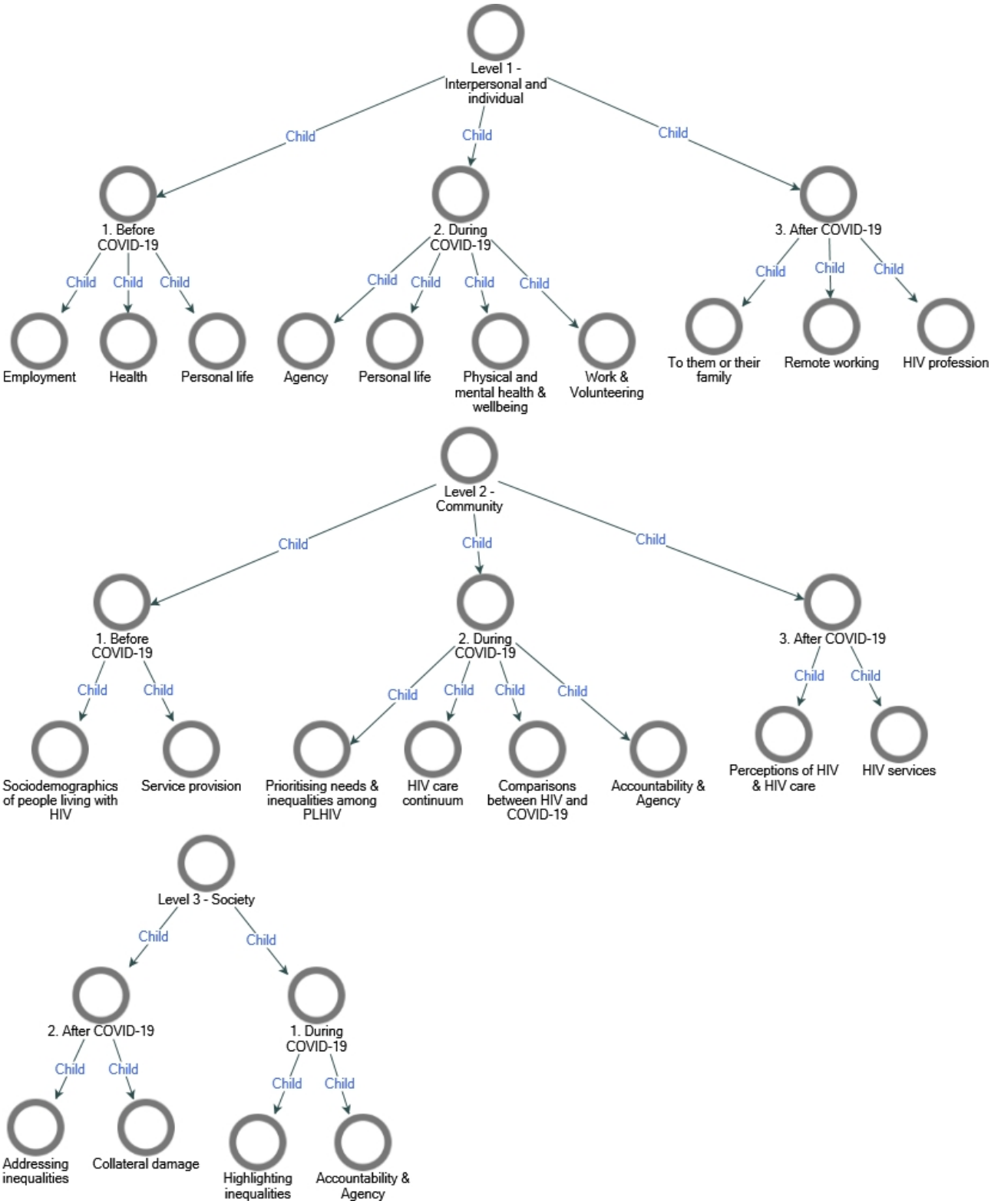
- **Every Mind Matters** - tips and advice on mental health (including coronavirus and wellbeing)
- **Mind** - charity providing advice and support on mental health (including coronavirus and wellbeing)
- Supermarkets and other community offers for those who are vulnerable e.g. **food boxes,** support from the **NHS Volunteer Responders Programme** as well as from **COVID-19 mutual aid groups**

You can also **speak with your GP** who can direct you to the appropriate service for you if you would like further mental health support.

Please note that Imperial College London does not directly endorse any particular service.

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NVivo map of themes and sub-themes from interviews with HIV service providers

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SUMMARY REPORT:
Experiences of COVID-19 Epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

ICREC reference: 20IC5893

THANK YOU

Firstly, thank you for participating in my study as part of my PhD. It was really interesting to hear your insightful views and experiences as individuals supporting people living with HIV in what has been a challenging time for all.

As recognition of your contribution to this research, this document provides a summary of what we found and next steps. I've also included a list of further resources that you might find helpful.

As we are hoping to publish these findings in the future, **please do not cite or circulate this work without permission**. We will be presenting some of our findings as an ePoster at the IAS conference in July 2021 and I will share this with you once it is published.

If you have any further questions about the study or our future work, please contact Vas at vp2017@ic.ac.uk

BACKGROUND

COVID-19 has posed a threat to the health and wealth of nations globally, with over 4.5 million people testing positive and over 150,000 recorded deaths in the UK since the start of the epidemic (1). The UK has been under nationwide restrictions since March 2020 with regional and local measures introduced at various time points. Many NHS and support services (including sexual health and HIV clinics) have been cancelled, reorganised, or temporarily postponed at different times.

We wanted to record the experiences of those supporting people living with HIV during COVID-19. This included understanding how COVID-19 had impacted people's personal lives, their working environment and their health and wellbeing. We wanted to speak to a diverse group of individuals based on geographical region and the type of service being provided – clinical, peer support, community-based organisations and charities. This project was informed by a community involvement Zoom call we ran in June 2020 in collaboration with Positively UK (2).

Here, we present our findings of one core aspect of our project, the **impact of COVID-19 on the HIV care continuum and service delivery models in the UK.**

METHOD



14 semi-structured online interviews by Microsoft Teams



Participants from **healthcare** (n=5) and **community-based/charity** (n=9) settings in England and Wales



Key themes annotated from interview transcripts **(thematic analysis)** and then constantly compared between/within participant transcripts **(grounded theory)**

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KEY FINDINGS

Overall, the study found that HIV services had adapted rapidly to the challenges presented by government restrictions and the COVID-19 epidemic leading to some problems but also some opportunities:

1) **Diagnosis –** the impact on diagnosis was mixed with some examples of earlier diagnoses as well as concerns of a lack of social contact for those newly diagnosed. COVID-19 had accelerated a shift towards online and self-testing which has had varied acceptability among service users.

2) **Clinical care –** at the early stages of the epidemic, HIV care shifted online, and some staff working in HIV clinics were redeployed to critical care units. Face-to-face visits were prioritised for the most vulnerable service users, and with participants reported that some people had re-engaged with care.

3) **Peer and community support –** overall, most groups shifted to virtual support and there were concerns for the mental health of service users who had reported issues relating to social isolation and loneliness. However, virtual support also provided an opportunity for people in remote locations to engage with peers.

4) **Treatment** – concerns were raised early on that service users must have an adequate supply of medication, and clinics rapidly coordinated responses with pharmacies and transport/courier services to ensure there were no gaps in supply.

5) **Health-related quality of life –** financial, job and food insecurity, social isolation, loneliness, and the worsening of other health issues including mental health because of the pandemic seems to have exacerbated inequalities. However, some opportunities presented by the provision of online support for those based in remote locations.

We identified that multi-agency partnerships have attempted to address inequalities through rapid and innovative solutions throughout the pandemic to support people living with HIV with many of these partnerships existing since the 'early days' of HIV.

CONCLUSIONS

COVID-19 has undoubtedly changed how HIV services look now and, in the future, with differing acceptability among service users. Collaborative cross-sectoral efforts have been fundamental in minimising disruptions to HIV care, as well as the wider determinants of health. However, concerns remain for the longer-term impact on charities and community-based organisations which have faced a loss of income over the past year whilst facing an increase in demand for services.

IMPLICATIONS AND NEXT STEPS

- Our findings and recommendations will be shared with Public Health England & Positively UK who we work closely with as part of my wider PhD looking at the impact of social & structural determinants on HIV outcomes. We are triangulating the findings of this study with grey literature provided by Public Health England & survey data from Positively UK service users during the March 2020 lockdown. These findings will be presented at the IAS 2021 conference as an ePoster.
- We are also planning to publish the findings of all themes in a research journal in the coming year, which will detail the impact at the individual, interpersonal, community and societal level.

June 2021, v1.2

- We have received additional funding for a second study to capture the experiences of people living with HIV who took part in the 2017 Positive Voices Study and will shortly begin recruitment for this. As part of this project, we have trained two Peer Researchers to conduct and analyse interviews alongside the research team & have formed an Advisory Group to steer the project. The project is in collaboration with Positively UK.

REFERENCES

1. Public Health England. *UK Coronavirus Dashboard*. [Online] Coronavirus (COVID-19) in the UK. Available from: https://coronavirus.data.gov.uk [Accessed: 18th May 2021]

2. Papageorgiou V, Cooper E, Bruton J, Petretti S, Pristerà P, Ward H. *Community Involvement Zoom Call 23.06.20 - Insight Report: HIV Care*. [Online] Patient Experience Research Centre, Imperial College London (in collaboration with Positively UK), 2020 Jul. Available from: https://www.imperial.ac.uk/media/imperial-college/medicine/sph/ide/perc/COVID-19-Community-Involvement-Call---HIV-care-23.06.20---Insight-Report---v1.1.pdf

USEFUL RESOURCES

Data published by PHE on the impact of COVID-19 on HIV & sexual health services

1. Public Health England. Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019. 2020;14(20): 16.

2. Public Health England. *The impact of the COVID-19 pandemic on prevention, testing, diagnosis and care for sexually transmitted infections, HIV and viral hepatitis in England*. [Online] 2020 Dec [Accessed: 6th April 2021]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/943657/Impact_of_COVID-19_Report_2020.pdf [Accessed: 6th April 2021]

3. Shah A. *Impact of the COVID-19 pandemic measures on HIV consultations in England*. 5th Joint Conference of the British HIV Association (BHIVA) with the British Association for Sexual Health and HIV (BASHH); 2021 Apr 19; Digital.

Article by NAM Aidsmap which summarises research presented at BHIVA/BASHH conference on the future of HIV services after COVID-19: https://www.aidsmap.com/news/apr-2021/how-will-hiv-services-be-provided-when-pandemic-over

Useful COVID-19 resources list (attached to email)

D

Chapter 4 Appendix

This Appendix includes:

- **Reporting guidelines:** Standards for Reporting Qualitative Research (SRQR) and Guidance for Reporting Involvement of Patients and Public (GRIPP) 2 checklist
- **Study documents**: Participant Information Sheet, Online Consent Form, Optional Demographics Survey, Interview Topic Guide and Resource List
- **Co-designed infographic for participants**
- **Outputs from co-production event**

Standards for reporting qualitative research (SRQR) checklist[a]

Adapted from O'Brien *et al* (2014).[1]

No.	Topic	Item	Section/page number
Title and abstract			
S1	Title	Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 130
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Section 4.1
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Section 4.2
S4	Purpose or research question	Purpose of the study and specific objectives or questions	Section 4.2; Section 4.2.4 and 4.2.5
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale[b]	Section 4.3; Section 4.3.1
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Section 1.8; Section 4.3.1
S7	Context	Setting/site and salient contextual factors; rationale[b]	Section 4.3.1
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	Section 4.3.2
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Section 4.3.5 and Appendix D
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	Section 4.3.3
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Section 4.3.3
S12	Unit of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Section 4.4; Section 4.4.1
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Section 4.3.3 and 4.3.4
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale[b]	Section 4.3.4
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	Section 4.3.4
Results/findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Section 4.4
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Section 4.4
Discussion			
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Section 4.6.1 and 4.6.3
S19	Limitations	Trustworthiness and limitations of findings	Section 4.6.2
Other			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	N/A
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 182

[a] The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

[b] The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

References

1. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine* 2014;**89**:1245–1251.

Guidance for Reporting Involvement of Patients and Public (GRIPP) 2 checklist

Adapted from Staniszewska *et al* (2017).[1]

No.	Topic	Item	Section/page number
Section 1: Abstract of paper			
1a	Aim	Report the aim of the study	Section 4.1
1b	Methods	Describe the methods used by which patients and the public were involved	Section 4.1
1c	Results	Report the impacts and outcomes of PPI in the study	Section 4.1
1d	Conclusions	Summarise the main conclusions of the study	Section 4.1
1e	Keywords	Include PPI, "patient and public involvement," or alternative terms as keywords	N/A
Section 2: Background to paper			
2a	Definition	Report the definition of PPI used in the study and how it links to comparable studies	Section 4.2.2
2b	Theoretical underpinnings	Report the theoretical rationale and any theoretical influences relating to PPI in the study	Section 4.2.2
2c	Concepts and theory development	Report any conceptual or theoretical models, or influences, used in the study	Section 4.2.3
Section 3: Aims of paper			
3	Aim	Report the aim of the study	Section 4.2.5
Section 4: Methods of paper			
4a	Design	Provide a clear description of methods by which patients and the public were involved	Section 4.3.1
4b	People involved	Provide a description of patients, carers, and the public involved with the PPI activity in the study	Section 4.3.1
4c	Stages of involvement	Report on how PPI is used at different stages of the study	Section 4.3.1
4d	Level or nature of involvement	Report the level or nature of PPI used at various stages of the study	Section 4.3.1; Section 4.3.3; Section 4.3.4; Section 4.3.5
Section 5: Capture or measurement of PPI impact			
5a	Qualitative evidence of impact	If applicable, report the methods used to qualitatively explore the impact of PPI in the study	Section 4.3.1
5b	Quantitative evidence of impact	If applicable, report the methods used to quantitatively measure or assess the impact of PPI	Section 4.3.1
5c	Robustness of measure	If applicable, report the rigour of the method used to capture or measure the impact of PPI	N/A
Section 6: Economic assessment			
6	Economic assessment	If applicable, report the method used for an economic assessment of PPI	N/A
Section 7: Study results			
7a	Outcomes of PPI	Report the results of PPI in the study, including both positive and negative outcomes	Section 4.5
7b	Impacts of PPI	Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts	Section 4.5.1; Section 4.5.2
7c	Context of PPI	Report the influence of any contextual factors that enabled or hindered the process or impact of PPI	Section 4.5
7d	Process of PPI	Report the influence of any process factors, that enabled or hindered the impact of PPI	Section 4.5
7ei	Theory development	Report any conceptual or theoretical development in PPI that have emerged	N/A
7eii	Theory development	Report evaluation of theoretical models, if any	N/A
7f	Measurement	If applicable, report all aspects of instrument development and testing (eg, validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)	N/A
7g	Economic assessment	Report any information on the costs or benefit of PPI	N/A
Section 8: Discussion and conclusions			
8a	Outcomes	Comment on how PPI influenced the study overall. Describe positive and negative effects	Section 4.6.2
8b	Impacts	Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge	Section 4.6.2
8c	Definition	Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes	N/A
8d	Theoretical underpinnings	Comment on any way your study adds to the theoretical development of PPI	N/A
8e	Context	Comment on how context factors influenced PPI in the study	Section 4.6.2
8f	Process	Comment on how process factors influenced PPI in the study	Section 4.6.2
8g	Measurement and capture of PPI impact	If applicable, comment on how well PPI impact was evaluated or measured in the study	Section 4.6.2
8h	Economic assessment	If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.	N/A
8i	Reflections/critical assessment	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study	Section 4.6.3

PPI: Patient and Public Involvement

References

1. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, Altman DG, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V, Tysall C. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 2017;**358**:j3453.

