

# HIV and AIDS in Greater Manchester: Service Delivery in Times of Devolution, Neoliberalism and Austerity

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HIV and AIDS in Greater Manchester: Service Delivery in  
Times of Devolution, Neoliberalism and Austerity

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## **Abstract**

This research examines the impact of devolution, neoliberalism and austerity on the governance and delivery of specialist HIV and AIDS physical and mental health services for service users across the Manchester City Region. This research further documents the decline of specialist HIV and AIDS healthcare, including mental health services, over the last decade and details the extent of these changes on people living with HIV and AIDS across the Manchester City Region. Focusing on the interplay of neoliberal policy interventions with the structural changes implied in devolution, the research locates the participants' accounts within the broader analysis of cultural, political and economic developments in health policy and (urban) governance.

This thesis draws on a queer-feminist methodology and a series of semi-structured interviews with service users of HIV and AIDS healthcare provisions; organisations specialising in HIV and AIDS support, advice and advocacy services to improve health outcomes; healthcare staff specialising in HIV and AIDS healthcare and those who advocate for improved treatments; academics who work in the field of HIV studies; and activists who are campaigning for improved HIV and AIDS services. The interview data was analysed to show how funding changes have affected the delivery of HIV and AIDS healthcare services. Secondary data sources, such as public health data, were also utilised to address gaps within the interview data. The interview data shows that the shift to cheaper generalist services results in poorer service provision because healthcare staff may not understand the full range of needs of service users with HIV and AIDS. Moreover, the study participants pointed to the persistence of discrimination in healthcare settings, leading to poorer mental health. As a result, service users may stop taking their antiretroviral treatments.

Historically, HIV has been heavily stigmatised, and this is a theme which arose in the data. This study focuses on specific campaigns, such as “U=U” and “You Can’t Pass It On,” which attempt to combat HIV-associated stigma and discrimination by creating awareness. Still, the efforts of these campaigns have only tended to reach those who

know about HIV. In response, there has been some work in Manchester to educate healthcare professionals, but this is limited and still in its infancy.

This study further argues that there is an urgent need for increased investment in specialist HIV and AIDS healthcare services. There needs to be a refocus on providing services across the Manchester City Region. Furthermore, the research data analysis suggests that even more funding may be required to achieve the goal of advanced specialist training among health professionals to secure adequate healthcare provisions for people living with HIV and AIDS within the Greater Manchester City Region.

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# Table of Contents

<b>ABBREVIATIONS</b>	<b>1</b>
<b>CHAPTER ONE: INTRODUCTION</b>	<b>2</b>
1.1 OVERVIEW RESPONSES TO HIV AND AIDS	2
1.1.1 <i>Early HIV and AIDS Responses in Central Manchester</i>	5
1.2 RESEARCH BACKGROUND	8
1.3 DEFINING THE TERMINOLOGY USED IN THIS STUDY	11
1.3.2 <i>The use of the Term AIDS</i>	11
1.3.3 <i>Men Who Have Sex with Men</i>	12
1.4 RESEARCH AIM AND OBJECTIVES	13
1.5 THESIS STRUCTURE	14
<b>CHAPTER TWO: THE ROLE OF NEOLIBERALISM AND AUSTERITY IN THE DELIVERY OF DEVOLVED HIV AND AIDS HEALTHCARE</b>	<b>15</b>
2.1 INTRODUCTION	15
2.2 SHIFTING RESPONSIBILITY: NEOLIBERALISING THE STATE	15
2.2.1 <i>Situating Neoliberalism in the Global Context</i>	15
2.2.2 <i>Austerity Politics: The Role of Neoliberalism in the Creation of Austerity</i>	19
2.3 DEVOLVING THE UNITED KINGDOM: FROM POLITICS TO HEALTHCARE	20
2.3.1 <i>Devolving Powers from Westminster to Scotland, Wales and Northern Ireland</i>	20
2.3.2 <i>Devolution as a Process of Rescaling the State</i>	23
2.3.3 <i>Devolving Healthcare to the Greater Manchester Regional Level</i>	25
2.4 HIV AND AIDS HEALTHCARE	27
2.4.1 <i>The Effect of Neoliberalism on HIV and AIDS Healthcare</i>	27
2.4.2 <i>Neoliberal Influences on Preventative HIV Treatments: The Case of PrEP</i>	29
2.4.3 <i>The Impact of Stigma on People Living with HIV</i>	30
2.5 ORGANISING: ACTIVISM AT THE CORE OF THE RESPONSE TO HIV AND AIDS	33
2.5.1 <i>Activist Responses to Changing HIV and AIDS Healthcare</i>	34
2.5.2 <i>Women and HIV and AIDS Activism</i>	36
2.6 CHAPTER SUMMARY	40
<b>CHAPTER THREE: RESEARCH METHODOLOGY</b>	<b>43</b>
3.1 INTRODUCTION	43
3.2 THEORETICAL UNDERPINNING	44
3.2.1 <i>Utilising Feminist Approaches to this Research</i>	44
3.2.2 <i>Queer Theory and the Research Approach</i>	45
3.2.3 <i>Utilising a Queer-Feminist Methodology</i>	47
3.2.4 <i>Positioning Myself within the Research Process</i>	51

3.2.5 <i>Interpretivism</i>	54
3.2.5.1 Interpreting the Reality Through Experience	56
3.3 RECRUITMENT	60
3.3.1 <i>Sampling</i>	61
3.3.2 <i>Inclusion and Exclusion Criteria</i>	61
3.3.3 <i>Recruitment Process</i>	62
3.3.4 <i>Barriers to Recruitment</i>	63
3.3.5 <i>Participant Demographics</i>	66
3.4 DATA COLLECTION	68
3.4.1 <i>Semi-Structured Interviews</i>	68
3.4.2 <i>Location of Interviews</i>	71
3.4.3 <i>The Impact of the COVID-19 Pandemic on the Data Collection</i>	73
3.5 SECONDARY DATA	75
3.6 ANALYSIS OF DATA	79
3.6.1 <i>Analysis and Coding</i>	79
3.7 ETHICAL CONSIDERATIONS	81
3.8 CHAPTER SUMMARY	84
<b>CHAPTER FOUR: CHANGING HIV AND AIDS HEALTHCARE IN THE MANCHESTER CITY REGION</b>	<b>85</b>
4.1 INTRODUCTION	85
4.2 HIV ACQUISITION: UNEMPLOYMENT, HOMELESSNESS AND SUBSTANCE USE	85
4.2.1 <i>Unemployment as a Factor for HIV Risk</i>	86
4.2.2 <i>The Link Between Homelessness and HIV</i>	87
4.2.2.1 HIV Risk: Linking Homelessness with Substance Use and Survival Sex Work	89
4.3 HEALTH AND SOCIAL CARE ACT 2012 IMPACT ON HIV AND AIDS HEALTHCARE	91
4.4 HOW GREATER MANCHESTER IS APPROACHING HIV AND AIDS	93
4.4.1 <i>The PaSH Partnership: Improving HIV Healthcare</i>	93
4.4.1.1 The PaSH Partnership's Impact on HIV Charities	99
4.4.1.2 The PaSH Partnership's Impact on HIV Knowledge	105
4.4.2 <i>Fast-Track Cities and the Future of HIV Services in Greater Manchester</i>	109
4.5 CHAPTER SUMMARY	111
<b>CHAPTER FIVE: PSYCHOLOGICAL SUPPORT FOR PEOPLE LIVING WITH HIV AND AIDS IN GREATER MANCHESTER</b>	<b>114</b>
5.1 INTRODUCTION	114
5.2 MENTAL HEALTH FACTORS FOR PEOPLE LIVING WITH HIV	115
5.2.1 <i>'Don't Die of Ignorance': HIV Associated Stigma for People Living with HIV</i>	117
5.2.2 <i>Combating Stigma: Does U=U Go Far Enough to Combat HIV-Related Stigma</i>	120
5.3 PROVIDING MENTAL HEALTH SUPPORT FOR PEOPLE LIVING WITH HIV	123

5.3.1 <i>Improving Access to Psychological Therapies and Mental Health Support</i>	124
5.3.2 <i>Specialist HIV Psychological Services: Is there a need?</i>	128
5.3.3 <i>Declining Specialist HIV Psychological and Mental Health Support in Greater Manchester</i>	132
5.4 THE IMPACT OF THE COVID-19 PANDEMIC ON SPECIALIST HIV SUPPORT	136
5.5 CHAPTER SUMMARY	140
<b>CHAPTER SIX: CONTESTED RESPONSES TO THE TRANSFORMATION OF HIV AND AIDS CARE LANDSCAPE</b>	<b>144</b>
6.1 INTRODUCTION	144
6.2 'HIV IS NOT MY PROBLEM, IT'S EVERYONE'S PROBLEM': THE LEGACY OF SECTION 28	145
6.2.1 <i>Educating Young People about HIV</i>	148
6.2.2 <i>Educating Health Professionals about HIV to Improve Awareness</i>	150
6.2.2.1 <i>Educating Health Professionals in Primary Care Settings</i>	151
6.2.2.2 <i>Educating Health Professionals in Secondary Care Settings</i>	154
6.3 PRE-EXPOSURE PROPHYLAXIS (PREP): HOW PEOPLE AT RISK OF HIV ARE RECLAIMING THEIR HEALTH?	156
6.4 (U)NDETECTABLE = (U)NTRANSMITTABLE: MESSAGING AROUND HIV AND AIDS	164
6.5 CHAPTER SUMMARY	169
<b>CHAPTER SEVEN: CONCLUSION</b>	<b>173</b>
7.1 INTRODUCTION	173
7.2 CORE FINDINGS	175
7.2.1 <i>Changes in HIV and Healthcare Provision and Governance Structures in a Post-Devolved Manchester City Region</i>	175
7.2.2 <i>The Impact of Devolution, Neoliberalism and Austerity on the Lived Experience of Service Users in the Manchester City Region</i>	178
7.2.3 <i>The Impact of Devolution, Neoliberalism and Austerity on HIV and AIDS Mental Health Services across Greater Manchester</i>	180
7.2.4 <i>Overall Contribution</i>	182
7.3 REFLEXIVITY	184
7.4 RECOMMENDATIONS HEALTHCARE PROVIDERS AND POLICYMAKERS IN THE FIELD OF HIV AND AIDS HEALTHCARE	186
7.5 RECOMMENDATIONS FOR FURTHER RESEARCH	189
7.6 FINAL REMARKS	191
<b>REFERENCES</b>	<b>192</b>
<b>APPENDIX A: INTERVIEW SCHEDULE</b>	<b>236</b>
<b>APPENDIX B: INVITATION LETTER</b>	<b>238</b>
<b>APPENDIX C: PARTICIPANT INFORMATION SHEET</b>	<b>239</b>



<b>APPENDIX D: GATEKEEPER LETTER</b>	<b>244</b>
<b>APPENDIX E: CONSENT FORM</b>	<b>245</b>
<b>APPENDIX F: CONTACT LIST</b>	<b>246</b>

## ***Abbreviations***

BHIVA	British HIV Association
BME	Black, Minority, Ethnic
CBT	Cognitive Behavioural Therapy
CCGs	Clinical Commissioning Groups
GMCA	Greater Manchester Combined Authority
GMHSCP	Greater Manchester Health and Social Care Partnership
GUM	Genitourinary Medicine
IAPT	Improving Access to Psychological Therapies
MSM	Men Who Have Sex with Men
PaSH	Passionate About Sexual Health
PEP	Post-Exposure Prophylaxis
PPE	Personal Protective Equipment
PrEP	Pre-Exposure Prophylaxis

## ***Chapter One: Introduction***

This study investigates how devolution, neoliberalism and austerity have impacted on Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) healthcare provision in Greater Manchester. This research is valuable and timely, given that neoliberal measures through austerity policies have cut funding for HIV and AIDS healthcare services. The Manchester City Region's distinctiveness, the first devolved local landscape in England, makes it a particularly interesting case to study.

In this chapter, I present an overview of early responses, or lack thereof, to HIV and AIDS and how people responded to this in central Manchester. This context is vital because these early responses still resonate with people living with HIV and AIDS today (Shongwe et al., 2020). Considering these early responses, I then present an overview of the research. I subsequently outline some of the key terminology used in the thesis before introducing the research aim and objectives and, finally, the structure of this thesis.

### **1.1 Overview Responses to HIV and AIDS**

In December 1981, the first case of AIDS was detected in the UK, but it did not initially appear to be an unusual challenge (Day and Klein, 1989). At first, 'there seemed no reason to doubt that the problems posed by this new infection could be solved promptly and efficiently by applying the well-tested methods of surveillance, research, prevention, and treatment' (Fox, 2005: 11). This logic was attributed to the fact that these methods were successful in controlling both toxic shock syndrome and Legionnaires disease (Fox, 2005). Because little was known about HIV and AIDS, it was first thought that it only affected gay men as this group first presented with symptoms and was the largest group affected by the crisis (Hallsor, 2017). At the time, the British media used AIDS statistics and some of the early deathbed stories of well-known figures to stereotype AIDS as a "gay plague" (Braidwood, 2018). Despite this, in the early 1980s, it was also revealed that AIDS was not just linked to homosexuals.

Haemophilia Society (2022) highlighted that in the early 1980s, 6% of AIDS cases were haemophiliacs who had received HIV-infected blood. However, the risk of transmitting HIV via infected blood was eliminated in 1985 because it became possible to test all blood samples (Day and Klein, 1989). Another group at risk of HIV is intravenous drug users because they not only pose a risk to each other through sharing needles contaminated with HIV-infected blood, but they also pose a risk to their sexual partners (Turner et al., 1989). Women sex workers were also seen as an at-risk group who acquired and transmitted HIV (Scambler et al., 1990). Lastly, heterosexuals were known to be at risk of HIV, and a group acquired HIV when they went to Africa, where AIDS was prevalent amongst both men and women (Day and Klein, 1989). In short, it was clear that since the beginning of the AIDS crisis, it was not just homosexuals who were at risk of HIV and AIDS. These examples highlighted the need for a government response because cases of HIV and AIDS were rising amongst all groups.

The 1980s witnessed the start of the neoliberal era, which saw the Prime Minister, Margaret Thatcher, proceed with a strong focus on people being able to improve themselves. Under neoliberalism, governments should not hinder people from creating success; in this context, people can achieve economic independence free from state interference, buy private health insurance, buy their own homes and ultimately have their own families. However, the stigma and discrimination attached to HIV and AIDS stopped people from buying into this vision because of invasive lifestyle questionnaires, mandatory HIV testing and heavily loaded insurance premiums (NAT-ADMIN, 2017). These struggles were often experienced by gay and bisexual men, irrespective of their HIV status. They were often prejudiced against being ostensibly the only group living with HIV and AIDS (Durham, 1991; Smith, 1994a). If these relationships had been accepted under Margaret Thatcher, this would have been considered anti-neoliberal because 'moral decline was seen as a cause of economic decline '(Hoggart, 2005: 150). If lesbians and gay men had been accepted for mortgages, this would have led to their economic success. However, the tests imposed by the market to decide who could and could not obtain financial products reasserted the New Right's view of a traditional moral order. This meant

that the market, not the state, was the best guardian of political stability (Hoggart, 2005). As a result, people seen to be at risk of HIV were often prevented from accessing the same level of free enterprise as their counterparts.

Early responses were aimed at the lack of a government response to the HIV and AIDS crisis. One of the first groups was established in 1983 to respond to the growing impact of the AIDS crisis. Friends of Terrence Higgins, the first man to die from AIDS in the UK, set up the Terrence Higgins Trust to raise funds for research and create awareness of HIV and AIDS among the affected communities. Their actions also fought for the Government to respond to the crisis (Terrence Higgins Trust, no date-b). Despite their actions, the government failed to respond to the ongoing crisis. By 1984, it was evident that HIV and AIDS were not diseases the government could respond to using similar measures that they had employed to deal with other disease outbreaks, such as Legionnaires disease. The number of AIDS cases had risen to 108, and there had been 46 AIDS-related deaths in the UK by the end of 1984 (Terrence Higgins Trust, no date-b). By then, the number of people acquiring HIV was growing at a significant rate, and there was a need for governments to respond. According to the evidence provided by Norman Fowler, Secretary of State for Health and Social Security from 1981 to 1986, at the Infected Blood Inquiry, neither Number 10 nor the Treasury considered the AIDS crisis a priority in the mid-1980s. Overwhelming evidence showed that AIDS was becoming a significant public health issue because of a substantial increase in HIV and AIDS cases (Gallagher, 2021). By mid-1985, the number of HIV and AIDS cases had increased again, and it was reported that there had been 196 cases, 110 of whom had died (Bowcott, 2015). It was becoming increasingly clear that the government needed to respond to the crisis, and it did so the following year.

On 21st November 1986, the British government launched its public health campaign to stop the spread of AIDS. This campaign was launched five years after the first cases of AIDS were reported in Britain. The campaign aimed to counter the widely held misconceptions about AIDS, e.g., the view that homosexuals were the only at-risk group. Following this, on 9th January 1987, the government sent leaflets to every

home to inform people about the urgency of the AIDS crisis whilst, at the same time, trying not to cause alarm (Hildrew, 2014). On 27th February 1987, the government launched “AIDS Week”, where television programmes provided information about AIDS and doctors and epidemiologists advised the public about the disease. AIDS Week was consciously designed to bombard viewers with information about the disease so that virtually everyone was exposed to some information (Chuter and Seidel, 1987). This week included broadcasting the “AIDS: Don’t Die of Ignorance” campaign, which included icebergs, volcanoes, and coffins, associating sex with risk and death. This campaign spread fear amongst the British population (Burgess, 2017).

AIDS Week aimed to educate the public that AIDS was spreading in Britain and was a fatal disease with no known cure (Clarity, 1987). In addition to the television campaign, the government issued the “Don’t Die of Ignorance” pamphlets and printed the Switchboard telephone number on the back. Switchboard was established in 1974 to provide information to London’s gay community after homosexuality was partially decriminalised in the UK (Terrence Higgins Trust, no date-b). Including the telephone number caused Switchboard to be inundated with calls from concerned individuals about HIV and AIDS (Hunt, 2019). Because of this, Switchboard became a vital source of information for those concerned (Terrence Higgins Trust, no date-b). This response highlighted that people were hugely concerned about HIV and AIDS and how it passed through the population.

### **1.1.1 Early HIV and AIDS Responses in Central Manchester**

Just a year earlier than the campaign, in 1985, early HIV and AIDS activists in Central Manchester replied to the Conservative Minister for Health, Ken Clarke’s response to the AIDS crisis. In 1985, Ken Clarke enacted anti-AIDS powers, which enabled local authorities to detain people with AIDS in hospitals against their will. Manchester was the only place where this power was enacted, which saw the local council hold an emergency meeting which granted the Monsall Hospital authority to detain a gay man for three weeks after he had asked to go home for the weekend (Superbia,

2021). This decision sparked significant protests in Manchester, and a court case followed where a judgement resulted in the patient being able to leave the hospital ten days later.

In the same year, six gay activists founded AIDS-Line – a voluntary helpline – in Bloom Street, Manchester, to respond to the virus arriving in Manchester. Manchester City Council also formed an “AIDS Working Party”, and the North Western Regional Health Authority began to support the Manchester AIDS-Line financially. The AIDS-Line later went on to be succeeded by the George House Trust. However, on 20th February 1988, 20,000 people marched through the streets of Manchester in protest against the upcoming introduction of Section 28 of the Local Government Act 1988. The introduction of Section 28 was pivotal for LGBTQ people in the UK because it banned local authorities from “actively promoting” homosexuality and banned schools from educating young people on the ‘acceptability of homosexuality as a pretended family relationship’ (Local Government Act 1988). Although the government repealed the law in 2003 across the UK, its legacy resulted in young people not being taught about sexual acts deemed to be practised only in same-sex relationships, such as anal intercourse. Therefore, young people were unaware of the risks of having specific types of sex. In 1994, Healthy Gay Manchester launched a free condom and lube distribution in Greater Manchester, becoming a model for the rest of the country. Eventually, Healthy Gay Manchester partnered with Manchester’s Lesbian and Gay Switchboard, which became the LGBT Foundation. Manchester Pride – a UK-based LGBTQ+ charity – has continuously funded the programme since 1994.

Later, James Anderton, the Chief Constable of Manchester, raised what he believed to be a moral issue about AIDS and publicly stated that homosexuals, drug addicts and prostitutes living with AIDS were to blame. He noted that those people should be left in a ‘human cesspit of their own making’ (Clarity, 1987). His words caused concern, but Margaret Thatcher failed to establish a public inquiry and supported his right to speak out (Linton, 2012). This was problematic as it appeared to show that the government supported James Anderton's view. Margaret Thatcher failed to

establish an inquiry into the actions of James Anderton because it is argued that his words bought into her attack on homosexuals. In 1988, Section 28 of the Local Government Act was introduced, which banned local authorities from educating children about same-sex relationships (Sommerlad, 2018). In Central Manchester, thousands of people took a stand and flooded the streets, singing songs and waving banners over the introduction of Section 28 (Williams, 2018). It is argued by Anna Marie Smith (1994b) that introducing Section 28 was an attack on the Labour-controlled local government, which funded gay and lesbian political events and who were seen as “corrupt socialist allies” (Smith, 1994a). Labour-controlled councils were seen as such because they enabled “homosexual militants” to take over local educational institutions, and lesbians and gays were provided with “special privileges” in local programmes.

By the end of the 1980s, national statistics showed that men who had sex with men remained the most at-risk group nationally. By 1989, 2,228 cases of AIDS were reported; of these, 1,759 (84%) were identified as either homosexual or bisexual men (Day and Klein, 1989). However, 16% of the total did not identify as male, highlighting that anyone was at risk. In 1990, there was a significant rise in reported cases of HIV and AIDS. By the end of 1990, the National Audit Office (1991) reported that 15,166 people had a seropositive test for HIV, and 4,098 people were living with AIDS. The report also highlighted the rapid growth in the number of cases of AIDS acquired through heterosexual intercourse. It was evident from the report that health officials were aware that a significant number of people were living with HIV and AIDS. The data highlighted the need for a more robust response from the British government. From the 1980s to today, HIV is still prevalent across the Manchester City Region.

The Greater Manchester Health and Social Care Partnership reported that 6.21 people per 1,000 population in Manchester were diagnosed with HIV in 2019 (compared to the average in England of 2.37 per 1,000 population) (McQuillan, 2019). The number of people diagnosed with HIV has been declining yearly since 2019, attributed to the advancements in HIV treatment and prevention strategies. These advancements were partly possible because campaigning was undertaken for



improved treatment access and prevention strategies. For example, NHS England started to provide pre-exposure prophylaxis (PrEP) medication in late 2020. PrEP campaigners fought for these medications to be available for those most at risk of acquiring HIV.

## **1.2 Research Background**

Greater Manchester is a unique context because of the unique political makeup of the region. Greater Manchester has experienced a restructuring through devolution (Institute for Government, 2019), an ongoing transfer of power in the UK since the creation of autonomous, elected governments for Scotland, Wales and Northern Ireland in the late 1990s (Greer, 2016). In 2010, a new Conservative/Liberal Democrat Coalition Government introduced the Northern Powerhouse vision with the aim of a spatial rebalancing of the UK economy by encouraging investment in the North of England to act as a counterweight to London (Parr, 2017). The Conservative/Liberal Democrat Coalition could test whether the Northern Power vision would work by devolving powers to newly established city regions.

Devolution provided the answer because it links into the Northern Powerhouse vision by enabling decisions around economic and industrial restructuring to be managed locally (Schneider and Cottineau, 2019). In 2011, Greater Manchester became the first city region to be devolved from the central government. Devolving Greater Manchester did not offer anything new to the city region because the ten boroughs within—Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan—were already collaborating on several issues, such as transport, regeneration and attracting new investment to the region (Lowndes and Gardner, 2016). Therefore, testing out the city region model in Greater Manchester was not a significant risk for George Osborne, the Chancellor of the Exchequer from 2010 to 2016, because it required little investment. In 2015, the Manchester City Region evolved to take on strategic oversight for healthcare funding (Cox, 2016; Lowndes and Gardner, 2016; Vize, 2016). Devolving healthcare funding

further bought into neoliberal politics because it shifted power and gave the Manchester City Region greater economic freedom.

In 2012, the Health and Social Care Act 2012 was introduced, reorganising health and social care delivery. The Act provided greater autonomy for people to choose their health needs. It can be argued that the Health and Social Care Act 2012 has neoliberal traits because it focuses on the needs of the individual rather than the collective, and it has increased the role of private interests in delivering health and social care (Nevradakis and Giroux, 2015). However, the Health and Social Care Act has confused who is ultimately responsible for providing specific services. Across the Manchester City Region, the restructuring of HIV and AIDS healthcare services has resulted in the dismantling of these services and a loss of knowledge.

A study across the Manchester City Region highlighted that people are more likely to trust specialist services (National AIDS Trust, 2021). Walding (2016) also identified that HIV support groups are essential as they can be a place where people feel safe and open about their HIV status. Devolution has resulted in a centralisation of services within the Manchester City Region, leaving those communities out of Central Manchester with little support and austerity measures that have left support groups with little or no funding.

Biomedical interventions are one of the reasons why there has been a dismantling of funding for HIV and AIDS healthcare services (Adams et al., 2016). Antiretrovirals have significantly improved the health outcomes for people living with HIV. However, neoliberal governments have also used them as a weapon to reduce funding for HIV and AIDS healthcare slowly. Funding changes to healthcare services have left HIV services at breaking point (British HIV Association, 2016, 2018a). Therefore, people have been left to seek alternative arrangements through private means (Gregory, 2022) and manage their conditions with little support.

This attack on healthcare is not just limited to physical health services but also mental health services. In recent years, austerity measures have reduced funding for

specialist HIV mental health services in favour of a move to generalist services, such as Improving Access to Psychological Services (IAPT) (National AIDS Trust, 2017; Dhumma, 2020). This has further diminished the support available for people living with HIV. Despite evidence that Cognitive Behavioural Therapy provided through IAPT has some benefits because people have a higher chance of adhering to their antiretrovirals (Safren et al., 2009), for some, specialist provision is needed because they may have complex psychological needs (Dhumma, 2020). Additionally, people living with HIV can experience stigma and discrimination in generalist settings because healthcare professionals may not have any formal training for HIV (Dhumma, 2020). However, this also applies to physical healthcare services.

In recent years, there has been little challenge to the cuts made to HIV and AIDS services. Stop the Cuts is a national campaign established by a group of HIV organisations, such as Positively UK, service providers and community groups to ensure that the needs of people living with HIV across the UK are comprehensively met. This campaign aimed to ensure that physical health, mental health and social inclusion received the best results in terms of funding (Positively UK, 2016). Considering the deep funding cuts to HIV and AIDS healthcare services in recent years, there does not appear to be any other large-scale campaigns tackling this issue. However, part of this can be linked to the ongoing COVID-19 pandemic.

Since March 2020, the global COVID-19 pandemic has impacted the delivery of HIV and AIDS healthcare services. One example was the redeployment of healthcare staff, including those working within specialist HIV services in Greater Manchester, to the intensive care units. Staff reorganisation resulted in less support for people accessing mental health services. The COVID-19 pandemic also impacted the funding received by organisations as they could not operate in the same way as before the pandemic. As a result, Manchester Pride stopped funding the free condom and lube distribution scheme in 2021 (Parsons, 2021). The programme has provided over 31 million safer sex packs across the Manchester City Region for 27 years. Manchester Pride argued they stopped funding the programme because the COVID-19 pandemic had seriously affected their ability to raise funds (Maidment, 2021). Although funding

was stopped, the LGBT Foundation said they would continue funding this service. However, this decision may impact the Foundation's ability to fund other services because it will have to use its funds to continue this programme. Considering the unique devolution context of the Manchester City Region, neoliberalism and austerity measures, this study is needed to understand how these critical issues interlink.

### **1.3 Defining the Terminology used in this Study**

This thesis will explore the changing nature of HIV and AIDS healthcare provision across Greater Manchester, focusing on neoliberalism, austerity and devolution. This section will define how key terms will be used in this thesis. This is important, in particular, given that some of these terms are ambiguous and need to be unpacked.

#### **1.3.2 The use of the Term AIDS**

I use AIDS over other terms like advanced HIV. In recent years, there has been a move from health officials and those working within public health to utilise the term "advanced HIV" when referring to AIDS because they argue that AIDS holds a lot of stigma and trauma for people. Although more people die from AIDS-related illnesses in the developing world than in the UK, the UK still recorded 428 deaths in 2017 (Avert, 2018). Combined with the 680,000 AIDS-related deaths recorded internationally at the end of 2020 (UNAIDS, 2021), it is clear that AIDS impacts many people's lives. Until there are improvements in the early detection of HIV for all people globally, it is important not to erase the acronym from scientific texts on the subject matter.

The UNAIDS programme produced a terminology guidelines document identifying the preferred terms for HIV and AIDS. AIDS is a medical condition associated with multiple challenges to the immune system linked to viral infection (i.e., HIV). Eventually, high viral turnover leads to the immune system's destruction, and some people prefer the term advanced HIV infection, which leads to the manifestation of AIDS (UNAIDS, 2015). This definition makes a clear distinction between advanced HIV

and AIDS. HIV is a virus that destroys the body's immune system response to opportunistic infection. If untreated, the immune system is destroyed; some refer to this as advanced HIV. Once a person has developed advanced HIV, other infections, such as pneumonic conditions, have a more significant opportunity to reproduce in the body, which then develops into what we refer to as AIDS-related illnesses. There is no cure for HIV or AIDS, but highly effective treatments are available that fight HIV and its complications. To acknowledge this and to show that we are still fighting this epidemic today, I will use the term AIDS.

### **1.3.3 Men Who Have Sex with Men**

In the thesis, I will use the term men who have sex with men (MSM) instead of “gay men”. I have opted for this because some of the respondents in this study utilise this term, and the public health sources I have accessed use this same term to refer to gay, bisexual, and other men who have sex with men. Andrew Tucker (2021) offers both a rationale for the use of MSM but also critiques its use. Foremost, the category of MSM focuses on sexual behaviours instead of sexual identity, which is critical to its utility. This is important because MSM does not link the biological risk of HIV to a particular sexual identity or social group. Instead, MSM is linked to acts that may facilitate the transmission of HIV (Tucker, 2021). This conceptual category focuses on men who may present with diverse sexual identities, such as men who may identify as heterosexual and engage in sexual activities with other men. Despite this helpful flexibility, Young and Meyer (2005) critique MSM. They argue that it obscures the social dimension of sexuality and undermines the labels people attach to their sexuality, such as gay and bisexual, whilst not sufficiently describing the variations in sexual behaviour. Andrew Tucker (2021) argues that referring to the behaviour is helpful for epidemiologists, public health policy workers and HIV programmes to understand at-risk populations. However, this label excludes complex identities, cultures and communities. Considering these validations and critiques of MSM, I use the term when I am not referring to a concept which directly affects gay men, such as targeted stigma.

## 1.4 Research Aim and Objectives

Since the beginning of the AIDS epidemic, several studies have been published that investigate the impact of funding changes on HIV and AIDS healthcare services (Padarath et al., 2003; Rowden, 2009; Grimshaw and Rubery, 2012) and how devolved healthcare systems have also impacted on these services (Fredriksson and Winblad, 2008; Zolkefli, 2017). These studies have shown that the devolution of healthcare services has often been met with funding changes that have reduced services for people living with HIV and AIDS. In the Greater Manchester context, a limited number of studies examining the effects of the devolved healthcare system on the residents of Greater Manchester have been published. Walshe et al. (2018) found during the infancy of the devolution, Greater Manchester has not yet taken greater control of its healthcare systems. Britteon et al. (2022) found that devolution has improved the health of residents in Greater Manchester as life expectancy has increased for residents in eight of the ten boroughs.

This research aims to assess the impact of devolution, neoliberalism and austerity on the governance and delivery of specialist HIV and AIDS physical and mental health services and the impact this has on the lived experiences of service users across the Manchester City Region. This research has involved studying the changing nature of HIV and AIDS healthcare across the Manchester City Region in times of devolution, neoliberalism and austerity with people closely linked to the changes. To do this, I employed a queer-feminist approach to uncover the lived experiences of these changes on people in the Manchester City Region. Utilising this approach helped to create knowledge that worked against recreating another piece of research that just fulfilled ideas associated with traditional, positivist research. A queer-feminist approach will be explored fully in Chapter Three. However, I identified this methodology as the best approach to answer the aim and objectives of this research because it would help create an output unique to the Greater Manchester context. The main three objectives are:

1. To analyse changes in HIV and AIDS health provision and governance, post-devolution in Greater Manchester

2. To assess the impact of devolution, neoliberalism and austerity on the lived experiences of service users living with HIV and AIDS across the Manchester City Region
3. To determine the impact of devolution, neoliberalism and austerity on the delivery of specialist mental health care for people living with HIV and AIDS across the Manchester City Region

To achieve the aim and objectives of this research, I employed qualitative interviews as the data collection method for my primary data. I also accessed secondary data to validate some of the claims made by the participants, such as census data, reports published by HIV and AIDS organisations, and research papers which the respondents discussed in their interviews. I used thematic analysis to analyse the results.

### **1.5 Thesis Structure**

The structure of this thesis comprises seven chapters. Following this introduction, Chapter Two will review the literature on three critical themes: austerity, devolution and HIV and AIDS healthcare. The review focuses on critical research, investigating how neoliberalism and devolution have impacted the trajectory of HIV and AIDS healthcare. This review identifies a need for more research linking these topics, especially within the Greater Manchester context, hence the need for this study. Chapter Three describes the queer-feminist methodology I adopted for this research, from the theoretical underpinning to demonstrating my data analysis and ethical considerations. Chapters Four (HIV and AIDS healthcare), Five (psychological support for people living with HIV and AIDS), and Six (responses to the transformation of the HIV and AIDS care landscape) present the findings of this thesis. The data from the qualitative interviews are integrated into these chapters. Lastly, I conclude the study in Chapter Seven.

## ***Chapter Two: The Role of Neoliberalism and Austerity in the Delivery of Devolved HIV and AIDS Healthcare***

### **2.1 Introduction**

Since the HIV and AIDS epidemic began in the 1980s, service users, HIV and AIDS activists, and HIV and AIDS healthcare staff have been central to creating awareness and fighting for the rights of people at risk of and living with HIV and AIDS. To understand the radical transformation in HIV and AIDS healthcare provision since the 1980s, this chapter reviews the literature on neoliberalism, austerity and devolution, linking these themes to HIV and AIDS healthcare.

I begin this chapter by considering broader definitions of neoliberalism, situating this term in the global context before considering the role of neoliberalism in creating austerity politics. This discussion is vital because neoliberalism underpins the argument for the rest of the literature review. The review then discusses devolution, looking at how the broader use of this political ideology has been used to shift power from Westminster to Scotland, Wales and Northern Ireland. I then shift the discussion to consider devolved city regions, mainly focusing on the Greater Manchester context. In the final part of this section, I debate the literature on healthcare in the Manchester City Region. Next, I explore HIV and AIDS healthcare, explaining how neoliberalism has affected physical health and been a catalyst for the introduction of preventative treatments and the impact of stigma on people living with HIV and AIDS. In this section, I also consider debates around the responses to changing HIV healthcare.

### **2.2 Shifting Responsibility: Neoliberalising the State**

#### **2.2.1 Situating Neoliberalism in the Global Context**

Neoliberalism has played a significant role in UK politics and HIV and AIDS healthcare since it became prominent in the 1980s. Since then, a substantial body of literature has been published examining the impact of neoliberalism and austerity measures



on HIV and AIDS healthcare. Therefore, I will begin this chapter by defining neoliberalism and then discuss its role at the global level.

Neoliberalism has been described as producing a market-orientated model of politics where nations articulate themselves around the market-centred logic of the contemporary world (Helfgott, 2008). In doing so, governments have reinforced private interests and changed the state's role, as Larner (2003) discussed earlier. According to Larner (2003), neoliberalism is a descriptive term for contemporary forms of economic restructuring against a backdrop of globalisation. It refers to the deregulation, privatisation and marketisation of national economies, which are opened up to enable both multinational corporations and global institutions, such as the International Monetary Fund and the World Bank, to operate. By allowing global private interests into national markets, neoliberal governments can offer policies and processes that maximise profits for private interests and focus on personal interests rather than meeting everyone's needs (Ishkanian, 2019). Consequently, these private interests can act in a way that negates the need to meet the interests of subordinated classes.

The Health and Social Care Act 2012 shows an example of this. Section 5 of the Act defines the role of the Secretary of State as promoting people's autonomy over their healthcare. The Section states that people are 'free to exercise those functions or provide those services in the manner that it considers most appropriate' (Health and Social Care Act 2012: 3). People are promoted to make decisions over their healthcare, enabling the capitalisation of private interests. The role of privatisation and the shift to self-responsibility was highlighted by Nevradakis and Giroux (2015). They define neoliberalism as:

A particular political and economic, and social project that not only consolidates class power in the hands of the one per cent but operates off the assumption that economics can divorce itself from social costs, that it doesn't have to deal with matters of ethical and social responsibility, that these things get in the way.

This definition is helpful because it highlights that neoliberalism considers individual and economic interests and does not value the social costs associated with its implementation. For example, the Health and Social Care Act 2012 is neoliberal because it focuses on the needs of the individual rather than the collective. This legislation altered the responsibility for HIV services and changed how HIV services are delivered; emphasising individual needs rather than providing support collectively. The Act fails to account for the social cost of making these changes, for example, by meeting the needs of the collective. Neoliberalism has also been hostile toward the public realm and embodies anti-welfarism and anti-statism policies to dismantle the welfare state (Clarke, 2004). These descriptions of neoliberalism offer a view that perceives it as an economic model of politics that focuses on individual interests rather than the overall state interests.

The neoliberal doctrine has also evolved as an expression of the political will of the capitalist class, particularly the financial institutions, to re-establish their revenues and power (Connell and Dados, 2014). The doctrine reflects the self-interests of the capitalist class, emphasises the economy and gives power to corporations over a focus on transforming the administrative state responsible for human wellbeing (Apple, 2000). Neoliberal governance reduces the sense of communal solidarity since it anticipates that subjects act in their self-interest (Pickren, 2018) to maximise their benefit and reproduce economic entrepreneurs to elevate individual choice within an unregulated free market. In doing so, the individual is situated at the centre of economic acts (Kotz, 2015). In sum, neoliberalism positions state economic activity as ineffective, wasteful and harmful to individual choice and prefers an unregulated free market. This standpoint is contested by Saad-Filho and Johnston (2005) and Brenner et al. (2010), who argue that neoliberalism no longer refers solely to the ideological creed of the free market but a market which replaces state systems with a market-led regulatory system.

There is a view that the market and the state exist in a zero-sum relationship, and the state's destruction results in the individual's automatic expansion (Peck, 2012). In *Capitalism and Freedom*, Friedman (1982) asserts that 'to the free man, the country is the collection of individuals who compose it, not something over and above them '(Friedman, 1982: 1). As a result, the public, the social and the communal are denied, and replaced with a collection of individuals, reducing the central government's scope and power and dispersing it downwards to regions and localities (Philips and Whannel, 2013). This depends on the 'denial of shared communal and interdependent interests of humanity '(Philips and Whannel, 2013: 70). In other words, neoliberalism is only concerned with the individual and their interests and removes any reliance upon others.

Many studies on neoliberalism have been published, leading it to become a broad concept that cannot be understood as a singular set of ideas emanating from one source. Instead, neoliberalism has become a contested term and has been subjected to much debate. Frustrations with neoliberalism have been raised, with some viewing it as a chaotic concept that is 'inconsistently defined, empirically imprecise and frequently contested '(Brenner et al., 2010: 182). When the concept is discussed, its meaning is altered from paper to paper (Castree, 2006), resulting in neoliberalism becoming a broad and inflationary concept that compounds rather than aids an understanding of how the world works and changes (Adam, 2016). Many of its influential developers acknowledge that neoliberalism is a controversial, incoherent and crisis-ridden term (Rajesh, 2015). Much of the criticism of neoliberalism is partly due to the historical transformations and how it has been embedded at different levels within the global context (Moore et al., 2011). This inconsistency has led others to critique the concept.

Considering the references to neoliberalism in this section, I recognise some concerns with this expression because the currently existing terms do not provide a definitive meaning behind its use in this study. I present my concept of neoliberalism, which brings together these conceptualisations of the terms. Reflecting on the points I raise here; I define neoliberalism as a political ideology focusing on a new role for

the state where private interests play a pivotal role in providing services. In response, there is a push towards self-responsibility, which is free from collective governance, and the individuals are then encouraged to create their success through personal interests. With this in mind, I will demonstrate how this economic model has influenced austerity politics in England.

### **2.2.2 Austerity Politics: The Role of Neoliberalism in the Creation of Austerity**

So far, I have outlined neoliberalism's part in changing the state's role to enable self-responsibility and individualism to flourish. Neoliberal thinking can invoke austerity as a measure to push the agenda of self-responsibility and individualism forward. A growing body of literature has investigated the relationship between neoliberalism and austerity. However, before discussing this literature, I will define the meaning of austerity.

The term austerity is complex and political. Bramall et al. (2016) turned to anti-austerity groups across Europe to define the term. However, they found that definitions of austerity varied across European anti-austerity groups. Some movements were against the political structures which imposed austerity politics, such as the European Union (EU). On the other hand, austerity could have centred around cuts to public services or privatisation. In the UK, the UK Uncut campaign focused on the relationship between corporate tax avoidance and reductions in public spending. Some may argue that the UK Uncut campaign is not about an anti-austerity policy but about pointing to an alternative way of eliminating the deficit (Bramall et al., 2016). However, the question remains: What is meant by the term austerity?