Imperial College London

School of Public Health
Imperial College London

Experiences of COVID-19 Epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

Participant Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study aims to explore the experiences of people living with HIV during the COVID-19 epidemic and to use this to inform current policy. We have already completed 14 interviews with people working in HIV services (health workers, charity workers and community-based organisations).

Why have I been invited?

You are being invited to take part in this study because you are someone living with HIV who completed the 2017 Positive Voices Study and agreed to being recontacted. Also, you are aged 18 or older and have experiences of the COVID-19 pandemic.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form online. You are free to withdraw at any time and without giving a reason why.

What would I have to do?

This study involves filling out a short questionnaire and being interviewed. Because of the pandemic, the study is being conducted digitally using Zoom or by telephone.

The confidential online questionnaire asks basic demographic information. Demographic information are characteristics about you such as your age, where you live and your working status. This data will be aggregated (added together) to describe the sample of participants and will be used to ensure that we have reached a diverse group of people.

We will use the interviews to conduct research focused on understanding how people living with HIV, and HIV services, are currently being impacted by the pandemic, and we will use this information to inform research design and policy development. We will ask you to consent to participating in the study through Qualtrics. Qualtrics is an online platform used for surveys by Imperial College. Where not possible, we will ask for consent verbally.

If you agree to be interviewed, you will be contacted by email or telephone to discuss the study further and arrange your participation. We expect interviews will last between 60 and 90 minutes and will be informal. We will ask you to reflect on a series of questions about the COVID-19 epidemic. The interview will be conducted on Zoom and will be recorded. For participants who do not have digital access to Zoom, we will conduct and record interviews over the phone, and where not possible to consent via Qualtrics, we will ask for verbal consent from participants at the beginning of the interviews. Over the course of the interview, you may refuse to answer any question at any time. You may also retract your consent during the research process and any time after this research is completed. We will also give you the opportunity to be re-contacted, so that we can keep you updated with the progress we make, should you consent to this.

What will happen to me if I take part in the interview?

You will sign an electronic consent form via a link in the invitation email via ticking a box on the form.

Participants will be invited to contribute to one or more of these procedures:

1) Participants will be asked to fill out a confidential online questionnaire with basic demographic information. This data will be aggregated to describe the sample of participants and help us to select a diverse group to be invited to be interviewed.
2) Some participants will be invited for a video-chat interview with one of the researchers. Over the course of the interview, you may refuse to answer any question at any time. You may also retract your consent during the research process and any time after this research is completed.

The interview will be a little like a conversation, in which I will help you talk about yourself in your own words. Issues we would like to discuss include work life, family life, friendships and social connections and the impact of COVID-19 on HIV care.

After the interview, you will be offered a £25/hour payment as a thank you for taking part.

What are the possible disadvantages and risks of taking part?

There are no particular disadvantages to taking part in the interview. You may be asked about sensitive information, such as your health status. If you feel uncomfortable with any part of the interview conversation, you can refuse to answer any question or ask for part of the conversation to be removed from the transcript. You may feel inconvenienced by the time required as the entire interview process will require approximately 60 to 90 minutes. Finally, given the general public anxiety surrounding the outbreak, answering some of the questions may cause distress. A list of useful resources are given in an attached PDF handout.

What are the benefits of taking part in the interview?
You will not derive a particular benefit from participating in the interview, though many interview participants find the opportunity to discuss their experience to be satisfying or therapeutic. As researchers, we hope that your participation offers an opportunity for reflection. We expect that your perspective, alongside that of others in this study, will be of great value in developing public health policy now and in the future for people living with, and affected by, HIV.

What does taking part in the interview involve?
Taking part involves an interview with a qualified interviewer. It takes approximately 60-90 minutes to complete. If, when doing the interview, a topic of conversation arises that makes you feel uncomfortable, you can let the interviewer know that you wish to move on to another subject or terminate the session altogether. It is important for you to understand that you are not required to discuss anything that you do not want to.

In this study, we are also training two peer researchers (people living with HIV) to conduct and analyse interviews. You will be asked during the consent process whether you are happy to be interviewed by a peer researcher. You can opt-out if you would prefer to be interviewed by another member of the Imperial College research team.

What if I decide to withdraw after the interview has taken place?
You are free to leave the study at any time. If you decide to leave after an interview has taken place, all recordings, transcripts and typing of your interview would be destroyed. You can request to leave the study by emailing or telephoning the research team.

What would happen after the interview?
The interviews are recorded and transcribed using an automated, in-built Zoom transcription service or will be checked by a qualified professional based at UKTranscription.com of which Imperial College London has a confidentiality agreement with. Only the audio recording will be used in the study. We will record the interviews to ensure we do not forget or miss important information that you tell us. No identifying information, such as your name, would be kept with the interview transcripts and the interview recordings, and only people in the research team would have access to them subject to participant's agreement. The digital recording and the digital typed up record (transcript), identified only by the code number, would be kept on secure servers at the Patient Experience Research Centre at Imperial College London.

You will also be provided with an optional payment of £25/hour to recognise your contribution to the research study. The study coordinator (Vas) will share a payment form with you after the interview to arrange this.

How would the researcher use the interview recording and transcript?
If you do decide to allow your interview to be used for the research study, they would be used along with interviews from between 20-30 people living with HIV. We will use these in two ways. First, we will use the interviews to conduct research focused on understanding how people living with HIV are currently being impacted by the pandemic, and we will use this information to inform research design and policy development.

All data use is strictly within the terms of the General Data Protection Regulation [GDPR] which came into effect on 25 May 2018, and its implementing legislation, the Data Protection Act 2018. The study data may be looked at by individuals from Imperial College London, for the purpose of audit and monitoring.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator Professor Helen Ward, email: h.ward@imperial.ac.uk, telephone: +44 (0)20 7594 3303.

If you are still not satisfied with the response, you may contact the Imperial Joint Research Compliance Office.

Who is funding and organising this research?
Imperial College London School of Public Health is funding and leading the research. We have also received funding to appoint and train two peer researchers and two advisory group members to support our study through the Rapid Response Seed Funding provided by the Societal Engagement Team at Imperial College London. Payment is provided by funding received from the NIHR Imperial Biomedical Research Centre.

Who has reviewed the study?
The Principal Investigator has obtained approval from the Head of Department and Joint Research Compliance Office (JRCO). The day-to-day management of the study will be co-ordinated by Vasiliki (Vas) Papageorgiou.

Contact for Further Information

Participant Information Sheet – v2.1 28/06/2021

If you have would like more information about the study or have any concerns or questions, you can contact Vas Papageorgiou (email: vasiliki.papageorgiou17@imperial.ac.uk) who will do her best to help.

HOW WILL WE USE INFORMATION ABOUT YOU?

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

We will need to use information from you for this research project.
This information will include your

-Name

- Contact Details, including your email address and telephone number

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.
We will keep all information about you safe and secure.

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.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.
Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that

Participant Information Sheet – v2.1 28/06/2021

incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

- Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.
- The following Research Collaborators / Partners in the study;
  - Positive Voices Study team (HIV Section, Public Health England; Positively UK): we are partnering with them on this larger study interviewing people living with HIV.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, and normally we will keep information about you that we already have. If a participant decides to leave the study after an interview has taken place, all audio recordings, transcripts and typing of your interview would be destroyed if requested.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information

- by asking one of the research team
- by sending an email to vasiliki.papageorgiou17@imperial.ac.uk

COMPLAINT

If you wish to raise a complaint on how we have handled your personal data, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

Thank you very much for taking the time to consider taking part in this study.

Yours faithfully,

Vas Papageorgiou

Participant Information Sheet – v2.1 28/06/2021

Imperial College London

School of Public Health
Imperial College London

Experiences of COVID-19 epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

Online Consent form

Chief Investigator
Prof Helen Ward

Researchers
Vasiliki Papageorgiou
Jane Bruton
Emily Cooper
Kabelo Murray
Karl Dsouza
Husseina Hamza

Taking part is voluntary. If you agree, you will be invited to take part in an interview. You can withdraw from the study at any time and only anonymised data will be shared with the research team. More details on the project and how we process your data can be found in the participant information sheet [dated 28/06/2021, version 2.1].

Please read the following statements and confirm your agreement. At the end of the survey, you will be redirected to a second survey to share your contact details so that a member of the research team can contact you about your participation. Please ensure that your name on the consent form matches that provided in the second survey.

1. I confirm that I have read and understand the participant information sheet dated 28/06/2021 version 2.1 for the above study and have had the opportunity to ask questions which have been answered fully.	☐ Yes ☐ No
2. I understand that my participation is voluntary, and I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	☐ Yes ☐ No
3. I give consent for information collected about me to be used to support other research in the future, including those outside of the EEA.	☐ Yes ☐ No
4. I consent to take part in the above study.	☐ Yes ☐ No
5. I give consent to being contacted to potentially taking part in other research studies.	☐ Yes ☐ No
6. I understand that, with my permission, anonymised quotes from my interview may be used in reports, publications and presentations as part of publicising the study findings.	☐ Yes ☐ No
7. I understand the options for confidentiality and anonymity in participation. Please check off the options that reflect your consent:	☐ Yes ☐ No
SURVEY	
a) I agree to participate in the confidential survey.	☐ Yes ☐ No
INTERVIEW	
b) If invited to participate in an interview, I agree to do so and to contribute an anonymised transcript of my interview to the research project.	☐ Yes ☐ No
c) If invited to participate in an interview, I agreed to being audiorecorded for the purposes of generating an anonymised transcript..	☐ Yes ☐ No
d) If invited to participate in an interview, I agree to being interviewed by a peer researcher (optional)	☐ Yes ☐ No

_____ _____ _____

Name of participant Date Signature

SECOND SURVEY (CONTACT DETAILS)
Thank you for your interest in our study ("Experiences of COVID-19 epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK").

Details about the study and how we will process your data can be found in the Participant Information Sheet [version 2.1, dated 28/06/2021]. Please provide us with your contact details so a member of the study team can contact you about your participation.

- Name (mandatory):
- Email address (mandatory):
- Contact number (optional):

Consent form – v5.2 28/06/2021

Imperial College London

School of Public Health
Imperial College London

Experiences of COVID-19 epidemic: a qualitative study of people living with, affected by, or working in HIV in the UK

Thank you for your willingness to participate in this research project. This confidential questionnaire covers some basic topics that are important for us to make sure we're reaching people with varied perspectives. If you do not feel like answering a question, you do not need to answer it. You can always just click the "prefer not to answer" box. It should take you no longer than 15 minutes to complete this questionnaire.

None of the information you give in this questionnaire will be publicly linked to your interview materials. When you fill out the questionnaire, you will be assigned a "random identification number" and your personal contact information will be separated from your answers to these questions. That means we can guarantee that all of your answers will be confidential and only the research coordinators for this project will have access to individual responses.

If you have any questions about confidentiality or concerns while filling out the questionnaire, feel free to reach out with questions to Vas Papageorgiou at vasiliki.papageorgiou17@imperial.ac.uk

1) What is your age?
2) What gender do you identify with?(Please select the option that best applies. If your answer is not provided in the list shown, please type it in the 'in another way' box)

<1> Male (including transman)
<2> Female (including transwoman)
<3> Non-binary
<4> In another way, please specify
<5> Prefer not to say

3) Is this the same gender you were assigned at birth?

<1> Yes
<2> No
<3> Prefer not to say

4) Which of the following best describes how you think of yourself?

<1> Straight/Heterosexual
<2> Gay or Lesbian/Homosexual
<3> Bisexual
<4> Asexual
<5> Other sexual orientation (please specify)
<6> Prefer not to say

5) Which ethnic group do you identify with? Choose one option that best describes your ethnic group or background. (We ask the question in this way so that it is consistent with updated Census 2021 categories.)

White	a) English / Welsh / Scottish / Northern Irish / British b) Irish c) Gypsy or Irish Traveller d) Roma e) Any other White background
Mixed/Multiple ethnic groups	a) White and Black Caribbean b) White and Black African c) White and Asian d) Any other Mixed / Multiple ethnic background
Asian/Asian British	a) Indian b) Pakistani c) Bangladeshi d) Chinese e) Any other Asian background
Black/African/Caribbean/Black British	a) African background, please describe b) Caribbean c) Any other Black/Black British or Caribbean background
Other ethnic group	a) Arab b) Hispanic/Latino c) Any other ethnic group
Prefer not to say	

Questionnaire form - v1.3 12/03/2021

6) Which of the following statements do you identify with? You can select multiple options

<1>	Currently living with HIV
<2>	Currently caring for someone living with HIV
<3>	Loved one of someone living with HIV
<4>	Health professional supporting people living with HIV
<5>	Social care worker supporting people living with HIV
<6>	Charity worker supporting people living with HIV Long-term
<7>	Community worker supporting people living with HIV
<8>	HIV advocate supporting people living with HIV
<9>	Other, please specify

If <1>, <2>, <3>: how long have you been living with HIV? Did you receive a letter/message to shield?

If <4>, <5>, <6>, <7>, <8>: how long have you been working in HIV? What is your job title?

7) What is the highest educational or work-related qualification you have?

<1>	No formal qualifications	<11>	GCE A level or Higher Certificate
<2>	Youth training certificate/skillseekers	<12>	Scottish Higher Certificate
<3>	Recognised trade apprenticeship completed	<13>	Nursing qualification (e.g. SEN, SRN, SCM, RGN)
<4>	Clerical and commercial	<14>	Teaching qualification (not degree)
<5>	City & Guilds certificate	<15>	University diploma
<6>	City & Guilds certificate - advanced	<16>	University or CNAA first degree (e.g. BA, B.Sc, B.Ed)
<7>	ONC	<17>	University or CNAA higher degree (e.g. M.Sc, Ph.D)
<8>	CSE grades 2-5	<18>	Other technical, professional or higher qualification
<9>	CSE grade 1, GCE O level, GCSE, School Certificate	<19>	Don't know
<10>	Scottish Ordinary/ Lower Certificate	<20>	Prefer not to say

8) What is your current work situation?

<1>	Working full time (30 or more hours per week)
<2>	Working part time (8-29 hours a week)
<3>	Working part time (Less than 8 hours a week)
<4>	Temporary employment (fixed period contract, agency temping, casual work, seasonal work, other temporary work)
<5>	Full-time student
<6>	Retired
<7>	Long-term sick/disabled (for 3 months or more)
<8>	Temporarily sick/disabled (for 3 months or more)
<9>	Carer
<10>	Unemployed
<11>	Not working
<12>	Other, please specify

If <1>, <2>, <3>, <4>, <5>, <12>: do you have 'key worker' status? as defined by government 'critical workers': https://www.gov.uk/government/publications/coronavirus-covid-19-maintaining-educational-provision/guidance-for-schools-colleges-and-local-authorities-on-maintaining-educational-provision)

a. Yes
b. No
c. Unsure
d. Not applicable (not currently working)
e. Prefer not to answer

9) Where do you currently live?

<1>	Own or purchasing house or flat
<2>	Renting (privately owned)
<3>	Renting (council or housing association owned)
<4>	Rent free (provided by friends, family, etc
<5>	Sheltered accommodation/retirement housing
<6>	Residential care home
<7>	Temporary accommodation (housing, shelter, bed and breakfast)
<8>	Homeless
<9>	Other, please specify

10) Gross HOUSEHOLD income is the combined income of all those earners in a household from all sources, including wages, salaries, or rents and before tax deductions. What is your gross household income?

<1>	under £5,000 per year	<10>	£45,000 to £49,999 per year
<2>	£5,000 to £9,999 per year	<11>	£50,000 to £59,999 per year
<3>	£10,000 to £14,999 per year	<12>	£60,000 to £69,999 per year
<4>	£15,000 to £19,999 per year	<13>	£70,000 to £99,999 per year

Questionnaire form - v1.3 12/03/2021

<5>	£20,000 to £24,999 per year	<14>	£100,000 to £149,999 per year
<6>	£25,000 to £29,999 per year	<15>	£150,000 and over
<7>	£30,000 to £34,999 per year	<16>	Don't know
<8>	£35,000 to £39,999 per year	<17>	Prefer not to answer
<9>	£40,000 to £44,999 per year		

11) How many people live in your household?

a. Please choose a number between 1 and 10
b. 10+

Display question 8 if question 7 answer is 2 or more:

12) Is everyone in your household related to you in some way?

a. Yes
b. No
c. Not applicable
d. Prefer not to answer

13) What is the first part of your postcode (e.g. SW7)?

14) In what country were you born?

15) If you were born outside of the UK, how long have you lived here for?

a. Less than 1 year
b. 1-2 years
c. 3-4 years
d. 5-10 years
e. 11+ years
f. Not applicable
g. Prefer not to answer

Thank you for completing our survey. If you have any comments, questions or concerns please contact Vas at vasiliki.papageorgiou17@imperial.ac.uk

Notes to send to interviewee

Thank you for taking part in this interview which we are conducting as part of our coronavirus research.

We are designing research to explore the experience of the COVID-19 outbreak for people living, with HIV – whether directly or indirectly affected – and how it has impacted HIV care.

We would really value hearing about your experience, your thoughts and recommendations.

If it is OK with you, we will record the interview so that it can be transcribed and shared with colleagues to inform our research and education activities.

The areas I would like to ask about are:

- *Your experiences of life during COVID-19 as someone **living with** HIV*
- *Where you have sought information from*
- *How you are communicating with others*
- *Practical challenges for you:*
    - ***If living/caring for someone with HIV**: seeking/receiving HIV services, your work/social life; following government advice*

As the interview will touch on a number of personal areas of your life, which may be particularly difficult, please do let me know if you'd like to pause, take a break or would prefer not to answer a particular question. You are also free to end the interview at any time and withdraw your consent to take part, without giving a reason why.

The interview will take up to 1 hour.

TOPIC GUIDE

*N.B. items in **bold** to be edited depending on who is being interviewed*

Background

1. Can you tell me a little bit about yourself and your background? Whatever you think is important to share about your life up until now, before we get into questions about your recent experiences.
    a. Prompts: work, family, time living with/working in HIV

Personal experience

Start by reassuring interviewees that information shared is confidential (particularly in relation to receiving benefits and working status). Emphasise that when asking about situation of others, we do not need names or addresses.

2. Tell me about your working situation
    a. Prompt: How has that changed?
    b. Prompt: Has your job impacted your ability to manage your day-to-day during the outbreak?
    c. Prompt: Is anyone else you know having their work impacted?
    d. Prompt: Do you know what the situation is with people with other employers? (also people with manual / insecure jobs).

3. What new things are you doing because of this?
    a. Prompt: habits, skills, hobbies; why? What do these offer?

4. Tell me about some practical challenges that you are facing because of the outbreak?
    a. Prompt: at home (family/relationships);
    b. Prompt: daily life (friends/neighbours/relationships), housing, food and finances, feeling safe/at risk
    c. Prompt: work (work life, co-workers, people you manage, boss, income), feeling safe/at risk

5. **[if working in health/social care]:** were you re-deployed during COVID-19? How did you find that?
    a. Prompt: relationships with colleagues, dealing with trauma(?), feeling safe (e.g. PPE), risk management by their employer

6. [**If living with HIV/carer]:** you mentioned earlier that you **are living alone/with/support your [relationship]**. What is your plan if **you/they** get sick?

7. Have you had symptoms of COVID-19?
    a. Prompt: Were you tested?
    b. Prompt: have you noticed any longer-term impacts (e.g. to your health, wellbeing, living/working/financial situation? Tell me more about this

8. What are your views on the COVID-19 vaccine?
    a. If offered, would you accept the vaccine? Why?

9. Can you please tell me about how you have found the experience emotionally?
    a. Prompt: isolation/loneliness, support, mental health

Information and guidance

10. **[If living with HIV]:** Did you receive any information from the government about shielding? Tell me more about this.
    a. Prompt: letter, text, contact from GP - the language used, frequency of messaging

11. OR **[If working in HIV]:** are you aware of anyone you support (e.g. people living with HIV) receiving information from the government about shielding? Tell me more about this. Prompt: letter, text, contact from GP - the language used, frequency of messaging
    a. Did you agree with the decision and why?
    b. What is the most recent message that specifically affects people living with HIV that you recall from the government, other government officials or agencies? Prompt: shielding; being "clinically vulnerable"; ART prescriptions

12. **[If living with HIV]:** What guidelines are you following from the government?
    a. Prompt: shielding (if living with HIV and has been advised to); social distancing; hand washing; wearing a face mask in enclosed spaces
    a. Have any of the changes been particularly difficult to make?
    b. How do you think the government is doing so far handling it? Are they doing enough? What has been most helpful so far?
    c. Do you see other people following those guidelines?

13. Where have you been looking for information about COVID-19?
    a. Prompt: HIV charities, community groups, clinician, internet
    b. Prompt: What sources of information do you trust?

HIV treatment and care

14. **[If living with HIV]:** Have you experienced any changes to your HIV treatment and care? Tell me more about this
    a. Prompt (medication): ART prescriptions, maintain adequate ART supply, ability to adapt ART regimen, continuing adherence to ART
    b. Prompt (services): face-to-face versus online/phone consultations, delayed/cancelled appointments, paperless
    c. Prompt (peer support): virtual support groups
    d. Prompt: feeling towards changes

15. How about in the quality of the care you receive now compared to two years ago (before COVID-19)?
16. **[If living with HIV]:** How did you feel about attending appointments during the pandemic?
    a. Prompt: fear of acquiring COVID-19, lack of personal protective equipment, possible worst-case scenario, co-morbidities

17. **[If providing services]:** In your experience, what has been the impact of COVID-19 on the services you provide? Please tell me more about the potential risks and opportunities
    a. Prompt (practicalities): providing medication/prescriptions, arranging check-ups, logistics, personal protective equipment
    b. Prompt (service users): missing/vulnerable groups
    c. Prompt (communication): remote services rather than face-to face

Society and social support

18. What changes have you noticed in the HIV community? How about wider society? Prompt: discrimination, stigma

19. How have you changed how you interact socially? Prompt: peer support groups

20. Have you ever experienced anything like this before? Prompt: early days of HIV

21. What are you planning or doing to be ready for what you think will happen next?

Future/long-term

22. What long-term changes do you think this situation will have for

[If living with HIV]

    b. You/your HIV care (prompt: social life, job, housing)
    c. Your family
    d. Your community/HIV services
    e. Your country
    f. The world

[If working in HIV]

    a. People living with HIV that you currently support
    b. HIV community
    c. Your field/job/profession
    d. HIV services

23. Is there anything you would like to ask me?

Thank you for your time.

Vasiliki Papageorgiou (study coordinator) will share information about resources in a follow-up email (listed below) thanking the interviewee for taking the time to participate and share their experiences. These are provided in the PDF handout titled app_9(…)

Advice and support

- Positively UK – provide support for people living with HIV remotely
- Body & Soul - "Share the Love" campaign during COVID-19 including MindSET Livestream sessions and crisis counselling for NHS frontline staff
- NAZ – BAME-led sexual health agency with information on services available during COVID-19
- CHIVA – support for children, young people and their families living with HIV
- HIV Scotland – advice for people living with HIV in Scotland during COVID-19
- UK-CAB – a network for community HIV treatment advocates
- National AIDS Trust – includes advice on shielding, workers' rights and other resources
- PrEPster – advice for people using PrEP, including COVID-19 'tips and tricks'
- Terrence Higgins Trust – blogpost with FAQ on HIV and COVID-19

News/clinical guidelines

- British HIV Association – latest guidelines by the leading national advisory body on HIV care
- NAM Aidsmap – latest news on HIV and COVID-19
- HIV i-Base – HIV treatment information and advocacy with specific information on COVID-19

USEFUL COVID-19 RESOURCES FOR PEOPLE LIVING WITH HIV



Advice and support

- **Positively UK** - provide remote peer support
- **Body & Soul** - "Share the Love" campaign during COVID-19 includes crisis counselling for NHS staff
- **Naz** - BAME-led sexual health agency with information on services available during COVID-19
- **cliniQ** - services for all trans people, partners and friends, including a list of resources during COVID-19
- **CHIVA** - support for children, young people and their families living with HIV
- **HIV Scotland** - advice for people living with HIV in Scotland during COVID-19, including a coronavirus helpline (Monday-Friday, 10am-6pm)
- **UK-CAB** - network for community HIV treatment advocates
- **National AIDS Trust** - includes advice on shielding, workers' rights and other resources
- **PrEPster** - advice for people using PrEP, including COVID-19 'tips and tricks'
- **Terrence Higgins Trust -** blogpost with FAQ on HIV and COVID-19

News and clinical guidelines



- **British HIV Association** - latest guidelines by the leading national advisory body on HIV care
- **NAM Aidsmap** - latest news on HIV and COVID-19
- **HIV i-Base -** HIV treatment information and advocacy including specific content on COVID-19

Health and travel guidance

- **World Health Organization** - for answers to most frequently asked questions about COVID-19
- **NHS.UK** - for information about the virus and how to protect yourself
- **GOV.UK** - for the latest information about the situation in the UK and what to do if you think you're at risk

Other support

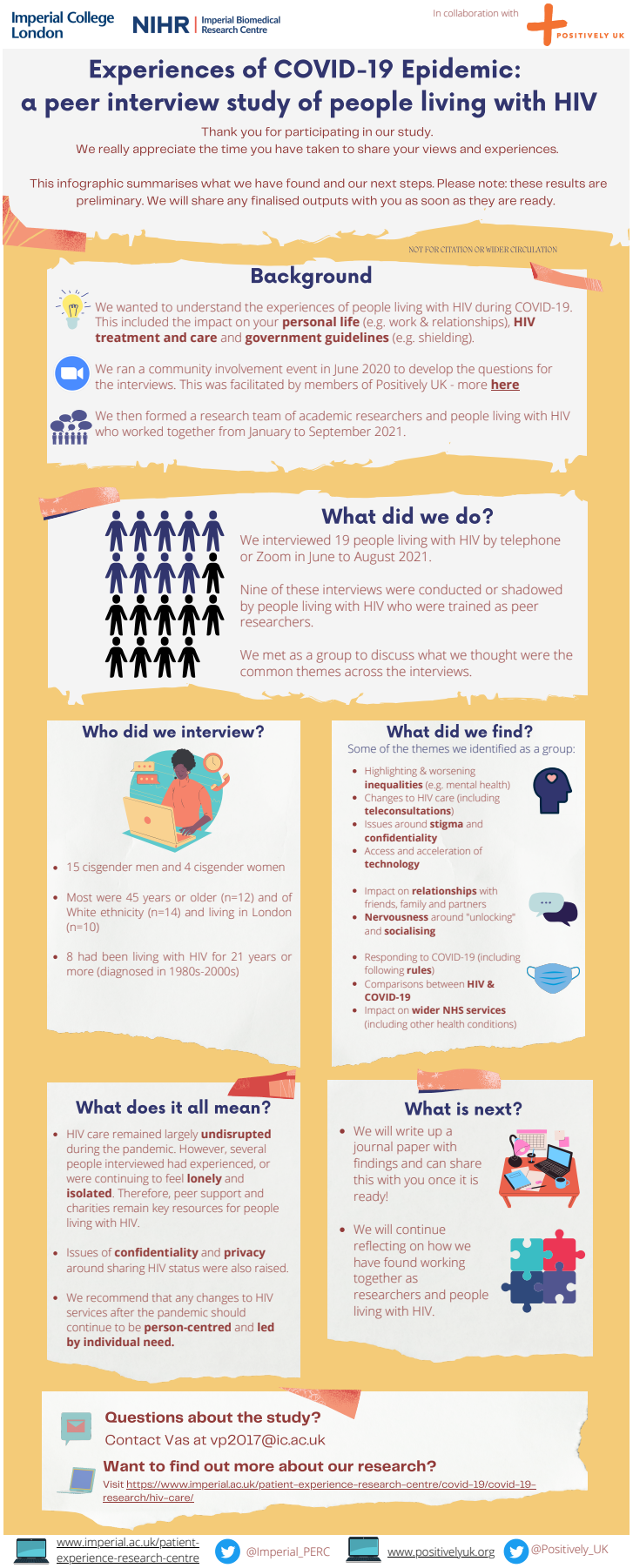


- **Every Mind Matters** - tips and advice on mental health (including coronavirus and wellbeing)
- **Mind** - charity providing advice and support on mental health (including coronavirus and wellbeing)
- Supermarkets and other community offers for those who are vulnerable e.g. **food boxes,** support from the **NHS Volunteer Responders Programme** as well as from **COVID-19 mutual aid groups**

Please note that Imperial College London does not directly endorse any particular service.

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Imperial College London
NIHR | Imperial Biomedical Research Centre
In collaboration with POSITIVELY UK
Experiences of COVID-19 Epidemic:
a peer interview study of people living with HIV
Thank you for participating in our study.
We really appreciate the time you have taken to share your views and experiences.
This infographic summarises what we have found and our next steps. Please note: these results are preliminary. We will share any finalised outputs with you as soon as they are ready.
NOT FOR CITATION OR WIDER CIRCULATION
Background
We wanted to understand the experiences of people living with HIV during COVID-19. This included the impact on your personal life (e.g. work & relationships), HIV treatment and care and government guidelines (e.g. shielding).
We ran a community involvement event in June 2020 to develop the questions for the interviews. This was facilitated by members of Positively UK - more here
We then formed a research team of academic researchers and people living with HIV who worked together from January to September 2021.
What did we do?
We interviewed 19 people living with HIV by telephone or Zoom in June to August 2021.
Nine of these interviews were conducted or shadowed by people living with HIV who were trained as peer researchers.
We met as a group to discuss what we thought were the common themes across the interviews.
Who did we interview?
15 cisgender men and 4 cisgender women
Most were 45 years or older (n=12) and of White ethnicity (n=14) and living in London (n=10)
8 had been living with HIV for 21 years or more (diagnosed in 1980s-2000s)
What did we find?
Some of the themes we identified as a group:
Highlighting & worsening inequalities (e.g. mental health)
Changes to HIV care (including teleconsultations)
Issues around stigma and confidentiality
Access and acceleration of technology
Impact on relationships with friends, family and partners
Nervousness around "unlocking" and socialising
Responding to COVID-19 (including following rules)
Comparisons between HIV & COVID-19
Impact on wider NHS services (including other health conditions)
What does it all mean?
HIV care remained largely undisrupted during the pandemic. However, several people interviewed had experienced, or were continuing to feel lonely and isolated. Therefore, peer support and charities remain key resources for people living with HIV.
Issues of confidentiality and privacy around sharing HIV status were also raised.
We recommend that any changes to HIV services after the pandemic should continue to be person-centred and led by individual need.
What is next?
We will write up a journal paper with findings and can share this with you once it is ready!
We will continue reflecting on how we have found working together as researchers and people living with HIV.
Questions about the study?
Contact Vas at vp2017@ic.ac.uk
Want to find out more about our research?
Visit https://www.imperial.ac.uk/patient-experience-research-centre/covid-19/covid-19-research/hiv-care/
www.imperial.ac.uk/patient-experience-research-centre
@Imperial_PERC
www.positivelyuk.org
@Positively_UK

Outputs from co-production event

The following section contains a sample (from one of five groups) of outputs from the activities completed at the co-production event in July 2022 – see **subsubsection 4.5.2** for further details. These photographs are also featured in a Patient Experience Research Centre (PERC) blog (449) on the event.