In *The Rise and Fall of Capitalism*, David Kotz (2015) discusses the concept of austerity. He recognised that neoliberalism played a significant role in austerity politics. Kotz (2015) further found that austerity policies focused on large government deficits and the rising ratio of public debt to gross domestic product (GDP) in each country affected by the recession. However, Berry (2016) noted that the UK had the lowest public debt of any of the G7 nations. The austerity agenda

focused on the high levels of private debt and the housing market, coupled with the specific impact of reduced credit availability. The government pursued a funding package that bailed out the banks and austerity politics, then reduced public spending.

Initialising a focus on public borrowing enabled Conservative governments to focus on the “big government” narrative (Kotz, 2015). The Conservative/Liberal Democrat Coalition government initiated the Spending Review, and as early as October 2010, significant cuts in public spending were confirmed (Lowndes and Gardner, 2016). This Review oversaw substantial changes to local government funding, with an overall cut of 27% in the proposed financing. As part of the Review, healthcare funding was protected, but the report suggested reform to the current model. The “Big Society” agenda was introduced and set about changing perceptions of individuals 'and states' roles over time. Reducing the role of central government came to the fore when Westminster started to devolve powers.

## **2.3 Devolving the United Kingdom: From Politics to Healthcare**

Neoliberalism and austerity politics have been central in the design of devolution politics. Before I discuss the role of devolution in the de-governance of England, I will briefly discuss its meaning. Etymologically, it originates from the Latin word “devolvò”, which translates to mean “roll down.” In the UK, devolution has been used to transfer powers from the central government to lower or regional levels, for example, the transfer of powers from the Central Government to Scotland, Wales and Northern Ireland (Deacon and Sandry, 2007; UK Parliament, 2021). As a result, devolution has created autonomous, elected governments in the respective nations.

### **2.3.1 Devolving Powers from Westminster to Scotland, Wales and Northern Ireland**

Devolution of the United Kingdom began in the 1990s when New Labour propagated multi-scalar power (Fuller and Geddes, 2008) and created legal frameworks for Scotland, Wales and Northern Ireland (O'Neill, 2014). In this case, multi-scalar power refers to the transfer of powers from Westminster to devolved administrations in

Scotland, Wales and Northern Ireland. A significant dimension of multi-scalar power is linked to the modernisation and rescaling of the state (Stoker, 2004); this involves various forms of managerialism and privatisation policies and the consolidation of the mixed market in local public service provision.

In Scotland, Wales and Northern Ireland, devolution 'is a highly asymmetric arrangement in which the UK government is responsible for not just shared policies such as defence, but also the public policies of England such as health care' (Greer, 2016: 18). This arrangement works because 85% of the UK's population resides in England, so Scotland, Wales and Northern Ireland can avoid those policies where support is primarily confined to England. Devolving Scotland, Wales and Northern Ireland created significant changes to the political and policy landscape of the UK. It saw these devolved administrations taking on powers to independently develop policy from Westminster in critical areas such as healthcare (Rummery and Greener, 2012). Devolving powers to the newly created National Assemblies in Wales and Scotland also provided opportunities to develop new forms of citizen engagement with governments.

These devolved nations have introduced innovative reforms, such as petition systems, encouraging participation by groups and individuals across these societies (Bochel, 2012). Although the political elites have enabled opportunities for broader citizen engagement, this can be seen as a sanitised form that fails to realise the far-reaching institutional change that could rebalance power relations within decision-making and governance. Despite the claims made by Labour and the Government to advance options to increase citizen engagement, 'governments tend to be reluctant to expand the scope for public deliberation when it is seen to constrain the power of institutional representation' (Davidson and Elstub, 2014: 381). In other words, governments tend to refrain from obtaining the public's opinion on projects that could restrict their ideological goal.

Although devolution has played a pivotal role in the evolution of the United Kingdom of Great Britain and Northern Ireland, its implementation has had some drawbacks.

Deacon and Sandry (2007) highlight three perceived disadvantages: it buys into separatist ideology, it can lead to more significant variations of standards in delivering public services, and it costs money. Devolution buys into the rhetoric around separation as it is one step further towards complete independence, as in 2007, nationalist parties were the second most powerful political parties in Scotland and Wales. However, it is essential to note that devolution can also be an attempt to prevent complete independence. Secondly, devolution can lead to more significant variations of standards in delivering public services, such as welfare or healthcare provision across the UK. Some nations provide a greater range of universal benefits for their citizens, for example, free prescriptions in Scotland and Wales; thus, the availability of free PrEP in Scotland since 2017. Consequently, this may lead to greater inequity in providing services across the UK.

Finally, devolution costs money, and the increased cost of running new government buildings and new devolved administrations can run into hundreds of millions of pounds (Deacon and Sandry, 2007). There are arguments that devolution brings about too many politicians: those living under devolved governments could be represented by up to five different layers of government—town council, county council, regional assembly or parliament, Westminster, and the European Union, depending on the timeframe being considered (Deacon and Sandry, 2007). There are numerous arguments against devolution because it can confuse who has responsibility for specific issues. Different layers of government create a 'buck passing' responsibility, and conflicts between the layers of government can result in chaos over the provision of services. In recent years, various acts of parliament, including the Health and Social Care Act 2012, and policies have been created, confusing who is legally responsible for delivering specific HIV services. The impact of the Health and Social Care Act 2012 on the legal responsibility for healthcare services will be explained later in Chapter Five.

Although devolution creates complexities in understanding who is responsible for providing public services, there continues to be a push from the central government to devolve powers from Westminster to regional levels. In doing so, governments

can shift responsibility for services. In the next section, I discuss how decentralising England has created a sub-national state.

### **2.3.2 Devolution as a Process of Rescaling the State**

The last decade has witnessed a significant shift in attitudes towards devolving powers from central government to regions across England. Since 2010, the British government has sought to reshape economic developments across England and emphasised developing a regional city scale to unlock economic growth (Beel et al., 2018). The Conservative/Liberal Democrat Coalition Government sought to address the recession's consequences by focusing on city regions (Cox, 2016). They enacted their vision by decentralising government systems downwards onto the local government and creating devolved city regions. Earlier, Gerry Stoker (2004) commented that devolution propagation led to the rescaling of the state into various forms of managerialism, privatisation policies, and a mixed market which had re-created the provision of local public services.

Devolution creates a system of governance where decisions can be made locally by those who know the key issues, although this has removed accountability from the centre. There can be significant advantages to building economic and industrial strategies and managing devolved budgets at the city region scale. One such example is presented by Schneider and Cottineau (2019). They write that 'integrating the provision of employment, housing and care at the scale of labour markets... [ensures] the benefits and costs are shared at the level of the combined authority' (Schneider and Cottineau, 2019: 18). In essence, devolution enables local policymakers to have control over the decisions which affect the local communities, thus creating informed-policy-making. It is beneficial to allow decision-makers to identify and promote local issues on the policy agenda because it is difficult to do this exclusively with a top-down, centralised approach. In theory, integrating healthcare provision locally might account for differences between local authorities in the same region (Schneider and Cottineau, 2019).



The first established combined authority in England was in Greater Manchester and was aptly named the Greater Manchester Combined Authority (GMCA). Established in 2011, the GMCA did not offer anything new to the region because the ten boroughs of Greater Manchester—Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan—were already working together. However, the GMCA built upon and centralised the work of the boroughs, such as transport, regeneration and attracting new investment to the region (Lowndes and Gardner, 2016). In 2015, the Manchester City Region evolved to take on strategic oversight of substantial health funding, conditional on the basis that a metro mayor was elected (Cox, 2016; Lowndes and Gardner, 2016; Vize, 2016). The Greater Manchester model provided a basis for other devolution trends across England.

Building on the Greater Manchester example, as of 2015, four other local authorities devolved and transformed into combined authorities: Liverpool City, North East, Sheffield City, and West Yorkshire (Lowndes and Gardner, 2016; Institute for Government, 2019). These combined authorities and the GMCA were pivotal to George Osborne's (the Chancellor of the Exchequer, 2010 to 2016) Northern Powerhouse vision. The Northern Powerhouse vision represents a significant part of the UK economy and covers nearly one-quarter of England's population. The 'primary aim of the programme was a spatial rebalancing of the UK economy by encouraging development in the North of England so as to create a counterweight to London' (Parr, 2017: 491). The aim of the Northern Powerhouse remains deliberately vague (Cox, 2016), though, and it could be presented as a programme which offers new opportunities for the North. According to Lee (2017), the Northern Powerhouse programme adopts a *laissez-faire* approach because it would require significant resources to achieve the (vague) aims. Thus, 'it seems more like a brand first and a strategy second' (Lee, 2017: 4). This is because the brand could be applied to focus and comprehend existing policies, for example, 'new motorways, enterprise zone and so on can all be branded as Northern Powerhouse projects—lending coherence to scattered policy initiatives and increasing 'brand awareness'' (Lee, 2017: 17).

Therefore, keeping the aim vague enables the government to change its vision to suit its ideology for the north.

The development of devolution across England has shaped 'an acutely uneven geography of localities, cities, and regions' (Danson et al., 2012: 5). It pays little attention to poverty and social inequalities (Etherington and Jones, 2009). This observation links to the work of Irvin (2008), who argues that cities have become powerhouses for the neoliberal agenda. As a result, unacceptable levels of inequalities of American proportions have been created (Danson et al., 2012). Schneider and Cottineau (2019) call for a reversal of neoliberalism and the reinstatement of Keynesian economics because they believe cities would generate more acceptable levels of inequalities and social democracy. In light of the literature above, it is possible to conclude that combined neoliberalism, austerity, and the focus on creating city regions across England shifts risk away from the centre and onto local politics.

### **2.3.3 Devolving Healthcare to the Greater Manchester Regional Level**

By 2020, the British government had established ten combined authorities—Greater Manchester, Liverpool City Region, Cambridgeshire and Peterborough, North East Combined Authority, Sheffield City Region, North of Tyne, Tees Valley, West Midlands, West of England and West Yorkshire Combined Authority (Institute for Government, 2019). Of these, Greater Manchester is the only combined authority which has taken charge of healthcare provision.

Against the backdrop of devolution, there has been a resurgence in the interest in a more significant role for local government in the decision-making process for local NHS services. The clearest possibility for the government to further devolve the UK lies in integrating NHS health and local authority social care (Greer, 2016). The creation of the Greater Manchester Health and Social Care Partnership (GMHSCP) merged the two budgets and created a joint commissioning board that negotiates with members of an overarching provider forum (Greer, 2016). Creating the GMHSCP

has resulted in decision-making for healthcare spending to remain locally within the Manchester City Region.

Walshe et al. (2016) argue that the devolving healthcare spending within Greater Manchester is part of the devolution movement, which has been happening since 2011. Devolving healthcare in Greater Manchester has two aims: to secure the greatest health improvement for the population and to reduce the health inequalities within the city region and between Greater Manchester and the rest of England (Walshe et al., 2016). The central tenet of devolving healthcare is enabling patients to have some choice over their health outcomes. This choice further strengthens the democratic process by allowing more direct local and sub-national decision-making (Petraatos, 2018). Walshe et al. (2016) reviewed the published reports, papers, documents and presentations from the leaders of Greater Manchester. In doing so, Walshe et al. (2016) found that the GMHSCP sets out four high-level reform themes: upgraded population health prevention, transformed community-based care and support, standardised acute and specialist care, and standardised clinical support and back office services. These reforms link to neoliberal views of healthcare delivery because they seek to remove specialist services, thereby focusing on cheap, generic healthcare services.

Due to the GMHSCP's infancy, more literature must investigate the impact of devolving healthcare to the Greater Manchester level. To understand the effect that devolving healthcare has on the health of Greater Manchester residents, I turn to the literature written from an international perspective. Internationally, devolving healthcare at the sub-regional level is a moderate move, as local and regional governments in Sweden, Norway, Spain, and Italy play an essential role in their healthcare systems (Walshe et al., 2016). In these systems, devolution arrangements for healthcare are established in primary legislation, which defines the extent and scope of devolved powers. However, the GMHSCP has no legal force; instead, it delegates power to a coalition of public bodies rather than introducing a single statutory authority (Walshe et al., 2016). The lack of UK legislation has had

implications for HIV services because there still needs to be consultation between each local authority and NHS services across the Manchester City Region.

In Sweden, Fredriksson and Winblad (2008) conducted a study which explored the impact of devolving a healthcare system. They found there to be an increased focus on patient choice, which, besides being viewed as a healthcare efficiency, is a way for the state to empower citizens to make decisions over their health outcomes. The reason for focusing on patient choice was because, during the 1980s, citizens criticised the Swedish healthcare system as there had been a discrepancy between the supply and demand of medical services, resulting in long waiting lists. Subsequently, introducing patient preferencing and patient participation in healthcare choices resulted in shorter waiting times. It also means that patients can elect for their care to occur at a hospital closer to their friends or relatives (Fredriksson and Winblad, 2008). Selecting where treatment is provided benefits patients because it can result in better outcomes.

Devolving healthcare can equate to increased patient choice. A body of literature has investigated this claim, and Zolkefli (2017) found that autonomy leads to improved patient satisfaction, and patients are more likely to engage with care. This decision has enabled people living with HIV to meet their needs more locally rather than travelling to a few specialist centres, which may not suit their needs. However, a neoliberal focus has recently witnessed a shift from specialist to generalist services, impacting health outcomes for people living with HIV and AIDS.

## **2.4 HIV and AIDS Healthcare**

### **2.4.1 The Effect of Neoliberalism on HIV and AIDS Healthcare**

HIV and AIDS provide an excellent case to understand how neoliberalism affects public healthcare. Neoliberalism has been pivotal in shaping political preferences over the past forty years and has been at the centre of HIV and AIDS healthcare systems. Neoliberalism has historically impacted global health and continues to shape global health through market-based approaches. Increasing reliance on the

private sector has become a feature of many health programmes (Zhou, 2021).<sup>1</sup> The reliance on the private sector for providing HIV and AIDS services has undoubtedly been a feature of many papers in the literature.

HIV is a novel epidemic because it is considered to be exceptional in its severity, long-term impact and the fact that it poses a unique challenge to public health (Zhou, 2021). In recent years, firm commitments to neoliberal values have underpinned the Conservative and Liberal Democrat Coalition Government and subsequent Conservative Government's agenda for the NHS and HIV healthcare. This strong commitment, coupled with the pursuance of an austerity programme and a fundamental restructuring of the NHS through the introduction of the Health and Social Care Act 2012, has seen the orchestration of a reduced role of the state in providing healthcare services. Furthermore, this model creates a framework premised on the forces of a competitive market and increased responsiveness to the needs of local patients (Pownall, 2013). Writing just before the introduction of the Health and Social Care Act 2012, Grimshaw and Rubery (2012) argued that the Act would provide a market-led system where any willing provider—public or private sector, voluntary, charity or social enterprise—could tender to provide services. The government believed it should not hold a monopoly over healthcare provision. The Act requires the provider to have a license, but as long as the individual or organisation holds the required license, they are permitted to provide services under it.

Others have commented on the neoliberalisation of healthcare from a labour perspective. In her text, Zelnick (2011) argues that the international labour situation for nursing is shaped by neoliberalism, which has been problematic for nurses and health systems worldwide. Within the framework of increasing the commodification and privatisation of healthcare services, the global nursing shortage has been driven

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<sup>1</sup> The paper presented by Zhou is within a Malawi context; thus, the funding structure of their response to the HIV and AIDS epidemic will be different to that in the UK. For example, Malawi is a developing nation and one of the poorest, which relies on non-governmental organisation (NGO) assistance for its HIV and AIDS response.

by low salaries and low working conditions (Zelnick, 2011). In an African context, the consequences of neoliberalism have resulted in a “brain drain” of skilled caregivers (Padarath et al., 2003; Rowden, 2009). The brain drain problem occurs when there are shifts in employment among healthcare workers, and it can manifest itself in three main areas: 1) healthcare workers moving to rich countries for work; 2) when workers move from working in public/national health systems to NGOs or the private health sector; and 3) nationally when the healthcare workers migrate from rural to urban areas to undertake work (Rowden, 2009). Although the brain drain problem relates primarily to developing countries, there is evidence that the UK is experiencing it, too.

In recent years, the focus on zero transmissions of HIV, the emphasis on generalist services and the introduction of biomedical interventions to suppress HIV are all creating a situation where specialist knowledge of HIV is being lost. I will now discuss how people accessing PrEP, an HIV-preventative treatment, are starting to witness this brain drain where there is a lack of sexual health workers.

#### **2.4.2 Neoliberal Influences on Preventative HIV Treatments: The Case of PrEP**

Several studies have investigated the availability of PrEP in healthcare systems and neoliberal influences. Before continuing, I will explore the differences between PrEP (Pre-Exposure Prophylaxis) and PEP (Post-Exposure Prophylaxis). PrEP is a medicine people at risk of acquiring HIV take to prevent contracting HIV from sex or injection drug use. It effectively prevents HIV (Centers for Disease Control and Prevention, 2021). PEP is a treatment available for people after the virus’s transmission. However, to be effective, PEP must be taken within 72 hours of exposure (Terrence Higgins Trust, 2019). The main difference between PrEP and PEP is that PrEP is used for people at risk of acquiring HIV (pre-event), whereas PEP is used for people who believe they have been exposed to HIV (post-event).

Although it might be expected that the prospect of protecting people against HIV infection via PrEP, a daily pill, would have received unqualified support, it has raised

and, in some ways, reignited a long-standing debate on the sexual cultures of gay men. The introduction of PrEP has also ignited debates around the reliance on self-responsibility, which links to further reductions in support. Before discussing this further, I will briefly outline the commissioning of PrEP.

In 2016, Public Health England established the PrEP IMPACT trial to understand whether providing PrEP to those at risk of acquiring HIV would reduce new HIV infections. The PrEP IMPACT trial has now concluded, and both Public Health England and the NHS agreed to commission PrEP for prescription in April 2020 (Kirby, 2020). However, due to the COVID-19 pandemic, the rollout of PrEP was indefinitely postponed (Kent, 2020). Currently, there is limited literature examining the impact of delaying PrEP access, especially considering the potential impact this delay will have on new rates of HIV.

#### **2.4.3 The Impact of Stigma on People Living with HIV**

Living with HIV requires adjusting and learning how to live with and manage a chronic health condition. At the same time, they may also experience social stigma, which can fundamentally change their self-perception and impact how they interact with others (Earnshaw and Kalichman, 2013). Some people internalise stigmatising experiences and start to fear that they will encounter social rejection because of their HIV status (Fekete et al., 2018). This anticipated stigma can cause people to think that they cannot disclose information about their HIV status or rely on others for support to manage their condition (Fekete et al., 2018). Although advancements in treatment have significantly reduced the long-term effects of HIV, service users are continuing to report HIV-related stigma and discrimination socially and in healthcare settings, for example.

The stigma and discrimination that service users experience can be linked to low levels of knowledge about HIV transmission, the treatments available and treatment outcomes (National AIDS Trust and Fast-Track Cities London, 2021). It is estimated that one in five people could identify the primary or potential routes of HIV

transmission, and only 16% of people know that HIV treatments could stop the virus from being transmitted. The National AIDS Trust and Fast-Track Cities London (2021) report found that only a quarter of people knew about the availability of PrEP and knew that it could prevent acquisition. Both Harris (2018) and the National AIDS Trust and Fast-Track Cities London (2021) found there to be confusion over how HIV is transmitted as there is a continued association of HIV acquisition with behaviours that are perceived as irresponsible or taboo, for example, condomless sex and multiple sexual partners. To understand the impact of stigma, it is essential to unpack the concept.

Foremost stigma has been defined as 'a characteristic of persons that is contrary to a norm of social unit' (Stafford and Scott, 1986: 80). However, it is also rooted within the individual socio-cultural contexts (Goffman, 2009) and can be 'an attribute which is deeply discrediting' (Goffman, 2009: 11). For example, the stigma attached to HIV and AIDS varies depending upon where the individual is situated, so community, religion or sexuality can play a significant role in others' understanding of HIV and AIDS. Stigma can be a marker of tarnished character within social relationships, and it can discredit or devalue anyone in various settings, including the workplace, education and healthcare settings. Some people may experience social ostracism from friends and family (Earnshaw and Kalichman, 2013) or be devalued because they bear the mark of HIV.

Other theorists conceptualise stigma as a social process involving distinguishing and labelling differences, stereotypes, separation, status loss and discrimination (Link and Phelan, 2001). Link and Phelan (2001) further emphasise that stigma is a social process reliant upon the ability to reproduce power hierarchies between stigmatised and non-stigmatised people. Parker and Aggleton (2003) conceptualise stigma as a social process which operates at an intersection between culture, power and difference. Moreover, they stress the importance of studying the relationships between power, culture and difference within social contexts to understand the stigma. Link and Phelan (2001) and Parker and Aggleton (2003) highlight the social processes of constructing stigma. Depending on the socio-cultural context, these



social processes may operate differently, which helps explain why and how HIV- and AIDS-related stigma varies across different cultures.

Stigma can have a traumatic impact on people who experience it, especially concerning those who self-stigmatise (Hodgson, 2007). Self-stigma can be hugely damaging and cause poorer mental health because it can fundamentally change how a person sees themselves in minutes. People may view themselves as being marked, different from everyone else and feel dirty, ashamed and guilty (Hodgson, 2007). Therefore, self-stigma and stigma are damaging and can affect successful health outcomes. They can hamper efforts to reduce new infections and engage people in treatment, care and support programmes (Stangl et al., 2013). One example of this has been offered by Turan et al. (2019), who found that stigma can intensely affect an individual's mental health and, therefore, affect adherence to their antiretroviral treatment. Addressing HIV-related stigma with the service user early in their diagnosis and treatment initiation process can be crucial in reducing the individuals' risk of suboptimal adherence.

In health settings, HIV-related stigma and discrimination can have a (un)conscious impact on the decisions made by and the abilities of non-HIV specialist healthcare staff to treat HIV healthcare service users (Nyblade et al., 2009). Despite improvements in knowledge and treatments, service users experience stigma in generalist healthcare settings. Reasons for this include staff perceptions of safety when delivering services to people living with HIV, HIV-related stereotypes, and perceived ethical obligations of treating service users (Yuvaraj et al., 2020). In addition, Lazuardi et al. (2019) write about the discriminative acts people living with HIV may experience when attending generalist healthcare settings. These acts include neglecting patients, treating patients with HIV differently, denying care, the testing and disclosure of a patient's HIV status without consent, unnecessary overuse of precautions to prevent "perceived" HIV transmission, the overt labelling of patients' belongings or files, and verbal abuse and gossip (Lazuardi et al., 2019). Although these are stigmatising and discriminatory actions, they are often found to come from a place of fear. The NHS has invested little in educating staff about

developments in HIV healthcare and treatments. At the same time, activists have been central to the response to improvements in HIV and AIDS healthcare.

## **2.5 Organising: Activism at the Core of the Response to HIV and AIDS**

Activism has been pivotal since the start of the AIDS crisis in fighting for improved developments in HIV and AIDS healthcare. In the US, for example, HIV activists played a unique and unprecedented role early in the epidemic. They became the voices, caregivers and advocates of an outraged community and confronted the new, lethal and highly stigmatised disease (Rabkin et al., 2018). Although activism is not central to this thesis, the literature must be reviewed because it is key to the history of HIV and AIDS healthcare developments.

Throughout the literature, scholars theorise activism differently. Svirsky (2010) has characterised activism as something where people undertake various actions to disrupt the status quo, which people have become accustomed to. Millward and Takhar (2019) argue that activism, or collective actions, are an established feature of society, and they challenge inequalities, exclusion and injustices rooted in oppression. Oppressive practices and exclusion policies can motivate people to become activists because their actions could shift cultural, social and political attitudes (Millward and Takhar, 2019). Activists have sought collective actions, subsequently improving the medical, political and social treatment of people living with HIV.

In the US during the 1980s, ACT UP (AIDS Coalition to Unleash Power) sieged the Food and Drug Administration Headquarters in Maryland on 11th October 1988. The siege occurred because AIDS activists were appalled by the entire Federal response to the AIDS crisis; 'we are disgusted with the inadequate state and local response as well' (Eigo et al., 1988). This was just one of the many acts undertaken to bring public attention to the AIDS crisis. Around a similar time, HIV activists in the UK formed Manchester's arm of ACT UP. On the 20th February 1988, 20,000 people protested through Manchester City Centre to show disapproval of the Conservative Government's introduction of Section 28 of the Local Government Act 1988

(Superbia, 2021). Section 28 was a homophobic provision which sought to "protect" children from gay identity (Greenland and Nunney, 2008) by 'restrict[ing] the use of positive representations of lesbians and men who have sex with men in education and other forms of local government provision' (Binnie, 2013: 245).

Introducing Section 28 within the Local Government Act 1988 was not accidental as it enabled the Conservative Government to attack Local Labour Governments, such as Manchester City Council, because they funded lesbian and gay political events (Smith, 1994b). Thatcher's Government saw Local Labour Governments as allowing "homosexual militants" to take over local educational institutions, and gays and lesbians were seen as having special privileges within local programmes.

### **2.5.1 Activist Responses to Changing HIV and AIDS Healthcare**

Since the 1980s, individuals have formed alliances with public health officials who wanted to boost responses to HIV and AIDS by fighting to propel the issue up the policy agenda (Weeks et al., 1994). HIV and AIDS activists have campaigned for officials to recognise the severity of and respond to the epidemic. Epstein (1996) discussed the impact of AIDS activism on official responses to the epidemic. He writes from within a US context:

The impact of the AIDS movement on biomedical institutions in the United States has been impressive and conspicuous ... [and] social movements often have a "hidden efficacy" which becomes apparent only over time.

(Epstein, 1996: 346)

This discussion of social movements demonstrates the role of activism in biomedical institutes during the 1990s, and the importance of activism may not appear instantly relevant. However, activism has since produced crucial developments for people living with HIV and AIDS. A few years later, Watney (2000) debated the emergence of AIDS treatment activism in the US during the second half of the 1980s. Treatment activism emerged in response to at least two significant factors: the direct experience

of acute illness and death presented by the epidemic and a lack of willingness from the medical and pharmaceutical industries to act in the interests of people living with HIV and AIDS.

Treatment activism was critical for HIV and AIDS activists, who lay claim to the production of treatment regimens because the activists encouraged people living with HIV to participate in treatment trials, thereby taking control of the medical knowledge (Epstein, 1996). Gay activists sought to resist the conflation of homosexuality with promiscuity and disease through a process called “de-gaying” the epidemic. Gay activists later reversed the de-gaying through a process known as “re-gaying” through strategic and political uses of the epidemiological data. However, recent movements have focused on preventative regimens (Keogh, 2008).

Treatment activism was also crucial for people living with HIV and AIDS as it was a suitable mechanism to question the medical information generated and who generated it. The ability to question information is embedded within the feminist methodological framework, which considers what exists and how people think about what exists (Ramazanoglu and Holland, 2002). Questioning knowledge is critical because it enables people to understand what they are told and not just accept the narrative informing their thinking. This interest in information was significant in the 1980s. This period saw profoundly negative social perceptions of the constituencies worst affected by HIV and AIDS in the developed world, such as gay and bisexual men, injecting drug users, their sexual partners, and their immediate friends, families, carers and communities (Watney, 2000). Activists, therefore, sought to challenge the narratives surrounding HIV and AIDS. Watney (2000) further identified that treatment activism in the UK at the turn of the century was still behind the US by about seven years. Material published in the US gave citizens a complete picture of available medical information and the debates and choices around HIV healthcare. In contrast, publications in the UK rarely published material that had immediate relevance for people facing treatment in clinics.

In recent years, activists have focused on creating awareness of HIV preventative treatments, such as PrEP, and have campaigned for health providers to prescribe

these medications routinely. Before its routine commissioning by the NHS, PrEP activists used market logic and techniques to characterise PrEP as a medical commodity. Some users engaged with these commodified ways to access PrEP due to the government's lack of provision. By doing this, activists created a grey market for PrEP, which circumvented government controls in England and bypassed the state without directly challenging it (Martinez-Lacabe, 2021). However, a small group of activists challenged the government's decision not to prescribe PrEP routinely. Globally, gay and bisexual PrEP activists created drug awareness within their locality (Gómez et al., 2022). However, this awareness is vital to ensure that we reach the goal of no new transmissions of HIV by 2030.

### **2.5.2 Women and HIV and AIDS Activism**

In 2021, it was reported by UNAIDS (2022) that women and young girls accounted for 46% of all new HIV infections globally. Part of the reason why HIV figures are high amongst women is that there has been a focus by governments and health authorities on aiming health programs at men (Campbell, 2013), gender inequalities (African Union & UN Women, 2021) and a lack of empowering women about HIV and AIDS treatments (Du Plessis, 2011). As a result, women activist networks have formed to respond to this lack of awareness around HIV and AIDS.

Globally, more women than men live with HIV (Anderson, 2012; UN Women, 2018). In the UK, the number of new HIV diagnoses in women rose from 10% in 1994 to 34% in 2009 (Anderson, 2012). In 2016, this figure had increased to 39%, but the following year, new rates of HIV amongst women decreased to 26%. Although new rates of HIV amongst women have fallen, it is still higher than new rates amongst heterosexual men in the UK (Public Health England, 2019). Jungar and Oinas (2004) write that the HIV and AIDS discourse has been constructed as something that primarily affects men.

The findings of Jungar and Oinas (2004) resonate with a recent study published on women ageing with HIV. In their research, Stevenson (2022) found that women who

are living with HIV in the UK have feelings of being left out of the prevailing narratives about HIV, and they 'experience intersecting stigma and discrimination based on their HIV status, sex, gender, race and other identities' (Stevenson, 2022: 8). Furthermore, women in the UK have tended to care for other women living with HIV and organised around their identities. When women are diagnosed with HIV and AIDS, Stevenson (2022) found that they reach out to women's networks due to fears of stigma in generic HIV and AIDS services.

In the Manchester City Region, women have been central in responding to the HIV and AIDS epidemic. To raise awareness of Black and Minority Ethnic people, women worked in the community to raise awareness, informed people about HIV and AIDS and gave them messages. Women also worked in needle exchanges, which enabled people at risk of HIV to swap dirty needles for clean ones (Nkwenti, 2017). Other women worked to create visibility by working with the council to erect a five-foot mesh red ribbon on top of the town hall for World AIDS Days and ensuring that messages were communicated (Griffiths, 2017). These instances of activism highlight some of the work that women have undertaken to create awareness.

In the US, one of the most visible instances of women's HIV and AIDS activism was in 1998. An article published in the January 1988 issue of *Cosmopolitan Magazine* informed women that they did not have to worry about acquiring HIV, even if they engaged in unprotected vaginal intercourse with an HIV-infected man. However, the Center for Disease Control (CDC), the US federal agency in charge of epidemiological research, had already registered two thousand cases of women living with AIDS. When the article was written, 26% of those women had acquired HIV through unprotected vaginal sex. As a result, women members of ACT UP organised and demonstrated in front of *Cosmopolitan Magazine's* office in icy cold weather. In total, 300 activists distributed around 5,000 fact sheets calling for a boycott of the magazine. Two months later, the magazine published its first article on women and safer sex (Elbaz, 2003). This was one of the first examples of women organising to create awareness of the impact that HIV and AIDS is having on them.

Women in the 1990s were also involved in a significant amount of activism which led to policy changes which changed the 'CDC definition of AIDS-related symptoms to include conditions more appropriate for women, as well as an increase in NIH [The National Institutes of Health] funds for research devoted to AIDS-related issues in women' (Baird et al., 2009: 9). A pivotal moment for women's activism was pressuring the CDC into expanding its list of indicator diseases to include fifteen opportunistic infectious diseases that women and injection drug users living with HIV tend to get (Christensen, 2009). The list of diseases includes 'atypical bacterial pneumonia, refractory (resistant to treatment) pulmonary TB, aggressive cervical cancer, refractory pelvic inflammatory disease, and invasive and chronic vaginal candidiasis' (Christensen, 2009: 64). Although expanding the list enabled doctors to identify HIV earlier, it meant that women living in poverty were unable to fund the sophisticated blood tests which identified these diseases. In most cases, impoverished women could not afford basic healthcare (Christensen, 2009). Despite this, increasing the list has meant that HIV can be detected earlier in women and those who inject drugs.

When considering the role of women's HIV activism, I must consider women's work in Africa. HIV and AIDS have significantly impacted women, and there has been a significant response to the epidemic in this region. A body of work has been published focusing on women living with HIV and AIDS and how they have responded to the epidemic (Jungar and Oinas, 2004; Du Plessis, 2011; Ramjee and Daniels, 2013). The spread of HIV and AIDS on this continent has significantly affected women (Jungar and Oinas, 2004). In particular, young women aged 15-24 are at a significant risk of HIV infection. UNAIDS (2022) estimated that 4,900 young women became infected with HIV globally, and of those, 4,000 women were infected in Sub-Saharan Africa.

In Sub-Saharan Africa, local grass-roots and women's activism has been involved in women's empowerment and HIV prevention (Jungar and Oinas, 2004; Robins, 2006), raising questions about dignity, rights and inequalities (Jungar and Oinas, 2010). In their study, the African Union & UN Women (2021) found that across the African

continent, gender inequalities are holding back the HIV response. As such, 'stigma and discrimination remain key barriers to the full realisation of women, men, girls and boys enjoy equal rights and access to HIV preventive and treatment services' (African Union & UN Women, 2021: 64). This resonates with the work of Stevenson (2022) in the UK who uncovered that women are being left out of the prevailing narratives on HIV. Therefore, African movements deal with these issues, specifically women's empowerment, issues around women's health and sexualised violence, and they emphasise the connection between HIV, sexuality and gendered-powered relations. By empowering women, these movements can provide platforms for women to talk openly about HIV and AIDS, subsequently generating local and contextualised knowledge (Jungar and Oinas, 2010). For example, in Zimbabwe, the Musasa Project highlights 'the difficulties most women face in negotiating safe sex in heterosexual relationships. This project is concerned with the connections between violence against women and HIV' (Jungar and Oinas, 2004: 100). The starting point of this group and others is that women, particularly young women, are acquiring HIV in more significant numbers than men (Jungar and Oinas, 2004). Although this point was put forward by Jungar and Oinas (2004) almost twenty years ago, UNAIDS (2022) reported that women and young girls accounted for 63% of all new infections in Sub-Saharan Africa in 2021.

In South Africa, HIV and AIDS activism has 'contributed towards new forms of health activism' (Robins, 2006: 320). These new forms of health activism are concerned with rights-based struggles and the creation of collectively shared meanings of the experiences of illness and stigmatisation that HIV and AIDS service users experience (Robins, 2006). At the start of the AIDS epidemic, women were subordinated from being able to attend support groups because of the burdens of care which was placed upon them. The gendered obligations of care, worsened by the COVID pandemic, may have also been one factor faced by women in Africa and across the globe. The 'overemphasis on female responsibility in curtailing new infections and caring for the sick and vulnerable.... [meant that] women were not empowered with knowledge about how to deal with ARV side effects, condom failures and the reluctance of husbands and male partners to be tested for HIV' (Du Plessis, 2011: 475). This left



women with little information about HIV and AIDS, putting them at greater risk of acquiring the disease. Therefore, women's movements in Africa have worked to empower women and create knowledge about HIV and AIDS.

Women's work has been pivotal in creating a knowledge base and ensuring that women and young girls are not significantly affected by HIV and AIDS. Their work has also been central in ensuring that everyone affected by HIV and AIDS is cared for and has access to information, education and treatment. Historically, women across the globe have worked to create awareness of HIV and AIDS, which is continuing today. Women have also worked to empower each other with knowledge about how HIV and AIDS are transmitted, provide women with information about preventative treatments and equip women with information about the range of available antiretroviral therapies. Amongst this, women also support women living with HIV and AIDS to reduce the stigma and discrimination they might experience.

## **2.6 Chapter Summary**

In conclusion, this literature review has shown that neoliberalism has been central to global politics and HIV and AIDS healthcare over the past four decades. There have been significant changes to the political landscape of the UK, from devolving powers from Westminster to respective authorities in Scotland, Wales and Northern Ireland in the late 1990s to decentralising powers to create the city region model. Greater Manchester was the test bed for the city region model because the devolution package also handed over control for health and social care spending. As a result, neoliberalism has started to undo "big government" in favour of shifting power to the local level. When this power shift happens, it is often delivered with lower funds. However, there is little research investigating how devolving not only politics but also healthcare impacts people. This project focuses on a local level, exploring how a devolved healthcare model affects people living with HIV and AIDS in Greater Manchester.

This literature review has also demonstrated that devolved healthcare models buy into the neoliberal model. This is because a devolved healthcare model enables patients to have some choice over their healthcare (Fredriksson and Winblad, 2008), making them more likely to engage with their care (Zolkefli, 2017). These insights into devolved healthcare models are interesting, but they have been undertaken from an international perspective and do not consider the unique political and social landscape of Greater Manchester. My research uncovers the complex political and social landscape of the Manchester City Region and questions how people engage with their healthcare providers. The study does this by analysing the health politics across the city region to understand the impact of changing HIV and AIDS healthcare provision within Greater Manchester.

The literature review has critically assessed the works on how neoliberalism and austerity politics impact the delivery of HIV and AIDS healthcare services. The introduction of the Health and Social Care Act 2012, coupled with the focus on biomedical interventions, has resulted in a loss of specialist services in favour of a shift towards cheaper generalist provisions. This impact affects not only physical health but also the mental health of people living with HIV. Changing to generalist services can result in stigma and discrimination from healthcare professionals (Nyblade et al., 2009; Stutterheim et al., 2009; Yuvaraj et al., 2020). Furthermore, people who experience stigma outside of healthcare may fail to seek support from generalist settings because of the anticipated stigma (Fekete et al., 2018). Currently, a limited number of studies explore the impact of moving from specialist to generalist services for physical and mental health services. It has been recognised by Ohrnberger et al. (2017) that physical and psychological health go hand in hand, and my study will address this gap in the literature.

Lastly, this literature review has highlighted the global responses of HIV and AIDS activists to the HIV and AIDS epidemic. The responses to the AIDS epidemic have been pivotal to improvements in HIV and AIDS healthcare; for example, the work of activists propelled the government to recognise the severity of HIV and AIDS (Weeks et al., 1994). Treatment activism has been vital to ensuring that people at risk of HIV

could acquire PrEP medication when it was unavailable on the NHS (Martinez-Lacabe, 2021). Furthermore, women have played a significant role in awareness raising, empowering other women and HIV prevention (Jungar and Oinas, 2004; Robins, 2006). In the next chapter, I discuss the methodology that I have adopted for this thesis and outline the research strategy that I have utilised in the thesis to explore the impact of devolution, neoliberalism and austerity on the governance of specialist HIV and AIDS physical and mental health services and the impact this has on the lived experiences of service users across the Manchester City Region.

## ***Chapter Three: Research Methodology***

### **3.1 Introduction**

This chapter will outline the methodology I utilised in conducting this research. This research aims to understand the impact of devolution, neoliberalism and austerity on the governance and delivery of specialist HIV and AIDS physical and mental health services and the impact this has on the lived experiences of service users across the Manchester City Region. Due to the complex and sensitive nature of conducting HIV and AIDS research, I adopted a qualitative methodology and an interpretative, analytical approach. This approach enabled me to collect a rich data set where I could uncover the challenges presented to HIV and AIDS service users living within the Greater Manchester Region, and it provided a platform for them to voice their realities.

Given the lack of research investigating the health politics of Greater Manchester, especially concerning HIV and AIDS healthcare, as identified in the literature review, I recognised that I needed to take a flexible approach through the utilisation of semi-structured interviews to capture the responses of the participants. I utilised a queer-feminist approach to investigate the changing HIV and AIDS healthcare provision within the Manchester City Region because of the sensitive nature of the research. Moreover, a qualitative approach was employed to collect the data because it allowed me to understand my participants views on the changing nature of HIV and AIDS healthcare across Greater Manchester. The chosen method of primary data collection through qualitative interviews, along with the use of secondary data, such as census data and data collected by HIV and AIDS-related organisations, has brought a nuanced understanding of the experiences of service users living with HIV and AIDS.

The structure of this chapter is as follows: first, it will describe the theoretical underpinning of the research and how I position myself within this research process. I then discuss the concept of interpretivism before outlining the recruitment phases of this study. Before considering the ethical challenges in conducting this research, I

discuss how I collected the primary and secondary data. Lastly, I summarise my chosen methodology.

## **3.2 Theoretical Underpinning**

In this section, I present the principles associated with a feminist approach to research and elements of queer theory before merging the two theoretical underpinnings to show why a queer-feminist approach was adopted to aid the data collection in this study. I will move on to discuss interpretivism, which has provided the epistemological foundation of this project.

### **3.2.1 Utilising Feminist Approaches to this Research**

I commenced this study utilising a feminist methodology to characterise and capture the responses of service users of HIV and AIDS healthcare provisions; organisations specialising in HIV and AIDS support, advice and advocacy services to improve health outcomes; healthcare staff specialising in HIV and AIDS healthcare and those who advocate for improved treatments; academics who work in the field of HIV studies; and activists who are campaigning for improved HIV and AIDS services. According to Taylor (1998), a feminist research methodology has four features (arguably there are possibly more): an emphasis on gender and inequalities, reflexivity and action. However, these four features are not exclusive to feminist research; we do not have to utilise them all.

At the centre of a feminist research approach is the recognition of gender and gender inequalities (Taylor, 1998). Beetham and Demetriades (2007) write that a feminist methodology tends to focus on the hierarchical power relations between women and men that have disadvantaged women throughout previous research processes. Considering the interconnected nature of race, ethnicity, sexuality, age and (dis)ability, I decided to put diversity and intersectionality at the core of my project. Moreover, feminist methodology invites us to take it seriously and pay special attention to the voices of marginalised individuals. Therefore, I was interested in the experiences of LGBTQ people and women with HIV and how different generations

living with HIV understand the services available to them in times of austerity and reduced service provision. This research sought to validate, give voice to, and understand the experiences of those women and men who have been marginalised or ignored in traditional positivist research (Taylor, 1998). However, to understand the experiences of those who participated in this study, another critical element of a feminist methodology was considered: reflexivity, which requires the researcher to reflect on their own experience within the social context (Letherby, 2010). Later in this section, I will position myself in this process to ensure the reader knows my standing.

Lastly, a feminist research approach lastly explores action, where the research undertaken informs those with power about what has been found. The researcher is responsible for informing those who have participated in the project about the findings and potentially taking those findings to those who can bring change (Taylor, 1998).

### **3.2.2 Queer Theory and the Research Approach**

Queer theory emerged out of and in response to feminism in the mid-1990s and developed partly in antagonism to some aspects of feminist, lesbian and gay politics of the 1970s and 1980s (Misgav, 2016). Early queer theory was preoccupied with questions of identity and the regulation of desire (Jacobs and Klesse, 2014). However, it has come to position sexuality as its main category of inquiry and is often associated with poststructuralist aspects of feminist thought and the HIV and AIDS epidemic (Namaste, 1994). Therefore, it seeks to deconstruct and decentralise the binaries of male and female, masculine and feminine, heterosexual and homosexual, that work to structure and organise social categories and relations.

Queer theory 'challenge[s] normative assumptions about sexuality and gender' (Nash, 2016: 132). The anti-normative character of queer theory 'seeks to subvert, challenge and critique a host of taken for granted 'stabilities' in our social lives' (Browne and Nash, 2016: 7). It does this by deconstructing the categories,

oppositions and equations that sustain sexual identities (Hennessy, 1994). Queer theorists tend to see binary identities as reinforcing problematic dualisms because you cannot have heterosexuality without homosexuality. To understand these “problematic dualisms”, I will demonstrate how one can use the term queer as both a noun and a verb. As a noun, queer refers to those who question conventional understandings of sex and gender, referring primarily to LGBT practices, relationships and subjectivities (Hennessy, 1994; Gorman-Murray et al., 2016). It is these identities that queer theorists seek to deconstruct. As a verb, the term queer unpacks essentialist understandings of normalcy by problematising its apparent neutrality and objectivity (Di Felicianantonio and Gadelha, 2017). A self-reflective approach works in some way to unpack arguments that the research is assumedly neutral and objective as it provides a basic epistemological standard by justifying the situated nature of the knowledge and the researcher's position.

It can also be argued that queer theory shares the “anti-categorical complexity” associated with poststructuralist thinking because it ‘deconstructs ’analytical categories ’(McCall, 2005: 1773). For instance, some queer theorists claim that there is an over-reliance on conceptual dualisms, such as male and female, and straight and gay, which helps to ‘reinforce the notion of minority as “other” and create binary oppositions which leave the “center” intact ’(Stein and Plummer, 1994: 182). By disrupting conventional understandings of gender, sex and sexuality, queer can problematise identity and the model of sexual orientation. Queer theory, therefore, marks queer as an ambiguous term which fails to subscribe to conventional identity standards. Jagose (1996) sums up the term queer as something which has ‘neither a foundational logic nor a consistent set of characteristics ’(Jagose, 1996: 96). There is nothing in particular that queer refers to because it deconstructs conventional dualist identities. The ambiguous nature of the term queer is often cited as one of the reasons for its mobilisation.

Politics in the 1980s, including the AIDS crisis, provided the climate needed to aid the popularisation of the term queer (Jagose, 1996). As discussed in the literature review, HIV and AIDS were constructed as something which primarily affected gay men

(Meyer, 1991), substance users and sex workers (Anderson, 2012; Doyal, 1994; Richardson, 1994). Although the AIDS epidemic cannot be said to have been a sufficient case for generating the conditions necessary for queer to emerge as an essential term, the need to resist dominant constructions of HIV and AIDS created a climate conducive to the growth of queer thought. Because of this historical affinity, queer is well suited to analyse and reconstruct the thinking associated with the AIDS crisis and how it comes to be constructed today, especially in the context of Greater Manchester.

### **3.2.3 Utilising a Queer-Feminist Methodology**

Queer and feminist perspectives share an emancipatory agenda because they strive to procure economic, social and political rights and equality for women and LGBTQ individuals. These perspectives also share a political goal of social progression (Panfil and Miller, 2015). A queer-feminist methodology is situated within social sciences, which have historically subscribed to a positivist approach. Positivism is grounded in objective, value-neutral and generalisable research. Queer theory, in contradistinction, debunks binary-structured critiques of gender power where feminist methodologies have tended to take up 'various concepts of 'otherness 'as constituting relationships of inequality '(Ramazanoglu and Holland, 2002: 108). The binary concept of woman, man and other cannot be sustained because those who are 'collectively constituted as 'other 'can be divided by multiple forms of power and by social division within and between categories of identity, community and locality ' (Ramazanoglu and Holland, 2002: 111). In other words, intersecting categories of identity need to be considered when looking at 'other 'identities, which may not have been previously researched. This means that collective groups, such as 'women 'or 'gay men 'do not share a singular identity or experience; instead, they each comprise multiple "categories of being" that must be accounted for.

There are certain features of these two theoretical perspectives that, when combined, demarcate a distinctive queer-feminist methodology. First and foremost, a queer-feminist methodology approaches the research field by focusing on social



categories of being: the lived experience, power relations and the subjective viewing of 'people as active, knowing subjects rather than passive objects of study' (Hesse-Biber and Piatelli, 2012: 182). In this context, I use the term "subject" to emphasise each participant's individuality rather than to label them as "research subject", as this would imply that they are subjected to the research requirements, which has been the case within traditional positivist studies. To avoid these connotations, I use the terms "participant" and "respondent" to refer to those who have participated in this study, emphasising their subjectivity and active participation in constructing knowledge. This approach could be viewed as placing too much emphasis on the participant and attempting to neutralise the power imbalance which will always exist—in some way—between the researcher and the researched (Cotterill, 1992; Webb, 1993). Given that I acknowledge and explore this imbalance throughout this thesis, I believe that the expressions "participant" and "respondent" are the most appropriate terms to describe those who have participated in this project.

The relationship between feminism and queer theory has been contested theoretically and politically. Tensions between these two theoretical perspectives have been observed since the 1990s when queer theory was established (Richardson, 2007). Even though feminist writings continue to deal with the interconnections between feminism and sexuality, the issue of gender is spotlighted over sexuality. For Wilkinson (1986), feminist research is carried out on, and for women, prioritising the female experience to develop a theory around their experiences. Recognising the complexities of gender identity about sex is necessary for feminists to move away from the traditional Western roles for men and women within these societies.

Feminist and queer perspectives share an emancipatory agenda, both in dialogue and divergence with one another, although they come in many forms (Panfil and Miller, 2015). Notwithstanding the scope of multiple theoretical and methodological approaches, (academic) feminism has a 'goal of understanding the sources of inequalities and advocating changes to empower women' (Williams, 2000: 9). Nevertheless, the feminist analysis does not advocate for specific knowledge claims that speak for all women (Benton and Craib, 2011). Instead, it offers new data

grounded within the lived realities of women's experiences because women are better positioned to inform us of how gender relations and the social world are socially and inequitably constructed (Hartsock, 1983). Feminist sociology validates this, as demonstrated by Copes and Miller (2015) and Panfil and Miller (2015). They argue that this is especially true in the North American context, where feminist sociology has been orientated to place women at the centre of enquiry.

Before the use of a queer-feminist methodology within the social sciences, research often reinforced a juxtaposition between 'science, knowledge, presence, identity, hierarchy, domination, white European males on the one side, and deconstruction, absence, difference, women, minorities, the formerly colonized peoples on the other' (Benton and Craib, 2011: 173). Given that queer-feminist research is borne out of the non-explorative and a "doing no harm" approach (Nash, 2016; Craddock, 2020), a hierarchy and an imbalance of benefits are problematic. Therefore, to assume that we can eliminate the trappings of a positivist objective approach is not only naïve but also dangerous because it can mislead participants (Craddock, 2020). The stories and experiences bestowed upon us should be viewed as "the gift" since giving is generally not conditional on the uses that the receiver makes of the gift' (Oakley, 2016: 208). Therefore, the research product is simply 'our story of their [i.e., the participants'] story' (Limerick et al., 1996: 450), which results in the research recording of the participants' lived experiences.

The lived experiences of those participating in this study have been central to this project. Tapping into the lived experience has revealed the complexity of meaning people assign to their lives (Schwandt, 1994; Panfil and Miller, 2015). A queer-feminist approach shares an understanding that empathic, interpersonal relationships are needed between the researcher and the researched. Therefore, rather than endeavouring to embody a researcher's position, which is detached from the social world under investigation and one that searches for pre-existing theories or doctrines (Gallagher, 2012; Wilson, 2015), I endeavoured to "bracket" any pre-existing knowledge and assumptions to refrain from judgement about "things out there" in spatio-temporal existence' (Pivcevic, 2015: 71). This required me to

suspend judgement about HIV and AIDS healthcare services across Greater Manchester and allow the participants' experiences to guide my understanding of these services.

Throughout my PhD, I kept a diary where I took notes about each interview, including my thoughts and feelings, and recorded my experiences. Making a diary enabled me to reflect critically on my subjective thinking behind the interview data and provided a more rigorous understanding of how the chosen methods impacted the findings (Sideras, 2017). During this process, I recognised that 'knowledge is relational and produced intersubjectively, and that the researcher's relationship with participants influences the subsequent knowledge produced '(Craddock, 2020: 50). When researching this topic, I was always aware that my conversations with the respondents would influence my thinking. I knew this because my role as the researcher was to re-tell the participants' stories. The relationship I formed with them would impact the subsequent knowledge production and the stories I could tell. Building good rapport with the participants meant that I had more stories to tell, whereas if I had built poor rapport, I would have fewer stories to tell, and their perspectives would have less chance of being included in the output. Anne Oakley reinforced this thinking, stating that a feminist methodology requires:

[T]hat the mythology of 'hygienic' research with its accompanying mystification of the researcher and the researched as objective instruments of data production be replaced by the recognition that personal involvement is more than dangerous bias – it is the condition under which people come to know each other and to admit others into their lives.

(Oakley, 1981: 58)

Holyoak (2015) asserts the importance of developing good working relationships with participants who may have been subjected to forms of abuse and, therefore, suspicious of people they do not know. Consequently, it was essential to foster good relationships with the participants. I achieved this by attending various HIV and AIDS

events, where I recruited some participants and built rapport at the start of each interview.

Understandably, individuals may have been wary of newcomers, which made me more determined to develop good relationships and build trust and rapport with those interested in the research and the respondents. Cotterill (1992) informed my thinking here because they write that building these relationships helped create an environment that neutralised power relations and space between myself and the participant.

At the same time, the researcher always maintains some form of power over the participants because the researcher decides what is and what is not included in the final output and how to interpret and present the participants' voices (Craddock, 2020), thereby creating an 'imbalance of benefits' (Scanlon, 1993: 643). For example, the researcher might benefit from the output, such as a career-related role, but the participant's life will likely continue as before their participation. Di Feliciano (2021) expresses concern over the common view that researchers are necessarily influential, knowing agents who formulate scientific methodologies that harm those who participate. This requires the researcher to protect the researched from possible harm through protocols and informed consent. Di Feliciano (2021) further highlights that these assumptions might appear necessary in medical research because of the physical risks involved. However, they appear to be less opportune in social research because this research does not include any more significant risks than those encountered in everyday life.

### **3.2.4 Positioning Myself within the Research Process**

A queer-feminist approach actively acknowledges and reflects on the power imbalance between the researcher and those who are researched. A crucial part of this is recognising the researcher's positionality and influence on the research process, from selecting the topic to data analysis and presentation (Craddock, 2020). As Cohen (1994) notes, '[w]hen we consult ourselves about who we are, that entails

something more than a negative reflection on “who we are not”. It is also a matter of autobiography: of things we know about ourselves, of the persons we believe ourselves to be ’(Cohen, 1994: 120). Researchers must reflect on their position because feminist research practice denies the possibility (and desirability) of value-neutral social science and objective research (Harding and Norberg, 2005). Taking this further, Mills (2000) argues, ‘the social scientist does not see himself [sic] as some autonomous being standing ‘outside society ... no one is ‘outside society’; the question is where each stand within it’’ (Mills, 2000: 184) because there cannot be a ‘view from nowhere ’(Browne et al., 2017: 1377). Browne et al. (2017) assert that the researcher’s positionality is a reiterated performativity, which is not fixed throughout the project, but something which is ‘relationally constituted, (re-)created through interactions between people, places and things ... and requiring explicit and ongoing self-reflectivity ’(Browne et al., 2017: 1379). Throughout the research process, I always endeavoured to be aware of my position and how it was reiterated through my performance as the researcher. For example, when interviewing women, I was mindful of my position of a male identity, which could have affected how they answered their questions. To limit this, I used the semi-structured interview approach, which gave power back to the participants over how they answered the questions, thus reducing the power imbalance during the interview process.

However, I know that the researcher cannot hold a fixed positionality and identity, understood as reiterated performativities because they are recreated and shaped by interactions between people, places and things (Browne et al., 2017). The traditional focus of objectivity has tended to search for the ‘acquisition of truth within the individual researcher ’(Hawkesworth, 2014: 103). This approach requires the researcher to control the inner self to accurately research the external reality, ‘mask[ing] the social construction of subjectivity ’(Hawkesworth, 2014: 104). Instead, a queer-feminist approach promotes reflexivity, not as a vain attempt to “achieve” objectivity, but as a way for the researcher to recognise their biases and make us aware of those biases to produce more rigorous research (Hammers and Brown III, 2004; Sideras, 2017; Craddock, 2020). This approach involves recognising the impact of the researcher’s position on the research field and the knowledge produced.

Letherby (2010) uses the “research field” as a metaphor to think about the researcher’s impact as ‘[w]hen we enter a field we make footprints on the land and are likely to disturb the environment. When we leave, we may have mud on our shoes, pollen on our clothes ’(Letherby, 2010: 6). Therefore, the researcher can have a lasting impact on those who partake in the research project; another reason why a reflexive process needs to be undertaken.

Throughout, I conducted qualitative interviews, which positioned me as the instrument of data collection (Bourke, 2020). As a result, it is reasonable to expect that my beliefs, political stances, and cultural backgrounds, such as gender and educational background, are important variables which could affect the research process (Bourke, 2020). A self-reflexive approach was vital to ensuring that I was not ‘an invisible anonymous “voice of authority” but an actual, historical individual with concrete, specific desires and interests ’(Harding, 1987: 9). As a queer-feminist researcher myself, I was interested in uncovering the subjugated knowledge of the diversity of the respondents which have remained hidden and unarticulated, but, as part of this process, it was also vital that I uncover who I am. I was fully aware of the nature of my relationship with those I interviewed. I was careful to understand my personal, political and research standpoints and my role in the interview process regarding the power and authority I held over the interviews. For example, I ultimately had a choice over whom I contacted and whom I chose to interview. At the same time, I was aware that those who had either expressed an interest in the research or those I interviewed would have formed their own opinions about who I am. However, it was essential that I also recognised that this reflexive process depended on the social reality I chose to reflect upon (May, 2013). The institutions shaped my thoughts I accessed.

Taking a reflexive approach was challenging because it required me to look deep inside to understand who I am as a researcher truly. Therefore, I must situate myself here. First, I am a white cis-gendered gay male born in 1993 after the AIDS crisis and grew up under Section 28, where I was never taught about HIV and AIDS. Instead, I was taught heteronormative understandings of sex. Therefore, I only learned about

HIV and AIDS when I started university in 2012. I joined the university LGBT society and attended talks with people who discussed HIV and AIDS. These encounters made me interested in knowing more about HIV and AIDS, hence one of the reasons I undertook this PhD.

Throughout my PhD, I had to work part-time to support myself because I received a fee-only scholarship from Manchester Metropolitan University. I am aware, however, that the participants may have read me as having access to funding which could have been used to reimburse them for any expenses they incurred as part of their participation—not having access to funds made me realise that this could have caused a boundary between the potential participants and me. Therefore, I needed to build rapport with the potential participants to ensure that such boundaries, possibly formed through our first interactions, were broken down.

### **3.2.5 Interpretivism**

Utilising an interpretative approach enabled me to understand the “self” and how others have come to interpret me as an individual entering their spaces. This research's epistemological foundations came from an interpretive understanding of the world. In contradistinction to positivism, interpretivism is the idea that positive knowledge is empirical knowledge and, therefore, the only sound source of knowledge (Halfpenny, 1982). In other words, drawing upon knowledge obtained through observation or experience enables us to understand better the world in which we exist. Foremost, interpretivism was established to develop a natural science of the social world with the aim of applying this framework to human inquiry (Crotty, 1998). Social perceptions are subjective understandings of truth and reality relative to a set of circumstances (cultural, historical, subjective and temporal) and exist in diverse forms as interpretations of reality (Benoliel, 1996; Ryan, 2018). Thus, an interpretive methodology focuses on cultural, political, socio-economic and interpersonal contexts, lived experiences and social pressures, considerations of reflective intelligence, and a conscious choice, and emphasises the construction of meaning (Wilson and Hutchinson, 1991; Benoliel, 1996). Therefore, interpretive

investigators are tasked with writing the world based on the meaning and value people assign to their unique context. This approach is necessary to understand how service users interpret their experiences and come to understand how funding changes have affected HIV and AIDS healthcare services.

Interpretative sociology, in the tradition of *verstehen*, is linked to understanding by applying cultural meaning to social actions through intersubjective readings of community through the study of lived experiences (Schutz and Natanson, 1962; Snape and Spencer, 2003). Conducting research from a *verstehen* perspective requires the researcher to adopt an emic position, aiming to understand an event by engaging with the interpretations of the insider (Mills et al., 2009). This is because *verstehen* research taps into the lived experiences of people within a historical and social context, which requires the insider to inform us of their experience within that moment (Snape and Spencer, 2003). Utilising this negates the need for designing constructs, which later translate into abstract concepts. Instead, it requires the researcher to view the life world of participants with all its emotional and subjective depth.

Interpretivism is associated with phenomenology, which studies the structures of consciousness from the insider's point of view (Smith, 2008a) to bring understanding to their experiences and give importance to experiences as genuine and meaningful (Van Manen, 1990). Phenomenology is like *verstehen* because it requires the researcher to push aside any doctrines or theories by "bracketing" any pre-perceived knowledge and assumptions to see how subjects 'experience matters (Gallagher, 2012). The concept of "bracketing" was not designed to deny the existence of the fact-world; instead, it stops the researcher from making any judgement about "things out there 'in their spatio-temporal existence' (Pivcevic, 2015: 71). For example, in one interview, the answers provided by the respondent brought up memories about my childhood, but I had to "bracket" these feelings by writing them down in my research diary to enable the participant's story to be realised in the interview. Although researchers can attempt to push aside any pre-existing knowledge or assumptions to cognise the lived experiences of "others", our



knowledge and assumptions will always inform how we understand the stories being told. However, these methods are geared towards collecting and analysing data in a way that is not prejudiced towards the researcher's subjective character.

Advocates of interpretivism assume a relativist ontological perspective, which accepts that there are multiple constructed realities instead of a single shared reality (Ritchie and Lewis, 2003). These realities are subjective and based on social interactions with others and the sociocultural environments within which we exist (Benoliel, 1996). For instance, this is reflected in the comment by Asia, an HIV healthcare service user in Greater Manchester, who informed me about their experience when they visited a sexual health clinic:

*As soon as you walk through that door, you see the specialist HIV service because HIV-positive people have to go down one way, and obviously, people that are just going for normal sexual health screen sit in the reception. To me, it's kind of personal, but at the same time, I always feel a little bit paranoid in a sense because people who are sat in reception and going for their sexual health screen know that us HIV-positive people are going down another route to the specialist HIV area.*

This experience was uncomfortable for Asia because she felt anyone could find out someone's HIV status if those individuals were aware that people living with HIV were contained in one waiting room within the GUM (Genitourinary Medicine) clinic in Manchester. Asia's interactions with the staff, other patients and sociocultural understandings of HIV impacted their reality of living with HIV.

### **3.2.5.1 Interpreting the Reality Through Experience**

These experiences are constructed as 'reality' because people assign meaning and value to them. The notion of experience has been taken for granted as something all people share and have easy access to, but questions have rarely been asked about how the concept of selves (of subject and their identities) has been produced (Scott, 1991; Borer, 2013). Experience has often been taken as evidence of the past, as a

metaphor for visibility and access to the real, but this can be problematic. Research which has taken the evidence of experience as a metaphor for visibility has often reproduced ideological systems of oppression because there is an assumption that the facts of history speak for themselves. These narratives have repeatedly reinforced the trajectory of [heterosexual, white] men within [heteronormative] institutions which leave no place for women, their lives and other identities that fail to 'fit professional historical procedures and categories' (Kitch, 1999: 115). This is because men have generally written into literature our understanding of what it means to be a woman and the woman's identity.

Taking experiences as uncontested truths is also complicated because we perceive experiences as ideas within our thoughts and its procedures and through feelings, memories, families, languages, religion and culture (hooks, 1991). These moments are also experienced through a world of strangers and public encounters as subjects (Borer, 2013). One such example has been offered by MacKinnon (1982), who writes, 'women's distinctive experience as women occurs within that sphere that has been socially lived as the personal-private, emotional, interiorized, particular, individuated, [and] intimate' (MacKinnon, 1982: 535). This alludes to the idea that our experiences within the world are formulated not only by structures placed before us but also by other subjects with intersecting categories of being, which determine how we are situated within a specific moment and how we recount that moment. Experience is a memory that people tell and lay before their fellow subjects and can determine how that person will act in the future. Therefore, I cannot naturalise subjects' experiences because the moments people have experienced are intimate and specific to them.

These debates informed the data collection as each participant was asked to recount stories about changing HIV and AIDS healthcare provision. I designed the interview schedule (Appendix A) to capture the unique experience of each respondent. I recognised that recounting stories may have triggered emotion within some of my respondents; for example, some may have lost friends and family to the AIDS crisis. Therefore, I needed to build rapport with each participant to relax them into the

interview. Enabling the respondent to choose the time and location of the interview ensured that they could fit their participation into their everyday lives and participate when they were ready. A few times, the respondent and I had to negotiate the location so that we were both in a safe environment. As subjects, the stories recounted by the participants were similar; for example, those who identified as gay men or allies told similar experiences of the AIDS epidemic during the 1980s and how it impacted them. My interview schedule consisted only of open-ended questions to let the participant tell me their stories and eliminate stereotypes reproduction (Jost and Hamilton, 2005). By only including open-ended questions, the participants could apply meaning to the question from their own experiences, which enabled me to collect rich data for the study.

Also, at some stages, protecting the participants' voices from becoming essentialised in the research process was ethically essential. Exploring experience under an essentialist lens can reinforce what we already know (or think we know) and highlight what has been taken for granted (Scott, 1991). However, it can also perpetuate negative beliefs held against specific groups. In the recruitment phase, I reached out to a cross-section of society, which consisted of people with different intersecting identities, which complicated essentialised views of who is living with HIV. For example, people continue to perceive HIV as a "gay man's" problem, but the participant base of this study shows that HIV does not discriminate. This approach upheld the narrative that HIV does not discriminate, but should the research process have essentialised views of HIV and AIDS; it would have buttressed the symbolic violence that affects people living with HIV.

Before continuing, I will present an overview of symbolic violence. Connolly and Healy (2004) contend that symbolic violence is pivotal in enabling us to understand how inequalities are (re)produced. They write, 'it represents the way in which people play a role in reproducing their own subordination through the gradual internalisation and acceptance of those ideas and structures that tend to subordinate them' (Connolly and Healy, 2004: 15). Dalton (2018) further defines people's role in subordination by the "dominated group". This allows the powerful to exercise

invisible and pervasive forms of power with ‘the very structures of power in society’ (Dalton, 2018: 174). The powerful exercise their power through ‘legitimate organisations, such as government agencies and powerful social actors imposing their own “vision of the social world”’ (Bourdieu, 1991: 239). In essence, symbolic violence allows governments to push through their ideology via official government departments and create a veneer of legitimacy, thereby obscuring power relations.

One example of essentialising voices is through stereotypes—the perpetuation of prior beliefs and prejudices (Jost and Hamilton, 2005)—which are the essence of discrimination against subjects with particular identities, such as female, gay, bisexual or trans. Those with stereotypical views against homosexuals are likely to essentialise homosexuality because they link it to a more profound immoral value (Newman and Knobe, 2019). However, people who identify with particular identities may essentialise their identity; for example, some homosexuals essentialise arguments that they are “born this way”. Stereotypes are often used as a justificatory device to either categorically accept or reject a group and as a screening or selective device to maintain simplicity in how people perceive and think about a group (Jost and Hamilton, 2005; Rhodes et al., 2012). Rhodes et al. continue and suggest that this is known as category essence—the idea that people share a profound, underlying inherent nature which causes them to be essentially similar to one another in both obvious and non-obvious ways.

Experience, therefore, is an individual moment which needs to be understood from the point of view of the person telling the story. In her seminal essay, Scott (1991) grew impatient with her fellow historians who assumed that experience was transparent, denying that a direct link can be found between economic circumstances and, for example, a person’s political action. By assuming this, historians did not need to ask what counts as experience. However, even when questions are asked about the subjects’ account of their lived experience, it appeals to the notion of ‘experience as uncontested evidence’ (Scott, 1991: 777) and ‘offered not only as truths but the most authentic kind of truths’ (Williams, 1985: 90).

This serves to constitute subjects not only as fixed and autonomous beings but as reliable sources of knowledge because of their undisputed access to applied meaning (Scott, 1991). Nevertheless, viewing experience in this way negated the need for historians and others to understand that people narrate their experiences through 'cultural expectations and norms of storytelling' (Borer, 2013: 965). For example, some participants may have felt that they had to recount their story from a heroic perspective because they wanted to historicise their experience positively.

Historically, accounts of the HIV and AIDS crisis have tended to focus on the experiences of gay men. Feminist writers, such as Gould (2009) and Young (1989), have documented the history of the AIDS crisis and called into question existing interpretations of mainstream history which have failed to account for gender differences. By uncovering women's experiences, researchers can expose false claims to objectivity in previous studies where questions relating to the researcher's positionality were not raised, and we can start accepting that the knowledge they produced reflects all but themselves (Scott, 1991). It could be argued that this was done as an ideological cover for masculine bias because, from the outset, many previous projects were designed to investigate HIV and AIDS in men. Like this project, feminist projects have been designed to unmask [false] claims by pointing out mainstream histories shortcomings, incompleteness, exclusiveness, and exclusionary practices (Scott, 1991). Therefore, interviewing women has been a critical part of further reimagining the history and struggles experienced by women living with HIV when accessing HIV and AIDS healthcare services in Greater Manchester.

### **3.3 Recruitment**

This research aimed to recruit activists (as reflected in my recruitment materials) across the Manchester City Region about changing HIV and AIDS healthcare provision. Despite best efforts, I only managed to recruit three self-identified activists; the rest were people with personal experiences of HIV and AIDS healthcare services. These included individuals who identified as support workers, healthcare professionals and political figures. This might reflect the weakening of activism around HIV and AIDS in the Greater Manchester region (and perhaps more widely)

due to improved access to antiretrovirals, funding changes resulting in less funding available for charities who campaign for improved healthcare services, for example. As a result, my analytical focus shifted from a study of activism to a study of how devolution and changing governance structures can be seen reflected in the experiences of the research participants of services aimed at people living with HIV and AIDS across Greater Manchester. This required a change in the thesis's focus to reflect the conversations. As this change in direction was not prevalent until after my data analysis, I could not change the recruitment materials. Therefore, they will continue to reference feminist and LGBTQ activists.

### **3.3.1 Sampling**

Cluster sampling was employed to identify potential participants. I developed a map identifying well-established HIV and AIDS networks and healthcare providers across the city region. The map was crucial in capturing diversity within the Manchester City Region, and it helped me identify key individuals and organisations representing a wide range of diverse backgrounds.

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

#### **Inclusion Criteria**

A series of informal interviews were conducted on the topic of feminist and LGBTQ activist responses to changing HIV and AIDS healthcare provision in Greater Manchester with people who:

- have knowledge of these topics
- are involved with a campaign or campaigning groups on these topics
- are involved in the policy-making process on these topics

#### **Exclusion Criteria**

As respondents self-selected, the only exclusion criteria were anyone who was unable to provide informed consent.

The inclusion and exclusion criteria were selected in line with my queer-feminist methodology: not to prevent potential participants from approaching me if they did not feel they fit under the feminist or LGBTQ activist umbrella but had knowledge of the research topic.

### **3.3.3 Recruitment Process**

In total, I approached 236 potential participants, including service users of HIV and AIDS healthcare provisions; organisations specialising in HIV and AIDS support, advice and advocacy services to improve health outcomes; healthcare staff specialising in HIV and AIDS healthcare and those who advocate for improved treatments; academics who work in the field of HIV studies; and activists who are campaigning for improved HIV and AIDS services. I only contacted these people if their details were available on a public profile. At the same time, I emailed 38 potential gatekeepers, and 15 contacted me to say they would pass the project details on to other people. I also searched on Facebook and Twitter for HIV and AIDS groups, where administrators were contacted to ask if I could post some recruitment material on their page. While doing this, some people contacted me to inquire about participating. Before the impact of the COVID-19 pandemic, I attended several HIV and AIDS social events where local service users and artists came together to demonstrate their work. I also attended several events hosted by HIV and AIDS organisations, bringing people living with HIV together. At these events, I could discuss the project with the attendees, resulting in a few people contacting me about participating in the study.

During the COVID-19 pandemic, I attended online events where people discussed their experiences of living with HIV today.<sup>2</sup> Before attending each event, I contacted the organisers and asked them if they were happy for me to participate in my capacity as a researcher. For those who agreed, I asked if I could share details of my project during the event or if they would act as gatekeepers and disseminate information about the research project.

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<sup>2</sup> In Section 3.4, I discuss in depth the impact of the COVID-19 pandemic on this research project.

Each individual who shared an interest in participating was provided with a copy of the invitation letter (Appendix B) and participant information sheet (Appendix C). Likewise, those identified as potential gatekeepers were provided with a copy of the gatekeeper letter (Appendix D) and participant information sheet. The participant information sheet detailed the study's procedures. It explained all aspects of participation, including the inclusion criteria, the participant's withdrawal rights, risk issues, confidentiality and data protection and the complaints procedure.

Each potential participant and the gatekeeper were given two weeks to read the participant information sheet, consider any questions, and contact me to express their interest in contributing to the study. If they did not respond within two weeks, a second email was sent to ask if they had received the initial email and if they would still be interested in participating in the project or being a gatekeeper. To incentivise people to participate, I offered my respondents a summary of the research findings (Bamidele et al., 2019). In line with my queer-feminist methodology, I needed to offer the participants an overview of the results because it ensured that I was not just taking something from the respondents and community but was providing something back to those who had shared their stories with me.

Once I had established that the potential participant wanted to participate in the study, we agreed on a suitable date, time and location. All interviews after March 2020 were conducted via proprietary telecommunication applications, such as Skype or Microsoft Teams (herein referred to as 'online technologies'). I ran 17 interviews, with six conducted in person and 11 conducted via online technologies.

### **3.3.4 Barriers to Recruitment**

Despite the positives, some barriers were faced when recruiting individuals from specific backgrounds. Based on the findings from the literature review, it was essential to include the voices of underrepresented groups within this project because they have generally been overlooked in previous studies. Several attempts



were made to reach out to individuals in the following categories (Office for National Statistics, no date):

- Mixed/Multiple Ethnic Groups (White and Black Caribbean, White and Black African, White and Asian, and Other Mixed/Multiple Ethnic Backgrounds)
- Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, and Other Asian Backgrounds)
- Black/African/Caribbean/Black British (African, Caribbean, and Other Black/African/Caribbean backgrounds)
- Other Ethnic Groups (Arab and Any Other Ethnic Groups)

I attempted to reach out to people from these groups because the 2011 census recorded 251 ethnic groups within Greater Manchester. Even though it would have been difficult to represent each ethnic minority within the city region for various reasons, such as time limitations, I needed to reach out to individuals from each category to understand how they experienced changes in HIV and AIDS healthcare provision in Greater Manchester. Several attempts were made via email or telephone to reach out to a cross-section of active individuals and groups who are known for their work in campaigning for improved HIV and AIDS healthcare provision across Greater Manchester.

Search engines, such as Google, were used with terms such as HIV, Greater Manchester and health care to scope the field. However, links would often be returned on the first few pages with contact details that needed correcting. Multiple attempts were made to contact the groups/organisations by telephone, but the call would sometimes go straight to voicemail, or the line would ring out. Moreover, I often received an undelivered response if I emailed a group or organisation that no longer existed. These attempts presented a digital ghost between the online trail of these organisations and their sometimes transient existence. Many of these groups represented women and black, Asian and ethnic minority individuals.

Funding changes have caused many HIV networks to organise differently. I contacted someone who was part of a women's group that organised itself on WhatsApp. Still, due to funding limitations, I could not recruit anyone from the network because they wanted payment for their participation. Although I explained that I was willing to travel to them to conduct an interview or that we could conduct an interview online, I was told by their gatekeeper to keep trying to access funds to pay the respondents for their time. However, I could not seek any funds, resulting in the loss of approximately 15 participants. This was frustrating because these potential participants were actively creating awareness of issues relating to HIV and AIDS healthcare provision within the city region. Documenting their concerns about changing healthcare within the city region would have been beneficial. Not only this, but the voices of women I collected within this study were mainly employed within healthcare settings. In contrast, these potential participants had a patient perspective of HIV, or so I was told by the gatekeeper of the WhatsApp group.

Bureaucratic challenges were also present in the recruitment process. I was initially naïve because I believed that service users, allies and HIV and AIDS organisations would have wanted to participate in this project actively. After all, it may have been linked to their organisational aims. However, I failed to account for the rigorous policies and procedures of the larger groups and organisations. Each gatekeeper had a set process for researchers to follow should they recruit potential participants from their organisation. These processes included providing information about the project which aligned with their policies or creating a poster they could share within their organisation. The gatekeeper process often fails to reach people from within their organisation.

The role of the gatekeeper is to ensure that 'expectations are clarified before the encountering of problems' (Brear et al., 2008: 100), yet this is subjective and based on their experience of "gatekeeping" as well as their role within the organisation. I understood that those controlling access to people had to ensure that any problems arising from the research process were discussed in detail before passing information on. However, in most cases, I either did not receive a response, even though I had

emailed them a few times, or they informed me that they could not promote my research project because their organisation had a policy preventing the employees from participating in student research.

Like the gatekeeping issues presented in the Bamidele et al. (2019) study, I had difficulties recruiting participants from support groups and organisations. The problem emerged because I could not effectively reach out to those with whom I wanted to participate, and members not being made aware of the project. This was confirmed to be the case when one of the participants passed the project details onto a prospective respondent who worked for one of the larger HIV organisations within the city region, an organisation I had previously contacted and from which I had received no interest. I did not ask the participants if they had heard of the research before. Still, from their enthusiasm and comments made during our conversation, it was clear that they would have participated earlier if they had been informed of the research at an earlier stage.

### **3.3.5 Participant Demographics**

Although attempts were made to include ethnic minorities within the research, the response rate was the highest among individuals who self-identified as white. In total, 88% identified as white, whereas only 12% of respondents identified as black. Moreover, 71% of respondents identified as male and 29% as female. Age groups were represented according to the following percentages: 18% were aged 20 to 29 years, 24% were aged 30 to 39 years, 34% were aged 40 to 49 years, and 24% were aged 50 to 59 years. Many respondents identified as gay men (47%), with 29% identifying as heterosexual, 18% identifying as queer and 6% identifying as bisexual. Table 1 shows the participants' demographics, and each participant provided the terms I used to describe their identity in the thesis.

#### **Table 1. Participant Demographics**

Participant	Age	Gender	Ethnic Background	Sexual Preference	Biography
<b>Alex</b>	35	Male	White, British	Queer	A support worker at a Manchester-based HIV Charity
<b>Andy</b>	33	Male	Afro Caribbean	Gay	A Greater Manchester-based HIV activist
<b>Asia</b>	30	Trans Woman	Black, Caribbean	Heterosexual	An HIV healthcare service user in Greater Manchester
<b>Connor</b>	25	Male	White, British	Gay	A healthcare professional in Manchester
<b>David</b>	55	Male	White, British	Heterosexual	A London-based HIV healthcare worker
<b>Drew</b>	40	Male	White, British	Bisexual	A North East-based academic
<b>Harry</b>	42	Male	White, Irish	Queer	A Greater Manchester-based HIV activist
<b>Jonny</b>	24	Male	White, British	Gay	A Greater Manchester HIV support worker
<b>Judy</b>	23	Female	White, British	Queer	A HIV healthcare service user in Greater Manchester
<b>Lyn</b>	43	Female	White, British	Heterosexual	A healthcare professional in Manchester
<b>Nathaniel</b>	33	Male	White, British	Gay	A HIV healthcare service user in Greater Manchester
<b>Ollie</b>	56	Male	White, British	Gay	A HIV healthcare service user in Greater Manchester
<b>Paul</b>	54	Male	White, British	Gay	A Greater Manchester-based HIV activist
<b>Richard</b>	57	Male	White, British	Gay	A political figure in Greater Manchester
<b>Sally</b>	43	Female	White, British	Heterosexual	A Manchester-based academic
<b>Simone</b>	43	Female	White, British	Heterosexual	A Manchester-based mental health professional

Participant	Age	Gender	Ethnic Background	Sexual Preference	Biography
Stephen	44	Male	White, British	Gay	A political figure in Greater Manchester

### 3.4 Data Collection

#### 3.4.1 Semi-Structured Interviews

A qualitative approach was employed using semi-structured interviews to understand and demonstrate how funding changes have affected HIV and AIDS healthcare services in Greater Manchester. Furthermore, this approach brought an understanding of how people across the city region have responded to changing healthcare provisions. With semi-structured interviews, the interviewer usually has a list of questions and topics to cover. However, this can be flexibly followed to fit each specific interview. This approach allowed the interviewee to answer whichever questions they chose, allowing further questions to be asked or elaborated on.

I used interviews as a research method because they have successfully collected data in other studies (Roulston, 2010) and are steeped within a narrative tradition. Gudmundsdottir (1996) notes that narratives are made up of ‘four closely integrated elements: observational tell, the stories informants tell, the stories we hear, and the theoretical models (which themselves are narrative structures) guiding our research ’ (Gudmundsdottir, 1996: 294). Using a narrative structure, people tell stories of their experiences, and it is the role of the researcher to develop rapport between the informant and themselves to create a space where the respondent can share their stories (Gudmundsdottir, 1996). I needed to build rapport with the participants to reassure them that they were in a safe space where they could openly and safely share their stories with me. I achieved this through having a general conversation with each participant at the start of each interview and reiterated that they could ask any questions about the research. I was also aware of my body language throughout the interviews and in some instances, I found commonalities with the respondents, such as talking about places where we had both lived. This was essential to achieving my objectives because this approach enabled me to delve into the respondents' lives,

probe beyond their answers, and understand how specialist HIV and AIDS healthcare services have changed in recent years.

Seventeen semi-structured interviews were conducted with service users, advocates, healthcare workers and political figures to capture their stories about changing HIV and AIDS healthcare provision in Greater Manchester. Four interviews formed the pilot study, and the other 13 were part of the main study.

I initially conducted pilot interviews to test the data collection instrument (Hassan et al., 2006) and understand whether the initial questions collected data that best answered the research questions. I needed to conduct a pilot interview phase to gain experience carrying out research at a PhD level, and I had not conducted interviews as part of a research project. As discussed above, I ran four interviews for the pilot study. I specifically approached individuals with different characteristics because this gave me an understanding of how different groups of people understood the questions being asked. This approach also provided an early indication of whether the responses provided by the participants answered the research questions. During the pilot interviews, I identified the need to add specific questions about the respondent's identity, such as their pronouns. Some questions were altered to ensure they collected the data needed to answer the research questions, such as removing acronyms. In line with a queer-feminist methodology, identity is important; as such, it was essential to capture the identity of my participants as they self-identified. I needed to capture this data during the interview to ensure I referred to them as authentically as possible. When describing the respondents in this thesis, I may substitute their names for their pronouns, such as she, he, they or them, to make the sentence or paragraph flow. I also removed acronyms because the pilot study taught me that some participants discussed PEP (post-exposure prophylaxis) when I asked them about PrEP (pre-exposure prophylaxis). The pilot interviews showed that the interview schedule was feasible, and not many changes were needed for the main study.

The insights from the pilot study led to alterations to the research tools, and I developed an interview schedule incorporating the changes. I ran the new interview schedule past my supervisory team, and this schedule was used during the main study (Appendix A). However, having a semi-structured interview approach meant that I did not have to maintain the interview schedule because I had the freedom to probe beyond the issues raised by my respondents (Hinton and Ryan, 2020). Having a flexible approach allowed the participant to reflect on their experiences and allowed these experiences to guide the interview rather than fitting their stories into a theoretical framework. The wording of the scheduled questions was standardised, but there were times when the questions were slightly altered during the interview to fit the narrative. Although the questions were set out rigidly, the order in which they were asked depended on the interviewee's response to the previous questions. This flexibility provided a platform for the individual to discuss essential topics not part of the interview schedule (Hinton and Ryan, 2020). Furthermore, there were times when the order of the interview schedule was altered during our discussion. I changed the order when either the participant started to answer another question during their response or when I intentionally asked a question because it benefitted the flow of the conversation.