'Drawing concepts' exercise

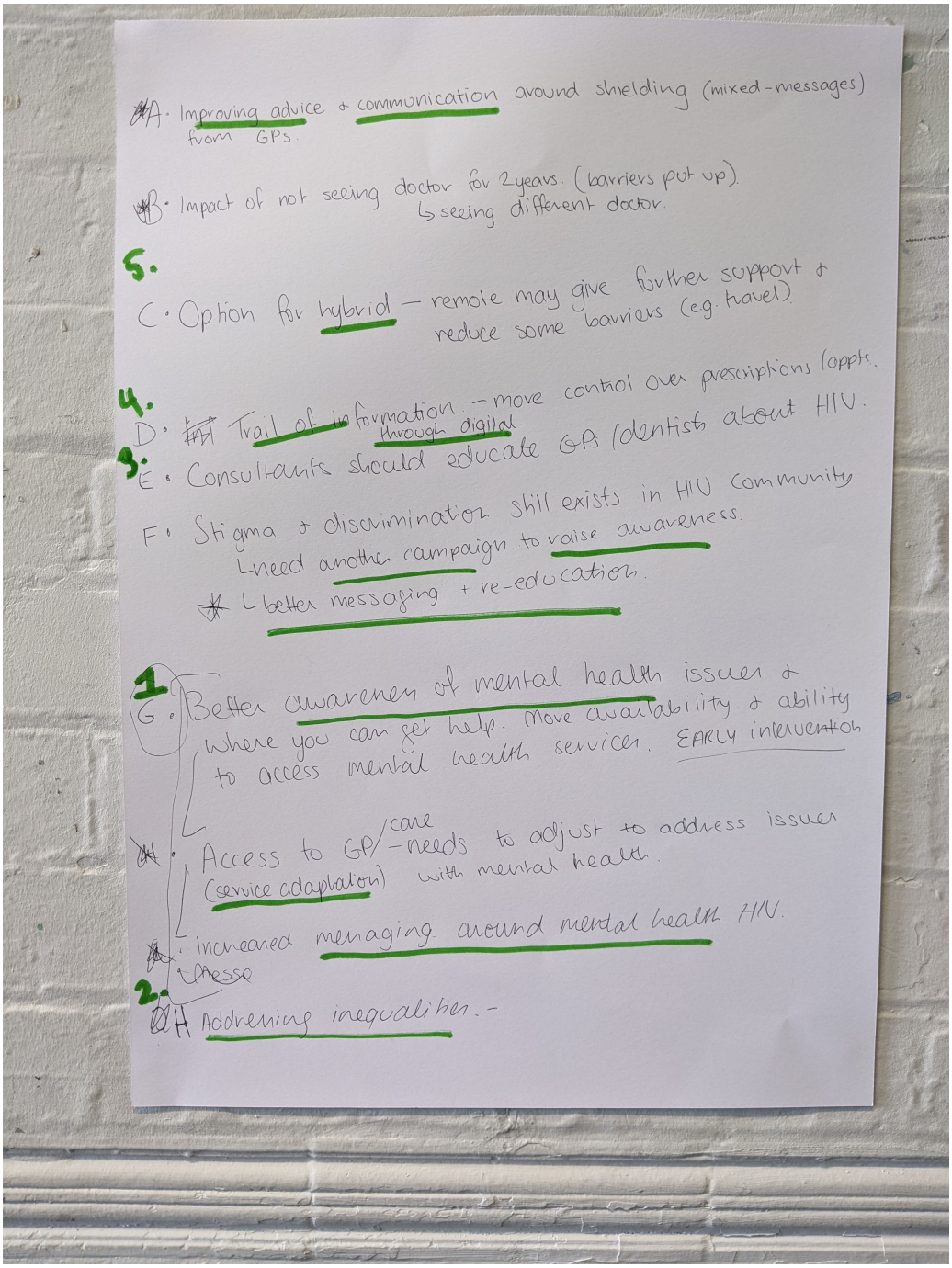
Here, Group 1 lists "what co-research means to them" on post-it notes including "diverse involvement", "power sharing" and "having my ideas incorporated in the research process."



Feedback from 'drawing concepts' exercise. Patient Experience Research Centre, Imperial College London Copyright © 2022 (449).

'So what? Now what?' exercise

Here, Group 1 prioritises the findings from the COVID-19 research studies **(Chapter 3 and Chapter 4)** by numbering them; the group decides that "better awareness of mental health issues" should be a priority moving forward. The group also specifies that this should be in the form of "early intervention" including "where you can get help" and increased availability and access.



Feedback from prioritisation exercise – group 1. Patient Experience Research Centre, Imperial College London Copyright © 2022 (449).

Group collage exercise

The collages created were for co-production principles of:

1. Be kind, have fun and learn (see below)
2. Build and strengthen relationships
3. Make things simple
4. Share power
5. Stay connected

These principles were originally co-created with co-researchers across three research projects including people living with HIV, people living with learning disabilities and young people with experience of mental health difficulties and presented at a research methods conference (584, 585).



Principle 1: Be kind, have fun and learn. Patient Experience Research Centre, Imperial College London Copyright © 2022 (449).

E

Chapter 5 Appendix

This Appendix includes:

- **Data recoding:** demographic, social determinant, clinical and GHQ-12 variables
- **Tests for collinearity:** independent variables
- **Summary frequencies:** social determinants by demographics; pre-existing mental health diagnoses
- **Multivariate model building and goodness of fit**
- **Post-hoc analysis**: Sensitivity analysis, collinearity diagnostics and stratified analysis (by gender identity, ethnicity and sexuality)
- **Missing data**

Data recoding

I recoded data from initial categories collected in the Positive Voices survey (482). 'Prefer not to say' or 'unclassified' were treated as missing observations in the regression analysis. Other data captured but not included in the analysis:

- Diagnosis: country where received diagnosis (B2), sharing HIV status with others (B3) and testing site where they received diagnosis (B4)
- Treatment: taking medication (B5, B6), amount of medication and adherence (B7, B8) experienced side effects (B9), bothered by side effects (B10)
- Co-morbidities [cardiovascular (C1), bone and joint (C2), cancer (C3), mental health conditions (C4) & counselling (C5) other long-term condition e.g. dementia (C6), viral infections (C7), STIs (C8)]
- Women's sexual and reproductive health (C9-12)
- Health service use and satisfaction e.g. GP (D1-7), HIV clinic (D7-10); NHS and social care services (D11)
- Stigma/discrimination (D12-13)
- HIV support services (D14-17)
- Met and unmet needs: HIV-related services (E1), health services (E2), social/welfare services (E3)
- Health and wellbeing: life satisfaction (F1), health rating (F2), EQ-5D-5L (F3-F7)
- Sex and relationships (G1-G8)
- Lifestyle: weight (H1), height (H2), alcohol (H3, H4), smoking status (H5), drug use (H6-H10)
- Social and demographic: religion (I2) and importance of religious beliefs (I3)

Recoding of demographic variables from the PV-2017 dataset for this study

PV-2017 Question	Type of data	Transformed variable categories
A1: How old are you?	Numerical (continuous)	**Age group** 18-34 35-44 45-54 55-64 65+
A2: How do you identify your gender? Woman (including transwoman) Man (including transman) Non-binary In another way Prefer not to say		
A3: Is this the same gender you were assigned at birth? Yes No Prefer not to say	Categorical (nominal) Categorical (binary)	**Gender identity** Cisgender man Cisgender woman Transgender woman, non-binary, in another way[1] Prefer not to say
A4: In what country were you born?	Categorical (nominal) – free text	**Country of birth**[2] High-income (UK) High-income (Other) Low/middle-income Unclassified[3] or missing
A5: To which of these groups do you consider you belong? White (British; Irish; Any other White background) Black or Black British (African; Caribbean; Any other Black background) Mixed/multiple ethnic groups (White & Black Caribbean; White & Black African; White & Asian; Any other mixed) Asian/Asian British (Indian; Pakistani; Bangladeshi; Chinese; Any other Asian background) Other ethnic groups (Arab; Hispanic/Latino; Any other ethnic group)	Categorical (nominal)	**Ethnicity**[4] White British Any other White background (including Irish) Black African Any other Black background (including Caribbean) Mixed background (including White and Black Caribbean; White and Black African; White and Asian; any other) Asian background (including Indian; Pakistani; Bangladeshi; Chinese; any other) Any other ethnic background (including Arab, Hispanic/Latino)
I1: Which of the following best describes how you think of yourself? Straight/heterosexual Gay or lesbian/homosexual Bisexual Asexual Other Prefer not to say	Categorical (nominal)	**Sexuality** Straight/heterosexual Gay or lesbian/homosexual Bisexual Asexual/other[5] Prefer not to say

[1] Dropped observations in regression analysis as small sub-sample.
[2] Based on 2019 World Bank classification (278).
[3] Includes countries not classified by the World Bank (in this case Yugoslavia – as no longer exists).
[4] Created new categories with at least 150 people in each group.
[5] Reformatted to combine asexual/other categories as <150 people.

Recoding of social determinant variables from the PV-2017 dataset for this study

PV-2017 Question	Type of data	Transformed variable categories
I4: What is your highest level of education that you have completed? Primary school or less Qualifications at age 16 (GCSE, NVQ, O Levels) Qualifications at age 18 (A-Levels, AS Levels, high school diploma) University/first/undergraduate degree Postgraduate degree City and Guilds/equivalent Other (please specify)	Categorical (ordinal)	**Highest educational level** ISCED1/2: Primary or less ISCED3: Upper secondary education (to age 18) ISCED4/5: Technical and vocational education training ISCED6: Bachelors or equivalent level ISCED7/8: Postgraduate degree
I5: What is your current work situation? Tick all that apply Employed or self-employed full-time (at least 30 hours/week) Employed or self-employed part-time (less than 30 hours/week) Full-time student/education/training Unemployed Long-term sick/disabled (for 3 months or more) Long-term sick/disabled (for less than 3 months) Carer Retired Other (please specify)	Categorical (nominal)	**Employment status** Employed Unemployed Economically inactive
I6: Where do you currently live? Own or purchasing house or flat Renting (privately owned) Renting (council or housing association owned) Rent-free (provided by friends, family etc) Sheltered accommodation/retirement housing Residential care home Temporary accommodation (hostel, shelter, bed and breakfast) Homeless Other (please specify)	Categorical (nominal)	**Housing status** Own or purchasing house or flat Renting – privately owned Renting – council or housing association Unstable or other[1]
I7: In the last year, indicate all of your sources of income. Tick all that apply. Earnings from employment (e.g. salary or wages) Supplementary income from ad-hoc, casual or consulting work State pension Private/employer pension Disability Living Allowance (DLA) or Personal Independence Payment (PIP) Carer's allowance Universal credit Employment and Support Allowance (ESA) or Incapacity benefit Jobseeker's allowance (JSA) Income support Pension credit Tax credits (working tax credits and child tax credits) Child benefit Housing benefit Other state benefit National Asylum Support Service (NASS) Interest from savings and investments (e.g. stocks and shares) Other kinds of regular allowance from outside your household (e.g. maintenance, student grants, rental income) Family/friends support me Prefer not to say	Categorical (nominal)	**Source of income, past year** All other income sources[2] Received welfare benefits[3]
I8: In the last 12 months, how has your household been keeping up with bills and credit commitments? Up to date with bills Behind with some bills Behind with all bills Prefer not to say	Categorical (ordinal)	**(Kept original categories)**
I9: Do you have enough money to meet basic needs (food, rent, gas, electricity, water etc)? Yes, always Yes, most of time Yes, some of time No	Categorical (ordinal)	**(Kept original categories)**
I10: In the last year, what was your total household income before tax? [listed annual, weekly & monthly amounts] Under £5,000 £5,000-£9,999 £10,000-£19,999 £20,000-£29,999 £30,000-£39,999 £40,000-£49,999 £50,000-£59,999 £60,000-£69,999 £70,000-£89,999 £90,000-£109,999 £110,000-£129,999 £130,000-£149,999 £150,000 or more Don't know Prefer not to say	Categorical (ordinal)	**Total annual household income**[4] ≥median (£20,000) <median (£19,999)

[1] Includes rent free (provided by friends, family etc), sheltered accommodation/retirement housing, residential care home, temporary accommodation (hostel, shelter, bed and breakfast), homeless, other (please specify).

[2] Includes earnings from employment, supplementary income, pension, interest from savings and investments, other kinds of regular allowance from outside household and family/friends' support.

[3] Includes Disability Living Allowance (DLA) or Personal Independence Payment (PIP), carer's allowance, universal credit, Employment and Support Allowance (ESA) or Incapacity benefit, Jobseeker's allowance (JSA), income support, pension credit, tax credits (working tax credits and child tax credits), child benefit, housing benefit, other state benefit, National Asylum Support Service (NASS).

[4] Created dummy variable based on median equivalised disposable household income in 2017 of £29,000 according to ONS (509).

Recoding of clinical variables from the PV-2017 dataset for this study

PV-2017 Question	Type of data	Transformed variable categories
B1: In which year were you diagnosed with HIV?	Numerical	**Year of diagnosis** 1981-1995 1996-2005 2006-2015
CD4 cell count (cells/mm^3)[1]	Numerical	**CD4 count (cells/mm^3)** <200 200-349 350-499 ≥500
Viral load count (copies/mL)[1]	Numerical	**Viral load count (copies/mL)** Undetectable (VL<50) Detectable (VL≥50)

[1] Not recorded in PV-2017 but linked from HARS.

Recoding of GHQ-12 variables from the PV-2017 dataset for this study

PV-2017 Question	Type of data	Transformed variable categories
Below are some questions about your recent mental state. Please tick the box which describes how you feel over the last few weeks. Have you recently: tick one box per question **F8: Been able to concentrate on whatever you're doing?** Better than usual; same as usual; less than usual; much less than usual **F9: Lost much sleep over worry?** Not at all; no more than usual; rather more than usual; much more than usual **F10: Felt you were playing a useful part in things?** More so than usual; same as usual; less useful than usual; much less useful than usual **F11: Felt capable of making decisions about things?** More so than usual; same as usual; less so than usual; much less capable **F12: Felt constantly under strain?** Not at all; no more than usual; rather more than usual; much more than usual **F13: Felt you couldn't overcome your difficulties?** Not at all; no more than usual; rather more than usual; much more than usual **F14: Been able to enjoy your normal day-to-day activities?** Better than usual; same as usual; less so than usual; much less than usual **F15: Been able to face up to your problems?** More so than usual; same as usual; less so than usual; much less able **F16: Been feeling unhappy and depressed?** Not at all; no more than usual; rather more than usual; much more than usual **F17: Been losing confidence in yourself?** Not at all; no more than usual; rather more than usual; much more than usual **F18: Been thinking of yourself as a worthless person** Not at all; no more than usual; rather more than usual; much more than usual **F19: Been feeling reasonably happy, all things considered?** More so than usual; same as usual; less so than usual; much less than usual	12 items (ordinal) to generate score (0-36) – continuous	**GHQ-12 score**[1] No evidence of probable mental health (=0) Less than optimal mental health (=1-3) Probable psychological disturbance or mental ill health (=4+)

[1] Based on GHQ scoring system of 0011 (490). Score of one indicates sign of mental distress, 0 not therefore maximum score for each participant is 12.

χ^2 associations (df) and p-values for independent (exposure) variables included in models

	Gen	CoB	Eth	Sexu	Edu	Emp	Home	Welf	Bills	Needs	Inc	YoD	CD4	VL
Age	**χ2(4)=102.5***	**χ2(8)=209.8***	**χ2(24)=314.5***	**χ2(12)=69.4***	**χ2(16)=99.7***	**χ2(8)=779.4***	**χ2(12)=347.8***	**χ2(4)=18.3***	**χ2(8)=78.7***	**χ2(12)=64.7***	χ2(4)=6.6; p=0.161	**χ2(8)=595.2***	**χ2(12)=59.0***	χ2(4)=8.1; p=0.089
Gen	-	**χ2(2)=935.6***	**χ2(6)=1.3e+03***	**χ2(3)=1.8e+03***	**χ2(4)=34.5***	**χ2(2)=44.5***	**χ2(3)=247.4***	**χ2(1)=118.7***	**χ2(2)=139.8***	**χ2(3)=232.4***	**χ2(1)=108.1***	**χ2(2)=33.2***	χ2(3)=2.1; p=0.550	χ2(1)=3.4; p=0.065
CoB	-	-	**χ2(12)=5.3e+03***	**χ2(6)=1.2e+03***	**χ2(8)=89.2***	**χ2(4)=145.6***	**χ2(6)=368.0***	**χ2(2)=19.7***	**χ2(4)=217.6***	**χ2(6)=389.1***	**χ2(2)=102.6***	**χ2(4)=111.0***	**χ2(6)=32.1***	**χ2(2)=11.7; p=0.003**
Eth	-	-	-	**χ2(18)=1.7e+03***	**χ2(24)=117.2***	**χ2(12)=185.9***	**χ2(18)=497.2***	**χ2(6)=47.3***	**χ2(12)=363.9***	**χ2(18)=580.5***	**χ2(6)=111.9***	**χ2(12)=139.4***	**χ2(18)=34.8; p=0.010**	**χ2(6)=22.7***
Sexu	-	-	-	-	**χ2(12)=104.2***	**χ2(6)=103.1***	**χ2(9)=321.4***	**χ2(3)=132.6***	**χ2(6)=240.8***	**χ2(9)=364.3***	**χ2(3)=150.3***	**χ2(6)=77.2***	**χ2(9)=37.5***	**χ2(3)=10.8; p=0.013**
Edu	-	-	-	-	-	**χ2(8)=193.4***	**χ2(12)=200.1***	**χ2(4)=205.7***	**χ2(8)=30.9***	**χ2(12)=125.2***	**χ2(4)=262.3***	χ2(8)=10.1; p=0.259	χ2(12)=19.5; p=0.078	χ2(4)=3.1; p=0.538
Emp	-	-	-	-	-	-	**χ2(6)=408.1***	**χ2(2)=850.1***	**χ2(4)=171.7***	**χ2(6)=331.5***	**χ2(2)=448.0***	**χ2(4)=231.6***	**χ2(6)=43.1***	**χ2(2)=12.7; p=0.002**
Home	-	-	-	-	-	-	-	**χ2(3)=683.0***	**χ2(6)=443.4***	**χ2(9)=761.8***	**χ2(3)=597.1***	**χ2(6)=138.9***	**χ2(9)=21.6***	**χ2(3)=25.1***
Welf	-	-	-	-	-	-	-	-	**χ2(2)=256.1***	**χ2(3)=485.0***	**χ2(1)=660.6***	**χ2(2)=115.0***	**χ2(3)=31.1***	**χ2(1)=15.2***
Bills	-	-	-	-	-	-	-	-	-	**χ2(6)=1.9e+03***	**χ2(2)=336.3***	**χ2(4)=36.5***	χ2(6)=11.4; p=0.077	**χ2(2)=16.8***
Needs	-	-	-	-	-	-	-	-	-	-	**χ2(3)=756.9***	**χ2(6)=27.9***	**χ2(9)=28.3***	**χ2(3)=21.8***
Inc	-	-	-	-	-	-	-	-	-	-	-	**χ2(2)=14.0***	**χ2(3)=27.8***	χ2(1)=2.3; p=0.132
YoD	-	-	-	-	-	-	-	-	-	-	-	-	**χ2(6)=17.4; p=0.008**	χ2(2)=1.1; p=0.582
CD4	-	-	-	-	-	-	-	-	-	-	-	-	-	**χ2(3)=74.5***
VL	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Bold values indicate significance at p<0.05 and *p<0.001. Excluding missing/prefer not to say data.

Abbreviations: Gen, gender identity; CoB, country of birth; Eth, ethnicity; Sexu, sexuality; Edu, education; Emp, employment; Welf, welfare benefits; Needs, enough money to meet basic needs; Inc, Income; YoD, year of diagnosis; VL, viral load.

Excludes categories (e.g. transgender women, non-binary or in another way) with small number of observations.

Demographics

It is likely that collinearity explains the associations seen between country of birth and ethnicity; for instance, there was being born in the UK predicts being of White British ethnicity and being born in a low/middle-income country predicts being of Black African ethnicity.

Ethnic group x country of birth

Ethnic group	**Country of birth**			**Total**
	HIC – UK	HIC – Other	LMIC	
White British	1,947	72	58	2077
Any other White background	49	384	65	497
Black African	27	8	1,065	1,100
Any other Black background	57	35	76	168
Mixed background	56	10	74	140
Asian background	31	11	92	134
Any other ethnic background	10	29	64	103
Total	**2,177**	**549**	**1,493**	**4,219**
Pearson $\chi^2(12) = 5.3e{+}03$; $p<0.001$				

Social determinants

In the dataset, there are several variables which indicate various measures of financial status – this includes: annual household income, ability to keep up with bill/credit commitments, having enough money to meet basic needs and receiving welfare benefits. Therefore, I cross-tabulated each of these indicators.

Up to date with bill/credit commitments x median income

Bill payments	**Median annual household income**		**Total**
	≥median	<median	
Up to date	1,617	760	2,377
Behind with some	274	474	748
Behind with all	16	103	119
Total	**1,907**	**1,337**	**3,244**
Pearson $\chi^2(2) = 336.2909$; $p<0.001$			

Enough money to meet basic needs x median income

Basic needs	**Median annual household income**		**Total**
	≥median	<median	
No	57	280	337
Yes, always	1,341	363	1,704
Yes, most of the time	414	443	857
Yes, some of the time	99	310	409
Total	**1,911**	**1,396**	**3,307**
Pearson $\chi^2(3) = 756.8698$; $p<0.001$			

Enough money to meet basic needs x up to date with bill/credit commitments

Basic needs	**Bill payments**			**Total**
	Up to date	Behind with some	Behind with all	
No	72	206	104	382
Yes, always	1,890	72	2	1,964
Yes, most of the time	683	330	6	1,019
Yes, some of the time	165	291	31	487
Total	**2,810**	**899**	**143**	**3,852**
Pearson $\chi^2(6) = 1.9$ e+03; p<0.001				

Enough money to meet basic needs x receiving welfare benefits

Basic needs	**Welfare benefits**		**Total**
	All other income sources	Received welfare benefits	
No	181	246	427
Yes, always	1,649	316	1,965
Yes, most of the time	644	383	1,027
Yes, some of the time	238	273	511
Total	**2,712**	**1,218**	**3,930**
Pearson $\chi^2(3) = 485.0390$; p<0.001			

Receiving welfare benefits x up to date with bill/credit commitments

Welfare benefits	**Bill payments**			**Total**
	Up to date	Behind with some	Behind with all	
All other income sources	2,129	469	51	2,649
Received welfare benefits	645	420	87	1,152
Total	**2,774**	**889**	**138**	**3,801**
Pearson $\chi^2(2) = 256.1288$; p<0.001				

Receiving welfare benefits x median income

Welfare benefits	**Median annual household income**		**Total**
	≥median	<median	
All other income sources	1,700	662	2,362
Received welfare benefits	214	719	933
Total	**1,914**	**1,381**	**3,295**
Pearson $\chi^2(1) = 660.5625$; p<0.001			

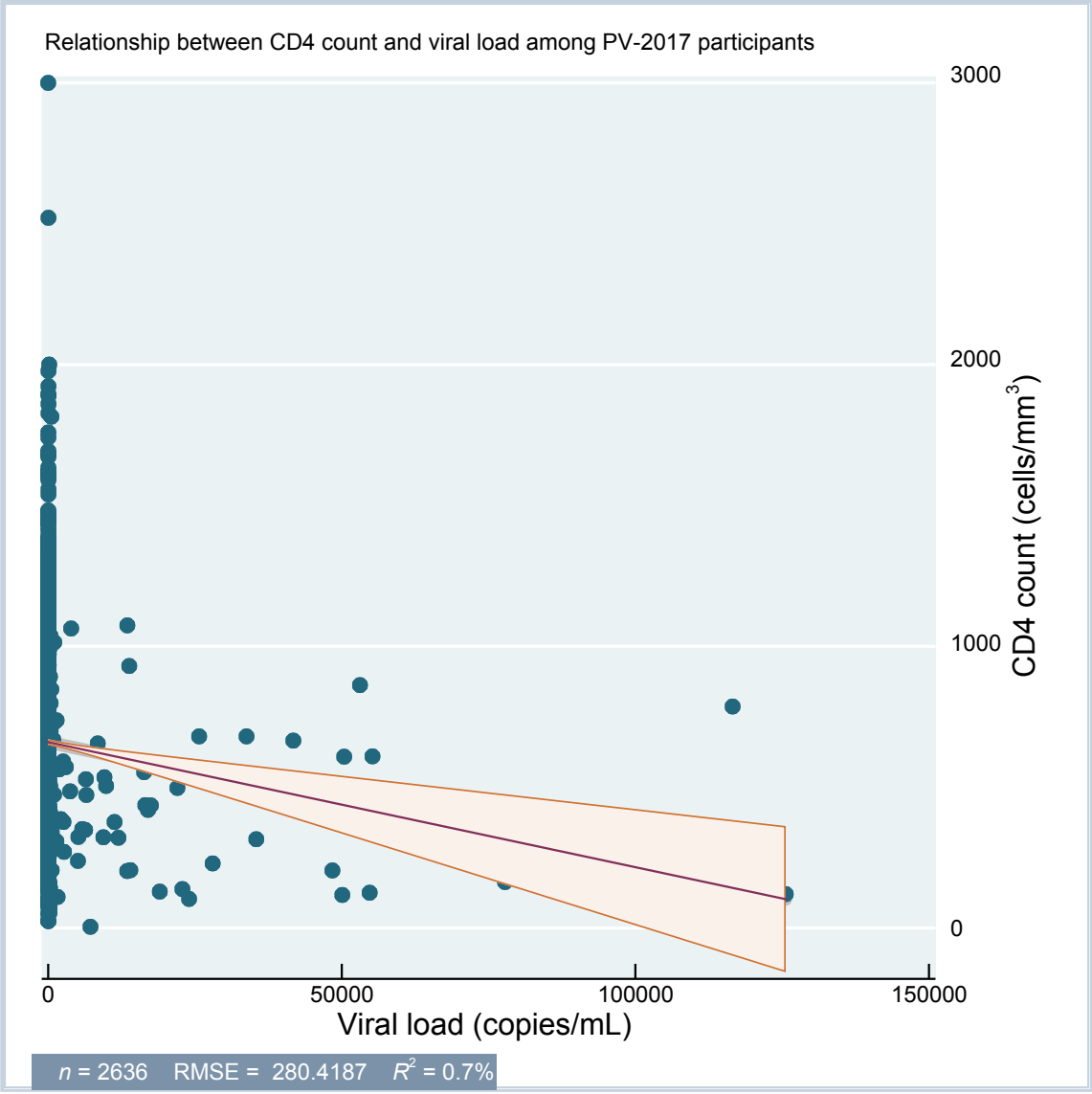
Clinical

CD4 count is slightly positively skewed. A scatterplot **(see below)** indicates a negative linear relationship between the two variables, which is as expected – as CD4 count increases, viral load[1] decreases and vice-versa; however, it is important to note that there is a time lag between seeing these changes when initiating ART (586–589). The R^2 was calculated at 0.7% indicating no linear relationship; in other words, only 0.7% of the variance in viral load count in the sample can be explained by their CD4 count. I also calculated the Spearman's rank correlation coefficient between CD4 and viral load count of 2,636 observations and found a negligible relationship, which was statistically significant (ρ= -0.0813, p<0.001).

[1] N.B one outlier for viral load count detected so recoded it to missing.

CD4 count x VL count

CD4 count	Viral load (VL)		Total
	VL<50	VL≥50	
CD4<200	46	18	64
CD4 200-349	187	28	215
CD4 350-499	470	36	506
CD4 ≥500	1,764	88	1,852
Total	**2,467**	**170**	**2,637**
Pearson $\chi^2(3) = 74.4850$; p<0.001			



Scatterplot of relationship between CD4 and VL count with fitted values and a confidence interval for the mean. Purple line: line of best fit (fitted values), light orange box: 95% CIs.

I also ran CD4 count against VL count by year of diagnosis however this raised a number of cells with either no or very few (<5) people so it was not possible to draw any meaningful conclusions.

Summary frequencies

Pre-existing mental health diagnoses

Cross-tabulations and associations between pre-existing mental health conditions and GHQ-12≥4

	GHQ-12<4	**GHQ-12≥4**	**Probable mental ill health (GHQ12≥4)**	
	n	n	OR (95% CI)	p-values
Anxiety (N=3,980)				
No	2,428	511	Ref	Ref
Yes	449	592	**6.26 (5.36, 7.32) *****	**p<0.001**
Depression (n=4,073)				
No	2,281	412	Ref	Ref
Yes	629	751	**6.61 (5.69, 7.67) *****	**p<0.001**
Personality disorder (N=3,771)				
No	2,793	890	Ref	Ref
Yes	19	69	**11.40 (6.82, 19.04) *****	**p<0.001**
Bipolar disorder (N=3,782)				
No	2,798	917	Ref	Ref
Yes	24	43	**5.47 (3.30, 9.06) *****	**p<0.001**
Eating disorder (N=3,796)				
No	2,789	884	Ref	Ref
Yes	36	87	**7.62 (5.13, 11.33) *****	**p<0.001**
Insomnia (N=3,901)				
No	2,629	676	Ref	Ref
Yes	215	381	**6.89 (5.71, 8.31) *****	**p<0.001**
Post-traumatic stress disorder (N=3,785)				
No	2,764	841	Ref	Ref
Yes	56	124	**7.28 (5.26, 10.07) *****	**p<0.001**
Psychosis (N=3,771)				
No	2,782	907	Ref	Ref
Yes	36	46	**3.92 (2.52, 6.10) *****	**p<0.001**
Other mental health condition (N=3,656)				
No	2,721	852	Ref	Ref
Yes	27	56	**6.62 (4.16, 10.55) *****	**p<0.001**

Bold indicates values significant at p<0.20. ***p<0.01, **p<0.05, *p<0.10.

Multivariate model building and tests for goodness of fit

Goodness of fit was tested using an adapted stepwise regression whereby a variable is removed from the full model one at a time and compared by the AIC. Specifically, I removed pairs of variables where collinearity may exist based on existing theory. The Likelihood-ratio test makes the assumption that the adjusted model is nested in the full model; therefore, for each table, statistical significance(*) of the likelihood-ratio test indicates the full model is preferred and the highlighted model indicates variable(s) that could be dropped from the full model as is affecting model fit. Tables indicate statistical significance at ***p<0.01, **p<0.05 and *p<0.1.