Semi-structured interviews enabled me to meet the respondents and clarify any questions they did not fully understand. My interviews aimed to explore changes in HIV and AIDS healthcare provision across Greater Manchester and understand how people have responded to these changes.

The interviews focused on three key areas:

- Collective responses to funding cuts to HIV and AIDS healthcare provision
- Institutional and structural barriers faced by service users when accessing HIV and AIDS healthcare services
- Political agendas relating to HIV and AIDS healthcare services within the region

These interviews focused on HIV and AIDS healthcare services, access to medications like PrEP, and mental health support services linked to HIV and AIDS holistic care needs. I considered it essential to ask individuals directly about their responses to

changing HIV and AIDS healthcare through interviews to obtain a depth of information which would not have been achievable through other methods of data collection, for example, questionnaires. I chose not to utilise questionnaires because this method has drawbacks. In their essay, Jones et al. (2008) identified that the response rates to questionnaires may be low, and there can be an associated bias because those who do respond to it may not be typical of the subject group. Bowling (2014) also identified some of the drawbacks of using questionnaires. They found that the pre-coded response choices on the questionnaires may not capture all the participants' responses, and the answers provided by the participants may not easily be accommodated. This can force the respondents to choose inappropriate pre-coded answers which may not fully represent their views. Moreover, I would have been distanced from those who participated if I had used questionnaires. The participants also may not have understood the wording of the survey questions (Bowling, 2014).

I chose to conduct individual interviews rather than focus groups because of the sensitive nature of the discussion and concerns around confidentiality. Although some of the participants decided to be named in the study, there were some stories and experiences the respondents wanted to keep within the bounds of the relationship we formed. I either omitted or did not record these stories. If I had chosen to use focus groups, the same level of privacy would not have been afforded, which could have impacted the rapport that the participant and I built and, thus, the data quality.

### **3.4.2 Location of Interviews**

All participants were offered the choice of being interviewed at Manchester Metropolitan University, over the phone or via online technologies, such as Skype. I provided the respondents with the option of online technologies because they can benefit some people. A benefit of using online technologies is that it transcends geographical boundaries by nullifying and eliminating the need to visit an agreed location for the interview (Lo lacono et al., 2016). This meant the respondents could



participate in this study at a familiar and comfortable place, often their home. This method allowed me to talk to participants who would have otherwise been inaccessible (Deakin and Wakefield, 2014). There are disadvantages associated with using online technologies to conduct interviews, including some people not having suitable technology, access to the internet or the will to use this technology (Sullivan, 2012), especially if they only need to learn how to use it for my study. Sometimes, participants did not want to conduct the study at Manchester Metropolitan University, over the phone or via online technologies, because they may have had family commitments or privacy concerns. To accommodate this, some interviews took place at the LGBT Foundation or within a familiar clinical setting. Consent from these settings was obtained before the interview was carried out.

From March 2020 until the final interview, due to the COVID-19 pandemic, I had to conduct all interviews over the phone or using online technologies to ensure the safety of the participants and myself. Some of those affected by this decision raised security concerns, which I addressed before their interview. One of the concerns was around being recorded, where I confirmed with the respondent that they would only be recorded on an external voice recorder. However, some respondents asked for their interviews to be recorded using the integrated recording facility built into the online technology. Where requested, this was accommodated.

All interviews took place at a convenient time and location for the participant. At the same time, the schedule was adjusted to ensure that the discussion did not affect any personal commitments of the participant. For example, one participant needed to attend a medical appointment straight after the interview, so I ensured that timers were set to remind us of the time. All face-to-face interviews took place in a private location with easy access to refreshment facilities in case the participant needed these. If the interview had taken place using online technologies, they were asked if they were comfortable, in a safe place and happy to commence with the interview once introductions had been made.

### **3.4.3 The Impact of the COVID-19 Pandemic on the Data Collection**

The COVID-19 pandemic significantly impacted my ability to maintain the project milestones, and I subsequently had to extend the end date of the research project from October 2021 to July 2022. When the COVID-19 pandemic started to affect people in the UK, the government imposed restrictions on the movement of people from March 2020. Manchester Metropolitan University also imposed restrictions which required all research to be conducted online and banned in-person events. This meant I could no longer attend any HIV and AIDS events or conferences in person, thus restricting my access to potential participants who may have wanted to participate in the project.

Over the past two years, a body of literature has emerged which discusses the impacts of the COVID-19 pandemic on attempts to undertake research. UK Research and Innovation (2021) conducted a survey between February and March 2021, which revealed that 61% of researchers reported that lockdown or shielding had negatively impacted their research. The impact of the COVID-19 pandemic was researched earlier by Harper et al. (2020). They found that COVID-19 had highlighted gender inequalities within the field of research because female academics were publishing less and starting fewer projects than their male peers. They argue that this might be the result of the lockdown and links to the feminist political economy where more women than men were juggling caring responsibilities despite both working from home. In addition, travel restrictions imposed by the government and academic institutions resulted in recruitment for research being impacted because neither the researcher nor participants could partake in research in the same way as before the COVID-19 pandemic.

This links to one of the critical impacts of the pandemic on my research, where my ability to network and carry out in-person interviews was hampered. Many potential respondents either wanted to complete their interview face-to-face, which was impossible due to the pandemic, or they were unwilling to use other methods, such as phone interviews, because they had no idea whom they were talking to. I had offered these individuals a Skype interview, but this was impossible because some

did not have access to or trust Skype. This resulted in me needing more time to find people comfortable sharing their stories via Skype or telephone.

Conducting this research through a global pandemic could have brought up many emotions for those with knowledge of the AIDS crisis in the 1980s. These emotions could have affected the difficulties I faced recruiting people for this project. Mackenzie (2022) presents a paper highlighting the connections between the 1980s AIDS crisis and the ongoing global COVID-19 pandemic. During the pandemic, patient groups formed to express emotions such as grief, frustration and anger over the number of people who experienced COVID or Long COVID themselves or faced the loss of a family member to COVID-19. The emotions people felt during COVID-19 were also experienced during the AIDS crisis, and HIV and queer social movements formed to create awareness of the AIDS epidemic under these emotions. Thus, the links between COVID and the AIDS epidemic may have opened up the archives of feelings which could have taken a toll on some of my participants.

Overall, COVID-19 impacted the research process significantly, resulting in me having to take steps to navigate the complexities of doing research during a global pandemic, from changing how I recruited participants to how the data could be collected. Furthermore, it required me to consider the impact of COVID-19 on those who experienced the HIV and AIDS epidemic by taking steps to ensure that the participants were comfortable throughout the research process. Additionally, I realised that the uncertainty of the pandemic impacted people's choices to participate in this research project because they may have been worried about the health impacts of contracting COVID-19, given that people living with HIV can be at higher risk of comorbidities (Centers for Disease Control and Prevention, 2022). As a result, I had to consider that potential participants living with HIV may have had other health concerns to deal with.

### 3.5 Secondary Data

Secondary data has been utilised throughout this study in all the empirical chapters. I used secondary data in this study because I faced challenges when carrying out the primary research, such as financial constraints and the COVID-19 pandemic, which prevented me from recruiting many potential participants. In this study, I systematically analysed secondary data from various sources (see Table 2).

**Table 2. Secondary Data Sources**

Type of Sources	Name of Publication	Dates	Details
<b><i>Reports on HIV and Homelessness</i></b>	Albert Kennedy Trust; Crisis UK; GTD Healthcare; Shelter	2017 to 2020	Reports providing a key link between homelessness and HIV risk. Homelessness is high across Greater Manchester and there it was key to understand the link between homelessness and HIV to demonstrate the impact of governance changes on this population.
<b><i>Reports on Devolution</i></b>	Greater Manchester Combined Authority; Greater Manchester Health and Social Care Partnership; UK Parliament	2016 to 2021	Reports informing the role of devolution on politics and healthcare provision across the Manchester City Region. These sources provided insight into the rollout of devolution and how it has impacted on the delivery of healthcare.
<b><i>Reports on the funding of HIV and AIDS services</i></b>	Buck (2020); Tameside Metropolitan Borough Council (2021)	2020 to 2021	Reports detailing how funding changes have affected the delivery of HIV and AIDS services. These sources provided insight into how the City Region has adapted to funding changes.
<b><i>Reports, newspaper articles and specialist websites on PrEP</i></b>	Cairns (2021a); Gómez et al., (2022); Hojilla et al. (2018); Kirkby (2020);	2020 to 2022	Reports, newspaper articles and specialist websites on PrEP in the UK. These sources provided the thesis with a context about the history of PrEP availability and

Type of Sources	Name of Publication	Dates	Details
	iwantprepnw.co.uk		enabled me to link the responses provided by my participants with current arguments about PrEP provision.
<b><i>Newspaper articles on the history of the AIDS epidemic</i></b>	Guardian and BBC	2013 to 2022	Articles relating to the history of the AIDS epidemic, particularly the role of Conservative politics on HIV and AIDS cases. These sources provided a greater historical context which was not drawn out during the interviews.
<b><i>Newspaper articles on the impact of funding cuts to healthcare provision</i></b>	Guardian	2022	Articles relating to the impact that austerity measures have had on healthcare provision. These sources enabled me to understand how recent changes to healthcare funding has affected the delivery of healthcare provision.

Secondary sources have enriched the study findings as they have provided greater insight into neoliberalism, austerity and devolution's role in the governance and delivery of HIV and AIDS healthcare. Secondary data sources were essential to this research project as they provided access to data already collected. Utilising data which had already been collected enabled me to access historical data which provided insights into HIV and AIDS healthcare and governance changes since the start of the AIDS epidemic.

Access to secondary data presented opportunities for me in this project as I could draw on international research to understand, such as the work of Fredriksson and Winblad (2008), how the devolution of healthcare affects patients in Sweden. Without secondary data, I would not have been able to collate primary data on the devolution of healthcare in other countries without significant expense, such as by employing a team to conduct this research. This would have been challenging, given the time and funding constraints.

Accessing a range of datasets prepared by experienced researchers was essential because these individuals and organisations may specialise in data collection and have years of experience working on that survey (Boslaugh, 2007). This is particularly the case for the British Social Attitudes survey, which ‘asks a representative sample of the population what it’s like to live in Britain’ (National Centre for Social Research, 2023). Utilising these datasets was essential to the research process purely from a novice point of view. I was new to the field of sociology, and this was the first time that I had carried out qualitative research.

Another benefit of utilising secondary sources was accessing data “frozen in time,” which enabled me to analyse changes in HIV and AIDS service over time in the Manchester City Region, the UK and globally (Boslaugh, 2007). The findings of these comparisons were integrated into the current research, and I could demonstrate how the Greater Manchester context compared to the national and global context. For example, I was able to utilise the Kirwan et al. (2021) study to highlight that one in five trans women living with HIV globally and compare this with the study of Jaspal et al. (2018) to emphasise that the UK is poor at recording the number of transgender and gender-diverse people on the census. This finding made me realise the difficulties in finding transgender voices in this study.

The secondary data findings were utilised in conjunction with the results from my primary data. As Smith (2008c: 336) highlights, ‘secondary data analysis is most effective when combined with other research approaches.’ This worked particularly well when my research participants quoted statistics. In some instances, I utilised the secondary data to verify some of the claims made by my respondents (Pederson et al., 2020). For example, Alex, a support worker at a Manchester-based HIV Charity, quoted the work of Shongwe et al. (2020) regarding the lack of knowledge about U=U –a message about people who have an undetectable viral load cannot pass HIV on– in a central London. The ability to correlate the claim made by Alex with the study findings of Shongwe et al. (2020) enabled me to keep Alex’s claim in the study and also led me to a piece of research which was essential to the study.

Despite the benefits of secondary data, it has some limitations, which I shall discuss here. Foremost, I was not involved in the research design of the sources I used, which meant that I could not control any biases that may have existed (Johnston, 2017). For example, the individual and organisation who conducted the research may have been seeking specific answers to the research question and subsequently designed the project to reflect this (Pederson et al., 2020). Therefore, the secondary data may have contained bias. Still, to understand whether this was the case, I reviewed the research documentation from the original study and information published from the findings. This ensured that I had a good understanding of the data and helped me with any limitations of the secondary data.

Further limitations of the use of secondary data were raised by Boslaugh (2007), who argues that the data was collected for some other purpose. The secondary data that I accessed did not set out to answer my specific research questions. There were instances when the research questions I would have liked to have answered were not included in the secondary research (Johnston, 2017). As my research is unique, studies on the devolution of healthcare were conducted in other geographies, meaning they did not have the focus of the Manchester City Region. Although these studies were limited, their data was valid because it enabled me to understand the impact of neoliberalism, austerity and devolution on HIV and AIDS healthcare governance in other geographical contexts.

Considering the benefits and shortcomings of secondary data, it has proved helpful in this study because it has allowed me to access a comprehensive dataset, which was only possible with access to secondary data. Furthermore, without secondary data, the research would be limited in scope because the data has filled the gaps in this research. Lastly, secondary data has embedded my research in the wider sociology and health studies field because it has supported some of my research findings.

## 3.6 Analysis of Data

### 3.6.1 Analysis and Coding

To analyse and code the data, I used the techniques applied by thematic analysis, developed in psychology by Virginia Braun and Victoria Clarke (2006), to identify, analyse and interpret patterns of meaning within the qualitative data. The use of thematic analysis is unusual in the tenet of qualitative analytic approaches because 'it offers a method – a tool or technique, unbounded by theoretical commitments – rather than a methodology (a theoretically informed, and confined, framework for research) '(Clarke and Braun, 2017: 297). I chose thematic analysis because it has been developed within the social sciences and focuses on the importance of coding reliability. The approach was primarily for use within the qualitative paradigm. The version produced by Braun and Clarke (2017) emphasises both an organic approach to developing codes and themes and the researcher's role in this process. Braun and Clarke (2006) outline six phases of thematic analysis as identified in Table 3.

**Table 3. Phases of thematic analysis (Braun and Clarke, 2006: 87)**

Phase	Description of the process
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, and noting initial ideas.
2. Generating initial codes	Coding interesting features of the data systematically across the entire data set, collating data relevant to each code.



Phase		Description of the process
3. Searching for themes		Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes		Checking if the themes work with the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes		Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report		The final opportunity for analysis. Selection of vivid, compelling extract examples, the final analysis of selected extracts, relating the analysis to the research question and literature, producing a scholarly report of the analysis.

### 1. Familiarisation with the Data

I wrote the transcript myself to familiarise myself with the data. I immersed myself in the data by listening to each interview at least once before transcribing. This allowed me to hear the interviewee's in-depth response to each question. I created an orthographic transcript—a verbatim account of verbal and non-verbal utterances—and made notes while listening to the interviews. Once I had transcribed the recording, I inserted the notes into the transcript.

### 2. Coding

Working systemically through each transcript within NVivo, I began to write notes and highlighted the text with initial codes. Working systematically, I ensured that I gave full and equal attention to each data item—notes made during the familiarisation process aided with the coding stage. The coding of the interviews was an iterative process, and the codes were driven by the data rather than the literature review. Once the initial coding had occurred, each transcript was re-read as part of the iterative process to ensure I had captured all the codes. Two coded interviews

were sent to the supervisory team to review my coding approach and provide their analysis. This process enhanced the rigour of the coding process because it provided insight into different approaches and made me rethink my coding style. Moreover, it enriched the codes that were drawn from the data.

### **3. Searching for themes**

All the codes were exported from NVivo into a Microsoft Excel workbook and sorted into potential themes. I utilised a table within Excel to visualise the data and possible codes. When unsure of where some codes fit, I revisited the specific coded data to familiarise myself with the data set, which helped with the decision. I then used a mind map to visualise the relationship between the themes to create overarching themes and sub-themes.

### **4. Reviewing the themes**

At this stage, the candidate themes were refined, and it became clear that some of these were irrelevant because they needed more data to support them or they were themes that needed an overarching heading. For example, the mind map was revisited to understand how the revised themes fit together and to re-familiarise me with the data and the stories being told.

### **5. Defining and naming the themes**

The essence of each theme was identified at this stage and considered with other themes. Concise and punchy names for each theme were finalised at this stage to give the reader an immediate sense of the theme.

### **6. Producing the report**

The themes were utilised to produce elements for writing up the thesis.

## **3.7 Ethical Considerations**

Ethical considerations were paramount to the research project because of the nature of this research. The Manchester Metropolitan Arts and Humanities Research Ethics and Governance Committee gave this study a favourable ethical opinion on 3rd July

2019 (EthOS Reference Number: 3702). It was decided that some amendments needed to be made, and on 13th November 2019 (EthOS Reference Number: 3702), ethical approval was granted to the amended documents. Besides Manchester Metropolitan University's ethical guidance, I turned to the British Sociological Association Statement of Ethical Practice (British Sociological Association, 2017), which identifies the need for professional integrity.

Throughout the research process, steps were taken to protect the participants and support their mental, social, and psychological well-being. First, I ensured the participant and I agreed on the interview's location and time. In most cases, I made every effort to meet at a time and place that worked for the participants because they provided the stories, and I wanted to ensure that this was done at a convenient time for them. A queer-feminist approach recognises that participants are active contributors rather than passive objects being researched (Hesse-Biber, 2012). Within this, I also recognised that people had other commitments they needed to meet, such as those acknowledged in the feminist political economy, where women often have the burden of care (Smith et al., 2021). These factors were considered when arranging the interviews because it was essential to make every attempt to meet at a convenient time and location for the respondent.

It was important for the respondents to be informed of the research process and know how their data would be used, which I outlined in the participant information sheet (Appendix C). At the start of each interview, I asked each respondent if they had any questions about the study or if they would like me to go over anything outlined in the participant information sheet before providing them with a copy of the consent form (Appendix E). I took this step, ensuring each participant was fully informed about the project. This approach was essential given the sensitive nature of the topics we were about to discuss.

If the participant was happy to proceed, I went through each point of the consent form before asking them to sign and asked them if they had any further questions before continuing. If the participant could not sign and send the consent form back, I read each statement to the respondent and asked them if they agreed with all or

rejected any statement. In this situation, their consent was recorded for auditing purposes. When the interview started, I informed each respondent of their right to withdraw and stressed that they could pause or terminate the interview without providing a reason. A couple of interviews were terminated by the participant and rescheduled for another day due to personal reasons; for example, Judy, an HIV healthcare service user in Greater Manchester, was too warm on the first attempt to interview because it was a hot summer day. They decided to complete the interview on another day when it was cooler, and they were more comfortable. None of the interviews had to be terminated because of discomfort caused by the questions that I asked them. At the end of each interview, the informant was asked how they felt, and if needed, I provided them with a detailed contact sheet (Appendix F). Appendix F detailed various organisations the participant could have contacted, such as HIV and AIDS and mental health organisations, should they have needed to speak to a support line or professional about anything discussed during the interview.

The consent form asked the respondents if they would like to participate in the study as either a named subject or anonymously. It also ensured that the participants fully understood the purpose of the research and participated voluntarily. In addition, in all cases, the respondents disclosed identifiable data such as the name of their workplace or other ventures they are involved in. Unless they explicitly stated that I could use this data, I removed any identifiable data to safeguard the respondents' interests.

During the interviews, some participants disclosed their HIV status. I had to handle this data sensitively, especially if the participant wanted to remain anonymous. In the same light, if the participant was named and openly disclosed their HIV status, I had to decide whether to include this. Ultimately, if they were named and discussed their HIV status, I had no reason to eliminate this information because they told me this information to contextualise some of their answers.

There were also ethical considerations when interviewing those knowledgeable about the 1980s AIDS crisis. Some questions could have re-traumatised them by re-

imagining the history they might have wanted to overlook. I designed the interview schedule to focus only on HIV and AIDS healthcare provision. All interviews were transcribed verbatim and coded multiple times to ensure the data captured the participants' voices. Using spoken words rather than paraphrasing their comments was essential when using the respondent's words. The steps taken worked to mitigate any chance of misunderstanding and are in line with the British Sociological Association Statement of Ethical Practice.

### **3.8 Chapter Summary**

Utilising a queer-feminist methodological framework provided a platform to collect evidence around how changes to HIV and AIDS healthcare provision have affected service users across Greater Manchester. A qualitative approach was undertaken to emphasise how the social world is constructed using non-numerical data to gain understanding (Carter and Little, 2016). The assumed philosophical approach was a queer-feminist methodology, interpretivism and queer phenomenology, as these methodologies aid in the data collection of the participant's voices. Moreover, semi-structured qualitative interviews made it possible to understand and obtain in-depth accounts of the respondents' stories (Hale et al., 2007) through qualitative interviews. This methodological framework provided an opportunity to explore intersubjective readings of service users, healthcare workers and those working within HIV and AIDS organisations. It offered a chance to characterise the various responses to changing HIV and AIDS healthcare provision.

## ***Chapter Four: Changing HIV and AIDS Healthcare in the Manchester City Region***

### **4.1 Introduction**

Across the Manchester City Region, HIV and AIDS healthcare provisions have been impacted by devolution, neoliberalism and austerity politics. The reorganisation of services has also affected how the third sector delivers support. In recent years, there has been an underinvestment in physical health services as the City Region has shifted its focus on providing generalist healthcare. Moreover, there has been a shift to centralising services once offered across the region under one overall provider through the Passionate about Sexual Health (PaSH) programme. However, the Manchester City Region has gone some way in attempting to eradicate new HIV cases by joining the Fast-Track Cities initiative.

This chapter starts by exploring common HIV risk factors, such as unemployment, homelessness, substance use and survival sex work. I then discuss how the Health and Social Care Act 2012 has changed how HIV and AIDS healthcare is delivered. Lastly, I consider how the Manchester City Region approached HIV and AIDS healthcare post-devolution through the Passionate about Sexual Health (PaSH) Partnership and since it joined the Fast-Track Cities initiative.

### **4.2 HIV Acquisition: Unemployment, Homelessness and Substance Use**

Several behaviours and conditions can put an individual at greater risk of acquiring HIV. The World Health Organization (2022) has published a list of behaviours and conditions which includes having condomless anal or vaginal sex; having another sexually transmitted infection (STI) such as syphilis, herpes, chlamydia, gonorrhoea or bacterial vaginosis; engaging in harmful use of alcohol and drugs in the context of sexual behaviour; sharing contaminated needles, syringes and other injecting equipment and drug solutions when injecting drugs; receiving unsafe injections,

blood transfusions and tissue transplantation, and medical procedures that involve unsterile cutting or piercing; and experiencing accidental needle stick injuries, including among health workers. These factors require their own discussions, but they did not arise in the interviews. However, homelessness and survival sex work were two factors in some of my interviews. To understand homelessness, I have chosen to discuss unemployment as a risk factor because it regularly arose in the literature which discusses HIV risk.

#### **4.2.1 Unemployment as a Factor for HIV Risk**

People who experience an absence of work may start to observe a decline in their living conditions because a lack of work can remove their financial support, social status and identity (Annequin et al., 2016). It is known that structural factors, such as unemployment and low income, can heighten the risk of HIV acquisition (Millett et al., 2012). Delpierre et al. (2008) also found a link between unemployment and an increased risk of HIV. In their research paper, Möller et al. (2013) found that unemployment-related mental health problems in England are more severe for men and women in the North than in the South. The largest population with poor mental health were those aged 16 to 39, with 52.3% of unemployed people in this age bracket experiencing mental health problems. Considering the figures provided by Möller et al. (2013), younger people with poor mental health and unemployed have an increased chance of acquiring HIV.

Another study found unemployment to be a critical determinant of health-related quality of life (Conyers et al., 2021). The reason for this is that several factors associated with employment, for example, financial and life stability, can provide people with the ability to handle life difficulties and manage their health. However, removing these factors can cause instability in people's lives, making them more likely to engage in sexual behaviours, which could increase HIV risk.

A study conducted in 2013 found unemployment to be a risk factor for morbidities among people from vulnerable population groups, such as women, young people, those who are the least educated and people from lower socio-economic groups

(Möller et al., 2013). In 2017, the unemployment rate for Greater Manchester stood at 5.6% of the population. In 2019, the population of Greater Manchester was just over 2.8 million people. By July 2020, statistics revealed that just over 5% of the population (142,665 people) claimed unemployment benefits (Greater Manchester Combined Authority, 2020).

These figures suggest that the COVID-19 pandemic did not significantly impact employment rates across the Manchester City Region. However, although there is no direct link between the COVID-19 pandemic and employment rates, the research in this section suggests that unemployment can increase someone's risk of being exposed to HIV because there is a link between societal circumstances and unemployment, such as homelessness and substance use. I now move on to discuss the connection between homelessness and HIV risk.

#### **4.2.2 The Link Between Homelessness and HIV**

Homelessness is another factor that can increase someone's chance of acquiring HIV, and various reasons can cause someone to become homeless. In 2017, Shelter (2017) reported that 1 in 154 people was homeless in Greater Manchester. Social causes, such as a lack of affordable housing and unemployment, as well as life events, such as the breakdown of relationships, mental health problems or substance misuse, can lead someone to become homeless (Crisis UK, no date). The relationship between mental health and homelessness is complex and multidirectional, as mental health problems can function as both a cause and effects of homelessness (Chambers et al., 2014). There are also deeper issues linked to homelessness. People may become homeless because they have experienced domestic violence and must escape the situation (Malos and Hague, 1997; Calvo et al., 2021). Calvo et al. (2021) highlight that homeless people have 'reported being victims of numerous acts of physical, psychological, sexual, economic, and property violence '(Calvo et al., 2021: 13). In addition to this, women who experience homelessness have reported experiencing more violence than homeless men (Calvo et al., 2021).



At the same time, Rhoades et al. (2018) reported that, in the US, young people who self-identify as LGBTQ have a greater chance of being homeless than their heterosexual counterparts because their parents have rejected them due to disclosing their LGBTQ identity. The Albert Kennedy Trust (2020) reports that young people who “come out” or have been “outed” as being LGBTQ+ can become homeless because of their identity, and 24% of homeless young people identify as LGBTQ+. The Albert Kennedy Trust further reports that 77% of young people they work with believe that coming out at home was the main factor which led them to become homeless.

In 2019, Manchester’s Urban Village Medical Practice set up a dedicated healthcare service on Saturdays for the homeless people of Greater Manchester. This service runs a sexual health clinic where patients can obtain an HIV test. The Homeless Clinical Support Hub (GTD Healthcare, 2019) was established to provide a clinic for those needing treatment for acute illness, general health checks and signposting to other services in the city. Primary care services are fragmented for people experiencing homelessness, and this was the only service I could find that serves the homeless population of the Manchester City Region. The service is expected to support its entire population. Gunner et al. (2019) found that homeless people across the UK faced similar issues to those in the Manchester City Region, including fragmented services and a lack of awareness by primary healthcare providers of the complex healthcare needs of homeless patients. Therefore, it is clear that many homeless people across the UK face a lack of adequate healthcare provision, not just in Greater Manchester.

To better understand the health of a population, measures need to be in place to allow health providers to come into contact with patients. Having a single surgery to serve the entire homeless population of Greater Manchester is insufficient. The Fast-Track Cities initiative is an example of a political aim of Greater Manchester. I will discuss the Fast-Track Cities initiative later in this section. However, for clarity, the initiative is a global partnership to eliminate new HIV infections and AIDS-related deaths by 2030 (Fast-Track Cities, 2021). Setting up the dedicated healthcare service

only on Saturdays serves the political aims of the Manchester City Region, such as the Fast-Track Cities initiative. This is because the service requires little investment but could be considered an insufficient service provision.

The homeless surgery has placed a responsibility on homeless people to take charge of their sexual health and travel to access testing facilities. Placing this responsibility on homeless people is dangerous because they are often transient. Health workers may have only one opportunity to test and refer them to other services (Cairns, 2021b). Therefore, engaging the homeless community of Manchester in the Urban Village Medical Practice could be difficult. However, this Practice is there to serve the entire population of Greater Manchester. It is well documented that homeless people do not have the financial means to travel across the Manchester City Region. Coffee4Craig, a homeless charity based in Manchester, has called upon the regional transport bosses to make it easier for those living in temporary accommodation and rough sleepers to ride on buses, even though many of them are entitled to do so. The charity also argued that because of the chronic housing shortage in Manchester, people are often housed a long way from services which can help them (Nowell, 2022). As a result, it can be increasingly difficult for the homeless population in the other nine boroughs of the Manchester City Region to access the Urban Village Medical Practice.

These complexities show that the Greater Manchester Health and Social Care Partnership (GMHSCP) and the Greater Manchester Combined Authority (GMCA) need to establish a coordinated response to provide better care for homeless people at risk of HIV across Greater Manchester. Homeless people may engage in activities that can increase their risk of HIV, such as substance use and survival sex work, which I explore in the following sections.

#### **4.2.2.1 HIV Risk: Linking Homelessness with Substance Use and Survival Sex Work**

When people become homeless, they may start engaging in activities linked to an increased risk of HIV acquisition, such as using illicit drugs and sharing needles (Wolitski et al., 2007) and survival sex work (Marshall et al., 2013). Survival sex work

is when people exchange sex for money, drugs, food and shelter (McMillan et al., 2018). Often, people in vulnerable situations, such as drug users and homeless people, turn to this method of sex work because it is the only way they can survive. This method of survival is linked to increased exposure to HIV because people are less able to negotiate the exchange conditions (McMillan et al., 2018). A study by Vincent et al. (2021) in California found a link between homeless people injecting drugs and an increased risk of acquiring HIV. They found that people who inject drugs and have no secure housing are less likely to test for HIV but may continue to engage in activities that increase their risk of HIV acquisition. The issues presented here arose during a conversation with one of my respondents. David, a London-based HIV healthcare worker, informed me,

*The group of people I deal with are homeless; most of them tend to be drug users. One of the worst drugs is heroin, but I see a very quick trajectory to crystal meth. You can kind of function on heroin use for a relatively long period of time. The fall from grace, if I could use that term, is a lot quicker for people using crystal meth to the degree where you'll lose everything: your job, your partner, your house, your health. A lot of them are homeless HIV patients who resort to prostitution. I know that they're doing that in order to, literally, to make what ends they have meet, to put food in their belly. Having to sell their bodies for that and also to feed their habits as well ... The homeless groups tend to be sofa surfers, a lot of them ... they're transient. Why are they transient? Well, because they're prostitutes and selling their body, they don't know where they're gonna sleep from one night to the next ... they're trying to make ends meet in the only way they could possibly do that.*

The points raised by David are interesting because he highlights the connection between drug use, unemployment, homelessness and HIV. This connection is critical because it highlights the journey people take that causes them to undertake survival sex work, thus increasing the risk of passing on HIV. David's point is consistent with other studies showing that homeless people, particularly young people, will undertake survival sex work (Marshall et al., 2013). In contrast, being under the

influence of drugs or exchanging sex for drugs causes an increased risk of acquiring HIV (Ragonnet-Cronin et al., 2018). The study found these factors linked to one of the most significant increases in HIV acquisition since the 1980s.

Overall, people who are unemployed, homeless and engage in substance use and survival sex work are likely to be at a greater risk of acquiring HIV than those who do not experience these. In the next section, I will discuss the HIV risks associated with women.

### **4.3 Health and Social Care Act 2012 Impact on HIV and AIDS**

#### **Healthcare**

So far, I have presented risks associated with contracting HIV, and I now move to discuss the Health and Social Care Act 2012. The introduction of the Act has meant that people seeking support do not receive the same level of support and care they once did before its implementation. As stated earlier, the Health and Social Care Act 2012 was enacted in April 2013. However, before its implementation, funding for HIV prevention, treatment, and support came from primary care trusts (PCTs) and specialist HIV services (Gulland, 2017), where there was some funding from local authorities. The Act has split responsibility for HIV healthcare between NHS England, Clinical Commissioning Groups (CCGs) and local authorities. NHS England and CCGs share the responsibility for HIV services in primary care. NHS England is accountable for HIV treatment, and CCGs are responsible for diagnosing and treating other treatment episodes, such as maternity care, and for treating comorbidities, such as hepatitis (Baylis, 2016). Local authorities under the Act have taken on most public health functions, including the legal mandate to prevent the spread of sexually transmitted infections by testing and treating people with infection. However, local authorities have no legal mandate to treat and care for people living with HIV, though they can choose to do so. This overview shows the complexities of providing healthcare services for people living with HIV because it is unclear who is ultimately responsible for providing HIV healthcare (House of Commons Library, 2017). The complexities of HIV and AIDS healthcare services in Greater Manchester arose during

my conversation with Nathaniel, an HIV healthcare service user in Greater Manchester. He told me,

*I think HIV healthcare has got worse since I was diagnosed in 2003. Sexual health was still under the NHS remit then; gosh, I can't remember the year, but it split, and the NHS were no longer responsible for sexual health prevention, just treatment. Prevention went to local authority, and the whole sexual health service sort of fragmented a bit; well, that was my experience. I used to go to the GUM [Genitourinary Medicine] clinic at the Stepping Hill Hospital, which, granted, was a bit of a trek to get to, but when you felt like you were in a clinic that was specifically for sexual health and well-staffed, you got seen quickly, everyone knew you, you knew all the staff there, they were friendly and approachable. It felt familiar. It felt like a good service. Then that all moved when sexual health went back into local authority.*

The points raised by Nathaniel are interesting because they highlight that within two decades, HIV and AIDS healthcare delivery has become so fragmented that people who need access to those services cannot. Part of this fragmentation links to the introduction of the Health and Social Care Act 2012, which placed a legal responsibility on local authorities to prevent the spread of sexually transmitted infections by testing and treating people who present with an infection. Separating responsibility for delivering HIV services can be linked to the neoliberalisation of HIV care delivery. Earlier in the literature review, I focused on the work of Zhou (2021), who discussed the increased role of the private sector in healthcare delivery. Across Greater Manchester, the private sector has replaced the NHS in delivering some support services.

However, the *Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013*, Part 2, Regulation 6.5, place no legal mandate on local authorities to treat or care for people with HIV. These regulations state that '[t]he duty of the local authority under paragraph (1)(b) does not include a requirement to offer services for treating or caring for people infected

with Human Immunodeficiency Virus.<sup>3</sup> The lack of a legal mandate has been met with reductions in public health budgets for some local authorities across England, leading to the decommissioning of HIV services in certain areas (House of Commons Library, 2017). The British Association for Sexual Health and HIV found that between 2014 and 2020, public health budgets had decreased by £700 million in real terms (British Association for Sexual Health and HIV, 2018). However, the funding of the public health budget in Greater Manchester derives from a business rates retention scheme (Public Health England, 2018b). The Local Government Association conducted initial research into this scheme and found that some local authorities benefit from the devolution of funding responsibility. For these local authorities, it ‘mean[s] ambitious scope for how that money could be used and better linkages between services, i.e. those delivered by the council and NHS team ’(Local Government Association, no date). In Greater Manchester, minimal research suggests that retaining business rates to fund public health budgets negatively impacts service delivery.

The Health and Social Care Act 2012 has negatively impacted the delivery of HIV healthcare across the Manchester City Region. However, other factors, such as the PaSH Partnership’s introduction, have influenced decision-making around how HIV services are provided across the Manchester City Region. In the next section, I discuss how the PaSH Partnership has altered the delivery of HIV and AIDS healthcare across Greater Manchester.

## **4.4 How Greater Manchester is Approaching HIV and AIDS**

### **4.4.1 The PaSH Partnership: Improving HIV Healthcare**

The PaSH Partnership is a collaboration between three third-sector organisations across Greater Manchester: BHA for Equality, George House Trust and the LGBT Foundation. The Partnership aims to deliver a wide range of interventions that meet the needs of people newly diagnosed with HIV, those living longer with HIV and those at the most significant risk of acquiring HIV. In addition, the Greater Manchester

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<sup>3</sup> See the Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013, Part 2, Regulation 6.5.

Sexual Health Improvement Programme (GMSHIP) was also integrated into the PaSH Partnership. This integration occurred to deliver HIV testing, access to low-cost prevention methods, such as condoms, a dedicated sexual health website, outreach for people affected, and support for adults and children newly diagnosed with HIV or living with HIV long-term.

Established in 2017 by the Greater Manchester Combined Authority (GMCA), the PaSH Partnership delivers three main areas of support: to provide free and confidential sexual health advice for black and minority communities; to provide free and confidential support, advice and advocacy services for people who are living with HIV; and to provide advice, help and resources for LGBT people which enables them to take control of their sexual health and wellbeing (PaSH Partnership, no date). As of 2017, all ten boroughs within the Manchester City Region had collectively funded the PaSH programme. Before this, each local authority within Greater Manchester held individual contracts with the organisations which collaborated under the Partnership.

This collaboration between the three organisations of the PaSH Partnership is not new to the Manchester City Region. Before its implementation, local authorities across the Manchester City Region held individual contracts with these organisations. When the GMCA was formed in 2011, it inherited these old contracts, which leaders merged in 2017. One of my participants, Richard, a political figure in Greater Manchester, discussed the PaSH Partnership. They told me:

*This [PaSH Partnership] is a consortium of three providers under a single contract which covers all ten boroughs. As part of that process, there were some reductions in funding again. So, Manchester reduced funding, and there were some funding reductions in the other boroughs as well. Nevertheless, from then forward, contract prices stayed the same.*

Although merging the contracts under the PaSH Partnership anecdotally reduced funding for the three organisations that provide services, there are some reasons for

this. Foremost, costs for these organisations are lower because they have been able to deliver programmes jointly. Merging the contracts was also welcomed by some of my respondents within the Manchester City Region. These points were raised by Stephen, a political figure in Greater Manchester, during his interview when he informed me:

*In Greater Manchester, PASH works in a consulting arrangement, and I think personally that's been quite positive because absolutely recognising that HIV affects different communities in different ways. So, for organisations to be able to work collaboratively, I think it's been positive because we're not necessarily duplicating applications being taken out. I think it's led all the organisations to share learning amongst each other. So, I think there has been a slight reduction in funding, but I think the biggest change is actually the way that organisations are contracted and how services are delivered.*

Introducing a single contract for the three organisations to cover the whole of the Manchester City Region has been beneficial because it has meant that there can be a coordinated response to HIV within Greater Manchester. When there are meetings, only one representative needs to attend, which saves time and money. These savings can subsequently improve health outcomes for people within the Manchester City Region.

However, the PaSH Partnership is wrapped up in the neoliberalisation of the third sector because these organisations have experienced the paradox of “centralised decentralisation” (Evans et al., 2005). Evans et al. (2005) refer to the idea that services are managed from a distance and operationalised by emphasising devolution, performance measurement and increased focus on auditing and inspection. The professionalisation of services is an observation of this. BHA for Equality, LGBT Foundation and George House Trust were once pressure groups set up to create awareness and advocate for improved HIV services. Over the years, they have become professionalised and act as third-sector HIV organisations. The neoliberal governance structures imposed on these organisations have encroached



on their advocacy and autonomy to benefit from “secure funding”. Professionalising these services and the burdens imposed have strained the organisations’ capacity.

Outsourcing services to third-sector organisations is not just about relinquishing control of HIV service provision to the private sector because local authorities have a statutory duty to provide a range of services to their communities (House of Lords Library, 2019). Over the past decade, austerity has seen local authorities primary grants cut by 40% (Bounds and Tighe, 2017). Westminster has also increased the outsourcing of public services. The government did this because they decided ‘the old, centralised model of public service delivery was costly and no longer capable of meeting the challenge of delivering the personalised, joined-up public services that the public expect and need’ (Cabinet Office, 2014). The local authorities within Greater Manchester bought into this reform because they restructured the state and outsourced some of its core functions to provide HIV services to the third sector. In doing so, the GMCA were able to shift responsibility to the private sector to deliver services and limit state involvement in HIV healthcare. To use a metaphor from rowing, the regional government acts only as the cox as they steer the settling of policy and coordinate services through outsourcing.

In contrast, the delivery of the services is left to the rowers who are responsible for delivering the public services. Leaving the delivery of services to the rowers has created a situation where government and healthcare services can no longer supply HIV services alone. Outsourcing HIV services to organisations under the PaSH Partnership has thus enabled councils across Greater Manchester to shift responsibility for improving and protecting the sexual health of residents at the most significant risk of HIV exposure.

This approach enables local government to deflect blame for cuts in services because local authorities place the liability on the PaSH Partnership to deliver the services they are contractually obliged to. However, should the cost of running services rise, the organisation must find ways to fulfil the contractual agreement, which could result in them reducing other services. Hamann and Wilson (2001) write that

neoliberal economic policies enable governments to employ strategies that diffuse responsibility, allowing them to obfuscate their goals. As we have seen, local authorities do not have a legal duty to care for people living with HIV; therefore, providing services for people living with HIV could be a financial burden. HIV services might be funded by money that could be used to care for people for whom local authorities have legal responsibility. However, local authorities have a moral duty to provide HIV and AIDS services because the Manchester City Region has a significant proportion of its population living with HIV. Furthermore, people living with HIV across the Manchester City Region may have co-morbidities, so providing care is essential to living successfully with their co-occurring conditions.

Nevertheless, there is a potential that many people within Greater Manchester are not aware that local authorities have no legal responsibility to provide care and will expect their council to provide HIV services. By utilising the PaSH Partnership, local authorities have provided one source of funding for HIV services, resulting in them having little responsibility for delivering services. This approach has resulted in local authorities being able to care for people with HIV whilst having little input into how those services are provided. Responsibility for service provision is removed, which means that if people do not receive the care they expect, they have limited legal recourse.