Model 1: Demographics

Model 1a: Demographics - age + gender (N=4,116)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Age	Ref	Ref
18-34	0.97 (0.76, 1.23)	p=0.821
35-44	1.00 (0.79, 1.26)	p=0.991
45-54	1.17 (0.91, 1.49)	p=0.229
55-64	**0.64 (0.45, 0.90) *** **	**p=0.009**
65+		
Gender identity	Ref	Ref
Cisgender man	**0.86 (0.74, 1.00) ***	**p=0.057**
Cisgender woman		
Log likelihood: -2479.9041 (p=0.0019)		
Likelihood ratio $\chi^2(5)$: 19.06		
Hosmer-Lemeshow $\chi^2(4)$: 0.78; p=0.9416		

Model 1b: Demographics – age + gender + country of birth (N=4,024)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Age	Ref	Ref
18-34	0.99 (0.78, 1.27)	p=0.951
35-44	1.02 (0.81, 1.28)	p=0.874
45-54	1.17 (0.91, 1.50)	p=0.221
55-64	**0.60 (0.43, 0.85) *** **	**p=0.004**
65+		
Gender identity	Ref	Ref
Cisgender man	1.00 (0.83, 1.19)	p=0.965
Cisgender woman		
Country of birth	Ref	Ref
High-income (UK)	1.01 (0.82, 1.24)	p=0.924
High-income (Other)	**0.76 (0.64, 0.90) *** **	**p=0.001**
Low/middle-income		
Log likelihood: -2425.9562 (p=0.0001)		
Likelihood ratio $\chi^2(7)$: 31.35		
Hosmer-Lemeshow $\chi^2(7)$: 5.24; p=0.6304		

Model 1c: Demographics – age + gender + country of birth + ethnicity (N=4,009)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Age		
18-34	Ref	Ref
35-44	0.98 (0.77, 1.25)	p=0.886
45-54	1.02 (0.81, 1.29)	p=0.882
55-64	1.18 (0.91, 1.51)	p=0.211
65+	**0.59 (0.42, 0.84) *****	**p=0.003**
Gender identity		
Cisgender man	Ref	Ref
Cisgender woman	1.10 (0.91, 1.33)	p=0.323
Country of birth		
High-income (UK)	Ref	Ref
High-income (Other)	1.02 (0.74, 1.39)	p=0.911
Low/middle-income	1.08 (0.80, 1.45)	p=0.615
Ethnic group		
White British	Ref	Ref
Any other White background	1.00 (0.73, 1.40)	p=0.963
Black African	**0.58 (0.41, 0.81) *****	**p=0.002**
Any other Black background	0.76 (0.51, 1.13)	p=0.177
Mixed background	1.01 (0.67, 1.52)	p=0.957
Asian background	0.68 (0.43, 1.09)	p=0.123
Any other ethnic group	0.96 (0.59, 1.56)	p=0.864
Log likelihood: -2409.7014 (p<0.001)		
Likelihood ratio $\chi^2(13)$: 46.40		
Hosmer-Lemeshow $\chi^2(8)$: 6.37; p=0.6054		

Model 1d: Demographics – age + gender + country of birth + ethnicity + sexuality (N=3,824)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Age		
18-34	Ref	Ref
35-44	0.99 (0.78, 1.27)	p=0.967
45-54	1.00 (0.80, 1.28)	p=0.947
55-64	1.14 (0.88, 1.47)	p=0.335
65+	**0.58 (0.40, 0.82) *****	**p=0.002**
Gender identity		
Cisgender man	Ref	Ref
Cisgender woman	**1.22 (0.97, 1.54) ***	**p=0.090**
Country of birth		
High-income (UK)	Ref	Ref
High-income (Other)	1.01 (0.74, 1.39)	p=0.944
Low/middle-income	1.07 (0.79, 1.45)	p=0.677
Ethnic group		
White British	Ref	Ref
Any other White background	1.04 (0.75, 1.45)	p=0.814
Black African	**0.62 (0.43, 0.89) *****	**p=0.009**
Any other Black background	0.78 (0.51, 1.17)	p=0.228
Mixed background	1.00 (0.66, 1.53)	p=0.999
Asian background	0.72 (0.44, 1.61)	p=0.176
Any other ethnic group	1.01 (0.62, 1.65)	p=0.965
Sexuality		
Gay or lesbian/homosexual	Ref	Ref
Straight/heterosexual	0.84 (0.67, 1.05)	p=0.131
Bisexual	1.02 (0.72, 1.44)	p=0.917
Asexual/other	1.35 (0.72, 2.53)	p=0.355
Log likelihood: -2293.9162 (p<0.001)		
Likelihood ratio $\chi^2(16)$: 49.32		
Hosmer-Lemeshow $\chi^2(8)$: 2.16; p=0.9756		

Goodness of fit

The Likelihood-ratio (LR) tests and AIC values above indicate that country of birth should be dropped from the full model as it is affecting model fit (see model h). This is supported by initial exploration of collinearity between country of birth and ethnicity. Statistical significance of the LR indicates that the full model is preferred. Therefore, the final model for demographics will include **age, gender identity, ethnicity and sexuality**.

Goodness of fit test output for demographics

Model	AIC	BIC	LR χ^2(df); p-value	H-L χ^2(df); p-value
a. Full	4621.832	4728.066	-	2.16 (8); p=0.9756
b. Excluding age	4631.925	4713.163	18.09(4); **p=0.0012 *****	1.01 (5); p=0.9618
c. Excluding gender	4622.737	4722.722	2.90 (1); **p=0.0883 ***	6.64 (8); p=0.5757
d. Excluding age + gender	4633.334	4708.323	21.50 (5); **p=0.0007 *****	1.20 (4); p=0.8774
e. Excluding sexuality	4619.474	4706.961	3.64 (3); p=0.3029	6.37 (8); p=0.6054
f. Excluding gender+ sexuality	4618.484	4699.722	4.65 (4); p=0.3250	5.18 (7); p=0.6382
g. Excluding ethnicity	4620.448	4689.188	10.62 (6); p=0.1010	11.60 (8); p=0.1701
h. Excluding country of birth	4618.019	4711.755	0.19 (2); p=0.9109	8.60 (8); p=0.3773
i. Excluding ethnicity + country of birth	4621.629	4677.871	15.80 (8); **p=0.0454 ****	1.41 (7); p=0.9854

Abbreviations: AIC, Akaike's Information Criterion; BIC, Bayesian Information Criterion; H-L, Hosmer-Lemeshow test; LR, Likelihood Ratio test.

Model 2: Social determinants

Model 2a: Social determinants – education + employment (N=4,034)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Education		
ISCED1/2: Primary or less	Ref	Ref
ISCED3: Upper secondary education (to age 18)	1.18 (0.88, 1.56)	p=0.269
ISCED4/5: Technical and vocational education training	1.12 (0.79, 1.57)	p=0.523
ISCED6: Bachelors or equivalent level	1.00 (0.74, 1.35)	p=0.993
ISCED7/8: Postgraduate degree	1.00 (0.73, 1.39)	p=0.980
Work		
Employed	Ref	Ref
Unemployed	**3.00 (2.40, 3.76) *****	**p<0.001**
Economically inactive	**3.01 (2.57, 3.52) *****	**p<0.001**
Log likelihood: -2320.4083 (p<0.001)		
Likelihood ratio $\chi^2(6)$: 244.18		
Hosmer-Lemeshow $\chi^2(6)$: 1.23; p=0.9754		

Model 2b: Social determinants – education + employment + housing (N=3,997)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Education		
ISCED1/2: Primary or less	Ref	Ref
ISCED3: Upper secondary education (to age 18)	1.27 (0.95, 1.71)	p=0.105
ISCED4/5: Technical and vocational education training	1.22 (0.86, 1.73)	p=0.256
ISCED6: Bachelors or equivalent level	1.13 (0.83, 1.54)	p=0.428
ISCED7/8: Postgraduate degree	1.18 (0.85, 1.65)	p=0.318
Work		
Employed	Ref	Ref
Unemployed	**2.77 (2.19, 3.51) *****	**p<0.001**
Economically inactive	**3.00 (2.54, 3.53) *****	**p<0.001**
Housing		
Homeowner (own or purchasing house)	Ref	Ref
Renting (privately)	**1.72 (1.42, 2.07) *****	**p<0.001**
Renting (council/housing association)	**1.77 (1.48, 2.12) *****	**p<0.001**
Unstable or other	**1.64 (1.23, 2.18) *****	**p=0.001**
Log likelihood: -2272.0669 (p<0.001)		
Likelihood ratio $\chi^2(9)$: 295.83		
Hosmer-Lemeshow $\chi^2(8)$: 14.19; p=0.0769		

Model 2c: Social determinants – education + employment + housing + income source (N=3,743)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Education		
ISCED1/2: Primary or less	Ref	Ref
ISCED3: Upper secondary education (to age 18)	**1.41 (1.03, 1.93) ****	**p=0.032**
ISCED4/5: Technical and vocational education training	1.34 (0.93, 1.94)	p=0.120
ISCED6: Bachelors or equivalent level	1.30 (0.94, 1.81)	p=0.115
ISCED7/8: Postgraduate degree	**1.44 (1.01, 2.05) ****	**p=0.042**
Work		
Employed	Ref	Ref
Unemployed	**2.31 (1.79, 2.98) *****	**p<0.001**
Economically inactive	**2.29 (1.91, 2.76) *****	**p<0.001**
Housing		
Homeowner (own or purchasing house)	Ref	Ref
Renting (privately)	**1.56 (1.29, 1.90) *****	**p<0.001**
Renting (council/housing association)	**1.39 (1.14, 1.69) *****	**p=0.001**
Unstable or other	**1.76 (1.30, 2.39) *****	**p<0.001**
Sources of income, past year		
All other income sources	Ref	Ref
Received welfare benefits	**1.97 (1.64, 2.36) *****	**p<0.001**
Log likelihood: -2101.4975 (p<0.001)		
Likelihood ratio $\chi^2(10)$: 332.21		
Hosmer-Lemeshow $\chi^2(8)$: 11.28; p=0.1863		

Model 2d: Social determinants – education + employment + housing + income source + ability to pay bills (N=3,592)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Education		
ISCED1/2: Primary or less	Ref	Ref
ISCED3: Upper secondary education (to age 18)	**1.49 (1.07, 2.09) *****	**p=0.020**
ISCED4/5: Technical and vocational education training	1.43 (0.97, 2.12) *	p=0.072
ISCED6: Bachelors or equivalent level	1.38 (0.97, 1.95) *	p=0.072
ISCED7/8: Postgraduate degree	**1.52 (1.05, 2.21) *****	**p=0.028**
Work		
Employed	Ref	Ref
Unemployed	**2.17 (1.65, 2.85) *****	**p<0.001**
Economically inactive	**2.35 (1.94, 2.84) *****	**p<0.001**
Housing		
Homeowner (own or purchasing house)	Ref	Ref
Renting (privately)	**1.38 (1.13, 1.70) *****	**p=0.002**
Renting (council/housing association)	1.09 (0.88, 1.35)	p=0.432
Unstable or other	1.17 (0.83, 1.66)	p=0.377
Sources of income, past year		
All other income sources	Ref	Ref
Received welfare benefits	**1.84 (1.52, 2.23) *****	**p<0.001**
Keep up with bill and credit commitments		
Up to date	Ref	Ref
Behind with some	**1.98 (1.65, 2.37) *****	**p<0.001**
Behind with all	**3.35 (2.25, 5.00) *****	**p<0.001**
Log likelihood: -1970.075 (p<0.001)		
Likelihood ratio $\chi^2(12)$: 391.64		
Hosmer-Lemeshow $\chi^2(8)$: 11.85; p=0.1578		

Model 2e: Social determinants – education + employment + housing + income source + ability to pay bills + enough money to meet basic needs (N=3,560)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Education		
ISCED1/2: Primary or less	Ref	Ref
ISCED3: Upper secondary education (to age 18)	**1.46 (1.04, 2.05) *** **	**p=0.028**
ISCED4/5: Technical and vocational education training	1.41 (0.95, 2.09) *	p=0.092
ISCED6: Bachelors or equivalent level	1.42 (1.00, 2.01) *	p=0.053
ISCED7/8: Postgraduate degree	**1.60 (1.09, 2.33) *** **	**p=0.015**
Work		
Employed	Ref	Ref
Unemployed	**1.98 (1.50, 2.62) *** **	**p<0.001**
Economically inactive	**2.37 (1.95, 2.88) *** **	**p<0.001**
Housing		
Homeowner (own or purchasing house)	Ref	Ref
Renting (privately)	1.18 (0.96, 1.45)	p=0.117
Renting (council/housing association)	0.91 (0.73, 1.14)	p=0.421
Unstable or other	1.02 (0.72, 1.46)	p=0.908
Sources of income, past year		
All other income sources	Ref	Ref
Received welfare benefits	**1.66 (1.37, 2.02) *** **	**p<0.001**
Keep up with bill and credit commitments Up to date	Ref	Ref
Behind with some	**1.29 (1.04, 1.59) *** **	**p=0.019**
Behind with all	**1.81 (1.16, 2.84) *** **	**p=0.010**
Enough money to meet basic needs (food, rent, gas, electricity, water etc)		
No	Ref	Ref
Yes, always	**0.33 (0.24, 0.46) *** **	**p<0.001**
Yes, most of the time	**0.60 (0.44, 0.81) *** **	**p=0.001**
Yes, some of the time	0.79 (0.58, 1.08)	p=0.137
Log likelihood: -1922.0001 (p<0.001)		
Likelihood ratio $\chi^2(15)$: 453.31		
Hosmer-Lemeshow $\chi^2(8)$: 24.92; p=0.0016		

Model 2f: Social determinants – education + employment + housing + income source + ability to pay bills + enough money to meet basic needs + median income (N=3,030)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Education		
ISCED1/2: Primary or less	Ref	Ref
ISCED3: Upper secondary education (to age 18)	**1.50 (1.01, 2.23) ****	**p=0.044**
ISCED4/5: Technical and vocational education training	1.42 (0.90, 2.24)	p=0.129
ISCED6: Bachelors or equivalent level	1.35 (0.90, 2.03)	p=0.148
ISCED7/8: Postgraduate degree	**1.60 (1.04, 2.47) *****	**p=0.033**
Work		
Employed	Ref	Ref
Unemployed	**2.48 (1.79, 3.43) *****	**p<0.001**
Economically inactive	**2.34 (1.88, 2.92) *****	**p<0.001**
Housing		
Homeowner (own or purchasing house)	Ref	Ref
Renting (privately)	**1.29 (1.03, 1.62) *****	**p=0.025**
Renting (council/housing association)	0.88 (0.69, 1.13)	p=0.316
Unstable or other	0.88 (0.58, 1.34)	p=0.556
Sources of income, past year		
All other income sources	Ref	Ref
Received welfare benefits	**1.76 (1.42, 2.19) *****	**p<0.001**
Keep up with bill and credit commitments		
Up to date	Ref	Ref
Behind with some	**1.26 (1.00, 1.59) ****	**p=0.052**
Behind with all	**1.84 (1.14, 2.99) *****	**p=0.013**
Enough money to meet basic needs (food, rent, gas, electricity, water etc)		
No	Ref	Ref
Yes, always	**0.32 (0.23, 0.47) *****	**p<0.001**
Yes, most of the time	**0.60 (0.43, 0.84) *****	**p=0.003**
Yes, some of the time	0.74 (0.53, 1.05) *	p=0.088
Annual household income		
≥median (£20,000)	Ref	Ref
median (£19,999)	0.91 (0.73, 1.13)	p=0.391
Log likelihood: -1621.0375 (p<0.001)		
Likelihood ratio $\chi^2(16)$: 376.61		
Hosmer-Lemeshow $\chi^2(8)$: 11.15; p=0.1935		

Goodness of fit

The goodness of fit tests below indicate that both income and education should be dropped from the full model as they are affecting model fit (see models 2b, 2h and 2i). Following discussions with the Positive Voices team, the face validity of the income question was raised (e.g. some participants selected multiple options likely answering the question on behalf of others in their household). Income also had a high number of missing observations in the full dataset (n=1047, 23.8%) and is represented by the other financial indicators (e.g. employment, bills, basic needs, and welfare benefits). I have, however, decided to keep the education variable as this is measuring something different to income. Therefore, the final model for social determinants will include **education, housing, employment, receiving welfare benefits, ability to keep up with bill/credit commitments and having enough money to meet basic needs**.