Some of the support services in the Manchester City Region have reduced the number of sessions they offer to their users, which buys into biomedical understandings of advancements in HIV and AIDS healthcare. This has left many people to navigate the complexities of their HIV status independently. I support the argument that we need to find a cure for HIV and that antiretrovirals can suppress the virus and stop people from passing it on. However, the argument that antiretrovirals lead people with HIV to live 'healthy lives' is less convincing when the available treatments do not overcome the stigma and discrimination people continue to face (Wu et al., 2017; Pepper and Cowley, 2023). In their study, Wu et al. (2017) found that as HIV treatments advance, persistent layered and synergistic stigma which is aimed towards men who have sex with men living with HIV cannot be

curtailed by biomedical advancements and cures alone. Similarly, Pepper and Cowley (2023) found that the focus on measuring ARV adherence in health services does not address the long term well-being of people living with HIV.

Antiretroviral treatments do not support the poor mental health that people may face when they receive their HIV diagnosis. I discuss the psycho-social effects of living with HIV in Chapter Five. However, I will discuss it here briefly because it is also relevant in this section. One of my participants, Nathaniel, highlighted how the provision of biomedical interventions fails to meet the psychological needs of people living with HIV. For context, Nathaniel received his HIV diagnosis in 2003, and he told me,

*I had a mental breakdown in 2017, which I attribute to keeping my HIV status a secret from my family and also the fact that I contracted HIV so young. I was 16, and I've not really dealt with the psychological trauma of that; I had this mental breakdown.*

Highlighting the psychological trauma of HIV is essential because politicians sometimes view biomedical interventions as the solution for people living with HIV. This is because there is a strong focus on antiretroviral therapies, while mental health support is slowly removed across the Manchester City Region. What became apparent throughout the interviews was that policymakers and some healthcare officials view biomedical interventions as the answer to "HIV problems". The reality is that people need psychological support and biomedical interventions to ensure that healthcare providers tackle the effects of HIV from a physical and mental health perspective.

There is a link between poor mental health, HIV and community factors, such as gender inequalities, stigma and silence, and socioeconomic deprivation, which can exacerbate poor mental health in people living with HIV (Woollett and Hatcher, 2016). It is not always known when a person living with HIV is experiencing poor mental health. The only opportunity for health providers to understand if an

individual is experiencing this is when they present at the service. The comments made by Nathaniel show that someone living with HIV may feel fine when they have been newly diagnosed. However, it may take more than a decade for them to understand and come to terms with their HIV status. Therefore, support services are essential to people living with HIV because they allow people to discuss, with their peers and professionals, their experience of their HIV status post-diagnosis.

#### **4.4.1.1 The PaSH Partnership's Impact on HIV Charities**

Introducing the PaSH Partnership has negatively impacted services provided by smaller organisations within the Manchester City Region. The impact of the PaSH Partnership on smaller HIV organisations arose during my interview with Drew, North East-based academic. Drew told me that many of the smaller HIV organisations outside of the PaSH Partnership,

*don't have paid members of staff or don't have the staff or skills to fill out lengthy tendering forms, never mind having the policies in place.*

The tendering process that Drew discussed was introduced in the Health and Social Care Act 2012. As a result, smaller charities struggled to compete for public contracts because some of these organisations needed professional expertise, time and additional power to tender for work successfully (McCurry, 2009). The lack of professional expertise, time and additional influence has resulted in some smaller HIV organisations reducing their services or closing down because they do not have sufficient funds to continue their work.

In the same conversation, Drew informed me how larger organisations tender for funding. He continued,

*Big organisations, like Terrence Higgins Trust, swallow up that money. All they simply need is a presence in that region. What I found from my research, although it's very controversial and I noticed a lot of the larger organisations didn't listen to it, let's say, being diplomatic. The Terrence Higgins Trust, for*

*example, could take over a small group, and therefore they have a presence in that region so they can access the money.*

Lyn, a healthcare professional in Manchester, informed me about George House Trust's attempt to establish a Bolton base. Talking about this attempt, Lyn told me that the base did not attract new service users; instead, it attracted a similar service base to those who travelled to Manchester to utilise the service offered by George House Trust. Funding and knowledge about the constituents living with HIV within the other nine boroughs outside Central Manchester are sadly lacking.

Attempts to establish a service that meets the community's needs are challenging because an organisation must understand their needs first to ensure they can meet them. Gibbs et al. (2015) emphasise the importance of community organisations. They completed research from a South African perspective and found that the community must be at the heart of any meaningful response to HIV and AIDS. Therefore, for effective communication and campaigns for people living with HIV outside of the city centre, there should be community leaders who understand the community they serve.

Embedded within this is the concept of trust discussed by Jones (2002). They introduce the concept of trust as 'observations that indicate that members of a system act according to and are secure in the expected futures constituted by the presence of each other for their symbolic representations' (Jones, 2002: 225). In other words, trust depends on one person when it counts, and people will have faith in one another even when the future remains unclear (Jones, 2002). Trust is something that Andy discussed, and he stated,

*There might be great events, but the main barrier there is accessibility ... the trust issue that people have of actually leaving their local area and going into another area. You know it can feel like international travel. For some people to go into the borough of Manchester to go to an event that might be attended by*

*loads of people, it probably makes them nervous, or they're not accustomed to doing that.*

This interesting point highlights the disparities between Manchester and the rest of the Manchester City Region. Those living in Manchester may be used to constant change and meeting new people with different experiences. In contrast, for those who live in the nine other boroughs of the Manchester City Region, this could be something they are not accustomed to. Moreover, if someone resides in Manchester, they may be able to walk to the event being held, or, if travel is needed, they need only pay a small cost for transport. However, those who live in the nine other boroughs will need to spend a lot more for transportation and might need to plan to attend such an event.

Additionally, suppose the individual is keeping their HIV status confidential. In that case, they may need to find an excuse to travel to such an event; for example, if they live at home with their family and do not want them to know where they are going. Therefore, for people outside of Central Manchester to attend such events, the organisers need to build that trust with the individuals should they wish for the event to be accessible. In their report, the All-Party Parliamentary Group on HIV and AIDS (2019) found that it is essential to foster trust with people living with HIV to ensure they can get the best from the service. If people do not build trust with the service base, then this can result in people not accessing the support they need because they may be hesitant to access unfamiliar places.

Moving to the PaSH Partnership has saved local authorities a significant amount of money compared to the previous system, where each authority had individual contracts with the three services that comprise the Partnership. Tameside Metropolitan Borough Council (2021) reported that a £100,000 saving had been made since the establishment of the PaSH Partnership. This saving has resulted in the three organisations under the PaSH Partnership taking on responsibility for service changes. The shifting of responsibility links to the general tendency under neoliberal governance systems where responsibility is moved down to the individual

level (Taylor, 2002). Trnka and Trundle (2014) discuss the concept of responsibility and present its contemporary usage as referring to individual or collective accountability through 'judgements of one's rational capacities, assessments of legal liabilities, and notions of moral blame' (Trnka and Trundle, 2014: 137). Furthermore, the issues of responsiveness and answerability are central to the concept of responsibility, and agency is at the heart of how this concept has long been envisioned (Trnka and Trundle, 2014). Rose and Miller (2013) engage in a Foucauldian insight into the technique and technologies of the self, examining how responsibility as a facet of neoliberal forms of governance is depicted by its proponents as enabling empowerment and independence.

In their report, Buck (2020) found that austerity has impacted local government funding, particularly the public health grant, which needed to be prioritised compared to NHS funding and received real-term cuts from the central government. Further, Buck (2020) identified that from 2020/21, £1 billion of additional funding would be required to ensure that the grant would keep up with the population growth and inflation. Reduced funding for services was identified by one of my participants, Ollie, an HIV healthcare service user in Greater Manchester. Ollie informed me that he used to attend a weekly social event at George House Trust. He stated:

*So, I went nearly every week, which I found helpful, making new friends who were also not working, but the service gradually tailed off because the funding got tighter, of course. So, they now have that, I think, just once every three months instead of once a week.*

The reduction in this service can be blamed on increasing pressure on the PaSH Partnership. Blame can be placed on organisations delivering HIV services because they were involved in negotiating their contract with the local authorities. Therefore, if they cannot deliver the support they are contracted to provide, people are likely to blame these organisations for the deterioration of services. If this is the case, Greater Manchester can monitor the contract. At present, it would appear that the

partnership is providing the best value for money, and Tameside is seeking to extend the contract (Tameside Metropolitan Borough Council, 2021). However, should the Partnership fail to deliver on the promises, local authorities can blame these providers because they negotiated the terms of what they can provide.

These measures have ultimately led to a 'survival agenda' (Crowley, 2013) wherein funding for services is withdrawn, organisations are using their reserves to support increased demand, and people who work for these organisations are made redundant to save costs. To survive, some HIV and AIDS organisations must make a choice. They must decide whether to reduce their services, merge with other organisations, or close down. In May 2012, Body Positive North West, a prominent HIV charity, closed after losing £1.5 million over five years (Spencer, 2012). In 2021, Manchester Pride announced that it cut financial support to the LGBT Foundation for the free condom programme. Manchester Pride had been funding the programme since 1994 and blamed the cut on the COVID-19 pandemic and their loss of income. Manchester Pride also cut funding to George House Trust because they felt that the charity was also helping heterosexual people living with HIV (Pidd, 2021). As part of this research, I contacted numerous HIV and AIDS organisations in Greater Manchester to ask if they could participate in this project. However, many could not participate because they were run by part-time volunteers who also worked outside the service. The lack of funding for these groups meant they could not employ full-time people to run the charity.

Although the larger organisations, such as the George House Trust, offer support for anyone living with HIV, some of my study respondents felt they could not access services. They thought George House Trust only provided services for gay men and black African people. Therefore, they thought they could not access the support if they did not fit into either identity. Further, some of my respondents felt that George House Trust did not know the socio-political factors that individuals may face. For example, the location of George House Trust in Central Manchester may mean that the organisation lacks extensive knowledge of the communities across the



Manchester City Region. However, if the charity had a base in their service users' local areas, they might better understand those they serve.

Since the introduction of the PaSH Partnership, some services have been provided across the Manchester City Region. Anecdotally, some of the smaller organisations have closed, and the workload of the PaSH Partnership organisations has increased because they now need to support people across the entire Manchester City Region. This has resulted in these organisations needing to complete more work, but their budgets have not increased meaningfully to support that workload (Table 4).

**Table 4: Total Income for George House Trust 2012 vs. 2020 from Local Authority<sup>4</sup>**

	<b>31 March 2012 (£)</b>	<b>31 March 2020 (£)</b>	<b>Inflation Adjustment (2.4% Average Bank of England) as of 2020 (£)</b>	<b>Percentage increase / decrease (%)</b>
<b>Income (Primary Care Trusts/Local Authority)</b>	322,903	396,346	389,938	+ 1.643
<b>Total Income (excl. exceptional voluntary income)</b>	570,898	638.139	689,417	- 8.035

Table 4 demonstrates that the amount of funding received by George House Trust from primary care trusts<sup>5</sup> and local authorities increased by just over 22% in eight

<sup>4</sup> The table does not show the amount received for the LGBT Foundation because their accounts are complex, and there are various sources of funding which are also partly funded by the local authority. The LGBT Foundation aims to assist people nationally in improving and maintaining their health and wellbeing. In contrast, George House Trust aims to raise awareness of HIV, promote safe sex, and encourage all sexually active people in the North West to know their HIV status (George House Trust, 2021). It was not possible for me to differentiate the amount of funding received by the LGBT Foundation for programmes which included HIV.

<sup>5</sup> When the Health and Social Care Act 2012 came into power on the 1<sup>st</sup> of April 2013, funding from primary care trusts moved over to local authorities.

years. Their total income for the same period increased by just over 11%. Adjusting the 2012 figures to account for an average inflation figure of 2.4% year on year, income from local authorities increased by 1.6%. However, their total revenue decreased by just over 8%. The reduced income helps explain why George House Trust may focus on providing core services rather than expanding its work to people's desired campaigns. Nathaniel recalls,

*George House Trust are bogged down in the day-to-day supporting newly diagnosed people and getting people into counselling, buying people who are destitute new fridges. It's all-important work.*

Not only this, but the figures support the argument I present here for the survival agenda. The charity being “bogged down in the day-to-day support” highlights that they do not have the funding to support other concerns that could improve the daily lives of all people living with HIV. Paul, a Greater Manchester-based HIV activist, informed me about charities' challenges since the PaSH Partnership's introduction. He said,

*There has been a reduction in the number of service advisors at George House Trust. I think HIV and AIDS, in some way, is further down the political agenda than it has been in the past.*

Reducing the number of service advisors is concerning because it means that people living with HIV experience further reduced support. The service advisors could advise, signpost or advocate on behalf of the individual, and losing them means the support is reduced.

#### **4.4.1.2 The PaSH Partnership's Impact on HIV Knowledge**

Reducing the number of service advisors has led to a loss of specialist HIV knowledge that can give successful outcomes for people living with HIV. In addition to these changes, Dalton (2016, 2018) and Hickson et al. (2017) found that organisations

which support people from Black and other ethnic minorities have borne the brunt of funding changes despite these people facing disproportionately high levels of HIV. Across Greater Manchester, it is evident that Black and other ethnic minorities face challenges when they try to access HIV support or seek advocacy support from those who understand the socio-political impact of HIV on people from specific backgrounds. These challenges are linked to the current domain framework of funding changes, as this has created a situation where people living with HIV struggle to obtain support. Since 2010, the introduction of austerity measures has resulted in governments reducing their involvement in the lives of citizens. This links to the work of Bourdieu and Wacquant (1992), who introduced the theory of symbolic violence. As discussed in Chapter Three, symbolic violence 'represents the way in which people play a role in reproducing their own subordination through the gradual internalisation and acceptance of those ideas and structures that tend to subordinate them' (Connolly and Healy, 2004: 15). In this case, service users and those who work in the field of HIV have come to accept the denial of adequate funding even though it could affect them and their daily lives.

The Health and Social Care Act 2012 has provided patients with choices and gives them some input into how they want their healthcare delivered. Discussing this, McKenzie (2015) found that some people see this as a natural progression of healthcare delivery and, thus, become accustomed to these changes. This "natural progression" represents symbolic violence because restructuring funding for services has meant that some people have little choice when attempting to access HIV services. Ollie told me that he has had to seek and pay for private support, stating,

*Newly diagnosed ones just take it as bread that there aren't that many services, but the ones who have been diagnosed longer term, like me, are more used to a more supportive environment that's not really there so much anymore ... I don't really have any mental health problems, so I don't really have much need for support, but I enjoyed that social contact. I do miss having the free alternative therapies available, but I'm lucky enough to be able to afford to pay for them myself now, so I just do that instead. But I do miss the sort of overall*

*supportive environment of going in regularly and chatting to the staff, the volunteers or whatever. So, yeah, it's not the same as it was, but I'm managing okay without it.*

The lack of services for people who seek support is problematic because it means that those who used to access the support can no longer do so. Ollie is less affected by the reduction in services because he can pay for the support privately. Nevertheless, those who do not have the financial means to pay for the support are left to deal with their diagnosis alone. Moreover, newly diagnosed people may not be aware of the level of support that used to be offered. This is problematic because it defers responsibility from the state and places it on the individual. Self-responsibilisation of individuals was discussed by Bourdieu and Accardo (1999), who argued that neoliberalism defers blame from the government. It places it on the individual because they are more responsible for their healthcare outcomes because of their choices. This position blames the individual for their choices and makes them entirely responsible for their misfortune should their choices be detrimental to their health.

There has not been much response in recent years to challenge the financial cuts to HIV and AIDS healthcare services within the Manchester City Region. When I asked the participants about funding changes to services, I received answers about the closure of HIV organisations and how most funding went to larger charities within Greater Manchester. Alex, a support worker at a Manchester-based HIV Charity, was an exception because he discussed the recent campaign 'Stop the Cuts'. During his interview, Alex said:

*[W]e started to see a lot of local authorities removing HIV from their local agenda, cuts to HIV services as they faced cuts from their public health budgets and their local budgets.*

This movement aimed to raise awareness of the cuts to HIV services. It united sexual health organisations and charities, together with health professional bodies, such as

the British Association for Sexual Health and HIV (BASHH) and the British HIV Association (BHIVA), leading them to collectively campaign against cuts to HIV services (British HIV Association, 2016). Stop the Cuts, a national campaign was established by a group of HIV organisations, such as Positively UK, service providers and community groups to ensure that the needs of people living with HIV across the UK were comprehensively met. The campaign sought the best possible results for physical health, mental health and social inclusion (Positively UK, 2016).

One of the reasons for establishing the campaign was that several local authorities pulled funding for HIV services (May, 2016). The Director of Strategy at the National AIDS Trust, Yusef Azad, said,

HIV support services can be the only place where people are open about their status, the only place they can find advice and support, and the only place they can talk to other people with HIV. They are an essential component of the long-term care of people with HIV. To remove them would leave a lot of vulnerable people stranded.

(May, 2016)

The view expressed by Yusef is consistent with that provided by Ollie above. They both argue that support services may be the only option for some people living with HIV to discuss their status. However, no research exists on Stop the Cuts or online updates regarding the campaign's success.

Despite this, the introduction of the PaSH Partnership has benefited Greater Manchester because it has meant that organisations can work together to provide a consistent approach to HIV services. However, this approach has resulted in a reduction in other services once provided by these organisations. Although they are working together to improve the HIV landscape of Greater Manchester, they are leaving people behind, significantly impacting people's ability to live fulfilled lives with HIV. Creating the PaSH Partnership has aided the GMCA in having greater

control over the organisation of the three third-sector HIV organisations whilst limiting its responsibility for HIV services.

#### **4.4.2 Fast-Track Cities and the Future of HIV Services in Greater Manchester**

The GMCA, the GMHSCP and the PaSH Partnership have worked together and focused on some initiatives to eliminate new cases of HIV within a generation. In 2018, the Mayor of Greater Manchester, Andy Burnham, announced that the Manchester City Region would be a part of the Fast-Track Cities initiative, a global partnership between cities and municipalities to achieve zero new HIV infections and AIDS-related deaths by 2030 (Fast-Track Cities, 2021). The initiative was established to end new transmissions of HIV in Greater Manchester. The Fast-Track Cities initiative committee sits within the Greater Manchester Sexual Health Network. It comprises clinical and community sector representation, people living with HIV, public health, primary care, GMHSCP, and the GMCA (Fast-Track Cities, no date). The Fast-Track Cities initiative focuses on translating global goals, objectives and targets into local plans. The initiative is set on 'building upon, strengthening and leveraging existing HIV-specific and -related programmes and resources to attain the 90-90-90 targets, increase the use of combination HIV prevention services, improve the quality of life of those living with HIV, reduce to zero the negative impact of stigma and discrimination, establish a common, web-based platform to allow for real-time monitoring of progress' (Fast-Track Cities, no date). The 90-90-90 targets relate to 90% of all people living with HIV will know their status, 90% of all people with diagnosed HIV infection will receive sustainable antiretroviral therapy, and 90% of all people receiving antiretroviral treatment will have viral suppression by 2020 (UNAIDS, no date). Considering this, Greater Manchester is committed to its aim of working towards the elimination of HIV.

In total, six participants discussed the Fast-Track Cities initiative in some detail. Even though most of them discussed the aims of the Initiative, they did not have any evidence relating to what being part of it has achieved for the city. Despite this, Andy recognised Greater Manchester invested £1.3 million in the Fast-Track Cities

initiative. However, this funding is to eliminate new cases of HIV by 2030 across the whole of Greater Manchester, not just Central Manchester, as part of the initiative, as confirmed by the Greater Manchester Health and Social Care Partnership (2018). Alex discussed the Fast-Track Cities initiative and said there had not been much progress since its introduction. He said,

*The Fast-Track Cities initiatives are really useful tools at keeping HIV on the agenda in local areas. My personal opinion as someone living with HIV in Manchester is that I don't feel involved in the process here despite how kind of well-connected I am within in the sector; I don't really know what's going on in Manchester. I was at the Pride event when Andy Burnham came onto the stage of the [AIDS] vigil and announced it. It was like a really exciting moment, and it felt that Manchester was following the footsteps of cities like London and Brighton in the South. Whilst there are some ideas and initiatives going on, it's really important that they connect them back with the communities of people with HIV.*

The point made by Alex here is interesting because it highlights the importance of such initiatives and how the community wants to be involved in the process. However, removing the opportunity for the community to become involved in the initiatives is problematic as it could result in people living with HIV losing faith in the politicians to stop new rates of HIV. The engagement with the community is further diminished when there has been no update since 2018 on the websites which promote the initiative. The lack of engagement with the programme can be linked to the COVID-19 pandemic, which impacted service delivery within the Manchester City Region. There is currently no data to confirm this; however, I hypothesise this is because the COVID-19 pandemic has affected other services. Secondly, Andy told me,

*It's not to criticise Fast-Track Cities because a lot of money has gone into this, and lots of time and dedication that's been demonstrated, even now, across the three organisations that's leading it to support and make it a success.*

I interviewed Andy during the COVID pandemic, and it is clear that the organisations running the Fast-Track Cities programme are committed to ensuring its success. However, as I discussed, the PaSH Partnership are running services on less money, which reduces the services they currently run. Therefore, being a part of this initiative may cause more strain on their services. However, it is unclear exactly how this affects the organisations' commitment to HIV services, and more research will be needed to identify this.

Overall, it is hard to convey what the Fast-Track Cities initiative has achieved to combat the HIV-associated stigma for people living with HIV in Manchester. This is because the data that Manchester supplies has not been updated on the Fast-Track Cities web portal since 2020. One reason is that in 2020, the Manchester City Region declared it reached the 90-90-90 target, with 93% of all people living with HIV in Greater Manchester knowing their HIV status, 99% diagnosed with HIV receiving sustainable antiretroviral therapy, and 97% who receive antiretroviral treatment having viral suppression. Meeting the 90-90-90 targets demonstrates that the Manchester City Region is committed to ending new cases of HIV, and it has achieved the targets set out by the Fast Track Cities. However, these targets only focus on the physical health of living with HIV. These targets still demonstrate that Greater Manchester has not yet reached the entire population of people living with HIV. In Chapter Five, I discuss how these targets do not consider the mental health of people living with HIV, an area which requires some attention.

#### **4.5 Chapter Summary**

In conclusion, this chapter has presented the findings of qualitative interviews with service users of HIV and AIDS healthcare provisions; organisations specialising in HIV and AIDS support, advice and advocacy services to improve health outcomes; healthcare staff specialising in HIV and AIDS healthcare and those who advocate for improved treatments; academics who work in the field of HIV studies; and activists who are campaigning for improved HIV and AIDS services. I have comprehensively analysed individuals' inequalities when seeking HIV and AIDS healthcare within the



Manchester City Region. I have found a significant gap in access to HIV and AIDS care between those who live in Manchester and those who live in the other nine boroughs of Greater Manchester. This gap in service provision and access reflects the health inequalities in Greater Manchester (Codling and Allen, 2020; Marmot et al., 2021). I have explored the key factors which impact people's access to HIV and AIDS healthcare within Greater Manchester, evidencing a range of factors which put people at risk of acquiring HIV in the first instance. These include socioeconomic factors, from unemployment and housing to environmental factors, substance use, and survival sex work. These factors together increase someone's HIV risk.

In analysis, the Health and Social Care Act 2012 has complicated the delivery of HIV and AIDS healthcare by splitting responsibility and confusing who is responsible for delivering specific aspects of HIV and AIDS healthcare. Local authorities across England are responsible for providing sexual health services. However, they have no legal mandate to treat or care for people living with HIV and AIDS (House of Commons Library, 2017). The lack of responsibility for providing HIV and AIDS services is further complicated for Greater Manchester because the delivery of these services has devolved to the Manchester City Region level. However, Greater Manchester delivers HIV and AIDS healthcare services under a collaborative partnership between George House Trust, the LGBT Foundation and BHA for Equality, known as the PaSH Partnership. All ten local authorities within the Greater Manchester Combined Authority have bought into the contract that sexual health services are delivered as part of the contracted agreement.

However, the PaSH Partnership buys into the neoliberal healthcare delivery model because it allows services to be delivered at a lower cost. Along with the COVID-19 pandemic—which has caused further financial pressures—HIV services are being stretched and face challenges when they attempt to deliver services. For example, HIV services have been outsourced to third-sector organisations, which has resulted in local authorities relinquishing control of HIV services to the private sector at a reduced cost. The third-sector organisations making up the PaSH Partnership are also delivering more services with reduced funding, so there have been cuts to HIV

support in some cases. Furthermore, funding for HIV support services has shifted to the PaSH Partnership, which has left smaller charities and organisations across Greater Manchester with less funding because they cannot compete with the larger charities in this respect (McCurry, 2009). A lack of funding has resulted in the closure of these charities and organisations, reducing knowledge of the communities outside of Central Manchester. All of this has resulted in already marginalised people facing increased marginalisation in favour of cost-cutting measures and being unable to access HIV and AIDS services locally, where the healthcare professionals understand the needs of the individuals.

This chapter has highlighted the inequalities people in Greater Manchester face when accessing HIV and AIDS healthcare provisions. This is the first study highlighting the impact of the Health and Social Care Act 2012 and devolution on delivering HIV and AIDS healthcare services in Greater Manchester. The interview data tells us that people in Manchester have greater access to support, and those who live outside the city centre do not have the same access to support services. However, it can only tell us so much.

Devolution, neoliberalism and austerity have impacted the delivery of physical healthcare services and specialist mental healthcare provision. It is essential to discuss mental health services because poor mental health can impact the successful health outcomes for people living with HIV and AIDS (Stangl et al., 2013). Poor mental health can also affect how service users engage with physical health services, potentially resulting in them disengaging from service (Zolkefli, 2017). Considering this, I will discuss how devolution, neoliberalism and austerity measures have impacted mental health services.

## ***Chapter Five: Psychological Support for People Living with HIV and AIDS in Greater Manchester***

### **5.1 Introduction**

The devolution of healthcare to the Manchester City Region has impacted the delivery and availability of mental health services for people living with HIV and AIDS. Today, people live longer with HIV because of the biomedical interventions which enable them to take charge of their condition. These treatments can also prevent the individual from developing AIDS because they can reduce their CD4 T-cell count to undetectable levels, meaning they cannot pass the virus onto others when unprotected sex. Although these developments have significantly improved the lives of people living with HIV, they do not address mental health (Hickson et al., 2017). Psychological factors affecting people living with HIV are not just isolated to the condition itself. Still, they are also linked to stigma and discrimination, which service users may experience in their homes, communities and healthcare settings (Yuvaraj et al., 2020). Austerity measures have slowly reduced the availability of funding for support services, resulting in the decline of mental health services. However, stigma and discrimination continue to be a threat towards people living with HIV and AIDS but they are only able to access limited support (Tsiakalakis et al., 2021). In their study, Tsiakalakis et al. (2021) found that budget cuts to healthcare systems creates significant barriers to people receiving optimal care; which addresses social barriers and discrimination.

In this chapter, I draw on the data from my qualitative interviews and secondary data to analyse mental health service provision changes. I start this chapter by reviewing the mental health factors associated with living with HIV, in particular, focusing on stigma and discrimination and the ongoing campaigns across the Manchester City Region, which are working to remove some of the stigma and discrimination affecting service users. I then move on to discuss the importance of providing psychological support for people living with HIV and how current service provision, such as IAPT, is affecting successful outcomes, in particular, for people with complex mental health

needs. At this point, I discuss why there is a need for specialist mental health support. Lastly, I consider how the COVID-19 pandemic has affected mental health support in the Manchester City Region before concluding.

## **5.2 Mental Health Factors for People Living with HIV**

In 2018, the National AIDS Trust reported that many people living with HIV develop mental health problems (National AIDS Trust, 2018). Whilst people may develop a mental health condition post-HIV diagnosis, living with mental health problems can play a critical role in increasing the chances of someone acquiring HIV in the first place (Remien et al., 2019). Factors such as alcohol and substance use, depression and anxiety are some causal reasons for poor mental health. However, they often remain undiagnosed and untreated until the symptoms become severe (Thomas and Staiger, 2012). Thomas and Staiger found a link between late identification and treatment of these symptoms with poor physical and psychological health outcomes. Structural inequalities persist for people living with HIV and AIDS, with some factors impacting specific populations greater than others, such as discrimination and stigma. Hickson et al. (2017) highlight that discrimination, concerns about confidentiality, low access to HIV medications and few targeted HIV prevention interventions are prevalent factors in the diagnosis of HIV amongst men who have sex with men, leading to the development of poor mental health.

During her interview, Simone, a Manchester-based mental health professional, discussed stigma. She told me how it could affect the individual who experienced it and said,

*the power of stigma, you know stigma does kill, it stops people seeking care.*

Henderson et al. (2013) found stigma to impact mental health and people's willingness to engage with mental health services. Not only this, but Alvidrez et al. (2010) observed that black adults who have experienced stigma were less likely to engage with mental health services. They found it was one of the US's most

significant barriers to treatment. This view from the United States was echoed by Simone, who further stated,

*a lot of our patients who've come over seeking asylum, who are refugees and the experiences they have been through at the hands of authority are often too horrendous to even think about and sometimes, trying to bring those people into care can be really challenging.*

A lack of trust in official figures can cause individuals to develop severe mental health conditions.

Adults who present with severe mental health conditions tend to engage in riskier sexual practices, such as unprotected sex with multiple partners, consuming drugs and alcohol before sex, and inconsistent use of contraception measures (Remien et al., 2019). These factors can be linked to the stressors someone has experienced. Stressors include significant life events, such as the death of a loved one, childhood abuse, and parental divorce and conflict. However, they can also emerge from daily psychological or social events, including complex relationships or social stigma (Moustafa et al., 2018). Moustafa et al. write that a stressor can establish a cycle of distress and lead an individual to learn maladaptive coping strategies, including substance use and emotional numbing, which could eventually make them less able to cope with ordinary situations. Moreover, people exposed to trauma are likely to make decisions that risk their health, such as substance use and sexual practices, which can increase their chances of acquiring HIV (Rheingold et al., 2004). In our interview, Simone discussed how mental health issues and trauma might make some people enter unsafe relationships:

*[P]eople who come from really difficult backgrounds, history of abuse and neglect, causes early trauma [which] makes people much more likely to acquire this condition ... if you come from a place where your early template for relationships was a very messy one. People didn't care for you properly, you don't learn how to care for yourself, keep yourself safe, make safe choices ... A*

*lot of people might end up in situations where they haven't got the confidence to negotiate things like safe sex ... They may be looking for intimacy and engage in more risky sexual practices.*

Lundberg et al. (2011) found that engaging in unsafe sexual practices and substance use can increase their chances of acquiring HIV. The feeling of having multiple failed relationships can also create anxiety in someone about starting new relationships. Therefore, people may turn to self-medication with substances to deal with interpersonal anxiety (Ramrakha et al., 2013). Ramrakha et al. (2013) argue that a link can be made between people who experience feelings of loneliness and hopelessness to substance and alcohol use as a coping mechanism.

Hazardous drinking has been linked to HIV exposure (King'ola et al., 2014) and it is strongly correlated to unsafe sex (Fairbairn et al., 2017). However, it was found to play a role in HIV risk because people use condoms less frequently when they consume significant amounts of alcohol or take drugs. The National AIDS Trust (2018) found mental health and drug use to be well established in people living with HIV, as 23% of this population reported recent use of recreational drugs (compared to 9% of the general population), rising to 40% in gay and bisexual men living with HIV. Therefore, it is clear that alcohol use, substance use, and poor mental health are leading factors in exacerbating HIV risk behaviour.

### **5.2.1 'Don't Die of Ignorance': HIV Associated Stigma for People Living with HIV**

The "Don't Die of Ignorance" campaign is pivotal to understanding why there are still fears around HIV today and why there is a significant amount of misinformation about HIV and AIDS. Therefore, I consider this campaign as it is helpful to understand the impact that misinformation continues to make on the lives of people living with HIV and AIDS.

Since the 1980s, HIV-related stigma and discrimination have been directed at people living with HIV and AIDS (Avert, 2019). Julia Hussein and Laura Ferguson explain that

stigma is experienced when 'an individual or group is identified as being different from a perceived norm and subjected to labelling, shame, disapproval and discrimination' (Hussein and Ferguson, 2019: 1). The lack of community and public understanding of HIV has led to stigmatised behaviours around people living with HIV, from misunderstandings as to how HIV could be transmitted to physical acts of violence against people who are living with the virus (Hedge et al., 2021). Although there have been developments in antiretroviral drugs to make HIV a more manageable condition, stigma and discrimination continue today.

Clarke (2006) studied media portrayals of HIV and AIDS in Canada during the 1990s and early 2000s. He found that gay men were never portrayed positively and were often stigmatised as acquiring HIV due to perceived "sinful" sexual behaviours. Moreover, Hedge et al. (2021) found that the written words of journalists, especially those in tabloid newspapers, persuaded public opinion toward people living with HIV. The terms of journalists divided people living with HIV as either "guilty" or "innocent". People who were labelled guilty were seen to behave in a way where it was perceived that people brought infection upon themselves, such as homosexuals and people who injected drugs. People labelled innocent were seen as those given the virus, such as those with haemophilia who acquired HIV due to a blood transfusion contaminated with HIV in the early 1980s (Terrence Higgins Trust, no date-a). The Chief Constable of Manchester, James Anderton, raised what he saw as a moral issue and said 'homosexuals, drug addicts and the prostitutes who had AIDS were "swirling round in a human cesspit of their own making"' (Clarity, 1987). These factors are linked to how people perceive and misunderstand HIV today. Nathaniel commented on the 1986 public information campaign and told me,

*[T]he national campaign in the 80s with the tombstones absolutely terrified everyone, and we saw the biggest drop in sexually transmitted infections ever on record because everyone was terrified. In a sense, it worked [but] it led to a lot of stigma.*

The fear people experienced off the back of this campaign was not limited to men who have sex with men; the entire population was concerned about HIV and AIDS. Despite the government's intentions, the public information campaign has continued affecting people with HIV. The visual imagery still informs how some people picture HIV today and sustains the HIV-associated stigma (Florêncio, 2018; Ranscombe, 2019). Earlier, I introduced Tyler's (2020) concept of stigma power, which looks at the 'exclusion of others' (Tyler, 2020: 21). Although this campaign did not target specific groups previously thought to be at the most significant risk, such as men who have sex with men, the campaign did put fear in people and created a stigma which continues today. Ranscombe (2019) found that the historical view of HIV and AIDS as a death sentence still influences the public's perception, 'with people still equating diagnosis with an early grave' (Ranscombe, 2019: 220). In this study, several participants discussed the idea of a national television campaign to re-educate the general public about HIV and dismiss stigmatised understandings of the virus. Such a campaign is essential, considering an estimated 105,200 people living with HIV in the UK as of 2019, with 6,600 undiagnosed (Terrence Higgins Trust, 2018a). The Greater Manchester Health and Social Care Partnership (2019) estimates 5,650 people living with HIV across the Manchester City Region as of 2019, or just over 5% of the UK's HIV population. Alex said,

*It's really easy to say we need public campaigns, we have done some of that, but campaigns work better when they're targeted at certain populations, especially if you're trying to sell a good message ... Something that COVID has shown us is you can contact an entire population, but the information that's passed on doesn't always set in and digest for people. So, it's not always the right tactic to go down.*

Although some think a public information campaign would re-educate the public about HIV and debunk some associated stigmas, it may not achieve its aim. Alex's point links to the work of Janet Weiss and Mary Tschirhart (1994) as a result of the campaign. They highlight that public information campaigns are only effective if the objective is to influence the beliefs or understandings of the public. It creates the



context for anticipated social outcomes. The movement must also present a clear message which resonates with the right audience (Weiss and Tschirhart, 1994). The 'AIDS: Don't Die of Ignorance' campaign was established to inform the public about the risks of HIV and AIDS. It was successful because it influenced the public's sexual practices; as Nathaniel earlier stated, sexually transmitted infections went down in the 1980s. Cook (2017) notes how the 1986 public information campaign caused panic, and people were phoning the helpline in a fearful response to the leaflet they received through their letterbox. This overloaded the telephony system, and the lines subsequently crashed. However, scaring people was intentional. Malcolm Gaskin, the designer of the campaign advert, discussed the tombstone advert which accompanied the leaflet. Gaskin said they broadcast the campaign to scare people about HIV and AIDS so they would read the brochure (Jonze, 2017). The campaign messaging resonated with the right audience because the worried well did panic.

### **5.2.2 Combating Stigma: Does U=U Go Far Enough to Combat HIV-Related Stigma**

The U=U message was recently established to disseminate the science that people with an undetectable viral load cannot transmit the virus (Bereczky, 2019). The message is helpful because it relieves those living with HIV. After all, they know that they cannot pass on the virus. However, people's fears of acquiring HIV generally prevent people from accepting those living with HIV. Most of the participants in this study agreed that the U=U campaign is excellent, but they felt that it was only known in LGBTQ circles or among those who know about HIV.

David, A London-based HIV healthcare worker, discussed the visibility of the U=U campaign in London, he remarked:

*[W]hen I walk on the underground in London and see some of these U=U posters, it doesn't mean anything to the average punter on the street.*

Nathaniel echoed what David informed me and compared campaigns in London to Manchester; he said:

*[E]very time I go to London, campaigning is everywhere ... [but] I've always wondered why Manchester doesn't have the same visual presence.*

Nathaniel adds:

*I don't think ... generally, people know or see that message [in Manchester], and I also think U=U doesn't mean anything as a statement. So, every time I say it, I have to explain it to people.*

These comments show that some participants felt that U=U has not successfully educated the broader public about HIV because its messaging has not reached those who need to know about HIV. By failing to inform the public about U=U, the campaign also fails to educate the public about HIV. A study highlighted by Alex demonstrates that the U=U campaign has not reached those who live and work in London. Alex informed me about research recently conducted at Barts Health NHS Trust, which provides specialist HIV care:

*80% of the hospital staff they spoke to in the survey didn't know about U=U.*

This research was presented at the British HIV Association (BHIVA) Autumn Virtual Conference 2020 by Shongwe et al. (2020). They found that among those who participated in the study, 35% believed that women would pass HIV onto their children, 62% were aware of PrEP (pre-exposure prophylaxis) and PEP (post-exposure prophylaxis), and 45% thought that PrEP should be used after a needle-stick injury. 47% of the participants felt that they might get HIV from a needle-stick injury when treating a patient living with an undetectable viral load. The statistics presented by Shongwe et al. highlight how staff who work within an NHS trust which provides expert HIV care have limited knowledge of HIV. Considering there has been a campaign about U=U in London, it is concerning that Barts Health NHS Trust staff have little understanding of HIV.

This being the case in London causes concern for other secondary care services across the UK. The messaging around U=U has yet to reach secondary care services

(Shongwe et al., 2020). In the Greater Manchester context, Connor, a healthcare professional in Manchester, told me about the lack of knowledge of HIV. Connor discussed how healthcare professionals in critical care units tend to increase their use of personal protective equipment (PPE) when working with a patient with HIV, for example, when taking blood. Connor said:

*[I]f the nurse is doing bloods and there's someone with HIV, they'll wear visors, whereas if the person is living without HIV, then they won't wear a visor when they should be wearing a visor for both.*

This increased use of PPE for people living with HIV was highlighted by Yuvaraj et al. (2020). They found that patients living with HIV endure stigma and discrimination within healthcare settings despite global improvements in health outcomes for those with HIV. Stigmatising behaviours can manifest in various forms, such as neglecting patients, differential treatment, the testing and disclosure of HIV status without the consent of the patient, unwarranted use of precautions to prevent transmission (such as increased use of PPE), the labelling of belongings or files, and verbal abuse and gossip (Yuvaraj et al., 2020). Connor also told me he constantly challenges behaviour similar to those highlighted by Yuvaraj et al. because patients should not be singled out. A reason why the knowledge of healthcare staff may be limited can be linked to the restricted dissemination of HIV awareness within healthcare trusts. Connor said that in his Trust, HIV awareness campaigns are only prevalent around Gay Pride and LGBT History Month, as this is when the staff are more likely to talk about HIV in their memos or handovers. This is stigmatising behaviour because it links to the assumption that HIV continues to affect only gay men.

A lack of knowledge of U=U within healthcare settings is problematic. If the message is not being filtered to those working on the ground in healthcare settings, then the movement is limited in achieving its aim. Further work is therefore needed to tackle the stigma and discrimination experienced by people living with HIV when they enter certain secondary care services.

### 5.3 Providing Mental Health Support for People Living with HIV

Knowing that people living with HIV are likely to experience stigma, discrimination, and poor mental health should trigger a response to provide adequate patient-centred psychological and mental health support. Patient-centred care is the idea of,

*shaping services around the needs of people rather than the populations, [to work out] what is it that people need and try to tailor those services for people.*

(Sally, Manchester-based academic).

However, mental health has been a neglected priority (Vreeman et al., 2017), and they are not being resourced to keep pace with the demand in England (British Medical Association, 2023). I have identified four factors in my research which have led to the neglect of psychological and mental health support for people living with HIV. These factors include introducing the stepped care model through Improving Access to Psychological Services (IAPT) services, the decline of the emphasis on mental health services not being within public health priorities in recent years, improvements in antiretroviral treatments and funding changes.

In addition to the four factors I have identified, several participants discussed the Joint United National Programme on HIV and AIDS (UNAIDS), which launched the 90-90-90 targets in 2014 (UNAIDS, no date). These targets aimed to ensure that, by 2020, 90% of people living with HIV will be diagnosed, and antiretroviral therapies will be provided to the 90% diagnosed. Of those receiving antiretroviral treatments, 90% will have viral suppression or undetectable levels of HIV (UNAIDS, no date). In November 2018, Public Health England reported that the UK had reached its UNAIDS 90-90-90 targets with '92% of people living with HIV diagnosed; 98% of those on treatment; and 97% of those have an undetectable viral load, which means they can't pass on HIV' (Public Health England, 2018a). However, several participants noted that these targets only focused on the virus rather than the person (Guaraldi et al., 2019). The participants called for a fourth 90 target to be added to the UNAIDS focus,

ensuring that 90% of people with viral suppression have an excellent mental health-related quality of life. This was a view echoed by Sally, who said,

*Adding a fourth 90, focusing on quality-of-life issues for people living with HIV, is looking at the whole person because if you take your eye off the ball, if you get someone to be undetectable, great, but if they're living miserably and they've got no quality of life, then I'm not sure that's a good enough job. Also, I believe that if you focus more on the fourth 90, it will have a positive impact on the other cascade. So, if people know that their quality of life is going to be better, they're going to get access to better care, not just treatments, not just drugs, then actually people may want to take a test more.*

This discussion of a fourth 90 is interesting because it could bring a holistic approach to HIV healthcare. In *Greater Manchester's Population Health Plan 2017-2021*, the Health and Social Care Partnership recognised 'mental health and wellbeing as a key crosscutting priority', focusing on 'early intervention and prevention, supporting people in communities and improving access to services' (Greater Manchester Health and Social Care Partnership, 2016: 11). Focusing on the mental wellbeing of people living with HIV could enable those who are experiencing poor mental health to seek the necessary support to help understand their HIV status. Now, I will discuss mental health support for those living with HIV across Greater Manchester.

### **5.3.1 Improving Access to Psychological Therapies and Mental Health Support**

The early intervention and prevention approach to mental health services discussed in the Greater Manchester Health and Wellbeing Strategy refers to IAPT services. The IAPT model was launched in 2008 to transform the treatment of people with mild to moderate mental health problems in the first instance before the individual's mental health develops into moderate to severe or severe to recurrent depression and anxiety disorders (NHS England, no date). IAPT services are delivered using a stepped care model to enable clinicians to assess the patient and decide on the most suitable psychological treatment (Mental Health Matters, no date). A stepped care model has

two features which are supposed to ensure better health outcomes for the patient: efficient and effective. First, it should be efficient, meaning that the model should be the least restrictive in limiting the time a patient spends in care. Second, the model should be practical and self-correcting, meaning that a patient can move up and down the model to ensure they receive the most effective treatment (Bower and Gilbody, 2005). I demonstrate the stepped care model in Table 5 (see below).

The BHIVA Standards of Care 2018 (British HIV Association, 2018b) and BHIVA Monitoring Guidelines (British HIV Association, 2019) inform health providers that people living with HIV should be assessed within three months of diagnosis or at least once a year for mental health problems. Where it has been identified that onward support is needed, healthcare providers should refer patients. The level of mental health support varies across the four levels of IAPT services, outlined in the All-Party Parliamentary Group on HIV and AIDS report, The Missing Link: HIV and Mental Health (see Table ).

**Table 5. IAPT Stepped Care Model Levels for HIV Care**

Level	Type of Care
1	All healthcare professionals are required to deliver care at this level, which includes understanding the psychological issues associated with HIV, recognising overt distress and responding to distress with supportive communication, and providing relevant information and signposting patients.
2	A need for enhanced support is delivered by HIV Specialist Nurses, Advanced Practitioners or those clinicians with relevant additional HIV training. These healthcare professionals are expected to screen for distress and cognitive difficulties, risk assessment, discussions around acceptance and adaption, education sessions, brief behavioural interventions and signposting.

Level	Type of Care
3	Clinicians trained in delivering a specific mode of psychological therapy or counselling, such as cognitive behavioural therapists, assess and formulate psychological problems and risk and then deliver psychosocial interventions for specific psychological difficulties.
4	This level involves specialist mental health professionals, including Clinical Psychologists and Psychiatrists, who conduct in-depth assessments and interventions, including the formulation of longstanding, complex and interrelating psychological difficulties, neuropsychological assessments and cognitive rehabilitation, ongoing risk assessments and the delivery of psychological and psychiatric interventions for people with severe mental health issues.

(All-Party Parliamentary Group on HIV and AIDS, 2019)

In 2016, NHS England published a Five Year Forward View for Mental Health highlighting mental and physical healthcare disparity. The report found that there is a lack of promoting 'good mental health and prevention of ill health, and the links between mental and physical health' (Independent Mental Health Taskforce to the NHS in England, 2016: 39). As of April 2018, all Clinical Commissioning Groups (CCGs) within England were expected to expand IAPT services by integrating these services into physical healthcare (NHS England, 2018). The IAPT Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms (NHS England, 2018) guidance was published to assist with implementing IAPT services by setting out an ideal pathway.

Though IAPT services can support people who are adjusting to long-term health conditions, such as HIV, it is known that people living with HIV often present with more complex psychological and mental health needs (Paparello et al., 2014). This brings its complexities, and I argue that bespoke psychological and mental health support is needed for the HIV population. A recent report found that IAPT 'is not, for

example, designed to address co-morbidities around stigma, drug and alcohol use and sexual risk, and these matters do not form part of the IAPT curriculum' (All-Party Parliamentary Group on HIV and AIDS, 2019: 47). Healthcare professionals within IAPT services have not received any formal HIV training (Dhumma, 2020) which has subsequently led to disparities in psychological and mental health support. Sally commented,

*Speaking to people I supported, they were saying if they did get access to kind of psychological support, then HIV became the sole focus of that consultation. So, the therapists wanted to talk about the HIV acquisition when actually that wasn't necessarily the issue that the person living with HIV wanted to talk about. It wasn't the reason why they wanted to go there; they wanted to talk about the death of their mother, their changing relationships, their abusive relationships; that's what they wanted to talk about, but they were constantly drawn back.*

For some people living with HIV, generalist mental health services, such as IAPT, use Cognitive Behavioural Therapy (CBT), which 'aims to link thoughts, affect (feelings) and behaviour to enable clients to understand and manage these processes' (Munro et al., 2005: 96). A study conducted by Safren et al. (2009) found people who received CBT treatment had a higher chance of adhering to their antiretrovirals. These treatments may benefit people living with HIV who experience moderate to severe depression and anxiety. A course of CBT typically lasts between six weeks to six months and can help people change how they think and what they do (Royal College of Psychiatrists, 2015). There is an increased reliance on CBT for people living with HIV by healthcare professionals who do not understand the complexities of HIV. The NHS (2019) recognise that CBT may not be suitable for people with more complex mental health needs. I have demonstrated that people living with HIV often present with complex psychological and mental health issues.

People who access non-specialist psychological and mental health services, including IAPT, can experience stigma and prejudice because there is a lack of knowledge about



HIV in these services. In their report, the National AIDS Trust (2017) found that 'the clinical standards for psychological support for HIV, including community-based support, require a degree of HIV knowledge and experience not usually found in generic mental health providers such as IAPT' (National AIDS Trust, 2017: 31). A lack of knowledge of HIV in these settings can lead to stigmatised behaviours by practising professionals. David was talking about the lack of speciality within generic mental health services and told me,

*[M]ental health services are not geared to address the complex issues of patients living with HIV and the gay community. I see terrible discrimination, prejudices still prevalent in the mental health services at times. I kind of worry that the emphasis will be on mental health, which is good, but an investment is needed for the specialities.*

Disparities in HIV knowledge within IAPT have created a "postcode lottery" for people trying to access support. Should individuals seeking support live in an area with practitioners aware of HIV issues, they are more likely to receive the proper support and achieve better health outcomes. Until there is parity of esteem in support provision between IAPT, non-specialist HIV mental health services, and specialist HIV psychological and mental health services, discrimination and prejudice will continue to persist.

### **5.3.2 Specialist HIV Psychological Services: Is there a need?**

Specialist HIV services with in-house psychologists and mental health practitioners are associated with successful patient outcomes. People living with HIV can experience a wide range of factors which can exacerbate poor mental health, for example 'perceived stigma, widowed marital status, being symptomatic, fair and poor adherence, recent opportunistic infection, low CD4 count and non-disclosed HIV status were associated with depression' (Seid et al., 2020: 62). As a result, Seid et al. (2006) suggest that mental health services need to be integrated in HIV services.

The National AIDS Trust (2021) conducted research across the Manchester City Region, and the study reported that people living with HIV are more likely to trust specialist mental health services compared to general services, stating,

Participants who attend the HIV clinic service at North Manchester expressed the value of having access to psychology services that are embedded in the clinic. They have a higher trust level in this service than in general mental health services. The service can also be accessed more quickly. This was not reported as widely available across Greater Manchester.

(National AIDS Trust, 2021: 10)

North Manchester is the only hospital across the Manchester City Region which provides a wraparound service where people can access HIV specialist nurses and psychologists within the same service. Earlier, I discussed that people with HIV have complex needs, but specialist services for this population have declined recently (Dhumma, 2020). The psychosocial needs of people living with HIV are complicated because each individual has their own experiences. However, stigma is one of the main issues people living with HIV have to contend with (Morrow et al., 2001). When considering the psychosocial needs of people living with HIV, there is a strong need for specialist services that people can be directly referred to rather than starting at Step Two of the Stepped Care model. HIV is complex, and Simone, suggests that 60% of the clinical population in their specialist service have complex needs. She told me,

*Between 50% and 60% of our population have complex needs, and yet we are completely under-resourced. The way that services are set up feels askew because we've got loads of medical consultants and nurses, but me and Gill make up one psychologist for a population of probably two and a half to three thousand patients. In Central Manchester, they have a population of three thousand HIV patients, and they've got half a psychologist.*

There is little research which shows reductions in specialist HIV mental health services. However, the All-Party Parliamentary Group on HIV and AIDS (2019) report found that austerity measures through cuts to services have caused some services to reduce their provision, as in Greater Manchester. In contrast, other localities have seen the complete decommissioning of services. Cuts in funding can be linked to improvements in ARVs where people can live longer with HIV, and government and commissioning groups view this as a reason to reduce the need for specialist support (Adams et al., 2016). At the same time, mental health services for the general population, including IAPT, have received more significant investment because the government is committed to parity of esteem between physical and psychological health, but these services are not always suitable for particular mental health issues which surround HIV and stigma (All-Party Parliamentary Group on HIV and AIDS, 2019; Dhumma, 2020). However, looking at the support provided, it is clear that the focus of the NHS is to move towards more general services. Simone stated:

*In Greater Manchester, a large cohort of people living with HIV and complex psychological needs need to be met.*

Living with complex psychological conditions can harm antiretroviral adherence (Bolsewicz et al., 2015; Vreeman et al., 2017). For instance, poor mental health can lead someone to stop taking their antiretrovirals as prescribed or completely, impacting their physical health (Vreeman et al., 2017). Judy, an HIV healthcare service user in Greater Manchester, reinforced this point, and she told me

*[I]f you've got mental health problems and you're living with HIV, you may just not be taking your medication properly, and you might become resistant to your medication, so that affects your actual HIV status.*

The Terrence Higgins Trust (2018b) highlighted the importance of adherence to ARVs because if a person misses or takes their drugs late, it could mean that there are reduced levels of the drug in their body, which can allow HIV to make more copies of itself, including drug-resistant copies. Moreover, Bolsewicz et al. (2015) demonstrate

that non-adherence could result in treatment failure and, in some instances, lead to a faster progression of AIDS, eventually leading to death.

Although various antiretroviral combination therapies have been developed, drug resistance may mean that the patient develops a resistance to other antiretrovirals, called cross-resistance (Bolszewicz et al., 2015). If the individual is provided with a different antiretroviral therapy, it could be more complicated or cause other side effects (Terrence Higgins Trust, 2018b). As such, it is important that the mental health of people living with HIV is considered.

When considering older people living with HIV long-term, Murphy et al. (2004) found that they were more likely to adhere to their antiretroviral regimens because they tend to have greater stability in their lives, and they are more likely to be empowered to make decisions about their healthcare and prescribed regimes. It is documented that people over the age of 50 and on antiretroviral medication have a reduced risk of non-adherence when compared to younger individuals because they are more likely to be financially secure and more likely to have experience with taking medications or have more co-morbidities than younger people (Ghidei et al., 2013). Other studies have linked co-morbidities as a potential factor in decreasing antiretroviral adherence among people over 50. Althoff et al. (2016) report similar findings to Murphy et al. and found that ageing people living with HIV long-term may stop taking their ARVs because of medication fatigue. Therefore, it is clear that adherence to antiretrovirals is dependent upon the individual and other health factors. Simone told me that most people she sees are older and living with HIV. She said,

*It's interesting, actually, because the majority of people I work with in my clinic are in their 40s and 50s, and some people are in their 30s. I haven't worked with an awful lot of young people.*

Service users who are middle-aged and have been living with HIV long-term will likely have experienced specialist mental health support when they were first diagnosed.

Laugharne et al. (2018) write, 'the HIV psychiatrist emerged in the 1990s, but thankfully was soon not needed because of the rise of better treatments for HIV' (Laugharne et al., 2018: 230). The reduction in or closure of specialist HIV psychiatry can be linked to increased reliance on and advancements in ARVs. However, because treatments have advanced, it does not mean specialist support is no longer needed. One service user, Paul, told me about the support he received when he was first diagnosed with HIV. He said,

*There's a need for more specialised HIV support. When I was first diagnosed, I saw one of the specialised counsellors at North Manchester every week for probably seven or eight years, which is unheard of in Manchester. And I only stopped seeing him because he left, and I decided I wasn't going with somebody else. I think that level of support is gone now, and that level of really ongoing specialised counselling mental support is really valuable for people.*

The lack of funding has meant that newly diagnosed people face increased difficulties accessing specialist support. The National AIDS Trust (2021) found increased pressure placed upon the third sector in Greater Manchester, such as George House Trust, to support people with more complex needs. Furthermore, Robertson et al. (2017) found an increased demand for people to access mental health services in secondary care, but fewer appointments restrict their contact with the service. These factors show a need for people to access specialist mental health services, but funding changes have made it increasingly difficult to obtain appointments.

### **5.3.3 Declining Specialist HIV Psychological and Mental Health Support in Greater Manchester**

I have found three factors linked to the decline of specialist psychological and mental health support: the introduction of the stepped care model within IAPT provisions, improvements in ARVs, specialist services not being viewed as a public health priority and funding changes. In 2015, Public Health England (2015) published a strategic plan to assist them in achieving their priorities for improving sexual and reproductive health. However, it did not detail any specialist HIV psychological and mental health

support plans. In recent years, there has been an increase in the number of people seeking secondary mental health services, but the number of contacts for each person has fallen (Robertson et al., 2017). This is also the case within Greater Manchester, as noted by Simone, who informed me there is a,

*[S]ix-month waiting list here within this service specifically.*

This waiting list highlights the need for more partitioners because there is a clear need for specialist psychological and mental health support for people living with HIV.

In this study, some participants told me that improvements in ARVs have led to a perception amongst those making funding decisions about HIV and AIDS services that those adhering to their medications live fulfilled lives and do not require specialist psychological and mental health support. David compared the provision of HIV healthcare in the 1980s to today and told me that in the 1980s, all the services the person needed were provided in-house, but now,

*[T]here's your tablet; off you go.*

Viewing HIV this way is problematic because it fails to account for the mental health aspect of living with HIV and administering medication daily. This is consistent with current research, which has found that healthcare providers have pulled financial support for specialist HIV services because of biomedical improvements (Adams et al., 2016). Drew, a North East-based academic, discussed the impact of the narrative that healthcare providers are placing on ARVs as the resolution to HIV. He said,

*That narrative has been really damaging because we know the rates of mental health [amongst people with HIV] are higher ... There's been a presumption that by taking the tablets, the stigma also goes away, and that's not the case. You can look at any child living with HIV to see that. You can look at any gay man. The list goes on, as it were.*

Taking ARVs each day can impact the mental health of service users as some antiretroviral medicines can cause side effects, such as depression, sleeplessness and anxiety, as well as making some mental health issues worse (National Institute on Mental Health, 2023). Asia, an HIV healthcare service user in Greater Manchester, told me about the mental health issues they face taking antiretrovirals. They said,

*I thought once I got there, I'd feel a lot better about myself, but I don't think it does. I've been undetectable now a couple of months, but I don't sort of see much. I wake up every day to those three tablets.*

Some people living with HIV and successfully taking their antiretrovirals sometimes find it challenging to come to terms with their diagnosis (National Institute on Mental Health, 2023). They require specialist support because, although taking their medication suppresses the virus, it does not support their mental health. Simone told me,

*I would imagine they think HIV treatments are really good now; these people's needs lessen.*

This view can be linked to comparisons made by healthcare professionals and those who make decisions around HIV services between HIV and other chronic conditions, such as diabetes. David, a London-based HIV healthcare worker, told me,

*Many people say to me, "Oh, it's [HIV] a chronic disease like everything else; it's like diabetes." I say, "Oh please, really?" Telling somebody you've got diabetes and you can't eat cheesecake is very different than saying, "I've got HIV, by the way, if we're gonna have sex." I use that analogy because that gets people laughing as well as talking. Living with HIV is not the same as living with diabetes. You'll be surprised, but that's the rhetoric and narrative that people are trying to push in an attempt to cut back on funding for HIV services.*

Comparing HIV with other chronic conditions is problematic because it homogenises HIV with other chronic illnesses which have not been subjected to similar levels of

stigma and discrimination. This comparison means that healthcare providers can argue that the level of specialist support once provided is no longer required because of the advancements that have been made in HIV healthcare. Funding can, therefore, be reduced for specialist psychological and mental health support. This is evident nationally and across the Manchester City Region because, as discussed earlier, there has been a move towards general mental health services, such as IAPT, and reductions in specialist support.

Reductions in specialist mental health services can also be linked to these services not being viewed as a public health priority. David told me,

*HIV mental healthcare services are easy targets because they're not seen as public health issues.*

Across Greater Manchester, the Health and Social Care Partnership has focused on mental health services, but there has not been any focus on specialist services for people living with HIV (Greater Manchester Health and Social Care Partnership, 2016). Paul discussed the reductions in specialist mental health support and told me,

*That level of support is gone now, and that level of ongoing specialised counselling mental support is really valuable for people; there needs to be more available. HIV compounds to a range of other issues, and people need to be made aware that people need some specialised mental health support in terms of HIV. There's a huge general issue of this lack of support for mental health anyway, so it's not only on HIV, but I think that is one of the focuses. We need more support and more awareness for people working in the mental health field around HIV awareness.*

This lack of specialist support has positioned people to find alternative ways to seek help, including accessing private support. Although there has not been a direct cut to the funding of specialist psychological HIV support services, there has not been an increase in the number of mental health and psychological support staff within HIV



care. However, their workload has been increasing, thus resulting in the people needing help to seek support elsewhere at their own expense.

Advocates I spoke to informed me that they were working on formulating a business plan for decision-makers that outlined the need for increased funding for specialist services. This plan will enable them to employ more staff and provide more support for their patients. Simone said that these calls had been ignored and told me,

*We are working on a business plan to try and increase psychology input, but whether that will happen or not is a different question. The clinicians always want more psychology, but when it comes to getting people to open their purses up in the management stratosphere, it's really difficult.*

Ignoring these calls puts increased pressure on the third sector to provide more specialist support for people with complex needs. The National AIDS Trust (2021) found that people within the Manchester City Region increasingly rely on the third sector for mental health support, placing more pressure on the capacity of charities. Those who participated in the report's study 'were concerned about potential consequences in terms of access to support both for the ageing population with more complex needs and for those who may not have the same level of need but who still benefit significantly from support' (National AIDS Trust, 2021: 10). The National AIDS Trust focuses on George House Trust and earlier, in Chapter Four, I show that the total income for this charity has decreased by just over 8% in real terms over the last eight years. This reduction in funding may result in the organisation choosing to whom they provide mental health support or reducing other services vital to the community to fund an increased reliance on the charity's support.

#### **5.4 The Impact of the COVID-19 Pandemic on Specialist HIV Support**

The factors I discussed above are not the only influences that have impacted the governance and delivery of specialist psychological and mental health support in recent years. Since March 2020, the COVID-19 pandemic has also interrupted the delivery of these services. Jewell et al. (2020) found that HIV services were affected

by the pandemic, which impacted service users' access to their antiretrovirals. This is because some patients found it difficult to access their drugs during the pandemic; factors include their physical ability to collect their medications. To respond to the ongoing crisis, providers had to rapidly adapt to fluctuating coronavirus cases and redeploy healthcare staff and professionals to intensive care units. Redeploying staff to intensive care units occurred to 'achieve the sustainable delivery of patient care by providing adequate patient care' (San Juan et al., 2021: 2). However, the redeployment of staff has not benefitted all healthcare services, especially those providing services to people living with HIV. In another study, Shah and Delia Pereira (2020) found that maintaining the care continuum was difficult during the pandemic because healthcare staff provided care to HIV and COVID-19 patients. This split reduced the number of care hours available for specialist HIV care. Simone told me,

*A lot of our specialist nurses were redeployed for the first wave, and some of them have just been redeployed again, so we're working on a specialist nurse skeleton staff at the minute. There's only two nurses and a senior support worker who stayed with us, and three of our specialist nurses have gone.*

Working with limited capacity can have an impact on those who are seeking specialist support during the COVID-19 pandemic. The World Health Organization (2020) reported that the pandemic disrupts or halts critical mental health services in 93% of countries worldwide. Working in a limited capacity impacted those seeking support during the COVID-19 pandemic. At a general level, a large population cohort study was conducted with just over 14 million patients across 1,697 UK GPs by the National Institute for Health Research Greater Manchester Patient Safety Translational Research Centre. This research found a reduction in the number of people seeking mental health support at the beginning of the COVID-19 pandemic (Carr et al., 2021).<sup>6</sup>

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<sup>6</sup> When writing this thesis, the COVID-19 pandemic was ongoing, and new data was being published.

Across Greater Manchester, the referral rate to specialist psychological services for people living with HIV went down, according to Simone. This is consistent with the data published by NHS England on the number of new referrals to mental health services. The data shows that the average number of referrals to mental health services between March 2019 and January 2021 was 283,071, or an 11.2% decrease in the number of new referrals compared to the same period in the previous year (320,958) (NHS Digital, 2021). These figures highlight that the COVID-19 pandemic can contribute to the decreasing number of referrals. I could not obtain any data for the number of referrals to specialist psychological and mental health services for the same period in Greater Manchester.

Despite the negative impact of the COVID-19 pandemic on the delivery of services, there have been some positive impacts. Judy told me about the difficulties faced by those seeking access to specialist services before the COVID-19 pandemic:

*[T]he waiting list just gets longer because there's less resource. People just find it harder to get access as quickly as possible in terms of mental health provision.*

As discussed earlier, limited access to mental health services can harm people living with HIV because it can affect their adherence to antiretrovirals. In a specialist HIV mental health service in Greater Manchester, Simone observed that before the pandemic, there was a,

*six-month waiting list here within this service specifically,*

but during the pandemic, Simone observed that,

*We wrote to everybody on the waiting list saying, "Really sorry, we know that you've been waiting for ages, but because of COVID, we can't offer face-to-face appointments." We sent some re-opt-in letters saying, "Please let us know if you still want to be seen." We sent a first wave out to them [the patients]; some people said yes, they want to be seen. A lot of people didn't respond, so we sent out another letter saying, "You really need to let us know, or you'll be*

*discharged from the waiting list", and a lot of people didn't respond. So, we discharged a lot of the waiting list. Well, that doesn't mean the need isn't there. It just means that people didn't opt-in.*

There may be various reasons why people chose not to respond to the letter they received from the service, including the COVID-19 pandemic affecting their health. The pressures that people faced during the ongoing COVID-19 pandemic were highlighted by the UK Research Institute, which found that the isolation of people during the pandemic significantly impacted their mental health and factors such as loss of employment had an impact on their mental health (UK Research and Innovation, 2020). These factors may have played a role in non-engagement with healthcare services during the pandemic; however, further research is needed to understand whether these influences played a role in people not engaging with mental health services.

The decrease in the number of people accessing these services is consistent with the monthly data published by NHS England on the number of people in contact with adult mental health services. This data shows that between March 2020 and January 2021, an average of 875,276 people were connected with adult mental health services, including secondary services (psychological well-being services and community mental health teams) and NHS-funded psychological therapies (including IAPT). This data suggests a 16% (average) decrease in the number of people in contact with adult mental health services compared to the corresponding period in 2019/2020 (NHS Digital, 2021). This decrease has enabled services to rethink how they deliver their services. One of the participants, Simone, told me about some of the benefits that the COVID-19 pandemic has brought to the service:

*[B]ecause we can work remotely now; we've been able to take more trainees. So, we would normally have one trainee, two maximum, because you have to have the space for trainees to do the therapy and all the rest of it. Whereas at the minute, because we can work remotely, we've got three trainees, and we've got another one starting in April. So that has really helped.*

Increasing the number of trainees has allowed the service to provide more psychological and mental health support since the COVID-19 pandemic. However, this could be a temporary measure because this support was increased due to more available space. As of yet, there is limited evidence to suggest that this level of support is sustainable post-COVID-19 pandemic. This is because patients may choose face-to-face support over virtual support, which would mean that mental health services either have to increase the size of the site or reduce the number of trainees/staff to ensure they can meet demand. Suppose the conditions return to those before the COVID-19 pandemic. In that case, the service may only be able to employ one trainee again, putting pressure on the other staff and consequently reintroducing a waiting list. There is limited research into this, and further research would be needed to understand how services have changed post-COVID-19 pandemic.

## **5.5 Chapter Summary**

In conclusion, this chapter has covered the responses of various voices – service users of HIV and AIDS healthcare provisions; organisations specialising in HIV and AIDS support, advice and advocacy services to improve health outcomes; healthcare staff specialising in HIV and AIDS healthcare and those who advocate for improved treatments; academics who work in the field of HIV studies; and activists who are campaigning for improved HIV and AIDS services – to the austerity measures affecting HIV and AIDS mental health services across the Manchester City Region. It is well documented that people living with HIV and AIDS can experience stigma and discrimination (Hodgson, 2007), leading to their self-denial of medications (Turan et al., 2019). Remien et al. (2019) argue that people do not experience poor mental health only when they acquire HIV. However, poor mental health can be a critical factor in undertaking practices which could put people at an increased risk of acquiring HIV.

HIV-related stigma and discrimination can be linked to the 1980s and 1990s when campaigns, such as the “Don’t Die of Ignorance” and media portrayals, put fear across

the population. They divided people into either guilty, such as homosexuals and people who injected drugs, or innocent, such as those who acquired HIV through a blood transfusion (Clarke, 2006). There have been calls for a new public campaign which dispels the myths associated with HIV. However, Alex, a support worker at a Manchester-based HIV Charity, informed me that he does not think that having a new public campaign is not beneficial. I introduced a quote from Alex earlier, who told me,

*It's really easy to say we need public campaigns, we have done some of that, but campaigns work better when they're targeted at certain populations, especially if you're trying to sell a good message ... Something that COVID has shown us is you can contact an entire population, but the information that's passed on doesn't always set in and digest for people. So, it's not always the right tactic to go down.*

The view presented by Alex is interesting because although it does not dismiss the idea of a campaign, it does inform the literature that a carefully crafted campaign is required. This campaign must present a clear message which resonates with the audience (Weiss and Tschirhart, 1994). However, some campaigns have recently attempted to combat HIV-related stigma and discrimination, such as U=U (Bereczky, 2019). Although this message can be viewed, it has little impact in the Manchester City Region (Nathaniel). Since undertaking this PhD, I have only seen the U=U message when searching for it online. This message has yet to reach secondary care settings because stigma and discrimination continue in these settings, evidenced by some healthcare professionals' excessive use of PPE, as Connor and Yuvaraj et al. (2020) suggested. An effective campaign is therefore required to educate healthcare professionals about HIV today because these practices contribute to the poor mental health of people living with HIV.

People living with HIV have recently witnessed dwindling mental health services. The introduction of antiretrovirals has meant that people living with HIV can live healthy lives because they can suppress the virus. Although people may present as being

physically fit, it does not equate to good mental health. As discussed earlier, people living with HIV can have complex needs and, therefore, require specialist mental health support, but mental health services have become a neglected priority (Vreeman et al., 2017). The reasons for this can be linked to austerity measures where mental health services have not received adequate funding, and these provisions have fallen behind the rest of the NHS (British Medical Association, 2023); biomedicine, such as antiretrovirals; and the focus on the 90-90-90 which only deals with the physical health. Although there have been calls for a fourth 90 to be added to the 90-90-90 targets, which deal with mental health, this has been unsuccessful so far (Guaraldi et al., 2019). The government and BHIVA have recently focused on cheap mental health provisions, such as IAPT (British HIV Association, 2018b, 2019; NHS England, no date). For some people, IAPT services are sufficient and can result in them adhering to their antiretrovirals (Safren et al., 2009). CBT therapies under IAPT are cheap, and these health professionals receive no formal HIV training (Dhumma, 2020). Sally, one of my participants, told me that,

*[T]he therapists wanted to talk about the HIV acquisition when actually that wasn't necessarily the issue that the person living with HIV wanted to talk about.*

Sally's point is interesting and links to the debates offered by the National AIDS Trust (2017), which found that stigma and prejudice can be found in these settings. Therefore, some people living with HIV may fail to attend HIV services.

The decline in specialist HIV mental health services can be linked to neoliberalism because of funding changes and the view of self-responsibility to become independent and part of the capitalist machinery. In 2015, Public Health England (2015) published a strategic plan which failed to account for specialist HIV psychological and mental health support even though there has been an increased demand for secondary mental health services (Robertson et al., 2017). In Greater Manchester, Simone informed me earlier that there is a

*six-month waiting list here within this service specifically.*

This is an important point and links to the point that specialist services are not considered a public health priority. However, advocates in Greater Manchester are formulating a business plan to increase funding for specialist psychological and mental health support.

Lastly, the ongoing COVID-19 pandemic has impacted mental health services. In the Manchester City Region, staff at one mental health service were redeployed to assist with the COVID-19 response. Simone told me they were working on a skeleton staff through the COVID-19 pandemic. This links to the work of Shah and Delia Pereira (2020). They found that maintaining the care continuum was challenging during the pandemic because healthcare staff had to deliver care to HIV and COVID-19 patients, which impacted the number of hours available to provide specialist HIV care. As discussed earlier, the lack of availability of mental health services can affect an individual's adherence to their antiretrovirals. However, COVID-19 did enable a specialist mental health service in Greater Manchester to recruit more trainees. No data is available to understand how this has benefitted people living with HIV across the Manchester City Region. Further research would be required to assess this.

Overall, austerity measures through declining funding and the increased reliance on cheap alternatives, such as IAPT, significantly impact the mental health of people living with HIV across the Manchester City Region. Next, I provide an in-depth analysis of the contested responses to the transformation of the HIV and AIDS care landscape across Greater Manchester.



## ***Chapter Six: Contested Responses to the Transformation of HIV and AIDS Care Landscape***

### **6.1 Introduction**

Since the beginning of the HIV and AIDS epidemic in Britain, a lengthy and complicated history has unravelled, which has seen challenges brought against the decisions made by governments, Public Health England, and healthcare providers. During the 1980s, public policy underpinned governments' political and economic imperatives. Health authorities were influenced by scientific, medical and epidemiological debates about HIV and AIDS (Small, 1994). Public opinion and pressure group activity influenced decisions about HIV and AIDS healthcare locally and nationally. This chapter considers the ongoing work of service users, HIV and AIDS support, advice and advocacy services, healthcare staff, academics specialising in HIV studies and activists. In consideration of these groups, this chapter presents how they have responded to the changing nature of HIV and AIDS healthcare and mental health services, the extent and nature of which I discussed in Chapters Four and Five.

I begin this chapter by outlining PrEP (pre-exposure prophylaxis) because it has been one of the main areas discussed in HIV healthcare in recent years. I then discuss the U=U (undetectable equals untransmittable) campaign, health policies, and messaging around HIV and AIDS. Next, I discuss the legacy of Section 28, which builds upon the historical narrative I sketched in my Introduction and the Literature Review. I then move on to uncover the work of educating young people about HIV—thus undoing the legacy of Section 28—through to educating healthcare professionals about HIV in both Primary and Secondary care settings before I summarise this chapter.

## 6.2 'HIV is not my problem, it's everyone's problem': The Legacy of Section 28

Earlier, I introduced the figure that 80% of staff in a central London hospital who had a specialist HIV unit were unaware of the U=U message (Shongwe et al., 2020). This lack of education on HIV (as an issue that has been of central importance to gay males and other queer communities in the UK) can be traced back to 1988 when the government introduced Section 28, which banned local authorities from “actively promoting” homosexuality and banned schools from educating young people on what the government saw as the ‘acceptability of homosexuality as a pretended family relationship’ (Local Government Act 1988). Anna Marie Smith (1994a) writes about “Thatcherite homophobia” as subtle and complex and something which was not one-dimensional. Instead, Thatcherites constructed an “us” versus “them” frontier and presented themselves as tolerant centrists who mediated between two extremist camps: ‘the vociferous parents’ groups, violent queer-bashers, and the whole moral backlash on one side, and the flaunting, disease-spreading, child-seducing queers and their corrupt socialist allies on the other’ (Smith, 1994a: 58). The introduction of Section 28 fitted into this narrative because it was not aimed at a set of practices, such as sexual acts, neither was it aimed at a class of person, such as homosexuals; instead, it prohibited local governments from promoting homosexuality (Smith, 1994a). Thatcherite strong views on family values were threatened by homosexuality, which was blamed for the AIDS crisis and the increasing homophobia in the 1980s.

During the 1980s, a series of British Social Attitude surveys revealed that attitudes towards couples of the same sex were negative, with 64% of people believing that these relationships are always wrong (Park et al., 2013), which increased to 75% in 1987 (BBC, 2021). These attitudes aligned with the New Right's focus on the one-dimensional nuclear family unit. This unit was threatened by homosexuality and single mothers. The British Social Attitude surveys also highlighted that two-thirds of the respondents in the British Social Attitude surveys favoured the government messaging, which told people that certain sexual practices were morally

reprehensible. A third of the respondents believed that HIV and AIDS were a punishment to the world for the “decline in moral standards” (Burgess, 2017). Waites (2000) and Burgess (2017) claim that the introduction of Section 28 indicates homophobia, sexual moralisation and increasing demands for a debate which reduced the age of consent for gay males to 21.

Further, Smith (1994b) argues that Section 28 was introduced as an additional attack on local authorities and not just as a backlash against gay men. This is because ‘local governments became the sites of new leftist coalitions, in which the demands of feminists, black activists and lesbians and gays were granted an unprecedented degree of legitimacy’ (Smith, 1994b: 185).

In Greater Manchester, HIV activists demonstrated outside the town hall in Manchester (Maidment, 2022) to air their views on the Act, but these calls were ignored, and the Act came into force. It was felt by some of the participants in my study that Section 28 had a significant impact on those who have acquired the virus post-1988, in particular, young people who were in the education system whilst this legislation was enforced. Some participants also felt that the ban on teaching children about same-sex relationships led them to acquire HIV because they did not know how to navigate safe sex with people of their gender. Those who self-disclosed their HIV status and acquired the virus post-1988 said they did not know much about HIV until their diagnosis because the education system failed to teach them about HIV-associated risks at school. They stated that if they had known about the risks, they might have made different decisions, reducing their chance of acquiring HIV. Lyn, a healthcare professional in Manchester, made the point,

*I think if there was much more done from an early age ... if you hit kids at school age with information, they're little sponges. So, like it or loathe it, it's only going to go in, and I think if it's never going to become relevant in your life, it will dissipate eventually, but I think if HIV does become a prevalent part of their life, having that knowledge somewhere in the background, in a box you can reopen when needed, is invaluable.*

Lyn's view is consistent with what campaigners have argued for many years, that children should be educated about same-sex relationships. According to Stonewall, teaching young people about the full diversity of their world is critical. Many young people still face anti-LGBT bullying<sup>7</sup> and language in school settings (Stonewall, 2019). At the time of conducting this study, legislation was being passed that required all schools to teach children about inclusive relationships and same-sex education. Therefore, this discussion must be read in the context of a time when this was not required.

There continues to be a stigma attached to HIV as something that only men who have sex with men can acquire, but it is something anyone can acquire. Also, the Terrence Higgins Trust conducted a survey in 2018, which found that nearly one-third of British adults still believed HIV could be transmitted by kissing (Phillips, 2019). Education is needed to inform people about the risks imposed by HIV. As Lyn stated earlier, teaching children about our society can change attitudes towards people living with HIV. In 2019, the government announced that lessons would include 'up to date information about HIV, including how to prevent, test and treat HIV' (Phillips, 2019). Introducing compulsory inclusive relationships and same-sex education classes into the curriculum will increase knowledge of HIV among young people.

Moreover, Alex added that compulsory relationships and same-sex education are vital to ensuring students learn about HIV. Alex said:

*[L]ooking at the opportunities that we've got with RSE [relationship and same-sex education]. Now, that's compulsory in schools, ensuring students learn about HIV.*

There is hope that when young people are of an age where they can navigate sexual relationships, they will be able to navigate them safely because they know how HIV

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<sup>7</sup> A lack of education about HIV leads many people to believe that those who identify as LGBTQ are the only people who are at risk of acquiring HIV.

is transmitted, something the participants who acquired the virus post-1988 never had.

### **6.2.1 Educating Young People about HIV**

So far, I have discussed the benefits of introducing an inclusive and relationship education curriculum. However, there are still barriers, meaning that all children cannot access these classes. Before its implementation, there were a series of protests from families nationally and in Greater Manchester. For example, Conservative-Islamic thinkers staged protests in Birmingham over teaching children about inclusive relationships (BBC News, 2019). Parents complained to schools in Manchester about the same issue (Parveen, 2019). This is concerning because HIV does not discriminate and affects people of all faiths (Positive East, 2020). However, the number of people living with HIV who have a religious affiliation is not recorded in the UK.

Andy, discussed the ongoing work between HIV activists and, organisations and faith groups to better inform them of what HIV is and eliminate the stigma which may be attached to it by that group. Educating faith leaders can improve the acceptance of people living with HIV by filtering the knowledge down to their followers. A 2016 study has shown that people who hear about HIV and preventative medications are more likely to be receptive to those with HIV (Ransome et al., 2018). Based on this evidence, I speculate that increasing knowledge of HIV within faith groups will increase the acceptance of people with HIV in the community.

Earlier, I discussed the U=U campaign and how it has not yet been filtered to the general population. Until this campaign reaches everyone, there is a fear that parents who lack knowledge of HIV may withdraw their children from these classes, in particular those from a background of faith who do not accept LGBTQ people or those living with HIV. Vanderbeck and Johnson (2015) examine how religion shapes the curriculum and circulating knowledge about homosexuality and same-sex relationships. They found faith and religious teaching to impact children's

understandings of sex because faith educational settings want to refrain from teaching about same-sex relationships if their religious texts do not condone same-sex acts (Vanderbeck and Johnson, 2015). However, the government continues to allow parents to request that their children be withdrawn from these classes in secondary schools (Department for Education, 2020). If young people are removed from these classes, they might be at an increased risk of HIV because they do not know about it.

Educating young people is crucial because it will help them better understand HIV and what treatments are available for people at risk of acquiring and living with HIV. Inclusive sex and relationship education in the curriculum assists the government with its political aim of eliminating new cases of HIV by 2030. For many years, George House Trust has run the Positively Speaking programme, where they provide educational HIV sessions in schools and talk to children about what it means to live with HIV. The programme consists of people who have different experiences of HIV because of their intersectional identities. Paul told me about the makeup of the speakers on the programme. He said,

*We have a couple of black or Afro-Caribbean women speakers who are great [but] I'm trying to get more women speakers because it's often men rather than women. We've got two great heterosexual speakers; one is an ex-drug addict and been homeless and in prison. It's interesting to see the impact of having heterosexual men speak, which is good. We've just recruited some new younger people; we have a speaker who's in his early 20s, only been diagnosed a few years, which is great. A lot of these speakers have been diagnosed for a long time, so it's really important that young people do that.*

Having a diverse range of people represented on the programme is essential to reducing the stigma attached to people living with HIV by healthcare professionals. I address HIV-associated stigma in the next section because it is experienced in healthcare settings. A benefit of the programme is that it provides people living with

HIV with an opportunity to share their stories and raise awareness of HIV. Paul discussed the programme further and told me,

*We've had really positive responses from both staff and the young people. We've done a lot of sessions, and just before the lockdown, we did thirteen sessions for the year ten at Bury Boy's School. Now, we've got contact with, I think, 11 schools in Manchester. We've talked to all-year groups, and that's different year groups. My aim is to build ongoing relationships with schools, so we actually talk to the whole school or one group from the school.*

This programme is different from the curriculum because it enables young people to meet people who have lived experience of HIV. Moreover, running Positively Speaking, in addition to the relationship and same-sex education classes, enables young people to ask questions of those living with HIV that they may not otherwise ask their teachers because the educators may not have the answers. I interviewed Paul before the compulsory relationship and same-sex classes were introduced, and he informed me that schools see the programme's benefit. Despite this, further research is needed to understand the affect that the Positively Speaking programme is having on educating young people about HIV.