Goodness of fit test output for social determinants

Model	AIC	BIC	LR χ^2(df); p-value	H-L χ^2 (df); p-value
a. Full	3276.075	3378.352	-	11.15 (8); p=0.1935
b. Excluding education	3273.843	3352.056	5.77 (4); p=0.2171	22.75 (7); **p=0.0019 ****
c. Excluding employment	3340.393	3430.637	68.32 (2); **p<0.001 *****	7.40 (8); p=0.4942
d. Excluding housing	3280.935	3365.163	10.863); **p=0.0125 *****	9.75 (8); p=0.2828
e. Excluding welfare benefits	3299.57	3395.831	25.50 (1); **p<0.001 *****	11.76 (8); p=0.1622
f. Excluding bills	3278.285	3362.514	8.21 (3); **p=0.0419 ****	12.66 (8); p=0.1242
g. Excluding basic needs	3317.949	3402.178	47.87 (3); **p<0.001 *****	5.03 (8); p=0.7539
h. Excluding income	3274.814	3371.076	0.74 (1); p=0.3898	24.92 (8); **p=0.0016 ****
i. Excluding education and income	3272.898	3345.093	6.82 (5); p=0.2342	21.11 (7); **p=0.0036 ****
j. Excluding employment and income	3339.37	3423.598	69.29 (3); **p<0.001 *****	7.96 (8); p=0.4377
k. Excluding housing and income	3280.057	3358.269	11.98 (4); **p=0.0175 ****	18.75 (8); **p=0.0162 ****
l. Excluding welfare benefits + income	3297.572	3387.817	25.50 (2); **p<0.001 *****	19.33 (8); **p=0.0132 ****
m. Excluding basic needs + income	3316.699	3394.911	48.62 (4); **p<0.001 *****	11.85 (8); p=0.1578
n. Excluding income + bills	3278.285	3362.514	8.21 (3); **p=0.0419 ****	17.76 (8); **p=0.0231 ****

Abbreviations: AIC, Akaike's Information Criterion; BIC, Bayesian Information Criterion; H-L, Hosmer-Lemeshow test; LR, Likelihood Ratio test.

Model 3: Clinical

Model 3a: Clinical – CD4 count + year of diagnosis (N=2,557)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Year of diagnosis		
1981-1995	Ref	Ref
1996-2005	**0.59 (0.45, 0.77) *****	**p<0.001**
2006-2015	**0.58 (0.46, 0.76) *****	**p<0.001**
CD4 count (cells/mm^3)		
<200	Ref	Ref
200-350	0.77 (0.44, 1.37)	p=0.379
350-499	**0.43 (0.25, 0.73) *****	**p=0.002**
≥500	**0.59 (0.36, 0.98) ****	**p=0.043**
Log likelihood: -1532.7063 (p<0.001)		
Likelihood ratio $\chi^2(5)$: 34.28		
Hosmer-Lemeshow $\chi^2(4)$: 3.27; p=0.5137		

Model 3b: Clinical – CD4 count + year of diagnosis + viral load (N=2,512)

	Probable mental ill health (GHQ12≥4)	
	aOR (95% CI)	p-values
Year of diagnosis		
1981-1995	Ref	Ref
1996-2005	**0.60 (0.45, 0.78) *****	**p<0.001**
2006-2015	**0.60 (0.46, 0.77) *****	**p<0.001**
CD4 count (cells/mm^3)		
<200	Ref	Ref
200-350	0.82 (0.45, 1.48)	p=0.504
350-499	**0.46 (0.26, 0.81) *****	**p=0.007**
≥500	0.64 (0.38, 1.09) *	p=0.101
Viral load count (copies/mL)		
<50	Ref	Ref
≥50	1.15 (0.81, 1.62)	p=0.446
Log likelihood: -1504.640 (p<0.001)		
Likelihood ratio $\chi^2(6)$: 31.742		
Hosmer-Lemeshow $\chi^2(4)$: 3.58; p=0.4656		

Goodness of fit

The LR test indicates that the viral load variable could be dropped from the model as it is affecting model fit (see model d). Viral load has a high number of missing values (n=774, 17.6%) as does CD4 count (n=1,709, 38.9%). Therefore, the final model for clinical factors will include **year of diagnosis** and **CD4 count**.

Goodness of fit test output for clinical measures

Model	**AIC**	**BIC**	**LR χ^2(df); p-value**	**H-L χ^2(df); p-value**
a. Full	3023.28	3064.085	-	3.58 (4); p=0.4656
b. Excluding year of diagnosis	3035.625	3064.771	16.34 (2); **p=0.0003 *****	0.28 (2); p=0.8695
c. Excluding CD4	3032.053	3055.37	14.77 (3); **p=0.0020 *****	0.12 (2); p=0.9426
d. Excluding viral load	3021.853	3056.828	0.57 (1); p=0.4491	3.27 (4); p=0.5137

Abbreviations: AIC, Akaike's Information Criterion; BIC, Bayesian Information Criterion; HL, Hosmer-Lemeshow test; LR, Likelihood Ratio test.

Post-hoc analysis

Sensitivity analysis

I reran the multivariate model including each variable group type (demographics, social determinants, and clinical measures) whilst removing the CD4 variable which had a high number of missing observations. The sensitivity analysis was conducted on 3,302 observations and when testing for goodness of fit, the Hosmer Lemeshow χ^2 was estimated as 8 = 7.16 with the χ^2 probability of 0.5192. The AIC value was 1.060, BIC value of -22990.423.

Sensitivity analysis

	Univariate	All (n=2,027)	Sensitivity (n=3,302)
Age (ref: 18-34)			
35-44	0.90 (0.71, 1.14)	1.21 (0.83, 1.76)	1.04 (0.77, 1.40)
45-54	0.96 (0.77, 1.20)	1.12 (0.76, 1.63)	0.92 (0.68, 1.24)
55-64	1.13 (0.89, 1.44)	1.18 (0.77, 1.82)	0.88 (0.63, 1.24)
65+	**0.61 (0.43, 0.85) *** **	**0.53 (0.29, 0.96) ** **	**0.39 (0.25, 0.63) *** **
Gender identity (ref: cisgender man)			
Cisgender woman	0.88 (0.76, 1.02) *	**1.50 (1.03, 2.18) ** **	1.17 (0.88, 1.55)
Ethnic group (ref: White British)			
Any other White background	1.02 (0.83, 1.26)	1.22 (0.88, 1.67)	1.13 (0.87, 1.45)
Black African	**0.66 (0.56, 0.78) *** **	**0.42 (0.28, 0.63) *** **	**0.41 (0.30, 0.56) *** **
Any other Black background	0.76 (0.53, 1.08)	0.67 (0.37, 1.19)	**0.62 (0.39, 0.98) ** **
Mixed background	1.03 (0.72, 1.48)	1.22 (0.66, 2.26)	1.14 (0.71, 1.83)
Asian background	0.73 (0.49, 1.09)	0.64 (0.31, 1.33)	0.69 (0.39, 1.20)
Any other ethnic background	1.00 (0.66, 1.53)	**1.89 (1.03, 3.46) ** **	1.18 (0.71, 1.96)
Sexuality (ref: gay or lesbian/homosexual)			
Straight/heterosexual	**0.74 (0.64, 0.85) *** **	**0.56 (0.39, 0.80) *** **	**0.62 (0.47, 0.82) *** **
Bisexual	1.02 (0.73, 1.41)	1.11 (0.65, 1.91)	0.94 (0.62, 1.42)
Asexual/other	1.32 (0.76, 2.30)	0.39 (0.09, 1.64)	0.63 (0.26, 1.50)
Education (ref: ISCED1/2 primary or less)			
ISCED3: Upper secondary education (to age 18)	0.85 (0.64, 1.12)	1.33 (0.82, 2.16)	1.17 (0.80, 1.72)
ISCED4/5: Technical and vocational education training	0.86 (0.62, 1.20)	1.18 (0.67, 2.06)	1.26 (0.81, 1.96)
ISCED6: Bachelors or equivalent level	**0.67 (0.50, 0.89) *** **	1.31 (0.79, 2.19)	1.22 (0.82, 1.82)
ISCED7/8: Postgraduate degree	**0.65 (0.48, 0.88) *** **	1.40 (0.81, 2.42)	1.37 (0.89, 2.09)
Work (ref: employed)			
Unemployed	**2.99 (2.41, 3.72) *** **	**2.43 (1.62, 3.64) *** **	**2.08 (1.53, 2.82) *** **
Economically inactive	**3.03 (2.60, 3.53) *** **	**2.33 (1.72, 3.16) *** **	**2.59 (2.04, 3.28) *** **
Housing (ref: homeowner)			
Renting (privately)	**1.46 (1.22, 1.74) *** **	1.18 (0.88, 1.59)	1.19 (0.95, 1.50)
Renting (council/housing association)	**2.13 (1.80, 2.51) *** **	1.08 (0.79, 1.49)	1.09 (0.85, 1.38)
Unstable or other	**2.07 (1.59, 2.70) *** **	1.05 (0.63, 1.74)	1.05 (0.71, 1.56)
Sources of income, past year (ref: all other)			
Received welfare benefits	**3.04 (2.63, 3.51) *** **	**1.45 (1.09, 1.92) ** **	**1.59 (1.28, 1.98) *** **
Keep up with bill and credit commitments (ref: up to date)			
Behind with some	**2.33 (1.99, 2.73) *** **	**1.45 (1.07, 1.97) ** **	**1.38 (1.09, 1.74) *** **
Behind with all	**5.22 (3.69, 7.39) *** **	**2.07 (1.09, 3.93) ** **	**1.96 (1.16, 3.30) ** **
Enough money to meet basic needs (ref: no)			
Yes, always	**0.20 (0.16, 0.24) *** **	**0.20 (0.12, 0.32) *** **	**0.22 (0.15, 0.32) *** **
Yes, most of the time	**0.42 (0.33, 0.52) *** **	**0.41 (0.26, 0.63) *** **	**0.43 (0.30, 0.60) *** **
Yes, some of the time	**0.65 (0.51, 0.84) *** **	**0.55 (0.35, 0.86) ** **	0.76 (0.53, 1.08)
Year of diagnosis (ref: 1981-1995)			
1996-2005	**0.63 (0.51, 0.77) *** **	0.75 (0.53, 1.05) *	**0.76 (0.58, 1.00) ** **
2006-2015	**0.65 (0.53, 0.79) *** **	0.83 (0.59, 1.18)	0.88 (0.67, 1.15)
CD4 count (cells/mm^3) (ref: <200)			
200-350	0.77 (0.44, 1.35)	0.90 (0.43, 1.90)	
350-499	**0.43 (0.25, 0.73) *** **	0.55 (0.27, 1.10) *	
≥500	**0.59 (0.36, 0.96) ** **	0.73 (0.38, 1.42)	

Collinearity diagnostics

Model	Variable	VIF	SQRT VIF	Tolerance	R-squared
	Age	1.05	1.02	0.9534	0.0466
	Gender	1.54	1.24	0.6477	0.3523
1	Ethnicity	1.13	1.06	0.8844	0.1156
	Sexuality	1.52	1.23	0.6582	0.3418
	Mean VIF	**1.31**			
	Education	1.07	1.03	0.937	0.063
	Employment	1.24	1.12	0.8041	0.1959
	Housing	1.22	1.11	0.8165	0.1835
2	Welfare benefits	1.44	1.20	0.6968	0.3032
	Bills	1.13	1.06	0.8842	0.1158
	Basic needs	1.03	1.02	0.9664	0.0336
	Mean VIF	**1.19**			
	Year of diagnosis	1.00	1.00	0.9976	0.0024
3	CD4 count	1.00	1.00	0.9976	0.0024
	Mean VIF	**1.00**			
	Age	1.26	1.12	0.7929	0.2071
	Gender	1.60	1.27	0.6231	0.3769
	Ethnicity	1.17	1.08	0.853	0.147
	Sexuality	1.57	1.25	0.6356	0.3644
	Education	1.09	1.04	0.9174	0.0826
4	Employment	1.46	1.21	0.6836	0.3164
	Housing	1.32	1.15	0.757	0.243
	Welfare benefits	1.46	1.21	0.6848	0.3152
	Bills	1.17	1.08	0.8541	0.1459
	Basic needs	1.05	1.02	0.9566	0.0434
	Mean VIF	**1.32**			
	Age	1.21	1.10	0.8251	0.1749
	Gender	1.50	1.22	0.6667	0.3333
	Ethnicity	1.15	1.07	0.8731	0.1269
5	Sexuality	1.48	1.22	0.6743	0.3257
	Year of diagnosis	1.14	1.07	0.8759	0.1241
	CD4 count	1.03	1.01	0.9727	0.0273
	Mean VIF	**1.25**			
	Education	1.08	1.04	0.9232	0.0768
	Employment	1.28	1.13	0.7794	0.2206
	Housing	1.22	1.10	0.8219	0.1781
	Welfare benefits	1.47	1.21	0.6816	0.3184
6	Bills	1.16	1.08	0.8647	0.1353
	Basic needs	1.04	1.02	0.9627	0.0373
	Year of diagnosis	1.08	1.04	0.9256	0.0744
	CD4 count	1.02	1.01	0.9804	0.0196
	Mean VIF	**1.17**			
	Age	1.45	1.20	0.6919	0.3081
	Gender	1.56	1.25	0.6425	0.3575
	Ethnicity	1.18	1.09	0.8463	0.1537
	Sexuality	1.55	1.24	0.6460	0.3540
	Education	1.11	1.05	0.9025	0.0975
	Employment	1.48	1.22	0.6763	0.3237
7	Housing	1.31	1.15	0.7610	0.2390
	Welfare benefits	1.50	1.22	0.6668	0.3332
	Bills	1.20	1.09	0.8362	0.1638
	Basic needs	1.04	1.02	0.9578	0.0422
	Year of diagnosis	1.20	1.09	0.8366	0.1634
	CD4 count	1.04	1.02	0.9572	0.0428
	Mean VIF	**1.30**			

Abbreviations: SQRT, Squareroot; VIF, Variance Inflation Factor

Model		Eigenval	Cond Index
1	1	1.8116	1.0000
	2	1.0152	1.3359
	3	0.7525	1.5516
	4	0.4207	2.0751
	Condition number	**2.0751**	
	Det(correlation matrix)	**0.5822**	
2	1	1.9643	1.0000
	2	1.0521	1.3664
	3	0.9117	1.4678
	4	0.8918	1.4841
	5	0.6736	1.7076
	6	0.5066	1.9692
	Condition number	**1.9692**	
	Det(correlation matrix)	**0.5733**	
3	1	1.0491	1.0000
	2	0.9509	1.0503
	Condition number	**1.0503**	
	Det(correlation matrix)	**0.9976**	
4	1	2.3261	1.0000
	2	1.7528	1.1520
	3	1.1268	1.4368
	4	0.9645	1.553
	5	0.9214	1.5889
	6	0.7652	1.7435
	7	0.7118	1.8078
	8	0.5810	2.0009
	9	0.4500	2.2736
	10	0.4005	2.4100
	Condition number	**2.4100**	
	Det(correlation matrix)	**0.2328**	
5	1	1.8206	1.0000
	2	1.3628	1.1558
	3	0.9616	1.3760
	4	0.8159	1.4938
	5	0.6070	1.7318
	6	0.431	2.0525
	Condition number	**2.0525**	
	Det(correlation matrix)	**0.5106**	
6	1	2.0532	1.0000
	2	1.2289	1.2926
	3	0.992	1.4387
	4	0.9247	1.4901
	5	0.9001	1.5103
	6	0.7174	1.6918
	7	0.6767	1.7418
	8	0.5069	2.0126
	Condition number	**2.0126**	
	Det(correlation matrix)	**0.5127**	
7	1	2.3251	1.0000
	2	1.9962	1.0792
	3	1.2306	1.3746
	4	1.0183	1.5111
	5	0.9633	1.5536
	6	0.9051	1.6027
	7	0.7833	1.7229
	8	0.7130	1.8058
	9	0.6452	1.8983
	10	0.5867	1.9907
	11	0.4344	2.3136
	12	0.3988	2.4146
	Condition number	**2.4146**	
	Det(correlation matrix)	**0.1857**	

Abbreviations: Det, determinant

Stratified analysis

Stratified by gender identity

	Cisgender men (n=1,594)		Cisgender women (n=428)	
	OR (95% CI)	p-values	OR (95% CI)	p-values
Age				
18-34	Ref	Ref	Ref	Ref
35-44	1.19 (0.77, 1.85)	p=0.436	1.41 (0.63, 3.15)	p=0.404
45-54	1.13 (0.73, 1.75)	p=0.575	1.07 (0.47, 2.41)	p=0.879
55-64	1.13 (0.68, 1.86)	p=0.640	1.64 (0.63, 4.30)	p=0.313
65+	**0.47 (0.24, 0.92) ****	**p=0.029**	1.11 (0.27, 4.55)	p=0.890
Ethnic group				
White British	Ref	Ref	Ref	Ref
Any other White background	1.15 (0.82, 1.62)	p=0.426	2.28 (0.80, 6.48)	p=0.121
Black African	0.58 (0.31, 1.05) *	p=0.074	**0.47 (0.24, 0.91) ****	**p=0.026**
Any other Black background	0.60 (0.29, 1.25)	p=0.171	0.88 (0.30, 2.56)	p=0.813
Mixed background	1.49 (0.71, 3.15)	p=0.292	1.04 (0.31, 3.46)	p=0.949
Asian background	0.65 (0.28, 1.50)	p=0.312	0.43 (0.08, 2.35)	p=0.332
Any other ethnic group	1.98 (1.03, 3.82) **	p=0.041	1.34 (0.22, 8.09)	p=0.753
Sexuality				
Gay or lesbian/homosexual	Ref	Ref	Ref	Ref
Straight/heterosexual	**0.46 (0.30, 0.70) *****	**p<0.001**	0.50 (0.11, 2.27)	p=0.370
Bisexual	1.14 (0.64, 2.03)	p=0.659	-	-
Asexual/other	0.60 (0.13, 2.71)	p=0.505	-	-
Education				
ISCED1/2: Primary or less	Ref	Ref	Ref	Ref
ISCED3: Upper secondary education (to age 18)	1.28 (0.72, 2.25)	p=0.399	1.16 (0.42, 3.21)	p=0.779
ISCED4/5: Technical and vocational education training	1.08 (0.57, 2.06)	p=0.810	1.30 (0.39, 4.28)	p=0.666
ISCED6: Bachelors or equivalent level	1.21 (0.67, 2.19)	p=0.523	1.19 (0.40, 3.55)	p=0.757
ISCED7/8: Postgraduate degree	1.43 (0.77, 2.67)	p=0.258	0.58 (0.15, 2.27)	p=0.438
Work				
Employed	Ref	Ref	Ref	Ref
Unemployed	**3.15 (1.94, 5.11) *****	**p<0.001**	1.22 (0.54, 2.77)	p=0.638
Economically inactive	**2.65 (1.84, 3.81) *****	**p<0.001**	1.71 (0.91, 3.20) *	p=0.096
Housing				
Homeowner (own or purchasing house)	Ref	Ref	Ref	Ref
Renting (privately)	1.19 (0.86, 1.63)	p=0.299	1.28 (0.58, 2.82)	p=0.539
Renting (council/housing association)	0.89 (0.61, 1.29)	p=0.528	1.77 (0.85, 3.68)	p=0.128
Unstable or other	1.01 (0.56, 1.81)	p=0.972	1.42 (0.47, 4.29)	p=0.534
Sources of income, past year				
All other income sources	Ref	Ref	Ref	Ref
Received welfare benefits	**1.44 (1.01, 2.05) ****	**p=0.044**	1.53 (0.90, 2.60)	p=0.115
Keep up with bill and credit commitments				
Up to date	Ref	Ref	Ref	Ref
Behind with some	**1.42 (1.00, 2.02) ****	**p=0.049**	1.55 (0.78, 3.05)	p=0.208
Behind with all	2.10 (0.93, 4.74) *	p=0.074	1.89 (0.61, 5.81)	p=0.268
Enough money to meet basic needs				
No	Ref	Ref	Ref	Ref
Yes, always	**0.21 (0.12, 0.37) *****	**p<0.001**	**0.27 (0.11, 0.69) *****	**p=0.006**
Yes, most of the time	**0.49 (0.28, 0.85) ****	**p=0.011**	**0.30 (0.13, 0.67) *****	**p=0.004**
Yes, some of the time	0.69 (0.39, 1.25)	p=0.223	**0.38 (0.18, 0.82) *****	**p=0.013**
Year of diagnosis				
1981-1995	Ref	Ref	Ref	Ref
1996-2005	0.89 (0.61, 1.31)	p=0.558	**0.33 (0.14, 0.78) *****	**p=0.012**
2006-2015	0.97 (0.65, 1.44)	p=0.880	**0.41 (0.18, 0.98) *****	**p=0.044**
CD4 count (cells/mm^3)				
<200	Ref	Ref	Ref	Ref
200-350	0.84 (0.35, 2.00)	p=0.697	1.32 (0.25, 7.02)	p=0.745
350-499	0.50 (0.22, 1.13) *	p=0.094	0.70 (0.16, 3.04)	p=0.637
≥500	0.70 (0.32, 1.53)	p=0.369	0.78 (0.19, 3.13)	p=0.724

Stratified by ethnicity

	White British (n=1,105)		Black African (n=389)	
	OR (95% CI)	p-values	OR (95% CI)	p-values
Age				
18-34	Ref	Ref	Ref	Ref
35-44	1.48 (0.82, 2.69)	p=0.193	1.56 (0.53, 4.59)	p=0.416
45-54	1.28 (0.72, 2.28)	p=0.391	1.09 (0.38, 3.14)	p=0.877
55-64	1.17 (0.62, 2.21)	p=0.626	2.58 (0.72, 9.25)	p=0.146
65+	0.55 (0.25, 1.20)	p=0.134	0.78 (0.06, 10.67)	p=0.856
Gender identity				
Cisgender man	Ref	Ref	Ref	Ref
Cisgender woman	1.74 (0.90, 3.35) *	p=0.098	1.23 (0.66, 2.29)	p=0.511
Sexuality				
Gay or lesbian/homosexual	Ref	Ref	Ref	Ref
Straight/heterosexual	**0.50 (0.29, 0.83) *** **	**p=0.008**	0.40 (0.06, 2.73)	p=0.349
Bisexual	0.99 (0.47, 2.08)	p=0.985	2.17 (0.20, 23.76)	p=0.525
Asexual/other	0.61 (0.09, 3.94)	p=0.603	-	-
Education				
ISCED1/2: Primary or less	Ref	Ref	Ref	Ref
ISCED3: Upper secondary education (to age 18)	1.56 (0.84, 2.87)	p=0.157	1.40 (0.33, 5.90)	p=0.644
ISCED4/5: Technical and vocational education training	1.00 (0.49, 2.02)	p=0.990	1.08 (0.22, 5.35)	p=0.929
ISCED6: Bachelors or equivalent level	1.62 (0.84, 3.14)	p=0.154	0.88 (0.20, 3.80)	p=0.867
ISCED7/8: Postgraduate degree	1.49 (0.73, 3.08)	p=0.276	0.65 (0.13, 3.26)	p=0.605
Work				
Employed	Ref	Ref	Ref	Ref
Unemployed	**3.27 (1.69, 6.35) *** **	**p<0.001**	2.09 (0.93, 4.70) *	p=0.074
Economically inactive	**2.92 (1.89, 4.50) *** **	**p<0.001**	1.98 (0.91, 4.30) *	p=0.086
Housing				
Homeowner (own or purchasing house)	Ref	Ref	Ref	Ref
Renting (privately)	1.17 (0.78, 1.76)	p=0.437	2.32 (0.86, 6.30) *	p=0.098
Renting (council/housing association)	1.19 (0.76, 1.84)	p=0.451	1.33 (0.49, 3.58)	p=0.575
Unstable or other	0.94 (0.43, 2.06)	p=0.884	1.14 (0.31, 4.22)	p=0.842
Sources of income, past year				
All other income sources	Ref	Ref	Ref	Ref
Received welfare benefits	1.47 (0.96, 2.25) *	p=0.074	1.20 (0.63, 2.25)	p=0.581
Keep up with bill and credit commitments				
Up to date	Ref	Ref	Ref	Ref
Behind with some	1.19 (0.76, 1.86)	p=0.458	1.88 (0.90, 3.92) *	p=0.091
Behind with all	1.80 (0.55, 5.92)	p=0.332	1.81 (0.58, 5.67)	p=0.310
Enough money to meet basic needs				
No	Ref	Ref	Ref	Ref
Yes, always	**0.15 (0.06, 0.33) *** **	**p<0.001**	**0.24 (0.09, 0.69) *** **	**p=0.007**
Yes, most of the time	**0.42 (0.19, 0.92) ** **	**p=0.031**	**0.27 (0.11, 0.63) *** **	**p=0.003**
Yes, some of the time	0.69 (0.29, 1.63)	p=0.396	**0.47 (0.23, 0.96) ** **	**p=0.037**
Year of diagnosis				
1981-1995	Ref	Ref	Ref	Ref
1996-2005	0.96 (0.62, 1.51)	p=0.875	0.37 (0.12, 1.18) *	p=0.094
2006-2015	1.05 (0.66, 1.67)	p=0.828	**0.26 (0.08, 0.83) *** **	**p=0.023**
CD4 count (cells/mm^3)				
<200	Ref	Ref	Ref	Ref
200-350	0.99 (0.35, 2.83)	p=0.984	1.86 (0.31, 11.02)	p=0.494
350-499	0.58 (0.22, 1.55)	p=0.275	0.70 (0.13, 3.84)	p=0.678
≥500	0.67 (0.26, 1.72)	p=0.410	1.40 (0.27, 7.25)	p=0.685

Stratified by sexuality

	Straight/heterosexual (n=733)		Gay or lesbian/homosexual (n=1,195)	
	OR (95% CI)	p-values	OR (95% CI)	p-values
Age				
18-34	Ref	Ref	Ref	Ref
35-44	1.55 (0.75, 3.18)	p=0.236	1.26 (0.78, 2.04)	p=0.343
45-54	1.19 (0.57, 2.48)	p=0.637	1.20 (0.74, 1.93)	p=0.466
55-64	1.64 (0.73, 3.69)	p=0.234	1.28 (0.73, 2.25)	p=0.391
65+	0.73 (0.25, 2.16)	p=0.575	0.64 (0.30, 1.36)	p=0.246
Gender identity				
Cisgender man	Ref	Ref	Ref	Ref
Cisgender woman	**1.63 (1.08, 2.47) ****	**p=0.021**	-	-
Ethnic group				
White British	Ref	Ref	Ref	Ref
Any other White background	1.39 (0.64, 3.04)	p=0.409	1.15 (0.79, 1.66)	p=0.469
Black African	**0.47 (0.28, 0.80) *****	**p=0.005**	0.35 (0.06, 2.16)	p=0.256
Any other Black background	0.65 (0.26, 1.59)	p=0.342	0.71 (0.30, 1.69)	p=0.440
Mixed background	1.39 (0.53, 3.67)	p=0.502	1.59 (0.68, 3.75)	p=0.287
Asian background	0.29 (0.06, 1.40)	p=0.123	0.68 (0.27, 1.67)	p=0.395
Any other ethnic group	1.95 (0.47, 8.03)	p=0.358	1.70 (0.85, 3.41)	p=0.133
Education				
ISCED1/2: Primary or less	Ref	Ref	Ref	Ref
ISCED3: Upper secondary education (to age 18)	0.91 (0.45, 1.82)	p=0.784	2.04 (0.94, 4.45) *	p=0.072
ISCED4/5: Technical and vocational education training	0.92 (0.40, 2.13)	p=0.849	1.61 (0.68, 3.81)	p=0.274
ISCED6: Bachelors or equivalent level	0.88 (0.41, 1.87)	p=0.734	1.92 (0.86, 4.26)	p=0.110
ISCED7/8: Postgraduate degree	0.72 (0.29, 1.81)	p=0.491	2.15 (0.94, 4.94) *	p=0.071
Work				
Employed	Ref	Ref	Ref	Ref
Unemployed	**1.87 (1.03, 3.40) ****	**p=0.040**	**3.31 (1.79, 6.11) *****	**p<0.001**
Economically inactive	**2.00 (1.20, 3.32) *****	**p=0.008**	**2.26 (1.49, 3.44) *****	**p<0.001**
Housing				
Homeowner (own or purchasing house)	Ref	Ref	Ref	Ref
Renting (privately)	1.37 (0.77, 2.44)	p=0.285	1.13 (0.79, 1.61)	p=0.504
Renting (council/housing association)	1.36 (0.79, 2.35)	p=0.269	0.80 (0.52, 1.25)	p=0.334
Unstable or other	0.97 (0.42, 2.26)	p=0.952	1.40 (0.72, 2.75)	p=0.323
Sources of income, past year				
All other income sources	Ref	Ref	Ref	Ref
Received welfare benefits	1.37 (0.90, 2.10)	p=0.147	**1.66 (1.09, 2.55) ****	**p=0.019**
Keep up with bill and credit commitments				
Up to date	Ref	Ref	Ref	Ref
Behind with some	1.34 (0.81, 2.22)	p=0.254	**1.58 (1.04, 2.39) ****	**p=0.030**
Behind with all	2.10 (0.86, 5.16)	p=0.105	2.89 (0.98, 8.52) *	p=0.055
Enough money to meet basic needs				
No	Ref	Ref	Ref	Ref
Yes, always	**0.21 (0.11, 0.43) *****	**p<0.001**	**0.25 (0.12, 0.53) *****	**p<0.001**
Yes, most of the time	**0.34 (0.18, 0.64) *****	**p=0.001**	0.56 (0.27, 1.16)	p=0.121
Yes, some of the time	**0.42 (0.23, 0.77) *****	**p=0.005**	0.83 (0.37, 1.86)	p=0.656
Year of diagnosis				
1981-1995	Ref	Ref	Ref	Ref
1996-2005	0.57 (0.29, 1.12)	p=0.101	0.87 (0.56, 1.33)	p=0.511
2006-2015	0.52 (0.27, 1.02) *	p=0.059	1.10 (0.71, 1.72)	p=0.665
CD4 count (cells/mm^3)				
<200	Ref	Ref	Ref	Ref
200-350	1.01 (0.35, 2.92)	p=0.980	0.80 (0.27, 2.39)	p=0.688
350-499	**0.36 (0.13, 0.99) ****	**p=0.047**	0.60 (0.22, 1.68)	p=0.333
≥500	0.71 (0.28, 1.79)	p=0.469	0.72 (0.27, 1.91)	p=0.509

Missing data

Frequency of missing data

Variable number	**Variable name**	**Missing (n)**	**Missing (%)**
1	Age group	106	2.4
2	Gender identity	146	3.3
3	Country of birth (World Bank classification)	160	3.6
4	Ethnic group	65	1.5
5	Sexuality	299	6.8
6	Education	313	7.1
7	Work situation	210	4.8
8	Living situation	223	5.0
9	Sources of income	413	9.3
10	Keep up with bills and credit commitments	509	11.5
11	Ability to meet basic needs	328	7.4
12	Annual household income (median)	1,054	23.8
13	Year of diagnosis	135	3.1
14	CD4 count	1,722	38.9
15	Viral load	780	17.6
16	Anxiety	361	8.1
17	Depression	270	6.1
18	Personality disorder	579	13.1
19	Bipolar	568	12.9
20	Eating disorder	553	12.5
21	Insomnia	448	10.2
22	PTSD	566	12.8
23	Psychosis	578	13.0
24	Other mental health	694	15.7
25	GHQ (concentration)	133	3.0
26	GHQ domain (sleep loss)	113	2.6
27	GHQ domain (playing useful part)	221	5.0
28	GHQ domain (capable of decisions)	167	3.8
29	GHQ domain (constant strain)	203	4.6
30	GHQ domain (overcome difficulties)	195	4.4
31	GHQ domain (enjoy normal activities)	177	4.0
32	GHQ domain (face problems)	180	4.1
33	GHQ domain (unhappy)	191	4.3
34	GHQ domain (losing confidence)	176	4.0
35	GHQ domain (worthless)	172	3.9
36	GHQ domain (happy)	179	4.1
37	GHQ-12 threshold scores	91	2.1
38	GHQ-12 score ($<$ vs $\geq$4)	91	2.1

Missing defined as prefer not to say, don't know and missing