### **6.2.2 Educating Health Professionals about HIV to Improve Awareness**

While people might expect children to have little knowledge of HIV, they would not expect the same lack of knowledge when they present at healthcare services with HIV. There is a general belief that when people attend a healthcare appointment, they will be seen by a professional and treated equally. Chapter Five discussed the HIV-related stigma people experience in the Manchester City Region healthcare settings. Training healthcare professionals about HIV is not mandatory because it depends on the area of medicine they practice, and it would be impossible for them to learn about everything. Despite this, there is a higher chance for a healthcare professional to meet someone living with HIV in the Manchester City Region because

Manchester, for example, has one of the highest averages of people living with HIV in England.<sup>8</sup>

### **6.2.2.1 Educating Health Professionals in Primary Care Settings**

Although there have been advancements in HIV and AIDS treatments, people living with HIV continue to face stigma and discrimination when accessing primary healthcare settings (Smith et al., 2020; Yuvaraj et al., 2020). Both Smith et al. (2020) and Yuvaraj et al. (2020) found that people living with HIV can experience HIV related stigma and discrimination for their healthcare providers. My participant base within the Manchester City Region has acknowledged the lack of awareness and knowledge of HIV and AIDS within primary care settings. They have responded by extending the Positively Speaking programme to GP surgeries. Over the last few years, staff in Manchester GP surgeries have received some sessions from the programme to educate the staff about HIV.

Mason et al. (2001) highlight some of the stigma experienced by people living with HIV when they attend healthcare services, particularly the link between HIV and men who have sex with men. Geter et al. (2018) found that stigma can be manifested through inadvertent behaviours and ideologies, including homophobia, transphobia, racism and negative views of those who inject drugs. Therefore, cultural awareness can help reduce healthcare workers' biases and support improved care outcomes for people living with HIV.

Previously, I discussed the diverse representation of people living with HIV in George House Trust's Positively Speaking programme. Having diverse representation was vital to reducing the stigma attached to people living with HIV by healthcare professionals. This is because diversity demonstrates that not just men who have sex with men are at risk of HIV. Some of the participants in the programme said they had received some HIV training previously. However, they had never met anyone living with HIV nor had a personal experience (Paul, a Greater Manchester-based HIV

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<sup>8</sup> See the introduction chapter, where I discuss the statistics around HIV rates in Greater Manchester.



activist). However, their training did not address the stigma and self-stigma that a person living with HIV may experience in society and healthcare services. Paul continued to tell me about the lack of knowledge which exists within primary care settings:

*We do the whole staff; we do admin reception staff, nurses and GPs. Quite a lot of the admin reception staff have limited knowledge of HIV but, even GPs in a way. I found that some GPs don't really know about U=U; Undetectable equals Untransmittable; they're not aware of all the services that George House Trust provides, so it's been a bit of a mixture, really. But again, the feedback has been very positive, and it's useful for GPs, in particular, to hear the experiences of people living with HIV.*

The lack of knowledge by some GPs of the services that George House Trust offers can impact the person's HIV journey. George House Trust provides a range of services, including counselling and one-to-one and group support sessions, which can benefit someone seeking to understand their HIV status. GPs not being aware of these services means that they cannot direct their patients to the services that the charity offers if asked. This can harm the individual because accessing support and knowing they are not alone can help them adhere to their antiretrovirals.<sup>9</sup> Running the Positively Speaking programme in primary care settings across Manchester ensures that healthcare professionals are equipped with an improved understanding of HIV and provides them with a better understanding of which services are available for people living with HIV. Ultimately, this can help healthcare professionals better assist someone who presents at their surgery with HIV.

Despite the programme's impact on health professionals, core funding will only guarantee the programme's future. Paul told me that the programme has,

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<sup>9</sup> See Chapter Five.

*[B]asically, been funded for the last two years by a tiny underspend from the public health budget in Manchester, so there is no guaranteed or core funding for it.*

The Positively Speaking programme had received some funding from ViiV Healthcare—a specialist HIV pharmaceutical company which also researches HIV—for 12 months ‘to tackle issues of HIV knowledge and understanding in primary healthcare settings ... [and to equip] staff in healthcare settings to be more confident and knowledgeable about HIV’ (Charity Commission, 2020: 27). This funding was used by the programme to pay for a GP to work one day a week as an HIV specialist which enabled them to give primary care settings a joint clinical presentation by the GP or sexual health nurse, plus a positive speaker who enabled them to provide a detailed clinical update (Paul). This collaborative approach enabled healthcare professionals to ask clinical questions that could only be answered by a specialist HIV GP and ensure that GPs have a better understanding of HIV and can provide HIV-informed care when treating a patient who presents with HIV. However, a lack of funding for the programme means it cannot plan for the future and provide a systematic approach to the other nine boroughs within Greater Manchester. Not guaranteeing the programme's future will impact how people living with HIV experience primary healthcare settings. A lack of HIV education in these settings will see continued stigma and discrimination by some professionals.

I hypothesise that a postcode lottery will be created if the Positively Speaking programme funding is not extended to GP surgeries across Greater Manchester. Only educating healthcare staff in Manchester GP services means that people who live in Manchester are the only population across the Manchester City Region who have benefitted from the programme. This centralisation of training has resulted in people living with HIV outside of the city centre having a higher chance of accessing primary services with healthcare professionals who have little knowledge of HIV and, therefore, are likely to present stigmatising behaviours towards the patients.

### 6.2.2.2 Educating Health Professionals in Secondary Care Settings

One of the issues that emerged in my interviews was that there is a low amount of HIV knowledge within the NHS, even in acute trusts with established HIV clinics. In Chapter Five, I discuss the lack of awareness of HIV within a major London acute trust.

Alex said,

*80% of the hospital staff they spoke to in the survey didn't know about U=U. So, if you're looking at a major hospital that will see a lot of people with HIV, you know, has a really well-established HIV clinic within the Trust that's caring for a lot of people with HIV. If their staff are far behind, what do healthcare staff look like?*

This knowledge gap is linked to a lack of HIV training for healthcare staff in secondary care settings. Knowledge sharing within secondary care settings primarily occurs via memos and bitesize teaching on the hospital unit rather than the NHS providing courses provided by HIV specialists. Connor told me,

*[W]e tend to talk a little bit more about HIV in memos or handovers.*

Training staff in secondary care settings about HIV is vital to reducing associated stigma and discrimination. As Pulerwitz et al. (2015) found in Vietnam, training hospital staff about HIV and exposing them to people living with HIV, similar to the Positive Speaking programme, improved their understanding of HIV and reduced associated stigma and discrimination. Although knowledge needs to be passed on to generate better care outcomes for people living with HIV, training is often left to a few colleagues to provide the information they have researched. Connor continued and told me that staff in secondary care only receive information from those advocating for increased awareness:

*When a patient comes into hospital diagnosed with HIV or AIDS, I'll teach that nurse what it actually is and how that person might socially perceive it to help the nurses understand what the virus is and how it can affect people, especially in the stage of diagnosis ... I've not been given a PowerPoint to teach or*

*necessarily formal teaching. It's things what I've had to learn, talking to GUM [Genitourinary Medicine] specialists, information from NHS websites, and articles. Things I've had to learn myself to then spread knowledge.*

Colleague-led training within the NHS is increasingly commonplace with financial pressures experienced by the health service. In their report, Robertson et al. (2017) found that financial pressures impact the training of healthcare staff and the quality of care patients receive in some parts of the country. Earlier in Chapter Five, I discussed the excessive use of PPE (personal protective equipment) by some healthcare staff who are supporting patients with HIV. Simone discussed some of the discriminatory behaviours present within secondary care settings, including,

*I've opened up records on the mental health record system, I've seen alert warning come up 'patient living with HIV' as a warning which obviously doesn't do great things for stigma.*

Marking health records with the patient's HIV status is commonplace across healthcare settings. Lazuardi et al. (2019) also found that healthcare records labelled with the patient's HIV status lead to increased stigmatising behaviours. One of my participants, Connor, challenges this behaviour and educates his colleagues about risks and how patients perceive their practice. However, it is unknown how many of his colleagues or other healthcare professionals challenge similar discriminatory behaviours, and there is little research to date that examines healthcare advocates' role in reducing stigmatising behaviours in healthcare settings. These findings suggest that stigmatising and discriminatory behaviours will continue if the NHS fails to invest in HIV training for professionals within secondary care.

Most of the training has focused on educating healthcare staff in primary settings. However, there is a lack of HIV knowledge within secondary care settings. When people attend HIV services where staff know about HIV, people are more likely to receive informed care. Scaling up programmes to cover all settings across the Manchester City Region will cost a significant amount of money, and funding would

be needed to cover that cost. However, the private sector funded the first wave of training for primary healthcare settings through the Positively Speaking programme (see above), which demonstrates that the Greater Manchester Combined Authority (GMCA), Public Health or the Greater Manchester Health and Social Care Partnership (GMHSCP), as yet, have not made any provisions for funding this training. It is unclear if they are likely to provide any funding for this training in the future. A coordinated response is required from all bodies across Greater Manchester to ensure that people accessing secondary care services do not experience HIV-related stigma.

### **6.3 Pre-Exposure Prophylaxis (PrEP): How People At Risk of HIV Are Reclaiming their Health?**

PrEP has transformed the lives of many people at risk of HIV, and it has been on the agenda of HIV activists and health officials since September 2014, when NHS England formed a PrEP writing group—the writing group aimed to develop a plan for commissioning the drug. In 2015, a PrEP advocate, Greg Owen, met Alex Craddock—with whom he co-founded the PrEP advisory website “I Want PrEP Now”—who had just returned from New York and was taking PrEP, which Greg wanted. Alex’s supply was about to run out, and it was not available in the UK then. Greg had managed to obtain a small supply and started taking it; however, when he went for an HIV test, it came back that he was living with HIV, and he decided to post his status on social media. Greg received many messages from people asking how they could access the drugs. Greg and Alex realised limited information about PrEP was available, and they subsequently launched the website [iwantprepnw.co.uk](http://iwantprepnw.co.uk). Launching this website meant people at risk of HIV could safely purchase the drug from international suppliers (Castella, 2018). The website had many hits from people wanting to access the drug.

Around the same time the website was launched, the UK Medical Research Council ran the PROUD study. The study was a randomised trial carried out at 13 sexual health clinics in England where HIV-negative men who had sex with men within the previous 90 days were provided with either placebo-controlled drugs or PrEP. The

study aimed to determine if using PrEP reduced HIV transmission (McCormack et al., 2016). The trial concluded that PrEP reduced the risk of infection by 86% (Medical Research Council Clinical Trials Unit, no date). This PROUD study's findings helped HIV campaigners build a sustained case for PrEP to be available on the NHS.

In March 2016, NHS England concluded the writing group and refused to allow a draft policy on PrEP to go forward because they stated that it was not the responsibility of the NHS to fund PrEP. Instead, they argued that it was within the powers of local authorities under the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.<sup>10</sup> In response, the High Court of England and Wales heard a case and ruled that it was within the powers of the NHS to fund PrEP. NHS England appealed this decision, but the High Court ruled that it was within the powers of NHS England to fund PrEP (*National AIDS Trust v NHS Commissioning Board*, 2016; Maine, 2019). A few months later, NHS England and Public Health formed the PrEP IMPACT trial from October 2017 to July 2020. This trial gave hope to people at risk of acquiring HIV because routinely commissioning the drug would allow people who need it to access PrEP at no cost. In October 2020, people could routinely start to access PrEP.

HIV activists criticised the PrEP IMPACT trial. They argued that it only served white ethnicities because of the ethnic/racial composition of the test groups. Andy, a Greater Manchester-based HIV activist, criticised the trial from this perspective. He informed me that,

*as soon as the PrEP IMPACT trial came out, there was an influx of white gay males that rushed to engage with it, signed up really quickly, and that was the end of the story.*

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<sup>10</sup> The Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 accommodates Section 18, Health and Social Care Act 2012, which legislates the responsibility for certain public health functions at the local authority level.

The point raised by HIV activists like Andy is supported by the baseline data presented at the 2021 British HIV Association/British Association for Sexual Health and HIV Conference.<sup>11</sup> Dr Ann Sullivan presented some of the data at the conference and highlighted that many people who participated in the study were white. Additionally, there was limited recruitment of black African people on the medical trial despite large numbers of HIV diagnoses amongst this group (Cairns, 2021a). Andy went on to highlight two potential reasons why there was little uptake of black African people in the medical trial: the term “trial” and a lack of engagement with media consumed by those from this background.

This PrEP IMPACT trial was a clinical trial from a medical perspective because it aimed to evaluate if introducing PrEP would be safe and effective for people needing access. Although there was significant anecdotal evidence from those already accessing the drug through private means, including buying the medicine from HIV activist websites such as “I Want PrEP Now”, NHS England and Public Health had to be sure the drug was effective. However, labelling the IMPACT trial as a “trial” to the general public was damaging to those from a black African background because of their history with trials. Some black African people were wary of the trial because they were aware of previous studies conducted with black people, such as the Tuskegee Syphilis Study, which took place in the US between 1932 and 1972. The Tuskegee Syphilis Study recruited African-American men in the late stages of syphilis. It informed them that they would receive free healthcare from the federal government in return for their participation. What happened was that they received some initial treatment, but this stopped, and they were provided with a placebo pill consisting of aspirin and iron tonic. Once the men died, their bodies underwent autopsies so the scientists could try and understand syphilis (Reverby, 2009). This history of experimentation on black people of African descent, albeit in the US, led to people

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<sup>11</sup> See ‘The HIV pre-exposure prophylaxis (PrEP) IMPACT trial: baseline demographics, coverage and first regimen choice’ from the 5th Joint Conference of the British HIV Association (BHIVA) and the British Association for Sexual Health and HIV. A summary of the findings can be found here: <https://www.aidsmap.com/news/apr-2021/englands-big-prep-implementation-trial-releases-its-enrolment-data-young-people-under>

from this ethnic background not being sure they were safe to participate in the IMPACT trial. In the UK, Schraer (2021) has also linked the Tuskegee Syphilis Study and other trials in African countries with an associated mistrust of pharmaceutical companies because of the historical mistreatment of black people.

The mistreatment of black people in previous clinical studies was not considered in the PrEP IMPACT trial. Public Health England and NHS England did not provide any information specific to black people, alleviating any concerns they may have had over participating. The African Advocacy Foundation (2019) recognised the lack of black African people in the medical trial. The Foundation obtained some funding from Public Health England to establish a programme named 'PrEP & Prejudice', which sought to create awareness of HIV prevention in black African communities (African Advocacy Foundation, 2019). Andy discussed 'PrEP & Prejudice' in his interview, and he told me,

It was a fantastic campaign that had limited funding but ended up really increasing the uptake of PrEP by black African communities as a result of addressing the information issues and addressing misinformation around it as a trial.

The data from Public Health England (2020) suggests that HIV rates amongst black African groups are high, but no recent data can verify the uptake of PrEP amongst these groups as the data is not available yet. Despite this, data suggesting that HIV and AIDS continue to impact black communities significantly would have indicated that health authorities would approach this group to recruit participants for the trial. One of the reasons why this group was not approached when the PrEP IMPACT trial was first announced is because Public Health England and NHS England did not utilise channels that would reach at-risk groups. Continuing, Andy informed me that the lack of knowledge around PrEP was not due to ignorance but the lack of promotion on channels this community tended to access, such as black African Radio and black African, Asian, and Afro-Caribbean newspapers. Public Health England's choice not to promote the IMPACT trial on these channels links to the point raised by Alex, who told me:



*We've just finished a campaign about raising awareness of PrEP in black African communities because we know the uptake in MSM [men who have sex with men] is so much higher. That [campaign] wasn't about getting black African men and women necessarily to start taking PrEP; it was just to make them aware that it exists because so many of them don't. They're kind of so many years behind.*

Alex's point is concerning. This kind of thinking articulated here is potentially a reason why few participants from a black African background were in the IMPACT trial. Suppose there is an underlying belief that there is no reason to actively promote the uptake of PrEP within this community because they are "behind" the white community. In that case, this helps me to understand why the IMPACT trial did not seek to work with more non-white groups when they released the IMPACT trial. This alludes to my objective to analyse health politics within the Manchester City Region. Cheng (2019) writes, 'black feminist and queer intellectual projects continue to serve as antiracist and decolonising pedagogical tools precisely because of their historical interjections into systems of oppression' (Cheng, 2019: 170). This is precisely one of the purposes for conducting this research, and it is clear that people from ethnic minority backgrounds continue to face barriers in HIV and AIDS healthcare systems.

Introducing PrEP has enabled governments to alter fiscal support and slowly reduce funding for HIV services. Drew, North East-based academic, told me,

*[M]edicine is a powerful, dominant force ... who is gonna speak outside of that.*

PrEP activism advised those at risk of acquiring HIV to seek medication to reduce their chances of acquiring HIV. Over the past decade, support services have reduced as medication advancements have increased, and more emphasis has been placed on individuals taking charge of their health. Some people find it particularly important to have agency and control over their health (Bjertrup et al., 2021). In a study conducted in Eswatini, Bjertrup et al. (2021) found that PrEP encourages people to have a sense of self-worth and possibilities of self-care; however, long-

term use was 'often undermined by pill fatigue ... and stigma related to HIV, over which the women had less influence' (Bjertrup et al., 2021: 6). The effectiveness of PrEP is reliant on people adhering to the drug regime, yet some people may not adhere to it for various reasons, such as psychosocial issues or pill fatigue, which will increase their chances of acquiring HIV.

Moreover, if they are unaware that they are not adhering to their PrEP pills and go on to acquire the virus, the support available will be limited. In 2018, Hojilla et al. (2018) analysed a San Francisco sexual health clinic and found a 38% drop in the continuation of PrEP amongst men who have sex with men 13 months after they were prescribed the pill. A more recent study from Wood et al. (2021) found mental health factors to impact PrEP adherence significantly. However, PrEP activists have only focused on short-term goals, improving access to preventative measures which could lead to the development of pill fatigue and poor mental health.

Arguments have been put forward by Fries (2008), who claims that the biomedical architects of PrEP have ensured 'a good cultural fit with neoliberal strategies of governance in which the focus is on enabling citizens to accept personal responsibility for their health' (Fries, 2008: 353). This is because the state was responsible for promoting and producing healthcare under the old welfare state model. However, under neoliberalism's new "wellness" discourse, the citizen-come-consumer is primarily accountable for their health or lack thereof. However, Brown and Di Feliciano (2021) argue that PrEP is more than a neoliberal invention to shift responsibility for health from the state to the individual. They say that PrEP has been 'widely driven by the grassroots advocacy and campaigning of gay men' (Brown and Di Feliciano, 2021: 8). Brown and Di Feliciano (2021) go on to present the role that grassroots advocacy has played in the fight for access to medication which enables people to reclaim their health. Schwartz and Grimm (2017) analysed Tweets in the USA which used the terms "Truvada" (otherwise known as PrEP) and "PrEP between 14th May 2013 and 14th May 2015. These dates were selected because they are one year before and one year after the date the Centers for Disease Control

endorsed PrEP, which was 14th May 2014. Schwartz and Grimm (2017) found that over half of the tweets promoted awareness or information about PrEP.

In my study, the participants talked positively about PrEP. Ollie, an HIV healthcare service user in Greater Manchester, told me,

*I think it's [PrEP] had a massive impact already on infection rates ... so, if its freely available on the NHS, the impact will be enormous ... they'll be less people to treat, and the cost will pay for itself.*

Ollie's perspective views the impact of PrEP to be positive from both an infection rate and financial benefit. Another one of my participants, Paul, had a similar view to Ollie. Paul talked in terms of delaying the availability of PrEP, and he told me

*it's never made sense to delay PrEP because it's really clear, not only in terms of transmission but the cost because you know HIV drugs are really incredibly expensive, late diagnosis, people in healthcare is really expensive. So, I think it's really counterproductive.*

The perspectives offered by Ollie and Paul link with neoliberal debates around biomedicine introduced earlier by Fries (2008). The arguments put forward by both Ollie and Paul suggest that providing PrEP on the NHS will reduce new transmissions of HIV. This will result in fewer people needing to access HIV services.

Overall, introducing PrEP has been a significant move by health authorities because it has enabled those at risk of HIV to access medication that can significantly reduce their chances of acquiring HIV. HIV activists and HIV organisations have been at the forefront of campaigning for people's rights to access this drug-free at the point of need. By doing so, they may have (unknowingly and non-intentionally) bought into arguments around neoliberal governmentality and self-responsibilisation. However, should people acquire HIV, campaigns have been established to break down the stigma and discrimination attached to HIV and AIDS.



## 6.4 (U)ndetectable = (U)ntransmittable: Messaging around HIV and AIDS

Since 1996, antiretroviral treatments have been available for people who have acquired HIV. Those living with HIV can administer highly active antiretroviral medicines to suppress the virus and stop them from passing it on to others. Richard, a political figure in Greater Manchester, informed me that over the past ten years,

*the proportion of patients receiving antiretroviral therapy has gone up; it's pretty much 99% of patients who are living with diagnosed HIV are on antiretrovirals.*

Increasing the number of people on antiretroviral treatments has meant that the government could meet the United Nations (UN) 90-90-90: Treatment for all targets. The UNAIDS programme established these targets in 2013 to support country- and region-led efforts to scale up HIV treatments beyond 2015. Earlier, I showed that the UK claims to have reached its 90-90-90 targets in 2018. However, to maintain their undetectable HIV status, people must strictly adhere to their medication regime and undergo regular blood work to monitor their viral load, check for any possible drug resistance, and monitor whether the medication affects the liver and other organs.

Introducing these treatments has medically benefitted people living with HIV but has not eliminated HIV-associated stigma.<sup>12</sup> Campaigners and HIV activists recognised this, and the U=U message was launched at the end of 2016 to inform people that those living with an undetectable viral load cannot pass HIV on. However, this was not the first time a message was launched to educate people that people living with undetectable virus levels cannot pass it on. The Swiss Federal Commission for HIV and AIDS endorsed a similar message in 2008: undetectable equals undetectable, but the U=U campaign in 2016 has garnered global endorsement (Okoli et al., 2021). The participants agreed that the U=U message is essential to educate the general public

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<sup>12</sup> See Chapter Five, where HIV-associated stigma is discussed.

that people living with HIV who are on effective medication cannot pass it on. It aims to eliminate misunderstandings that HIV continues to be a “killer virus”.<sup>13</sup>

The success of the U=U campaign depends on people understanding its meaning. Even within those communities where rates of HIV are high, for example, black Africans living in the UK, knowledge of this message is lacking. The participants in the study by Grace et al. (2021)—a cross-section of society which included people from 18 years to 52+ years of age with different ethnicities and levels of education—had a general awareness that being undetectable was associated with a more significant reduction in the likelihood of people living with HIV sexually transmitting HIV. However, Grace et al. also found that many of the men who participated in their study believed that undetectable means that people had a lower risk of transmitting HIV rather than being at no risk of transmission. My participants raised this lack of knowledge about the message as a concern, feeling that the message was not far-reaching. Drew, North East-based academic, told me,

*I love the U=U campaign, but it's gone no further than HIV campaigners and people with an interest in HIV.*

These comments resonate with a consensus amongst the participants that U=U is only known by those who live with or are interested in HIV. Simone, a Manchester-based mental health professional, told me,

*I think it's a great message, but how far-reaching it is, I don't know ... but it's a bit of an echo chamber, isn't it? You can only come across it if you happen to follow somebody on Twitter or, you know, that kind of thing. I think there's still a lot of work to do.*

These comments demonstrate that Simone feels that the U=U message does little to reach those who may lack knowledge about advancements in HIV medicine and, therefore, risk and those who hold HIV and AIDS stigma. Ollie told me

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<sup>13</sup> See Chapter Five, where the tombstone adverts in the 1980s are discussed.

*[T]here's a couple of HIV Facebook groups that I'm the admin of ... So, the one that you saw me on is for everybody, and the other one is just for gay men. You hear a lot about people's experiences of being rejected by potential partners because of their [HIV] status. It's far more common for straight people to get that than gay people these days.*

The stigma and discrimination experienced by gay and heterosexual men living with HIV were discussed by Hibbert et al. (2018). Hibbert et al. (2018) found that all men reported high levels of stigma and discrimination across various social settings. However, it was gay men who were more likely to report experiencing stigma and discrimination as well as HIV-related sexual rejection. The data used in Hibbert et al. (2018) was captured from the people living with HIV stigma survey 2015, a study conducted several years before my research and a few years before HIV and AIDS organisations pushed the U=U message. Ollie suggested that gay men are far less likely to receive rejection by potential partners than heterosexual people because the U=U message is shared widely amongst the gay community. Sharing the message through an echo chamber, such as social media, is vital to creating awareness about the U=U message, but it excludes those who do not have access to the specific chamber where the message is shared.

Organisations can promote their campaigns online using social media or their website, as it is cheap to share the message in this way because there is little cost involved in using these platforms. However, the comments made by Ollie demonstrate that the message is only understood by those who access the social media pages or those who have an interest in HIV. There can also be challenges in accessing the information shared on these sites because people either have to know about them or search for related terms, which would return to the page. Once you have found the page, you need to request to join, some of them being private groups, and provide a reason for wanting to participate in the hope that you will be accepted. These pages have been created to enable people to obtain advice and information about HIV in a safe space, but they do not convey messages about U=U to the general public.

Across Greater Manchester, the participants noted that there is very little awareness-raising around U=U and they argued that a campaign would be beneficial to address the gap in knowledge about the message. In February 2020, the “HIV: Let’s sort this together” campaign was launched in Greater Manchester to inform at-risk groups about biomedical interventions, such as PrEP, and also told them about the U=U message. Some of the campaign material includes images of people with intersecting characteristics and living with HIV, which is hoped will eliminate some of the stigma and discrimination experienced by people. A recent study in the US found that using imagery can effectively elicit anti-stigma outcomes (Subramanian and Santo, 2021). However, the campaign was launched one month before the COVID-19 pandemic outbreak in the UK, which subsequently impacted the successful delivery of the movement within the Manchester City Region. Andy discussed this impact:

*[A] campaign was launched, but it was launched right at the cusp of lockdown. It was very difficult to sort of figure out how to keep that alive and how we were going to at the time. It just seemed like there was nothing but barriers. There was a plan to have billboards and have advertisements on buses and on benches. When everyone was asked to go home and stay at home, there was sort of a question of how we are going to promote this campaign, how are we going to make this a success if no one’s going to see it.*

To date, it is difficult to measure the impact of this campaign because, at the time of writing, the COVID-19 pandemic still impacts people’s lives. However, during the pandemic, the decision was made to launch the campaign online to gain visibility.

Berntzen et al. (2016) discuss technological advancements and how they have made it easier for organisers to initiate campaigns, enrol support and communicate with people following the campaign. I argue that technology enables organisers to update information quickly via mobile devices, which can be pushed out to the followers instantaneously. Enabling technologies, such as Facebook and Twitter, can assist organisers in spreading the message quickly (Berntzen et al., 2016). Instant



messaging is positive because it enables campaigners to reach people without considering spatial geographies. After all, campaigns can reach a global audience.

However, utilising online technologies to promote campaigns has compounded digital poverty, when people are 'digitally excluded because they lack internet access and have low levels of digital literacy' (Seah, 2020: 127). Digital poverty is linked to a lack of internet connection and unequal access to computers and other digital devices (Venkat, 2001). Although they were talking about HIV healthcare, some participants informed me of their frustrations with the reliance on technology to reduce stigma and create awareness around HIV, such as needing access to the internet and knowing how to navigate it to request appointments. Simone and Alex shared their concerns about the increasing reliance on technology. Simone said,

*There's a lot of digital poverty in HIV. Especially for those people who don't have a lot of money or perhaps some of our older cohorts that have never got to grips with technology, it's not easy for them to access the support that's on offer.*

Alex added to this, telling me,

*We know there's people who don't have digital devices or the data they need to upkeep appointments or access things online. So, we can't exclude people who experience digital exclusion and digital poverty just because it's cheaper and convenient. That's something which needs to be carefully considered going forward.*

The increased reliance on the internet to inform the general public about decreased risks of acquiring HIV from someone successfully administering their antiretroviral medications is problematic because some people do not have access to digital devices or the internet. In their article, Chiasson et al. (2010) found that homeless people, active drug users, and people living in poverty are likelier to have limited internet access. However, they may have access to mobile devices, meaning that text messages can communicate HIV. This form of communication may be successful for

people seeking HIV support but not at-risk populations because they must have their telephone numbers to send information for services to connect with these groups. People at risk may not want to provide their details because they may not want people to see that they are receiving messages about HIV, or they may not view themselves as an at-risk group. This makes it increasingly challenging to communicate HIV messaging.

## 6.5 Chapter Summary

In conclusion, this chapter has presented some of the findings from the qualitative interviews, which concern how HIV organisations and HIV activists have responded to changing healthcare provision in Greater Manchester. In recent years, these activists have focused on campaigning for the availability of PrEP for those needing access to it. Early in the PrEP conversation, in 2015, Greg Thorpe and Alex Craddock set up a website— [iwantprepnw.co.uk](http://iwantprepnw.co.uk)—to enable those at risk of HIV to purchase PrEP safely. Although this website benefited people at risk, it meant that only those who could afford to fund PrEP privately could do so. Later, the PROUD study was established, and the results highlighted that using PrEP reduced the risk of infection (Medical Research Council Clinical Trials Unit, no date). These results allowed HIV activists to campaign for PrEP to be routinely available through the NHS, which led to subsequent studies, such as the PrEP IMPACT study.

HIV activists had to campaign for the NHS to routinely administer PrEP (*National AIDS Trust v NHS Commissioning Board*, 2016; Maine, 2019), and they succeeded. People at risk of HIV can now access PrEP through their local sexual health clinic. However, the provision of PrEP also buys into neoliberal arguments over healthcare provision. Claims have been put forward by Fries (2008), who argues that the biomedical architects of PrEP have ensured ‘a good cultural fit with neoliberal strategies of governance in which the focus is on enabling citizens to accept personal responsibility for their health’ (Fries, 2008: 353). In the Manchester City Region, the participants talked positively about introducing PrEP. Ollie said,

*Its [PrEP] had a massive impact already on infection rates.*

It is too early to understand whether the PrEP positively impacts HIV rates across Greater Manchester. Whilst there has been an increased focus on PrEP in recent years, there has also been an emphasis on creating awareness around people living with HIV being unable to pass on the virus through public campaigns, such as U=U. These messages inform the public that people who have an undetectable level of HIV and successfully maintain their antiretrovirals cannot pass on the virus (Okoli et al., 2021). However, Grace et al. (2021) found that the message only resonated with those who knew about HIV. Drew, North East-based academic, raised this view and told me that,

*[I]t's [U=U] gone no further than HIV campaigners and people with an interest in HIV.*

One reason for this is that the message is generally shared online, where,

*[I]t's a bit of an echo chamber, isn't it? You can only come across it if you happen to follow somebody on Twitter or, you know, that kind of thing.*

(Simone)

Therefore, HIV and AIDS organisations must create more awareness around the campaign if the message reaches a broader audience. In Greater Manchester, there has been some work by HIV and AIDS organisations to create awareness. The “HIV: Let’s sort this together” campaign was launched at the beginning of the COVID-19 pandemic (Nathaniel). Therefore, the campaign did not receive much attention because the country was in a national lockdown.

HIV organisations across the Manchester City Region identified a lack of education about HIV and AIDS for young people and healthcare professionals. The legacy of Section 28 has led to stigmatising behaviours (Shongwe et al., 2020), and the relevant HIV organisations have responded by trying to reduce the stigma and discrimination experienced by people living with HIV and AIDS. Lyn linked the ban on inclusive same-

sex education under Section 28 with the acquisition of HIV. Earlier on, I reflected on her views in my section on the lasting legacy of Section 28. Earlier, I introduced and paraphrased her quote. Lyn told me that young children are like little sponges, and teaching them about HIV will go in and become relevant if needed. However, the Conservative government recently introduced inclusive relation education, which caused outrage among some Conservative-Islamic thinkers (BBC News, 2019). HIV activists in Greater Manchester responded to this, and there has been ongoing work between these activists and faith leaders across the Manchester City Region. However, HIV organisations across Greater Manchester have gone further because they go into schools across the City Region and provide children with an opportunity to meet a diverse range of people living with HIV. Anecdotally, Paul told me that this had been a success. It allows young people to ask people living with HIV questions they may not otherwise ask their teachers.

Lastly, it has been identified that HIV-related stigma and discrimination are experienced by people in primary healthcare settings (Carlisle, 2001; Elford et al., 2008) and in secondary healthcare settings (Pulerwitz et al., 2015). People living with HIV are likely to attend these settings regularly. They could experience some form of stigma and discrimination from a healthcare professional with limited to no knowledge of HIV and AIDS. In Central Manchester, a project was established with private funding from ViiV Healthcare to tackle this issue in primary healthcare settings (Charity Commission, 2020). However, this funding was only used to educate those providers in Central Manchester, which left the other nine boroughs of Greater Manchester with healthcare professionals who may hold unconscious biases against people living with HIV. My study participants found this programme to benefit healthcare professionals because it allowed them to meet people living with HIV and ask questions (Paul). This programme tackled the stigma and discrimination of these providers and ensured that providers in Central Manchester could provide HIV-informed care. Currently, there does not appear to be any funding that widens this programme's scope.

There are currently no programmes in secondary care settings to tackle HIV-related stigma and discrimination, despite a study highlighting that 80% of staff in a central London hospital with a specialist HIV unit are unaware of HIV initiatives, such as U=U (Shongwe et al., 2020). According to Connor, a healthcare professional in Manchester, staff in secondary care settings who are not directly involved in HIV care do not receive any formal HIV training apart from that provided by colleagues. Staff in these settings might be aware of the risks, but they do not have any training which formally educates them about HIV and AIDS. Therefore, as stated earlier, it would be beneficial for HIV-specific training to be scaled up to educate primary and secondary care staff.

Overall, there have been some initiatives in the Manchester City Region. These initiatives have tended not to consider the mental health element of living with HIV, which some people experience. Although HIV activists and organisations have organised, created messaging and educated children and healthcare professionals about HIV and AIDS, these issues continue to affect people living with HIV. Therefore, HIV activists and organisations need to rethink how they broach the subject of mental health and extend initiatives across the wider Manchester City Region.

## ***Chapter Seven: Conclusion***

### **7.1 Introduction**

This research highlights the impact of devolution, neoliberalism and austerity on the governance and delivery of specialist physical and mental health services for service users living with HIV and AIDS across the Manchester City Region. This study argues that devolving political power to the Greater Manchester Combined Authority and healthcare to the Greater Manchester Health and Social Care Partnership has created a situation where local policymakers can make informed choices. However, service users across the Manchester City Region no longer have the same level of access to healthcare since it has been devolved to the City Region. Added to this, austerity measures introduced via the Health and Social Care Act 2012 have further impacted the delivery of HIV and AIDS healthcare, negatively impacting the care people receive. Specifically, this research used a queer-feminist theoretical framework to give voice to my participants who have been marginalised or ignored in traditional positivist research (Taylor, 1998), as discussed in Chapter Three.

Conducting this research was essential because Greater Manchester is home to one of the largest populations of people living with HIV and AIDS in the UK (McQuillan, 2019). I selected the Manchester City Region because it is one of the first to be exposed to the Conservatives' vision for a city region model. It is the only region in England to have a devolved healthcare system. This research is, therefore, pivotal because the Manchester City Region can serve as an example to others of the outcomes of devolution. To achieve the research aim, specific objectives were set out:

1. To analyse changes in HIV and AIDS health provision and governance, post-devolution in Greater Manchester
2. To assess the impact of devolution, neoliberalism and austerity on the lived experiences of service users living with HIV and AIDS across the Manchester City Region

3. To determine the impact of devolution, neoliberalism and austerity on the delivery of specialist mental health care for people living with HIV and AIDS across the Manchester City Region

These objectives were operationalised using the data obtained from the interviews I conducted with service users of HIV and AIDS healthcare provisions; organisations specialising in HIV and AIDS support, advice and advocacy services to improve health outcomes; healthcare staff specialising in HIV and AIDS healthcare and those who advocate for improved treatments; academics who work in the field of HIV studies; and activists who are campaigning for improved HIV and AIDS services. As well as through the analysis of secondary data sources, such as reports on HIV and homelessness, devolution and the funding of HIV and AIDS services; Newspaper articles and specialist websites on PrEP, the history of the AIDS epidemic and the impact of funding cuts to HIV and AIDS services. I employed thematic analysis to analyse this dataset and systematically analysed various secondary sources. I present the findings of this study in Chapters Four, Five and Six.

In Chapter Four, I analysed the inequalities affecting service users accessing HIV and AIDS healthcare within the Manchester City Region. Chapter Four highlighted the impact of austerity measures, delivered through the Health and Social Care Act 2012, on service users within the City Region. In Chapter Five, I determined the impact of devolution, neoliberalism and austerity on HIV and AIDS mental health services across the Manchester City Region. Chapter Five further explored HIV-related stigma and discrimination in generalist healthcare settings. Additionally, I discussed the impact of the COVID-19 pandemic on specialist mental health services. Lastly, in Chapter Six, I examined the contested responses to changing HIV and AIDS services and how activists actively fought for PrEP to be freely available on the NHS for those at risk of HIV. Chapter Six highlighted the importance of educating people about HIV and AIDS and examines the messaging campaigns around HIV and AIDS across the City Region. This chapter summarises the core findings and contributions of this thesis. It provides a space where I can reflect on the research journey and make recommendations to policymakers and future research.

## **7.2 Core Findings**

This research highlights that devolution, neoliberalism and austerity have negatively impacted the governance and delivery of specialist physical and mental health services for service users living with HIV and AIDS across the Manchester City Region. The decisions made by policymakers since Greater Manchester devolved have reduced the funding once available to services and also shifted the focus from the City Region to the Manchester City Centre. Moreover, there has also been a shift in focus from delivering specialist care to generalist care, particularly within mental health service provision. This has severely impacted the care received by service users. This section focuses on the key findings of the thesis in relation to the objectives.

### **7.2.1 Changes in HIV and Healthcare Provision and Governance Structures in a Post-Devolved Manchester City Region**

This study builds upon the literature on the sociology of governance and delivery of HIV and AIDS healthcare post-devolution. Since decision-making over healthcare was devolved to Greater Manchester, it has enabled more direct local and sub-national decision-making (Petratos, 2018). Under devolution, Greater Manchester has altered the governance of HIV and AIDS healthcare provision in how the City Region manages service provision, which has impacted HIV and AIDS service provision. In some geographical contexts, such as Sweden, devolving healthcare has given patients greater choice over their healthcare (Fredriksson and Winblad, 2008). However, in Greater Manchester, services have been closed or centralised to Manchester City Centre, which has removed patient choice and deteriorated healthcare provision. I now discuss how devolution has created disparities for service users across Greater Manchester.

The findings of this study highlight that changes to HIV and AIDS healthcare policy have affected service provision. Devolution, neoliberalism and austerity have been key contributing factors to changing HIV/AIDS healthcare policy and the replacement of specialist services with generalist provisions. Dismantling specialist services and replacing them with generalist healthcare provisions has been enacted without fully



understanding the needs of patients. This adds to the literature on neoliberalism and the work of Nevradakis and Giroux (2015), who argue that neoliberalism considers the economic interests, not the social costs associated with its implementation. In the case of HIV and AIDS service provision, replacing specialist with generalist healthcare has left some service users unable to attend their appointments because they fear their status could be outed if they see someone they know (Sayles, 2007). My participants recounted similar stories. Before the dismantling of services, people could seek support from their local specialist service. However, since devolution, people have to attend generalist services for help, which could result in them not attending services because they fear being outed. Decision-makers and policymakers must understand the social impact of HIV and how people continue to be affected by it, particularly those ageing with HIV. Therefore, the patients affected by decisions must be consulted to understand how service changes affect different groups.

One way for service users to access support before devolution and funding cuts was via local support networks. However, since the PaSH Partnership was introduced, austerity measures have impacted the funding available for more minor services which do not form part of this Partnership. This has resulted in some services closing or they have been centralised and delivered within the city centre. This builds upon the body of work on neoliberal governance, which emphasises removing autonomy and advocacy functions within the third sector (Evans et al., 2005). In Greater Manchester, neoliberal governance is prevalent through the introduction of the PaSH Partnership, which has increased control over the governance frameworks of HIV and AIDS services through increased professionalisation. Professionalising services has enabled the City Region to monitor the performance of services and act accordingly.

The Health and Social Care Act 2012 has further impacted the delivery of healthcare services because it has complicated the delivery of HIV and AIDS healthcare. Under the Act, responsibility for providing services has been split between NHS England, Clinical Commissioning Groups (CCGs) and local authorities. Splitting responsibility for HIV and AIDS healthcare was discussed by my participants, who felt that services have deteriorated since the Health and Social Care Act 2012 and thus created further

inequalities for service users. Today, service users have to attend various healthcare settings to access support because of this split, whereas before the Act, they could access this support under one service. This builds upon the body of work on neoliberalism and self-responsibilisation, which was put forward by Nevradakis and Giroux (2015). People are now required to take responsibility for health decisions, demonstrated by the need to decide where they seek support. If people cannot access different services and their health deteriorates, they can be blamed for their choices.

The Health and Social Care Act 2012 has shifted the responsibility for sexual health services under the remit of local authorities, which impacted the introduction of preventative medications. In 2016, local authorities argued that they should not be responsible for providing PrEP; however, the High Court later ruled that it is the responsibility of local authorities to provide these medications (*National AIDS Trust v NHS Commissioning Board*, 2016). My participants discussed how the rollout of the PrEP IMPACT Trial was poorly executed and not representative of the City Region's population as it was primarily made up of white gay men and did not reflect the demographics of the City Region.

A lack of leadership resulted in people from non-white backgrounds being unable to access the Trial. The African Advocacy Foundation funded a separate programme, enabling black and African people to access PrEP. The lack of oversight on the Trial left the City Region with a lack of information about PrEP uptake amongst Black and African people living within Greater Manchester. This oversight was significant because it is known that large numbers of Black and African people are being diagnosed with HIV each year (Cairns, 2021a). This finding links into the body of work on the ethics of clinical trials because people from black backgrounds may not have signed up for the trial because of previous clinical trials, which have created mistrust between some black people and clinical trials, for example, the Tuskegee Syphilis Study.<sup>14</sup> Therefore, all future trials should consider the needs of potential

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<sup>14</sup> See Chapter 6.2, where I discuss the impact of the Tuskegee Syphilis Study.

participants and have education in place to inform those who may be cautious about what will happen with their data. Future trials also need to have procedures in place to obtain a representative sample and reach out to organisations that may assist them in finding willing participants.

### **7.2.2 The Impact of Devolution, Neoliberalism and Austerity on the Lived Experience of Service Users in the Manchester City Region**

Devolution, neoliberalism and austerity measures have created inequalities in access to healthcare provision and impacted the lived experience of service users living within Greater Manchester. Previous research highlights that service users outside of Manchester City Centre face severe obstacles when accessing physical and mental health HIV and AIDS service provision (Nowell, 2022). For example, it costs more to access services because people need to travel. Therefore, they need more money to pay for transport. They need more time to attend appointments because of their travel needs, or the service user may hesitate to travel to an unknown location (Nowell, 2022). These travel needs were brought up during the interviews, and my participants discussed how access to travel can be a barrier to service users reaching their appointments.

Governance changes to service delivery, through the centralisation of services and austerity measures, have resulted in the downscaling of service provision. This has resulted in people needing to travel outside their locality to access services once provided within. The extra cost of travel can be a financial burden for some service users. This builds upon the work of Nowell (2022), who found that the centralisation of HIV and AIDS services into Manchester City Centre, coupled with the lack of affordable housing in the city centre, is causing service users to travel long distances at their own cost, thereby causing extra strains on their finances. This can also impact those juggling caring responsibilities (Harper et al., 2020) while attempting to access HIV services. In particular, this can affect women and may result in them withdrawing from service because they might not be able to obtain childcare each time they attend an appointment. It is also important to note that some service users may drop

out because they may not be open about their HIV status and may feel that the new support group may not be safe because of the trust they have built with their previous service and not knowing what to expect at the new group (Walding, 2016). This builds upon the literature on stigma and HIV, as stigma can impact how people interact with others (Earnshaw and Kalichman, 2013), and self-stigma can make them feel deeply discredited (Goffman, 2009). These are just some examples of how centralising services can impact the service users' healthcare experience. When designing the future governance structures of healthcare, policymakers and decision-makers should consider all aspects of the service users' experience and ensure that adequate processes are in place so they do not drop out of service.

Neoliberalism, austerity measures and changes to governance structures within the Manchester City Region have reduced the amount of available funding for smaller HIV and AIDS charities (McCurry, 2009). This has created a competitive market for service funding, which is meant to generate a framework model which increases the choices of services for local patients (Pownall, 2013). Furthermore, this is intended to create a market-led system where any willing provider could tender to provide a service (Grimshaw and Rubery, 2012). However, in the context of HIV and AIDS services, this framework has dismantled specialist services, leaving service users with little choice over where they go to access services. This has created further inequalities and resulted in people living with HIV only having the option of three large HIV and AIDS charities to attend for support. Policymakers and decision-makers must reflect on their choices because it will ultimately lead to a 'brain drain' of skilled caregivers (Padarath et al., 2003; Rowden, 2009). Their knowledge may be lost because these qualified caregivers may move into a role where their knowledge and expertise are not required. Therefore, policymakers and decision-makers need to consider the broader impact of their choices on successful patient outcomes.

### **7.2.3 The Impact of Devolution, Neoliberalism and Austerity on HIV and AIDS Mental Health Services across Greater Manchester**

Devolution, neoliberalism and austerity have severely impacted specialist HIV and AIDS mental health services. The neoliberal notion of self-responsibilisation has also encroached on mental health care for service users by introducing cheap biomedical advancements (Fries, 2008). Biomedical advances have improved service users' health, enabling them to live longer with HIV and reducing the chance for AIDS to develop. Devolution and austerity measures have reduced the funding availability for specialist mental health services in favour of cheaper, generalist service provision through IAPT (Improving Access to Psychological Therapies) (Dhumma, 2020). This shift to generalist provision is apparent in Greater Manchester as there is only one specialist service to serve the entire City Region, which has resulted in some service users seeking alternative arrangements through private means (Gregory, 2022) or managing their conditions with little support.

The emphasis on IAPT services was formulated under the Health and Social Care Act 2012, and this service utilises CBT (Cognitive Behavioural Therapy) to treat patients. Although CBT is known to increase adherence to antiretrovirals (Safren et al., 2009), IAPT services are not 'designed to address co-morbidities around stigma, drug and alcohol use and sexual risk, and these matters do not form part of the IAPT curriculum' (All-Party Parliamentary Group on HIV and AIDS, 2019: 47). Another issue is that IAPT practitioners may not have received any formal HIV training (Dhumma, 2020). This can result in service users being subjected to some form of stigmatising behaviours, for example, verbal abuse and gossip (Yuvaraj et al., 2020). As a result, service users may drop out of treatment because their needs are not addressed (Safren et al., 2009) and stop taking their antiretrovirals (Vreeman et al., 2017). My participants discussed how generalist mental health services are not equipped to treat the mental health of service users living with HIV. This is because these services tend to focus on HIV rather than taking a holistic approach and understanding other factors which could be causing the service user's poor mental health.

This leads to healthcare inequalities as HIV and AIDS service users want to access ever-dismantling specialist mental health services. Still, my participants noted that there was up to a six-month waiting list in the Greater Manchester service. Changes to service provision are linked to austerity measures as they play a reduced state role in providing specialist services and instead replace them with cheaper generalist alternatives, which can create competitiveness (Pownall, 2013). This builds upon the literature on uneven service provision in times of devolution and austerity, as discussed by Danson et al. (2012) and Etherington and Jones (2009). They argue that devolution has created an acutely uneven geography, and it pays little attention to poverty and social inequalities. This is the case across the City Region because healthcare is now unevenly distributed, and the needs of its citizens are not considered concerning the increased costs of attending appointments.

One reason for this shift from specialist to generalist mental health services is that the Greater Manchester Health and Social Care Partnership has focused on biomedical advancements. This builds upon the argument put forward by Adams et al. (2016), who argue that biomedical advancements continue to be a motive to dismantle funding for HIV and AIDS services. These advancements have left people with improved physical health but fail to address service users' complex mental health needs. Choices made by policymakers to focus their interventions on antiretrovirals has led to a defunding of services. Antiretrovirals enable policymakers to diminish mental health services because the medication is seen as vital to improving the overall health of people living with HIV. This places an increased role on the individual to maintain their treatment with poor mental health and a lack of specialist mental health services, which can result in non-adherence (Bolszewicz et al., 2015).

Across Greater Manchester, the NHS delivers mental health services through specialist and non-specialist services. The third sector, such as HIV charities and organisations, provides support services. The increased focus on antiretroviral treatments and the austerity measures introduced in recent years has seen reduced funding for organisations that provide mental health support. For example, between

2012 and 2020, the total income for George House Trust decreased by just over 8%, which has impacted their service offerings. Diminishing the funding for services that support service users' mental health can be linked back to the increased focus on antiretroviral treatments as the resolution to ending HIV and AIDS.

The increased focus on antiretrovirals can be linked to the UNAIDS 90-90-90 targets, which fail to consider mental health. In Greater Manchester, mental health services have become a neglected priority (Vreeman et al., 2017). However, there have been calls in recent years for international recognition of poor mental health for people living with HIV by adding a fourth 90 (excellent quality of life) to the 90-90-90 targets, yet this has not been achieved. My participants working in the mental health field echoed these calls, arguing that including the fourth 90 may persuade people to test more because they know that their quality of life will improve because they will receive holistic care.<sup>15</sup> I hypothesise that should a fourth 90 be added focusing on mental health, the UK will respond to this and invest in mental health services for people living with HIV. This is because the UNAIDS set targets in 2014 for nations to achieve their targets. 2018 Public Health England (2018a) reported that the UK had reached its target. Therefore, should a target be set for the countries to focus on improving mental health services, funding could be available to introduce more specialist services.

#### **7.2.4 Overall Contribution**

This study shows that neoliberalism and austerity measures can significantly impact the delivery of HIV and AIDS healthcare services. A significant change in HIV and AIDS services is the shift from specialist to generalist healthcare services. This decline in service provision can be linked to neoliberal and austerity measures, as these ideologies have driven policymakers' thinking to seek cheaper treatment options. Furthermore, neoliberal and austerity measures have shifted the governance framework of HIV and AIDS healthcare delivery by emphasising the individual taking

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<sup>15</sup> This is a hypothesis created by my participants, and I do not have any sources to validate this claim. However, it is essential to include this as it demonstrates the importance that healthcare professionals feel a fourth 90 to the UNAIDS 90-90-90 targets will have on people living with HIV.

charge of their healthcare, for example, through a greater focus on cheap biomedical interventions. This thinking has weaponised policymakers' opinions with the idea that biomedical interventions meet the needs of service users. However, biomedical interventions fail to address the poor mental health which might be experienced by service users living with HIV and AIDS. This impacts the lived experience of service users because they are left to seek alternative treatments in the private sector at their own cost.

At the same time, centralising services can lead to an under-provision of HIV and AIDS service provision and a lack of specialism and competence. This translates into inadequate access to services and potentially exposes service users to increased stigma and discrimination due to a lack of specialist knowledge in generalist healthcare settings. This lack of specialist HIV and AIDS training across healthcare staff in physical and mental health services results in service users having an increased chance of coming into contact with healthcare staff who may demonstrate stigmatising and discriminatory behaviours. For example, healthcare professionals may unknowingly demonstrate this through excessive use of PPE (Yuvaraj et al., 2020). To improve service users' experiences in generalist healthcare settings, NHS trusts must invest in HIV and AIDS training to reduce the risk of healthcare staff demonstrating stigmatising and discriminatory behaviours.

This study illustrates the need for decision-makers and policymakers to review the impact of their choices on the governance and delivery of HIV and AIDS physical and mental health services. Decision-makers and policymakers need to ensure that the changes they make to HIV and AIDS healthcare services do not significantly impact the lives of service users. This is vital to ensuring that service users have successful health outcomes. To date, changes have been implemented which have complicated how service users navigate healthcare, for example, the centralisation of HIV and AIDS services to the Manchester City Centre, the shift from specialist to generalist healthcare, and the over-reliance on antiretrovirals to treat people living with HIV and AIDS. Comprehending the impact of the decisions will ensure that service users can access informed services where they are less likely to experience HIV-related



stigma and discrimination. Policymakers and decision-makers reviewing their decisions' impact on service users' experiences will go some way to ensuring parity of esteem between physical and mental health HIV and AIDS healthcare services. This will also ensure that service users can access services which understand their needs. However, to do this, there needs to be an investment in training healthcare staff about HIV and AIDS, which will work to reduce stigmatising and discriminatory behaviours presented by generalist service staff who may lack knowledge about HIV and AIDS. This illustrates the need for a re-focus on how healthcare services are delivered.

### **7.3 Reflexivity**

Undertaking this research has created knowledge and contributed to various fields of research. However, it is imperative that I reflect on the research journey in line with my queer-feminist methodological approach (Taylor, 1998; Letherby, 2010). Throughout this research journey, self-awareness was essential because of my position as a researcher and an outsider to this field. I needed to build rapport and trust with the participants because they allowed me to come into their lives and record their experiences. Moreover, it was vital to foster good working relationships with my participants because some may have been subjected to abuse previously and, therefore, have been suspicious of outsiders (Holyoak, 2015). In addition to this, I had to be aware of how I presented myself during the data collection. This was important because I utilised a queer-feminist approach to validate, give voice to, and understand my participants' experiences, who may have been marginalised or ignored in traditional positivist research (Taylor, 1998). This required me to endeavour to bracket any pre-existing knowledge and assumptions (Pivcevic, 2015) of HIV and AIDS healthcare services to allow the participants' experiences to guide my understanding of the Greater Manchester context.

Conducting this research was always more than an academic venture. It was more about providing a platform to record my participant's voices and understanding how the changing nature of HIV and AIDS healthcare across the Manchester City Region

affects service users. During the interviews, the study participants disclosed personal stories. I thank them for sharing their stories and entrusting me with them. Although I am grateful to the participants for trusting me with their stories, this did place some unexpected challenges on me. For example, the research findings drove the construction of the chapters in this thesis, but as the researcher, I had to decide which direct quotes to utilise in the thesis (Craddock, 2020). I included as many participants' voices as possible in this thesis to overcome this challenge. Despite this, I found it an honour to be in a position where people I did not know before their recruitment entrusted me to document, historicise and interpret their activist journeys and compile and present these stories in my thesis.

In this project, I wanted to include more women's voices; however, recruiting women was difficult. Many women's HIV networks are formed online and through social media tools like WhatsApp. Having a virtual presence, where only those in the network know about it, makes it impossible to contact these groups. Therefore, the access problem made recruiting from these groups difficult. I did recruit some women, but these women largely represented healthcare professionals. Part of this can be linked to the COVID-19 pandemic, where I could only access potential participants via the internet. My methodology identified that the imbalance of gender roles in the feminist political economy continued through the COVID-19 pandemic. Harper et al. (2020) found that despite women and men working from home, women were likely to juggle the responsibility of care over men with work. Considering this, the burden of care placed upon women during the COVID-19 pandemic could be a factor in why I did not recruit as many women as I had wanted.

The challenges in recruiting participants required me to turn to secondary data for the collection of data to include in this study—secondary data analysis provided opportunities to source a richer dataset that supported the primary data—including secondary data allowed me to observe historical trends and validate some of the claims made by the participants (Boslaugh, 2007; Pederson et al., 2020). Also, validating my data against the secondary sources ensured that I brought greater clarity and meaning to the Manchester City Region. Overall, secondary data has

provided this thesis with a richer understanding of how austerity, devolution and neoliberalism have impacted HIV and AIDS physical and mental health healthcare in other geographies and apply these findings to the Manchester City Region context.

#### **7.4 Recommendations Healthcare Providers and Policymakers in the field of HIV and AIDS Healthcare**

In this study, I have identified four recommendations for HIV healthcare providers and policymakers which could work to improve successful outcomes for service users. These recommendations are informed by the analysis of both primary and secondary data collection.

First, when altering the governance structures and design of physical and mental health HIV and AIDS services, policymakers and decision-makers need to consider how the impact of their changes will affect access for service users. When centralising service provision, policymakers and decision-makers need to be aware of potential disparities; for example, it can cause service users to need to travel further for access to specialist support, which can have negative financial implications because of extra costs (Nowell, 2022), they may not be able to travel due to caring commitments, or they may not feel that the new service is not a safe space. As a result, if service users cannot travel, they have three options that can have negative impacts. If they cannot travel, they may have to access non-specialist support, where there is an increased chance of stigma and discrimination because the healthcare teams may not have received formal HIV and AIDS training (National AIDS Trust, 2017; Dhumma, 2020). Service users may have to pay for support privately, which can have significant financial implications, particularly if they do not have disposable income to afford this level of care (Gregory, 2022), if service users are uncomfortable with accessing non-specialist services or cannot fund private care. In that case, they may drop out of service (Safren et al., 2009), which could cause non-adherence to their antiretrovirals and cause comorbidities (Vreeman et al., 2017). Therefore, when re-designing services and amending the governance structures, policymakers should account for the impact that changes will have on service users, particularly those

living with a stigmatised condition, such as HIV. Service users need to be informed of the changes and consulted, if necessary, and accommodations put in place to ensure that the newly designed services can be accessed easily. This could be achieved through transport provision for those who do not have disposable income. This will ensure that service users living with a stigmatised condition have input into the design of newly created services; it could work to ensure that they are less likely to drop out of service and engage with the new service.

Second, investment is needed in generalist healthcare settings to educate healthcare professionals about HIV and AIDS when decision-makers close specialist services. HIV-related stigma and discrimination can be experienced by service users when accessing generalist primary and secondary healthcare settings (Shongwe et al., 2020; Yuvaraj et al., 2020), something also uncovered in this research. One reason is a lack of formal HIV training (Dhumma, 2020). To date, initiatives have been carried out by the third sector to educate medical professionals about HIV and AIDS in an attempt to combat stigma and discrimination. However, the funding for these programmes has been provided by pharmaceutical companies and mandated to educate primary care settings in city centres, such as Manchester. This leaves areas outside the funding remit with a continued lack of awareness and creates a postcode lottery. Therefore, investing in training will ensure that services have access to the same level of education about HIV and AIDS and work to reduce potential stigmatising and discriminatory behaviours and views.

Third, NHS trusts need to invest in HIV training for IAPT practitioners to ensure that they understand service users' needs. Since the Health and Social Care Act 2012, there has been a push from specialist to generalist mental health services. However, this has created environments where service users can experience stigma and discrimination (National AIDS Trust, 2017; Dhumma, 2020). One reason is that IAPT training does not include basic training on HIV and HIV-related stigma (Dhumma, 2020). Another reason is that IAPT services are not designed to address co-morbidities, such as HIV-related mental health, stigma and sexual risk (All-Party Parliamentary Group on HIV and AIDS, 2019). These two reasons are having an

impact on successful health outcomes for service users. The lack of training and awareness in IAPT services is leading to disparities in delivering mental health services because service users' mental health needs are not being met. To ensure that health authorities do not ignore the needs of service users, they need to invest in the provision of top-up training, which will provide IAPT services with an understanding of HIV and create awareness about stigmatising and discriminatory behaviours. This training should further address the need for IAPT practitioners to understand that service users seek support not just because they are living with HIV but because there are other factors in their lives which cause them to experience poor mental health.

Last, I recommend that HIV and AIDS organisations focus on the message 'You Can't Pass It On' to inform the general population that service users with an undetectable viral load cannot pass HIV on. The stigma and discrimination experienced by service users are linked to a lack of knowledge about HIV and a historical understanding of the disease. Ranscombe (2019) highlighted that people still equate acquiring HIV with an early grave. Therefore, a single message needs to be formulated. This message also exists with 'You Can't Pass It On.' Running two campaigns with the same message can confuse those unaware of either message, and my study has highlighted that 'U=U' requires the person to explain its meaning. For service users, presenting the message can cause the resurfacing of HIV-related trauma and subsequently impact their mental health. However, it is clear from the findings of this study that 'You Can't Pass It On' informs the recipient that someone living with HIV cannot pass HIV on if they maintain an undetectable viral load. Once people start to understand developments in HIV medicine and the long-term impact on service users, such as being unable to pass on the virus, then some of the stigma and discrimination may start to reduce. There needs to be significant investment in this campaign, and HIV and AIDS organisations will need to work with stakeholders, such as local and national governments and the NHS, for this campaign to succeed. The campaign must present a clear message that resonates with the right audience (Weiss and Tschirhart, 1994). For a successful campaign, there need to be variations which target specific audiences to ensure it resonates with all target groups.

These recommendations inform decision-makers and policymakers that cuts to physical and mental health services under austerity and neoliberal policies have created a 'survival agenda' (Crowley, 2013) for service provision. Implementing my recommendations would improve physical and mental health services for people living with HIV and AIDS, not just across Greater Manchester but service provision in the UK and globally. Foremost, they highlight that funding cuts to services have severely impacted successful health outcomes for service users. Although there has been some investment in training for healthcare staff about HIV and AIDS, this has been provided by the private sector, but local and national governments and NHS trusts need to step in to provide this training centrally. The shift from specialist to generalist service provision has resulted in disparities for service users, as healthcare staff in these settings may not have the same knowledge level as those who work in specialist services. These recommendations serve to equip medical professionals with knowledge which will enable them to provide informed care. They also educate the public about advancements in HIV and AIDS treatments and risks today.

## **7.5 Recommendations for Further Research**

Now, I will provide some recommendations for future research. This research broadens our understanding of how changing HIV and AIDS healthcare provision has affected people across Greater Manchester. The study also highlights how various actors across the Manchester City Region have responded to changing healthcare provisions. Whilst this research includes some women's voices, further research is needed with this group to capture their experiences. The Sophia Forum and Terrence Higgins Trust (2018) report highlighted that not all women are equally treated when accessing HIV services. For example, minoritised women, pregnant women and women who inject drugs are primarily targeted by healthcare professionals when offering HIV tests. I would have liked to have understood if this was the case in Greater Manchester, but having limited access to women made me unable to ask questions about testing. Further research with more women would capture various voices and help understand how changing HIV and AIDS healthcare provision has impacted them in Greater Manchester.

Although I discuss mental health services concerning HIV and AIDS healthcare within Greater Manchester, it would be beneficial to carry out more research focusing solely on the impact of devolving healthcare to the Greater Manchester level. I have included a chapter on mental health in this thesis because many participants highlighted the significance of this issue. However, a study focusing solely on HIV-related mental health services could bring greater clarity and understanding of how austerity impacts these services within the Manchester City Region.

There is currently a lack of literature on trans and gender-diverse people living with HIV in the UK (Kirwan et al., 2021). The study conducted by Kirwan et al. (2021) suggests that one in five trans women globally could be living with HIV. However, less data is available for trans men and gender-diverse people. In the UK, the lack of census data on the overall number of people who identify as trans in the UK makes it increasingly complex to determine the impact of HIV on this group (Jaspal et al., 2018). Considering these findings, I wanted to include the voices of trans and gender-diverse people in this study. However, reaching these groups was complex, and I could only recruit one person who identified as trans. I included their voice in this study but recognised that this was one perspective and experience. More research is needed on the experiences of gender-diverse and trans people concerning changing HIV and AIDS healthcare services across the Manchester City Region.

Through this PhD, I had to work to support myself, meaning I could not volunteer for charities that work with people living with HIV. This impacted recruitment, as I had to contact the gatekeepers to access potential participants. I found it quite challenging to recruit people using this method. However, when I spoke to fellow researchers about recruiting, they had limited issues recruiting from charities because they volunteered for the organisation when they undertook the research. This meant they could instantly reach those who attended and discuss their research, increasing their opportunity to recruit participants.

Lastly, I recommend that future research uses a mixed methods approach. As discussed in the methodology, my research was impacted by the COVID-19 pandemic, which affected my ability to carry out interviews. Therefore, solely relying upon interviews as the data collection method meant that my participants had to find time during their busy lives and living through a global pandemic. However, other data collection methods, such as surveys, could afford flexibility and reach out to a greater number of participants, thereby collecting a more significant number of responses.

## **7.6 Final Remarks**

This research reaffirms the arguments made by others in the field that biomedical advancements have significantly enhanced the long-term outcome of living with HIV. Moreover, HIV activists and organisations have been central to improving the lives of people at risk of acquiring HIV by fighting for PrEP to be available on the NHS to fight for improved antiretrovirals. There has been some progress in eradicating HIV-related stigma and discrimination through campaigns such as U=U, and You Can't Pass It On. Still, these have limited progress because they have reached only those communities connected to HIV and AIDS. However, this study shows that a significant amount of work is still needed to improve the mental health services for people living with HIV and AIDS.



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## Appendix A: Interview Schedule

### INTERVIEW SCHEDULE

#### Opening remarks

- Thank them for their time
- You don't have to answer any question if you don't want to
- The interview can be paused at any time
- And you can terminate the interview at any time without giving a reason why

#### Anonymous participation?

- As you've selected to participate anonymously, any reference to your name will be removed and replaced with a pseudonym in the transcript. Do you have a pseudonym preference?

**ADVISE PARTICIPANT THAT RECORDER WILL NOW BE SWITCHED ON**

#### Biographical data questions

- Just to make sure the recorder is working; I just have a couple of questions about yourself. So, first, could you just tell me your age?
- How do you describe your gender, ethnic background and sexual preference?
- Also, what pronoun do you use?

#### Theme 1 – Political biography

- 1) I wonder, if first, you could tell me what your work around HIV and AIDS healthcare (activism) has been?
- 2) Are you involved with any feminist or LGBTQ networks? if so, could you tell me a bit about their work on HIV and AIDS healthcare activism in Greater Manchester?

#### Theme 2 – HIV and AIDS healthcare

- 3) Greater Manchester has taken charge of its own health and social care spending to improve the health, wealth and wellbeing of its residents, considering this, do you think there has been a consistent or improved focus on HIV and AIDS healthcare services? If yes, please explain – if not, please explain.
  - a) How have HIV and AIDS healthcare services, in Greater Manchester, changed in recent years?
  - b) Have funding cuts impacted these changes to HIV and AIDS healthcare provision? If so, how?
    - Has the integration of specialist HIV and AIDS services within the general healthcare setting impacted on better health outcomes for women and LGBTQ people?
    - How...
      - How are activist groups responding to these cuts?
      - How are third sector organisations responding to this?
      - How is the sector responding to these cuts?
      - How are professional groups and organisations responding to these cuts?
- 4) Are there any particular barriers faced by women and LGBTQ people when accessing HIV and AIDS healthcare services? If yes, what do they look like?
  - a) Is there any activist work going on at the moment which is challenging these barriers?

- b) Are people from minority backgrounds (such as BAME) disproportionately affected by these barriers?
  - c) Have changes in the benefits systems impacted access to HIV and AIDS healthcare services for women and LGBTQ people?
- 5) What would you say are the greatest challenges to HIV and AIDS healthcare provision at present?
- 6) Are there any external factors that are hindering women and LGBTQ people from accessing HIV and AIDS healthcare services?
- a) (Examples)
    - █ Language barriers
    - █ Lack of cultural competence
    - █ Stigma in communities
    - █ Lack of specialised services (around sexuality/ cultural difference/ lack of secure citizenship status)

### **Theme 3 – Politics**

- 7) Manchester is reported to have one of the highest averages of people living with HIV and subsequently joined the Fast Track Cities initiative to cut the rate of new HIV infection by 2030, and eliminate HIV associated stigma and discrimination. What are your thoughts on this, and do you think this goes far enough?
- a) The availability of pre-exposure prophylaxis [PrEP] is a commitment of Fast Track Cities but the rollout has been delayed due to COVID, what are your thoughts on this, and do you think this will impact new HIV infection rates?
    - o How...
      - █ How are activist groups responding to this?
      - █ How are third sector organisations responding to this?
      - █ How is the sector responding to this?
      - █ How are professional groups and organisations responding to this?

### **Theme 4 – Mental Health**

- 8) Poor mental health is linked to people living with HIV and AIDS, what is the mental health support like for people living with either HIV or AIDS?
- a) How is activism responding to your concerns?
  - b) Greater Manchester Mental Health claim that their services are delivered in a timely manner, is this the experience of women and LGBTQ people living with HIV or AIDS?

### **Theme 5 – Reflections**

- 9) Are there any important issues which we haven't discussed that you would like to add?
- 10) Is there anything you would like to see done differently in HIV and AIDS activism, if so, what?

### **Concluding remarks**

- Thank interviewee for their time

**SWITCH OFF RECORDER**

- Ask the participant how they are feeling?

## Appendix B: Invitation Letter



PARTICIPANT INVITATION LETTER

To whom it may concern,

**Research Project:** Contesting Austerity: Feminist and LGBTQ Responses to Changing Health and Social Care Provision in Greater Manchester

My name is Craig Carey. I am a PhD student at Manchester Metropolitan University, who is researching how women and LGBTQ people are organising and responding to changing HIV/AIDS and mental health service provision in Greater Manchester. I would like to invite you to participate in this research by the means of an interview. This would allow me to understand what issues you think are important in this context. The interviews will cover changes in health policy, namely issues relating to the experiences of women and LGBTQ people in relation to HIV/AIDS and mental health services, and political responses to perceived problems in these areas. These conversations will contribute to reflecting on what's happened so far, what's going well and what needs to change. Hearing your thoughts and experiences will help me to develop a deeper understanding, and thorough analysis, of the responses to changing HIV/AIDS and mental health service provision in Greater Manchester, which hopefully will stimulate further discussion in the field.

This invite briefly explains why I am inviting you and what participation will involve. I have attached the participant information sheet which contains more information about the project.

### Why I am inviting you?

Over the next few months, I am hoping to conduct informal interviews on the topics of changing HIV/AIDS and mental health service provision in Greater Manchester with people who

- ⇒ have knowledge of these topics
- ⇒ are involved with a campaign or campaigning groups on these topics
- ⇒ are involved in the policy making process on these topics

*\*Please note, I can only accommodate participants over 18 years of age*

### What will participation involve?

You will only be asked to participate in one interview, lasting approximately one hour. You can select to either conduct this in person or via Skype. The interview questions are open-ended and have been designed to draw upon your knowledge and experiences.

### Are you interested in participating?

You can contact me via email at [craig.carey@stu.mmu.ac.uk](mailto:craig.carey@stu.mmu.ac.uk) if you have any questions or want to participate in the project. Unfortunately, I cannot provide any payment for your participation.

I am looking forward to hearing from you.

Best wishes

Craig

Date of issue: 10 November 2020  
Version number: 6.0

Page 1 of 1

## Appendix C: Participant Information Sheet



PARTICIPANT INFORMATION SHEET

**Research Project:** Contesting Austerity: Feminist and LGBTQ Responses to Changing Health and Social Care Provision in Greater Manchester

### 1. Invitation

My name is Craig Carey. I am a PhD Student at Manchester Metropolitan University (herein referred to as 'the University'), who is researching how women and LGBTQ people are organising and responding to changing HIV/AIDS and mental health service provision in Greater Manchester. I would like to invite you to participate in this research by the means of an interview. Before you decide, I would like to explain in more detail why I am conducting this research and what I would like your help with. If you have any questions, please let me know; you will find my contact details at the bottom of this participant information sheet.

### 2. Purpose

The purpose of this study is to understand what issues you think are important in the context of changing HIV/AIDS and mental health service provision in Greater Manchester. The interviews will cover changes in health policy, namely the issues relating to the experiences of women and LGBTQ people in relation to HIV/AIDS and mental health services, and political responses to perceived problems in these areas. These conversations will contribute to reflecting on what's happened so far, what's going well and what needs to change. Hearing your thoughts and experiences will help me to develop a deeper understanding, and thorough analysis, of the responses to changing HIV/AIDS and mental health service provision in Greater Manchester, which hopefully will stimulate further discussion in this field.

### 3. Why have I been invited?

I am interested in conducting informal interviews on the topic of changing HIV/AIDS and mental health service provision in Greater Manchester with people who

- ⇒ have knowledge of these topics
- ⇒ are involved with a campaign or campaigning groups on these topics
- ⇒ are involved in the policy making process on these topics

### 4. Do I have to take part?

It is up to you to decide. I will describe the study, and we will go through this participant information sheet together. You will be asked to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving a reason.

### 5. What will I be asked to do?

If you wish to take part in the study, you will be invited to take part in one interview, lasting approximately one hour. The interview can be conducted either in person or via Skype, with as many breaks as you require. The interview will consist of a series of open-ended questions designed to draw upon your knowledge of changes to the provision of HIV/AIDS and/or mental health services in Greater Manchester.

Date of issue: 10 November 2020  
Version number: 6.0

Page 1 of 5



Should we conduct the interview in person, we will seek a date and mutually agree on the time and location, for example your workplace or a private room at the University. Should we conduct the interview over Skype, we will mutually agree on a date and time.

Your interview will be audio recorded to allow for transcription. Should you have any concerns, please raise this with me prior to us conducting the interview. I may take some notes during the interview, if you would like, I can show these to you at the end for the purpose of transparency.

No more action will be required on your part.

#### **6. What expenses, payments, and benefits will I receive for taking part?**

Unfortunately, I cannot provide any expenses or payment for your participation. There will be no direct benefit to you taking part in the study. However, the information you provide will contribute to the broader body of literature dealing with feminist and LGBTQ responses to changing HIV/AIDS and mental health service provision.

#### **7. Are there any risks in participating?**

Some of the topics raised in the interview may be perceived as sensitive and carry the potential to trigger distress. Every effort has been made to minimise the chances of this happening. If you find an interview question is causing you distress, you can pause the interview and take a break, or you can ask for the interview to be stopped entirely. You will have a chance to reconvene at a later date should you like to continue with participation in the study. I can provide you with a contact list containing a few HIV/AIDS and mental health organisations to access support, if required.

#### **8. Will taking part be kept confidential?**

All identifiable data collected from you will be kept strictly confidential; only I will know of your true identity. You will be given a unique participant code which I will hold on a password protected data file. Hard copy data will be stored in a locked cabinet, and electronic data will be stored on a password protected computer. The default position will be to anonymise you and your data; however, you can opt to be a named subject in the study. If you wish to remain anonymous, I will carefully transcribe the data to maintain your anonymity, in case there is a risk that you could be identified through the interview data. Pseudonyms will be adopted when directly quoting you in the thesis.

#### **9. How do I withdraw from the study?**

If you do not want to carry on participating in the study, you can withdraw at any time, without giving a reason. You can notify me of your withdrawal in person or via email.

At the point you withdraw, your data shall be destroyed in accordance with the General Data Protection Regulations. However, once I have started data analysis, it may be difficult for me to remove all your data, but anonymity will be maintained. Therefore, should you withdraw after the data analysis, your personally identifiable data will be destroyed.

**10. What will happen to the results of the study?**

The results of the study will be used to inform the thesis. The thesis will be published on e-space: the University's 'open access' research repository, which you can access. Should you opt to receive a summary of the findings, I will send this to you shortly after the thesis has been published on e-space. I may submit the thesis for book publication, and elements of the thesis could be used to inform my future published works.

**11. Who has reviewed the project?**

This project has been reviewed by my supervisory team (Dr Christian Klesse, Dr Jon Binnie and Dr Craig Griffiths), two scrutineers (Dr Benedicte Brahic and Dr Katie Milestone), and the University ethics committee.

**12. Who is organising or sponsoring the research?**

The research is being organised and carried out by myself, Craig Carey. I have obtained a fees only scholarship from the Faculty of Arts and Humanities, Manchester Metropolitan University. I may work with some organisations who form part of this research. There is no covert observation involved and I will disclose my identity as a researcher prior to undertaking any work with individuals or organisations. Should I use this work to publicise the research project, the organisations will not receive any payment or benefit which places them in a favourable position over yourself.

**13. Who do I contact if I have concerns about the study or wish to complain?**

If you have concerns about any aspect of the study, please speak to me in the first instance. If you have any concerns regarding the personal data I collect from you, the University's Data Protection Officer can be contacted via email: [legal@mmu.ac.uk](mailto:legal@mmu.ac.uk), by telephone: 0161 247 3331, or in writing to: to Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have the right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority, please see: <https://ico.org.uk/global/contact-us/>

If you wish to complain about the study, you can contact my Director of Studies, Dr Christian Klesse (details in Section 15).

**14. Legal**

As per the legal requirements of the University, I have incorporated the following (italicised) text into this information sheet.

*"When you agree to participate in this research, we will collect from you personally-identifiable information. The University is the Data Controller in respect of this research and any personal data that you provide as a research participant. The University is registered with the Information Commissioner's Office (ICO) and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy. We collect personal data as part of this research (such as name, telephone numbers or age). As a public authority acting in the public interest, we rely upon the 'public task' legal basis. When we collect special category data (such*



## PARTICIPANT INFORMATION SHEET

as sexuality or ethnicity), we rely upon the research and archiving purposes in the public interest lawful basis.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. We will not share your personal data collected in this form with any third parties. If your data is shared, this will be under the terms of a Research Collaboration Agreement which defines the use and agrees on confidentiality and information security provisions. It is the University's policy only to publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

We will only retain your personal data for as long as is necessary to achieve the research purpose.

For further information about the use of your personal data and your data protection rights, please see the [University's Data Protection Pages](#)."

Please note **Article 6(e)** and **Article 9(2) (j)** of GDPR for legal reasons:

**6 (e)** 'Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.'

Note: paragraph (e) applies only if the University is the Data Controller.' – Manchester Metropolitan University is the Data Controller

**9(2) (j)** 'processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.'

## 15. Contact information

### **Craig Carey (Researcher)**

Righton Building  
Manchester Metropolitan University  
Cavendish Street  
Manchester  
M15 6BG  
**Email.** [craig.carey@stu.mmu.ac.uk](mailto:craig.carey@stu.mmu.ac.uk)

### **Dr Christian Klesse (Director of Studies)**

462 Geoffrey Manton Building  
Manchester Metropolitan University  
Rosamond Street West  
Manchester  
M15 6EB  
**Email.** [c.klesse@mmu.ac.uk](mailto:c.klesse@mmu.ac.uk)  
**Tel.** 0161 247 6424



PARTICIPANT INFORMATION SHEET

**Prof. Susan Baines (Faculty Ethics Officer)**

PERU Office  
313 Geoffrey Manton Building  
Manchester Metropolitan University  
Rosamond Street West  
Manchester  
M15 6EB  
**Email:** [s.baines@mmu.ac.uk](mailto:s.baines@mmu.ac.uk)  
**Tel.** 0161 247 2511

**Data Protection Officer**

Legal Services  
All Saints Building  
All Saints  
Manchester Metropolitan University  
Manchester  
M15 6BH  
**Email:** [legal@mmu.ac.uk](mailto:legal@mmu.ac.uk)  
**Tel.** 0161 247 3331

**If you are interested in participating in this research, please contact Craig Carey (the researcher) via email: [craig.carey@stu.mmu.ac.uk](mailto:craig.carey@stu.mmu.ac.uk)**

**THANK YOU**

## Appendix D: Gatekeeper Letter



GATEKEEPER LETTER

To whom it may concern,

**Research Project:** Contesting Austerity: Feminist and LGBTQ Responses to Changing Health and Social Care Provision in Greater Manchester

My name is Craig Carey. I am a PhD student at Manchester Metropolitan University, who is researching how women and LGBTQ people are organising and responding to changing HIV/AIDS and mental health service provision in Greater Manchester. I am writing to ask for your assistance in identifying potential participants.

### **What is the study about?**

The study is investigating changes in health policy, namely issues relating to the experiences of women and LGBTQ people in relation to HIV/AIDS and mental health services, and political responses to perceived problems in these areas. I am wanting to conduct interviews with participants to understand the issues they think are important in this context. These conversations will contribute to reflecting on what's happened so far, what's going well and what needs to change. Hearing the thoughts and experiences of the participants will help me to develop a deeper understanding, and thorough analysis, of the responses to changing HIV/AIDS and mental health service provision in Greater Manchester, which will hopefully stimulate further discussion in this field.

### **What will participation involve for the participant?**

Participants will be invited to partake in one interview, lasting approximately one hour, either in person or via Skype, whichever they prefer. The interview questions are open-ended and have been designed to draw upon their knowledge and experiences.

### **How can you assist?**

I am writing to ask if it is possible to recruit participants from your organisation for the research. Over the next few months, I am looking to conduct informal interviews on the topics of changing HIV/AIDS and mental health service provision in Greater Manchester with people who

- ⇒ have knowledge of these topics
- ⇒ are involved with a campaign or campaigning groups on these topics
- ⇒ are involved in the policy making process on these topics

*\*Please note, I can only accommodate participants over 18 years of age*

If you are able to identify potential participants; please could you either ask them to contact me via email (see below) or pass on a copy of the attached participant information sheet which contains more information about the project.

### **How can you ask questions or obtain further information?**

You can contact me via email at [craig.carey@stu.mmu.ac.uk](mailto:craig.carey@stu.mmu.ac.uk) if you have any questions or want to obtain further information about the project.

## Appendix E: Consent Form



### CONSENT FORM

#### Contesting Austerity: Feminist and LGBTQ Responses to Changing Health and Social Care Provision in Greater Manchester

Participant identification number: HSC201821\_\_\_\_\_/\_\_\_\_\_

(Please initial boxes)

1. I confirm that I have read and understood the participant information sheet (version \_\_\_\_), dated \_\_\_/\_\_\_/20\_\_ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary, and I am free to withdraw at any time without giving a reason, without my legal rights being affected.
3. I would like to participate in this study as a **namedsubject / anonymously**. [please delete as necessary]
4. I consent to the use of audio-taping, with the possible use of verbatim quotation (the quotation of your words exactly as you spoke them), in this study.
5. I agree for the verbatim quotation's to be quoted **using my name / anonymously** through the adoption of pseudonyms. [please delete as necessary]
6. I want to be informed about the outcome of this study and receive a summary of the findings at the end of the project. Please send the summary to: \_\_\_\_\_
7. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Craig Carey  
(Researcher)                      Date                      Signature

*Please note, if you have any questions or concerns about the study, please speak to Craig Carey in the first instance.*

Date of issue: 10 November 2020  
Version number: 4.0

Page 1 of 1

## Appendix F: Contact List



### CONTACT LIST

If you have been adversely affected by any issues discussed in the study, I have provided a list of organisations who can be contacted. Please note: the organisations listed below do not have any formal links to my study.

#### HIV/AIDS

**GEORGE HOUSE TRUST** - <https://ght.org.uk/>

*'Provides services to people living with, and affected by, HIV'*

Telephone: 0161 274 4499

Email: [talk@ght.org.uk](mailto:talk@ght.org.uk)

**TERRENCE HIGGINS TRUST** - [tht.org.uk](http://tht.org.uk)

*'Offers free and confidential services for people with HIV and AIDS, including specialist advice and representation on welfare rights, housing and legal matters, practical help and befriending'*

Telephone: 020 7713 0444

**LGBT FOUNDATION** - <https://lgbt.foundation/>

*'A national charity delivering advice, support and information services to LGBT communities'*

Telephone: 0345 3 30 30 30

#### MENTAL HEALTH

**MANCHESTER MIND** - <https://www.manchestermind.org/>

*'Supports individuals with mental health in Manchester'*

Telephone: 0161 769 5732

**YASP** - <https://www.manchestermind.org/our-services/young-people/yasp/>

*'Designed to help young people from 15-25 years old struggling with mental health problems'*

Telephone: 0161 221 3054

**SELFHELP** - <https://www.selfhelpservices.org.uk/>

*'A wide range of support, services and opportunities for people living with mental health difficulties'*